

**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, AND EDUCATION, AND  
RELATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2006**

U.S. SENATE,  
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,  
*Washington, DC.*

MATERIAL SUBMITTED BY AGENCIES NOT APPEARING FOR  
FORMAL HEARINGS

[CLERK'S NOTE.—The Social Security Administration and the Railroad Retirement Board were unable to testify and the following information was received in support of their fiscal year 2006 budget requests.]

[The information follows:]

SOCIAL SECURITY ADMINISTRATION

QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

HUMAN CAPITAL PLANNING

*Question.* In January 2001, the General Accounting Office identified strategic human capital management as a government wide high-risk area. What steps are you taking to acquire, develop, and retain an appropriate mix of agency staffing/talent, particularly in light of the Agency's impending retirement wave? What is the Agency's plan for creating an organizational culture that promotes high performance and accountability and empowers and includes employees in setting and accomplishing programmatic goals? How does the fiscal year 2006 budget support these activities?

*Answer.* SSA has a long history of successful human capital planning. We first analyzed the impact of our impending retirement wave in 1998. This prompted development of a Future Workforce Transition Plan (FWTP) which laid out the strategies to ensure that a highly skilled staff was in place.

We update our analysis of projected retirements annually and make appropriate adjustments to our recruitment, retention and succession strategies. We expanded upon the FWTP to publish a comprehensive and strategic Human Capital Plan in January 2004. The plan lays out how SSA will use human capital to meet the Agency's mission and goals and ensure that we have employees in place with the skills necessary to continue SSA's tradition of excellent citizen service. Employees across the Agency work together to accomplish these initiatives and, as a result, SSA received a President's Management Agenda score of "green" for the Strategic Management of Human Capital in June 2004.

To date, we have maintained our green status by successfully completing planned activities, continuing with initiatives underway and adding new ones that will further improve our management of human capital.

Since 2001, we have implemented a new national recruitment strategy with the following key elements: (1) an integrated marketing campaign with a new SSA brand entitled "Make a difference in people's lives and your own;" (2) emphasis on the Inter/Intranet; (3) coordinated on-campus college recruitment; (4) automated staffing/recruiting; (5) practical methods for diversity recruitment; (6) streamlined hiring; and (7) maximum use of hiring flexibilities. We have expanded on these key

elements through other key recruitment successes, including the release of a National Recruitment Guide to ensure consistency and excellence in our recruitment activities and the establishment of partnerships with other Federal agencies to assist veterans with transitioning to civilian employment.

We are maximizing the use of technology to improve recruitment and hiring. SSA is in the process of transitioning to a new web-based staffing automated system. We are also working to improve methods of submitting, collecting, and processing electronic job applications. Improving the application process in those areas is expected to improve the hiring process by encouraging a larger number and more qualified applicants to apply for Federal positions and by facilitating more timely selections.

Our recruitment efforts have proven successful in attracting quality hires. We hired over 15,000 employees in fiscal years 2001–2004. For fiscal year 2005, we have hired 2,616 through March 2005. This includes employees who were recently hired in support of the recent Medicare legislation which will provide drug benefit subsidies to the elderly.

We develop employees from entry-level through the Executive level. Our orientation programs for new employees emphasize our organizational culture and public service values.

SSA has received many accolades for its national leadership development programs that have often been referred to as the “best in government.” This reputation is based upon our use of competency-based programs that include a rigorous selection process and a variety of program features that produce well-rounded graduates. The programs include the Senior Executive Service Candidate Development Program for executives, the Advanced Leadership Program for middle- and senior-level employees, the Leadership Development Program for employees at the journeyman level, and the Presidential Management Fellows Program for entry-level professionals.

SSA has redesigned entry level training, developing job-specific training competencies and delivering related training for about 24,000 positions in the claims representative, service representative, and teleservice representative occupations. In fiscal year 2006, SSA will develop competency-based training that will be used for another 4,000 positions in the benefit authorizer, claims authorizer and technical support technician occupations.

SSA is also delivering training to prepare employees for the new Medicare legislation. The intent of this training is to ensure all employees understand and can process the workloads associated with the new legislation.

We are also maximizing the use of technology in the training arena by implementing a project development plan to migrate to a common, government-wide electronic-learning service.

Our 2-year retention rate for new hires has been gradually increasing from 84 percent for 1998 hires to 89.9 percent for 2002 hires; a rate which is considered outstanding in the private and public sectors. We have enhanced our orientation process and are improving our exit interview processes to further support our high retention rate.

We are promoting high performance and accountability by improving our performance management systems. We implemented new multi-tiered appraisal systems for Senior Executive System employees in October 2002 and for GS–15s in October 2003. We are further improving our performance management systems by implementing a new multi-tier performance appraisal model for union-represented employees that, when implemented, will differentiate between levels of performance and enhance managers’ ability to hold employees accountable for results.

Full funding of the fiscal year 2006 President’s budget will allow us to continue to carry out our Strategic Human Capital Plan activities.

#### DIRECT SERVICE POSITIONS

*Question.* What is your plan to increase the number of direct service positions, while maintaining appropriate levels of technical, policy, and administrative support staff? The Subcommittee is aware that SSA met its long-term goal of reallocating 5 percent of headquarters positions to direct service in fiscal year 2004. Specifically, how was this accomplished? What does the budget assume for such redirections in fiscal year 2005 and fiscal year 2006?

*Answer.* We met our goal through a combination of redeployments and overall attrition in staff components. For example, 71 employees transferred from staff components to direct service positions in the Office of Central Operations in November 2002. The fiscal year 2006 budget request assumes no additional redirections for fiscal year 2005 or fiscal year 2006. The fiscal year 2006 budget request does assume an increase in full-time equivalents from fiscal year 2005, attributable mainly to the

2,200 direct service employees hired in fiscal year 2005 to handle workloads related to the new Medicare prescription drug program. Although hired initially to deal with this new Medicare workload, these employees will be trained on all of SSA's programs so they can ultimately help backfill for the 3,000–4,000 employees we lose each year due to retirements and resignations.

#### ENRICHMENT OPPORTUNITIES AND LEARNING

*Question.* One long-term outcome identified in SSA's Agency Strategic Plan is ensuring ongoing enrichment opportunities and training. Specifically, how does the fiscal year 2006 budget support this long term outcome?

*Answer.* SSA is dedicated to improving its training and development programs in order to build the skills our employees at all levels need to deliver quality customer service in the 21st century's technological environment. To fill emerging skills gaps, SSA is focusing on improving the training it provides all its employees—from the lowest levels to the top. We are using the lessons we learned from "getting to green" to stay focused on our commitment to improve learning at SSA so all of our employees are prepared to support SSA's mission.

Currently, SSA's Office of Training is moving forward to:

- Develop and implement a competency-based training approach to ensure that our employees on the front-line doing mission critical work have the skills and knowledge they need to effectively address the concerns of the American public.
- Ensure that the Agency has the number of well-rounded, competent leaders it needs by implementing a new leadership development strategy that will enhance SSA's nationally acclaimed career development programs.
- Open up more learning opportunities for SSA's employees by moving from SSA's Online University to the government-wide GoLearn online learning system. SSA employees nationwide will be able to select from over 2,000 courses that are designed to make the most of their potential.

Of the many influences that are shaping SSA's future, none may be more fundamental or influential than the training we provide our employees. Our shared learning helps us to forge a sense of common purpose nationwide and provides us with the knowledge and skills we need to do our jobs. SSA's future success at meeting the public's increasingly varied needs depends on our ability to open up learning opportunities that make the most of our employees. Because of this, SSA is continuing to reassess the needs of its workforce and investing in workforce learning and performance for each of our employees and the Agency as a whole.

- SSA provided an average of 48 hours of training per employee over SSA's Interactive Video Teletraining (IVT) network and Online University. SSA employees were particularly interested in new IVT broadcasts that covered the new Medicare policy, security in SSA's offices, and the growing use of the Internet.
- The Office of Training is continuing to work with Operations to redesign the training for new or recently promoted employees in our mission critical positions. In redesigning our training, SSA has been using results from private sector source surveys and studies to develop a competency-based training program. This approach provides our students with the knowledge, skills, and abilities they need to do their jobs in an environment that is becoming increasingly automated.

By the end of last year, the entry-level training for Title II and Title XVI Claims Representatives (CRs), Service Representatives (SRs), and Teleservice Representatives were redesigned to reflect this competency-based approach.

Redesigned training lessons improve the way our new employees learn their jobs by integrating information regarding SSA's programs and policies with structured off-air activities and on-the-job-training. This plays a key role in helping new employees master the technology and automated processes that are a critical element of today's SSA work environment. Mentors help guide and support students as they develop new skills by practicing on SSA computer systems, taking part in role-playing, and having on-the-job experiences that will serve them well when they take on their new roles full time.

The Office of Training has also been developing training for specific groups of employees. Working with Operations' offices across the country, they have completed the development of competency-based training for Benefit Authorizers, Claims Authorizers, and Technical Support Technicians in the Program Service Centers by 2006. They have also improved fundamentals training for employees who do not provide direct services to the public. This training gives general information about the Title II and Title XVI programs and strengthens our commitment to work purposefully together in shaping and managing these programs.

Because of the continuing changes in the disability programs, SSA is working to update and expand the disability training materials for new or recently promoted disability adjudicators. SSA also provides a significant amount of training for OHA employees who process disability claims at the appeals levels. Topics that SSA provides on its IVT network focus on OHA's Case Processing Management System, Speech Recognition Software, Digital Recording, Dismissals, Remands, and Docket Management.

The Office of Training is evaluating the training needs of SSA's Executive Officers and expects to develop a core curriculum for that position by the end of the fiscal year.

Technology has also played an important role in SSA training.

—During fiscal year 2004 and into fiscal year 2005, Social Security continued to move forward towards realizing its vision of providing IVT nationwide. By the end of 2004, employees in more than 100 additional offices were linked to the IVT network. Today, over 98 percent of Agency and Disability Determination Service (DDS) employees have access to IVT.

—The IVT network continues to play an important role in ensuring that our employees learn what they need to know, when they need it. The first part of the Medicare Part D subsidy training on policy was developed and successfully delivered over the IVT network. The second part of this training, which will cover systems and subsidy changing events, is being readied for delivery this May.

—SSA is working behind the scenes to improve the delivery of its IVT broadcasts. With the conversion of the headquarters' practice studio, SSA now has a fully functional digital broadcast facility in Baltimore that helps us improve our ability to get up-to-date programs to our employees. SSA is also upgrading its other six broadcast facilities and enhancing our automated scheduling and evaluation procedures as well in an effort to better ensure that our IVT programs reach the employees who need them.

—SSA is expanding the benefits and values of online learning through the SSA GoLearn training site. SSA GoLearn replaces SSA's current Online University (OLU). All employees and their managers will have unprecedented opportunities to take over 2,000 courses at their workstations or at home, at no cost to them or their offices. Each employee will learn at his or her own pace and be able to select courses that will help them learn and perform better or become eligible for other, more rewarding work. Successful learners will automatically get credit for completed courses on their personnel records, without filling out any paperwork.

—IVT provides disability policy training to SSA and the DDS employees. IVT broadcasts provide these employees with help in handling a host of difficult technical issues, including electronic disability, evidence in childhood cases, disability fraud detection, and disability onset. SSA also broadcasts vocational and adjudicative tips in case development and processing for employees who handle SSA's disability workloads.

Since 2004, SSA has ensured that it has the talent it needs to lead the Agency by supporting the expansion of the national leadership development programs.

—60 employees have been selected to take part in the Leadership Development Program (LDP) that will begin mid-year. The GS-9 through GS-11 employees who will participate in the program will have the opportunity to move forward in the Agency by making the most of the training and rotational assignments available to them in the 18-month program.

—The Senior Executive Service Candidate Development Program (SES CDP) is expected to be announced later this year. The SES candidates are expected to begin their program in 2006. In order to develop the qualifications they need to become the government's top executives, SSA's SES candidates will take a variety of Agency rotational assignments and some will spend time at other Federal agencies to prepare them to successfully lead change within the Federal Government.

—Approximately 26 top graduate students are expected to be selected at the end of this calendar year for the Presidential Management Fellows (PMF) 2-year development program.

SSA is continuing to seek new ways to ensure that the Agency has the leadership it needs to succeed in the 21st century. Earlier this year, a national workgroup of manager and trainers in headquarters and from the field worked together to establish a new strategy for developing leaders at SSA. The Office of Training is getting nationwide comments on the strategy which is designed to foster competencies that leaders and managers need to effectively manage people, achieve results, and promote performance management. SSA anticipates implementing this new, improved approach to leadership by the end of this year.

Full funding of the fiscal year 2006 President's budget request for SSA will permit us to continue to carry out these training and development programs.

#### INITIAL DISABILITY CLAIMS

*Question.* Over the period fiscal year 2000–fiscal year 2004, initial disability claims pending have increased by more than 16 percent and now total more than 620,000, despite an increase in agency resources from \$6.6 billion to \$8.3 billion, or almost 26 percent. Please provide a breakout of DDS (Disability Determination Service) resources (dollars and staffing) over this period. What explains this growth in backlogs, despite increasing Agency resources? What specific actions are underway or planned in fiscal year 2005 and fiscal year 2006 to ensure more timely adjudication of disability cases and more cost-effective expenditure of agency resources?

*Answer.* The growth in initial disability claims pending is the result of a dramatic growth in initial claims receipts. Over the fiscal year 2000–2004 period, DDS initial claims receipts increased almost 24 percent.

SSA responded within available resources to this increase in receipts by: (1) increasing DDS resources; (2) initiating fewer continuing disability reviews in fiscal year 2003 and fiscal year 2004 and redirecting those resources to process initial claims; and (3) improving productivity in the DDSs. In spite of these efforts, we were unable to keep up with the growth in receipts.

In fiscal year 2005, we implemented a plan to lower initial pending levels to 592,000 by the end of the fiscal year. Thus far this year, we have succeeded in lowering pendings to 608,000. To help achieve the pending goal, increased funding was provided to the DDSs, and DDSs were authorized additional hiring and increased overtime. In addition, where requested and needed, Federal assistance in case processing is being provided to some DDSs. In fiscal year 2006, the President's budget request reflects productivity and processing time improvement for the DDSs, mainly through an electronic disability claims process (eDib).

Despite not receiving the full President's budget request for the last two fiscal years, my Service Delivery Budget goal is still to reduce disability claims pending to 400,000 by 2008. To achieve this, we need the Committee's support, including full funding for the President's budget request of \$9.403 billion for SSA's administrative expenses.

A breakout of DDS resources (dollars and staffing) for fiscal year 2000–fiscal year 2004 is provided in the chart below.

[Dollars in millions]

Year	Workyears	Amount
2000 .....	14,231	\$1,461
2001 .....	14,397	1,513
2002 .....	14,947	1,588
2003 .....	14,700	1,593
2004 .....	14,772	1,672

#### eDIB AND IMPLEMENTATION

*Question.* The Government Accountability Office (GAO) added Social Security's disability programs to its list of High-Risk programs. SSA's fiscal year 2006 budget request supports complete implementation of an electronic disability process—eDIB—as a means to improving the timeliness of and efficiency associated with disability decision. How much funding is included in the fiscal year 2006 request to support the eDIB? In several recent reports, GAO has raised concerns about the cost-benefit analysis, risk assessment and mitigation, and implementation plan for this initiative. Given the difficulties experienced in previous attempts to improve this process, what contingencies are in place to deal with challenges in implementing eDIB? Specifically, what resources are available and supports in places to deal with any potential implementation challenges?

*Answer.* SSA has requested approximately \$50 million in fiscal year 2006 for information technology (IT) hardware/software services, as well as internal IT staff to support eDib.

The most important thing to note is that eDib functionality was implemented by January 2004 and has been working effectively since that time. This includes the Internet Disability Report, the Electronic Disability . . . Collect System (EDCS), new hardware and software for the State legacy systems, the Document Management Architecture (DMA), and the Office of Hearings and Appeals (OHA) Case Proc-

ess Management System (CPMS). We are well on our way to the completion of the eDib rollout to all of the Social Security and State offices.

SSA has put many controls and resources into the process to assure our success as we implement these features, as we build upon them, and as we continue to roll-out full electronic folder capability across the nation to all components involved in processing the disability workload. This includes regular high level monitoring of the project status. There is frequent contact among all of the SSA components involved in eDib including staff from systems, policy and operations. SSA also deploys policy, systems, workflow, and usability experts to field offices, Disability Determination Service (DDS) offices, OHA offices, and Office of Quality Assurance (OQA) sites to learn first-hand about the issues faced by staff working with the eDib applications and works to resolve any problems quickly.

In addition, SSA is conducting an Independence Day Assessment (IDA) before moving a DDS, OHA, or OQA office to a fully electronic process (i.e., new cases can be processed in the electronic folder with no new paper folder created). This assessment ensures that everything is working properly before going fully electronic by validating the business process, the systems functionality, and other processes and procedures. The assessment also makes sure the electronic folder meets all documentation standards set forth by SSA and the National Archives and Records Administration (NARA).

SSA has assigned an "integrator" for each State. The integrator is responsible for tracking the progress of testing and implementation in each State and is the single point of contact for the DDS should they encounter issues. The integrator is responsible for identifying the component/person that can address and resolve each issue. This has proven to be a very successful model for eDib implementation. In addition, each DDS receives onsite support by their legacy system vendor and SSA Systems staff during testing and training, as well as during the first week of production.

We have placed a strong focus on risk management. We hired a contractor to work with our Project managers to develop Risk Management Plans for each of the major eDib projects. We have assigned each of the risks to the appropriate Project Managers for their use in addressing the risks. Our contractor updates these plans with the Project Managers to assure continued monitoring and mitigation of risks.

#### DISABILITY REDESIGN PROCESS

*Question.* According to SSA's service delivery assessment of the disability process completed in 2002, persons pursuing their disability claims through all levels of Agency appeal wait an average of 1,153 days for that final decision. Due to backlogs, cases that go through all levels of appeal spend nearly 50 percent of the time (535 days) waiting for SSA action. Commissioner, you have proposed an ambitious redesign concept for the disability determination process, and also have established a date of January 2006 as the earliest major changes in the disability determination process may become effective. Improvements to this process are needed, as the current process takes too long. What process will you follow for making final decisions about the redesign plan and what is the timeline for making those decisions? How much funding is proposed in the FY'06 budget associated with redesign implementation (OB) and what redesign activities do they support?

*Answer.* Improving the disability process is one of my highest priorities as Commissioner. I am close to making the final decisions that will convert my new approach for improving disability determinations into a proposed regulation which will provide the right decision as early in the process as possible and create work opportunities for people with disabilities.

When I announced my new approach, I stressed that the changes envisioned were predicated on successful implementation of our electronic disability system (which we call eDib) and that it was critically important to listen to the ideas of all interested parties as we developed the disability determination improvements.

I am pleased to report that our State-by-State roll out of eDib is on track. All of our field offices across the nation are now using the Electronic Disability Collect System (EDCS) that initially creates the electronic folder. This system was implemented at the first State Agency Disability Determination Services (DDS) in January 2004, and additional DDSs have continued to implement eDib ever since. Currently, eDib has been rolled out in all States except North Dakota, Alaska, Nebraska, New York and Washington, DC. With the exception of New York, all remaining States will be rolled out by the end of June 2005. At the same time, our Office of Hearings and Appeals (OHA) has begun using the new Case Processing and Management System (CPMS), which is a new software for processing cases and managing OHA office workloads. CPMS will enable OHA to work with the electronic file.

In view of the complexity and importance of the disability programs, my second strategy, having an open process, has been invaluable in my decision making. Last year, I launched a massive outreach effort to obtain and give thoughtful consideration to all comments on the current system and our proposed improvements. I created the Disability Service Improvement Staff within my immediate office to coordinate this effort and I have been taking a personal role in listening to those involved and interested in the disability process. I have personally participated in more than 60 meetings with more than 40 organizations—both within SSA and outside of the Agency. As I have been making decisions, I have carefully considered hundreds of views and suggestions received from the Congress, the general public, and many public and private sector groups and individuals.

With respect to fiscal year 2006 funding, I anticipate that our plan to roll out the new process region by region will enable us to implement these improvements without seeking additional resources beyond those the President requested for SSA from the Congress for fiscal year 2006.

#### SPECIAL DISABILITY CASES

*Question.* The Subcommittee is aware that SSA's latest plan is to complete the entire review of the special disability cases by 2010. What specifically is the Agency's plan for accomplishing this goal and how much funding will be required to review all of these cases?

*Answer.* As of fiscal year 2004, we have processed 96,600 cases of the estimated 300,000 individuals eligible for Supplemental Security Income (SSI) who are also entitled to (but not receiving) Social Security Disability Insurance benefits. In fiscal year 2005, we plan to process 30,500 cases at a cost of \$78 million. The fiscal year 2006 budget includes \$79 million for the processing of 30,600 special disability cases.

Through fiscal year 2004, SSA spent approximately \$175 million on the processing of Special Disability cases. Assuming full funding of the President's fiscal year 2006 budget request, as well as sufficient funding in future years to support continued processing of this workload, we expect to complete case processing by September 2010 at an administrative cost of about \$630 million.

#### CDRs

*Question.* The Subcommittee notes that one of the Agency's Long-Term Outcomes under its Stewardship goal is to remain current with Disability Insurance CDRs and to regain currency with SSI CDRs. What are the performance outcomes the Agency needs to achieve during the years fiscal year 2005 through fiscal year 2009 to meet this long-term outcome measure? What is SSA's plan for meeting this goal? What best practices did SSA develop during the period when Congress provided special funding that are being applied to the process currently that will ensure the most cost-effective expenditure of LAE resources? How will the Agency determine an appropriate balance between Continuing Disability Reviews processed through mailers and those cases requiring a full medical review?

*Answer.* To remain current in Title II CDRs and achieve currency in Title XVI CDRs by the end of fiscal year 2009, SSA would need to process over 7.5 million CDRs, including those that will come due during the period fiscal year 2006–fiscal year 2009 and CDRs that we have been unable to initiate through fiscal year 2005 because of funding limitations. While we are updating our CDR plan to reflect more current information, including the latest projections of initial disability claims receipts, we do not believe that we will be able to achieve Title XVI currency until after fiscal year 2009.

The President's fiscal year 2006 budget includes budget enforcement legislation that would place caps on net discretionary budget authority and outlays. The legislation would permit adjustments to these caps for spending above a base level for several government-wide program integrity activities, including SSA's CDRs. The amount of the adjustment for CDRs is \$189 million, which means if the President's proposal is enacted, \$189 million of SSA's budget request would not be counted towards the overall cap on discretionary budget authority.

Congress provided SSA with special funding for CDRs, outside the discretionary budget caps, from fiscal year 1996 through fiscal year 2002. During this period and continuing, SSA has worked continuously to improve the efficiency and effectiveness of the CDR program. The results are borne out by the following passage from SSA's most recent Annual Report to Congress on CDRs covering fiscal year 2003:

"SSA's CDR process has consistently yielded a favorable ratio of savings to costs in the Disability Insurance (DI) program. Prior to the implementation of the current process for case selection, it was estimated that we were achieving \$3 in DI program

savings for each \$1 in administrative costs invested in full medical CDRs. The addition of the mailer process beginning in 1993 was estimated to result in a doubling of this ratio to approximately \$6 to \$1.

“Actual results to-date for the period during which supplemental administrative funding has been available have been even better than anticipated. During this period, the number of cases processed has expanded significantly, especially in the review of SSI cases. This expanded process has yielded savings-to-cost ratios for the seven fiscal years 1996–2002 averaging roughly \$10.3 to \$1.”—From SSA’s Annual Report of Continuing Disability Reviews, fiscal year 2003; published October 27, 2004.

The breakthrough innovation was the implementation of a statistical profiling/ mailer process in 1993 which permitted SSA to reliably identify large cohorts of beneficiaries with a low probability of cessation due to medical improvement for whom the expensive full medical review process is not required. The CDR statistical scoring models are a series of mathematical formulas designed to predict the likelihood of medical improvement for each Retirement Survivors Disability Insurance (RSDI) beneficiary and SSI adult recipient. Based on the scores generated by these models and a statistical threshold which determines whether a mailer or full medical examination would be the most cost effective type of review to perform, cases scoring below the threshold are targeted for CDR mailers, and those scoring at or above the threshold are targeted for full medical reviews.

During the early years of the special funding we focused primarily on improving internal systems and operational processes needed to reliably control and track more than a million reviews annually. SSA engaged a statistical contractor in fiscal year 2000 to improve the performance of the statistical modeling. Since then, the contractor has updated and expanded the data and mathematical formulas upon which the statistical scoring is based.

SSA has been able to implement several processing improvements based on research findings by our statistical contractor. Since fiscal year 2002, SSA has been able to use the profiling/mailer process to identify RSDI disabled workers with a statistical model score signifying “medium” probability of medical improvement who do not require a full medical review. The process was extended to SSI disabled adult beneficiaries in fiscal year 2005. In fiscal year 2003, we were able to apply Medicare usage data to identify additional RSDI disabled workers with a low or medium probability of medical improvement. Altogether since fiscal year 2002, these innovations have avoided well over 500,000 full medical reviews, more than \$300 million in administrative costs, and significantly reduced unnecessary burden on our most severely disabled beneficiaries.

We continuously monitor the performance of the statistical models and can readily make enhancements that are suggested. In addition, the models have been scrutinized by several teams of auditors and found to be accurate and reliable. And, together with our statistical contractor, we continue to look for additional processing efficiencies that can be implemented in the future.

With respect to determining the appropriate balance between CDRs processed through mailers and those performed as full medical reviews, this decision is determined through the CDR statistical scoring models. For cases with medical re-examinations due to be scheduled in the particular fiscal year, we begin releasing CDR mailers and full medical reviews at the start of the fiscal year, and continue the release process throughout the year, with the goal of releasing all cases due for a CDR in that year.

#### TICKET TO WORK

*Question.* According to the “Justification of Estimates for Appropriations Committees” for the fiscal year 2006 budget request, the Ticket to Work Program will be expanded to all States and U.S. Territories by September 2004. Specifically, how much funding is available within the fiscal year 2006 request for the Limitation for Administrative Expenses account to support implementation of the Ticket to Work program and what activities are supported? How much funding from other sources within the fiscal year 2006 budget request support the program?

*Answer.* The administrative budget for fiscal year 2006 includes \$39.4 million for Return to Work activities. This funding is for Benefits Planning and Assistance Cooperative Agreements (\$23 million), Protection and Advocacy grants (\$7 million), and the Program Manager Contract (\$9.4 million).

The following chart summarizes other objects administrative costs of the Ticket to Work program by major category:



## RETURN TO WORK

[In millions of dollars]

	Fiscal year	
	2005 estimate	2006 budget submission
Benefits Planning & Assistance Cooperative Agreements (including training and technical assistance) .....	23.0	23.0
Protection & Advocacy Grants .....	7.0	7.0
Program Manager Contract .....	<sup>1</sup> 6.9	9.4
<b>Total</b> .....	<b>36.9</b>	<b>39.4</b>

<sup>1</sup> The fiscal year 2005 contract is only for nine months. The contract is being re-competed for fiscal year 2006. The President's budget estimates \$9.4 million for fiscal year 2006, the same as the full year cost for fiscal year 2004.

Benefits Planning and Assistance and Cooperative (BPAO) Agreements are intended to ensure that community based benefits planning and assistance outreach services are available across the United States and its territories. The law authorized \$23 million to be appropriated each year and the Social Security Protection Act of 2004 (Public Law 108-203) extended this authorization through 2009.

The Protection and Advocacy (P&A) grants are used to provide advice to beneficiaries and to provide an avenue for resolving disputes. The Social Security Protection Act of 2004 also extended authorization to provide funding for P&A grants through fiscal year 2009. The budget continues funding of \$7 million for P&A grants in fiscal year 2005 and fiscal year 2006.

The Program Manager Contract provides funds to an outside contractor to help SSA manage the Ticket to Work program. The contract will be re-competed and the required funding has been estimated to be \$9.4 million for fiscal year 2006.

The budget also includes program funding to cover outcome and milestone payments made to Employment Networks (ENs) under the Ticket to Work program. State Vocational Rehabilitation (VR) agencies have the option, on a case-by-case basis, to elect to be paid under the reimbursement payment system or as an EN. The Beneficiary Services Budget for fiscal year 2006 includes \$262 million to cover reimbursement payments to VR agencies and Ticket payments to ENs (see chart).

The chart below summarizes the estimated Beneficiary Services payments:

## BENEFICIARY SERVICES PAYMENTS

[In millions of dollars]

	OASDI		SSI	
	Fiscal year		Fiscal year	
	2005	2006	2005	2006
Reimbursement Payments (VR) .....	80	104	52	67
Ticket Payments (EN) .....	25	54	25	37
<b>Total Payments</b> .....	<b>105</b>	<b>158</b>	<b>77</b>	<b>104</b>

## DISABILITY PROGRAM NAVIGATOR

*Question.* How has SSA collaborated with other federal agencies and partners to increase the work opportunities of individuals receiving Social Security and SSI disability payments and what resources are included within the fiscal year 2006 budget request to carry out such activities? Specifically, what has been the experience in increasing work opportunities through the Disability Program Navigator housed in One Stop Centers and the Area Work Incentive Coordinators? Why is funding for the Disability Program Navigator position being discontinued in 2005?

*Answer.* On September 30, 2002, SSA and DOL entered into an interagency agreement to jointly fund a two-year pilot and evaluation of a new position within the One-Stop Career Center system, the Disability Program Navigator (DPN). This funding, in the form of cooperative agreements, was distributed to 14 States in fiscal year 2003. A primary objective of the Navigator is to increase employment and self-sufficiency for individuals with disabilities by linking them to employers and by facilitating access to programs and services that will enable their entry or reentry into the workforce.

SSA and DOL funded the DPN's for a second year which will support the project through June 2005. During the second year of this joint initiative, Navigators experienced increased activity in the area of relationship building within the One-Stop Center as well as with employers, Vocational Rehabilitation agencies, Benefit Planning, Assistance and Outreach (BPAO) providers, and SSA Area Work Incentive Coordinators (AWIC). Evaluation survey data is currently being collected and, based on the results, SSA will make a decision regarding funding for an additional year.

The SSA AWICs are the Agency focal point for public information outreach and education efforts for the Ticket to Work program. The fifty-five nationwide AWICs work closely with the external Ticket to Work partners, such as Protection and Advocacy representatives, BPAO representatives, Employment Networks (ENs), Disability Program Navigators, Vocational Rehabilitation and other disability advocates. In some regions AWICs are included in regional training events with the BPAOs and have partnered with Maximus to provide training to the ENs. AWICs, Plan for Achieving Self-Support (PASS) specialists and SSA regional office staff participate in the training and refresher training sessions.

In addition, SSA has entered into a number of interagency agreements and cooperative agreements which are focused on increasing work opportunities for individuals receiving disability benefits.

SSA has entered into a \$100,000 interagency agreement with HHS' Office of the Assistant Secretary for Planning and Evaluation (ASPE) to subcontract the evaluation of the Florida Freedom Initiative (FFI). The FFI is an expansion of a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS), which is targeted to a subpopulation of participants in the section 1115 waiver demonstration called Consumer-Directed Care Plus. This subpopulation consists of adults with mental retardation/developmental disabilities. In addition to the financial commitment to the evaluation of the FFI, SSA will be waiving certain SSI and SSDI program rules for FFI participants to test whether the combination of Social Security and CMS waivers fosters greater self-sufficiency among demonstration participants.

SSA's Youth Transition Demonstration (YTD) consists of seven cooperative agreements in six States (California, Colorado, Iowa, Maryland, Mississippi, and New York). The goal of these cooperative agreements is to find more effective ways to enable youth who receive SSI and SSDI as well as those who are at risk of receiving these benefits, to transition successfully to work or post-secondary education and ultimately to maximize their economic self-sufficiency. These seven cooperative agreements were awarded September 30, 2003 for up to five years. The latest budget estimate for fiscal year 2006 includes \$11.8 million for funding the demonstration projects, evaluation and technical assistance. These partners are collaborating at the State level with the Vocational Rehabilitation Services, Department of Education, Department of Labor One Stop Centers as well as other State and local agencies.

Since 2001, SSA has been working under an Interagency Agreement with DOL's Office of Disability Employment Policy (ODEP) to promote SSA's Ticket to Work Program within DOL's "Employer Assistance Referral Network" (EARN). DOL has incorporated Ticket to Work into a specialized unit of EARN called "Ticket to Hire" (TTH). EARN's primary purpose is to provide employers with a one-stop service to help them locate and recruit skilled candidates with disabilities for jobs. TTH matches employers' job openings with qualified, job-ready candidates from the Ticket to Work Program. Presently, there is \$600,000 budgeted for the continuation of this Interagency Agreement for fiscal year 2006.

#### OHA HEARINGS

*Question.* Over the period fiscal year 2000–fiscal year 2004, the number of social security hearings pending have increased by 90 percent to more than 590,000, despite an increase in agency resources from \$6.6 billion to \$8.3 billion, or almost 26 percent. Pending hearings grew by nearly 80,000 during the last fiscal year and the average processing time increased by almost 14 percent, despite the provision of additional staff support to OHA and the hiring of 103 administrative law judges. Please provide a breakout of Office of Hearings and Appeal resources (dollars and staffing) over this period. What accounted for this growth in backlogs, despite increasing agency resources? What actions are underway or planned in fiscal year 2005 and fiscal year 2006 to ensure more timely dispositions and more cost-effective expenditure of agency resources?

*Answer.* The inability to hire ALJs between fiscal year 2001 and fiscal year 2004 resulted in increased cases pending, even though we were able to hire 103 ALJs in fiscal year 2004. This ALJ shortage, along with a 14 percent increase in case receipts during the same time period, has also increased processing time. OHA has

hired an additional 100 ALJs during fiscal year 2005, and anticipates hiring additional ALJs during fiscal year 2006 which will, when these ALJs are fully trained, facilitate case processing. Other actions being implemented to decrease processing time include the:

- development of File Assembly Units for assembling files for hearings;
- establishment of a Centralized Screening Unit which reviews and prepares cases for potential On-The-Record Decisions;
- implementation of various initiatives at the hearing level to expedite the issuance of decisions. These include the following: screening cases for on-the-record allowances; issuance of fully favorable decision by the ALJ at the hearing (bench decisions); providing an easily prepared decision format for ALJs to prepare decision findings; and
- electronic developments such as eDib, the Digital Recording Acquisition Program and the Case Processing Management System (CPMS), are expected to expedite case processing and tracking.

Despite not receiving the full President's budget request for the last two fiscal years, my Service Delivery Budget goal is to eliminate the hearings pending backlog by 2010. To achieve this, we need the Committee's support, including full funding for the President's budget request of \$9.403 billion for SSA's administrative expenses.

The breakout of OHA's resources (dollars and staffing) over the period covering fiscal year 2001 through fiscal year 2004 is as follows:

[Dollars in millions]

Year	Workyears	Amount
2001 .....	7,945	\$692.8
2002 .....	8,049	751.1
2003 .....	7,903	815.7
2004 .....	8,204	867.0

HIRING ALJs

*Question.* What is SSA's plan for hiring Administrative Law Judges in fiscal year 2005 and fiscal year 2006? How does the fiscal year 2006 budget request support continued improvement in Administrative Law Judge productivity, one way to help reduce the growing average processing time for hearings, which is up 31 percent from fiscal year 2000 to fiscal year 2004? The Committee is aware of the more than 100 day decrease in average processing time for hearings associated with the use of the video teleconferencing capability. What are the savings associated with the expansion of these facilities proposed in the fiscal year 2006 budget request?

*Answer.* OHA hired 100 ALJs for fiscal year 2005 and plans to hire additional ALJs in fiscal year 2006 depending on the level of funding available. After the nine-month learning curve, we expect that the increase in ALJ resources will help reduce the hearings backlog, and as a result, reduce the average processing time.

Including the 80 additional sites installed this fiscal year, there now are a total of 240 video teleconferencing sites in operation. We have conducted nearly 12,000 video hearings this fiscal year through April compared to 4,000 through April of fiscal year 2004. Video hearing usage contributes to ALJ productivity improvements because fewer hearings are postponed, ALJ travel is decreased, and expert resources are more accessible.

OHA'S CASE PROCESSING MANAGEMENT SYSTEM

*Question.* The new Office of Hearings and Appeals Case Processing Management System was scheduled to be completed by September 2004. What training resources are being expended to support its successful implementation? What does the fiscal year 2006 budget assume about savings related to this new system in fiscal year 2005 and fiscal year 2006?

*Answer.* The Case Processing Management System (CPMS) conversion began in May 2004 and was completed in August 2004. The following training resources supported successful implementation of the Case Processing Management System (CPMS):

- CPMS training began in April 2004 and ended in July 2004;
- CPMS training took place "onsite" at each hearing office (HO);
- CPMS training was performed over a 40-hour week;
- Training was broken into several categories, general training for all staff then job specific training for each job type;

- The on-site trainers were in the HO to help with the conversion of all Hearing Office Tracking Systems data to CPMS;
- The trainers remained onsite the week after training to address any CPMS issues that arose; and
- Further support has been provided after the training was completed:
  - A CPMS help desk in Falls Church is now maintained full-time;
  - CPMS training manuals have been made available on the OHA's website;
  - CPMS training material is on the OHA Website;
  - Continual updates are made to the training materials on the website;
  - Net meetings are conducted with HO's on the use of CPMS; and
  - A series of three Interactive Video Teletraining sessions on the use of CPMS were completed in March 2004.

No specific savings were associated with implementation of CPMS. However, the system is an essential element for implementation of the electronic folder process at the hearings level and will assist us in our plan to achieve an annual productivity improvement of 2 percent.

#### ELECTRONIC SERVICE DELIVERY

*Question.* Given the focus SSA has placed on electronic service delivery as a means of providing appropriate service to growing workloads, how is the agency monitoring electronic service delivery use and experience to alter and build its electronic service delivery infrastructure in a secure and user-friendly way?

*Answer.* E-Government services within SSA are maturing as a service delivery alternative to face-to-face contact, mail, and telephone. Substantial investments in infrastructure have been made with the expectation that electronic services will continue to grow and become a viable, efficient channel for the delivery of SSA's services. In fiscal year 2004, over 611,000 electronic entitlement and supporting actions, i.e., applications, Medicare replacement cards, change of address, etc., were processed. This represents an increase of 179 percent over the fiscal year 2002 baseline.

Electronic services are monitored using management information data. This data is analyzed to identify usage trends and to determine the level of resources required for these workloads. Customer feedback using email, surveys and telephone calls are additional ways to monitor usage.

#### *Customer Feedback*

- We have general feedback mechanisms on most web-pages that allow customers to send us their comments or complaints via email.
- Some on-line applications on the SSA web site also allow general customer feedback through the use of surveys. In addition, SSA has incorporated several American Customer Satisfaction Index (ACSI) surveys on its web site. Sponsored by the Department of the Treasury's Federal Consulting Group, ACSI surveys use a standardized set of questions to measure user satisfaction.
- SSA's Office of Quality Assurance uses telephone surveys to measure customer satisfaction with the Agency's programs, including services available from the web site.
- SSA subscribes to demographic data services that allow us to identify who is visiting the SSA site, from where, how long they stay, how many pages they visit, etc. This data helps us identify both popular and problem pages/services on the web site, and to focus marketing of the web site and its services.

*Question.* What new electronic services will be supported by the fiscal year 2006 budget and how will current services be improved to enhance user experience and Agency efficiency?

*Answer.* The following services will be supported:

- SSA's Internet Change of Address application has been enhanced to allow access through Knowledge Based Authentication in addition to the pin/password access.
- Speech technology provides citizens with the option to use automated telephone applications on the National 800 Number Network to access claims, benefits and related programmatic information.
- Last year, we completed speech-enabled automation of the transcription process over the National 800 Number Network. Prior to this conversion, callers left a message which was manually transcribed by SSA employees. Now callers hear a message confirming that their request was received and is being processed. If the request was not successful, the caller is directed to an agent for assistance.
- SSA's Electronic Wage Reporting initiative encourages employers to report their employees' wages electronically rather than via paper, magnetic tape or diskettes/CD ROMs. SSA offers online assistance and staffs an Employer 800 Num-

ber to provide information and technical support to employers. At least 70 percent of all W-2s will be filed electronically in fiscal year 2006, resulting in WY savings for the Agency and in more accurate, timely postings to the Master Earnings File.

- The Electronic Special Redetermination Mailer is an approved project in the Agency IT Systems Plan fiscal year 2005–2006. Under this project, High Error Profile (HEP) redeterminations will be processed using a new, expanded redetermination mailer that will be scanned in the Office of Earnings Operations (OEO). Mailer responses will be extracted electronically and compared to the Supplemental Security Record, and decision logic will be applied which clears cases or refers them for manual review/exception resolution in OEO or the Field Offices. Testing of the electronic special mailer is planned for April 2006 with implementation by October 2006.
- Social Security Number Verification Service (SSNVS) was recently approved by OMB. SSA plans to begin implementation in June 2005, with full nationwide implementation in October 2005. Employers who previously called the Employer 800 Number to verify employee SSNs will be able to obtain that confirmation via the Internet, instead. SSA plans extensive marketing of electronic SSNVS, which is expected to reduce SSN verification calls to the Employer 800 Number, verifications requested by tape/diskette, and the processing of paper listings.
- Electronic Freedom of Information Act (EFOIA) is expected to expand the use of the Internet to provide faster and better access to Government services and Information. The EFOIA system will employ technology that will automate SSA's internal FOIA processes to substantially reduce the FOIA processing time and allow us to respond to citizens within the legally required 20-day timeframe. The new system will accept electronic credit card payments and respond to requests via aggressive use of the Internet. EFOIA is expected to reduce the OEO unit time for FOIA actions by 20 percent effective with fiscal year 2006.
- The Microfilm/Microfiche Replacement Project was approved by the Information Technology Advisory Board in fiscal year 2004 after evaluation of Proof of Concept (POC) results. The processes SSA has used to produce, store, and access microfilm/fiche data have been among its most labor-intensive and costly. Microfilming technology is outdated and increasingly difficult to maintain. Online access by Operations employees from their workstations will enable SSA to process related workloads on a timely basis and ensure both the availability and integrity of SSA's databases. Based on POC results, the unit time required for employees in the PSCs, ODIO and OEO to access data will decrease from an average of 12 minutes to an average of 2 minutes.
- W-2C Online will continue to decrease the volume of W-2 corrections received in OEO for manual processing (examination, data entry/balancing, microfilming, etc.).
- As part of the e-Authentication initiative of the Presidential E-Government Initiatives, SSA has signed a Memorandum of Understanding with GSA to implement the federated authentication architecture with several SSA applications through fiscal year 2006. The federated authentication architecture will allow SSA to use the authentication of an online customer by a trusted partner (e.g., a financial institution whose authentication process has been certified by GSA) to conduct business online. The federated authentication architecture offers the potential for millions of online customers of banks and other financial institutions to use their existing pin/passwords to gain secure access to SSA electronic applications, improving and simplifying user access to our electronic applications without SSA (or any other government agency) having to establish or maintain pin/passwords.
- Development of the electronic folder to replace the paper disability folder will continue with processes to speed the request and retrieval of electronic evidence from medical, educational, and other third parties.
- SSA is studying ways to enhance the claims process to incorporate secure messaging with claimants as an alternative communication approach to the more-expensive telephone and in-person channels.

*Question.* What specific activities are supported in the fiscal year 2006 budget to promote the use of electronic services to employers, covered workers and current recipients/beneficiaries?

*Answer.* Through our network of field office managers and Public Affairs Specialists, we conduct ongoing outreach to raise awareness of online services and to encourage their use. Each year, working in their local communities, these professionals deliver speeches, submit newspaper articles, conduct workshops, lead seminars, and conduct radio and television interviews on all aspects of Social Security's programs, including the benefits of doing business with us online. We include infor-

mation about our online services in all our Social Security publications, including the Social Security Statement, which we send to all workers age 25 and older.

We also use a variety of other tools tailored to specific target audiences, as follows:

*General Public*

- An Online Services Marketing Kit, which includes:
  - A Fact Sheet (also available in Spanish);
  - Links to Special Places, a one-page handout that lists webpages such as the Glossary, the Immigration page, Most Popular Baby Names—items that draw people of all ages and ethnicities to the site;
  - A tri-fold leaflet, Apply Online for Social Security Benefits, that answers questions about our online retirement application;
  - A one-page “URL Handout” that provides addresses for the online retirement application, the Social Security Statement page, the Benefit Planners and Social Security card information; and
  - An Internet bookmark
- 800 Number on-hold messages promoting online services
- Partnerships with local libraries to distribute Social Security Online bookmarks and conduct educational seminars

*Third Parties With Clients Applying for Disability Benefits*

- PowerPoint overview of the i3368PRO (Internet Adult Disability and Work History Report)
- Instructional CD containing examples of the i3368PRO online application screens
- “eColleague letters” (email messages that formerly were paper-based “Dear Colleague” letters) to national organizations (advocates, attorneys, social service agencies, etc.)
- Webpage [www.socialsecurity.gov/i3368prohelp](http://www.socialsecurity.gov/i3368prohelp) that provides background information, helpful tips, etc.

*Covered workers*

- Cost-of-Living Adjustment (COLA) notices sent to all beneficiaries in January each year inviting them to visit [www.socialsecurity.gov](http://www.socialsecurity.gov)
- Panel on homepage promoting online retirement application
- Door signs that show office hours and encourage visitors to do business online
- Posters, tent cards, leaflets
- PowerPoint presentations
- PowerPoint overview of the i3368 (Internet Adult Disability and Work History Report)
- Instructional CD containing examples of the online application screens
- Draft redesign of Baby Names page to promote online retirement planners and calculators
- 800 Number on-hold messages promoting online services

*Current recipients/beneficiaries*

- Change of Address:
  - Articles for local news outlets, organizations’ house organs, etc.
  - Correspondence with people who wrote to the Commissioner, the Congress, or the White House
  - Fact Sheet
  - Partnership with USPS to place a link to SSA from their homepage
- Direct Deposit:
  - Partner with Fidelity to allow their online customers to set up direct deposit of their Social Security benefits into an eligible account
- 800 Number on-hold messages promoting all online services

*Employers*

- Articles in SSA/IRS Reporter
- Electronic Wage Reporting CD
- Posters, pamphlets, fact sheets
- Inserts for inclusion in IRS correspondence with employers
- Seminars at national conferences, such as the IRS Tax Forums the American Payroll Association and the National Restaurant Association to promote online wage reporting and filing for retirement online
- Partnerships with Chambers of Commerce across the country to encourage small business owners to file their wage reports online

- Partnerships with Human Resource Managers including the Society of Human Resource Managers to encourage their employees to file for retirement online
  - CD for Human Resource Managers promoting online retirement and providing useful tips
  - Screen calendars (calendar strips that people affix to their computer monitors)
  - Survey of non-electronic filers to identify (and help us overcome) barriers to online wage reporting
  - Website covering all aspects of online wage reporting
  - Toll-free call center specifically for employers with wage reporting issues
  - W2News e-mail specifically for employers discussing wage reporting issues
- Question.* How much savings does SSA expect through its electronic service delivery initiative in fiscal year 2005 and over the period fiscal year 2004–fiscal year 2007?

*Answer.* Although savings have not been specifically identified for most of these initiatives, we expect that the efficiencies gained through implementation and expansion of these efforts will be an essential element in our ability to reach a goal of a 2 percent annual improvement in productivity.

#### BI-PARTISAN SOLVENCY EDUCATION PROGRAM

*Question.* Please provide the Subcommittee with additional information related to the proposed bi-partisan solvency education program. What resources are requested within the fiscal year 2006 budget for these activities? How does this planned level of expenditure compare with fiscal years 1999–2004?

*Answer.* Among the many services provided by the Social Security Administration is educating the American public about the programs and finances of Social Security. One of the stated objectives in our Agency Strategic Plan is: “Through education and research efforts, support reforms to ensure sustainable solvency and more responsive retirement and disability programs.” No specific amount was included in SSA’s fiscal year 2006 budget request for solvency education. As in prior years, this effort is part of the ongoing educational program conducted by SSA to educate the public about the Social Security program, including the financing challenges facing them, through our ongoing communication efforts. As the national discussion continues on how best to strengthen Social Security for the future, we will work to continue to ensure that policymakers and the public have the information needed to assess the implications of all proposals under consideration.

Messages about the current status of the Trust Funds, as described in the Annual Report of the Board of Trustees of the Federal Old-Age and Survivors Insurance and Disability Insurance Trust Funds are included in a number of our public information resources, including:

- On our website—[www.socialsecurity.gov](http://www.socialsecurity.gov);
- In our publications—“The Future of Social Security” and “Understanding The Benefits” pamphlets;
- In the annual Social Security Statement mailed to all workers age 25 and older not currently receiving benefits; and
- When appropriate, as part of the presentation by our Agency communicators when speaking to groups and organizations.

#### SOCIAL SECURITY EARNINGS

*Question.* Each year approximately nine million wage records cannot be reconciled due to a mismatch associated with the name or Social Security Number of a person. According to the Inspector General of the Social Security Administration, as of July 2002, the Earnings Suspense File contained 236 million wage items totaling roughly \$374 billion. Of these amounts, roughly 80 million items worth \$13 billion are more than 30 years old. What activities are proposed in the fiscal year 2006 budget to update the records of wage earners whose current or future social security benefits would be lower than provided under current law due to processing mismatches? What steps are being taken to ensure that earnings are posted to the correct social security number upon initial submission and how does the fiscal year 2006 budget support these actions?

*Answer.* In fiscal year 2003, SSA began developing new matching software to associate earnings items in the Earnings Suspense File (ESF) with the correct individual master earnings file. The new routines use data housed on the ESF, enumeration records, benefit records and earnings records to confirm that the correct earnings records were identified. In fiscal year 2003 and 2004, SSA removed about 10 million items from the ESF and posted them to the correct earnings records for tax years 1937 through 2000. In fiscal year 2005, we are continuing to expand our

new software and are focusing on tax year 2001. The improvements will also be used to remove additional ESF items for years prior to 2001.

To prevent future earnings from going into the ESF, SSA works with employers to provide tools to allow them to determine if they have a name/Social Security number (SSN) mismatch on their payroll records prior to sending W-2s to SSA for processing. SSA provides a free Employee Verification Service where an employer can verify if a name and SSN match. SSA has piloted an Internet-based version of this service, the Social Security Number Verification Service (SSNVS). SSA anticipates offering this free Internet-based service to all employers.

SSNVS allows an employer to verify up to ten names/SSNs at a time with SSA over the Internet while receiving a response within seconds. In addition, an employer may submit a file over the Internet of up to 250,000 names/SSNs and receive a response on the next business day.

#### LEGISLATIVE PROPOSAL—SSI DISABILITY CLAIMS

*Question.* The fiscal year 2006 budget request includes a legislative proposal that would require SSA to review at least 50 percent of favorable decisions for adult SSI disability claims before starting payments. What are the administrative costs of this proposal in fiscal year 2006, and are these costs requested within the LAE account? What are the anticipated programmatic savings from this proposal?

*Answer.* Under current law, SSA reviews at least 50 percent of all Title II initial disability allowances made by State agencies on behalf of SSA. The budget proposal would apply the same requirement for adult disability allowances in the SSI program. When fully phased in, 50 percent of initial SSI disability allowances would be reviewed.

The administrative costs in fiscal year 2006 are estimated to be about 45 workyears and \$6 million which would be absorbed under the LAE account if the legislation is enacted.

The estimated program savings to general revenues of the preeffectuation proposal in the budget are about \$493 million over 10 years in the SSI program alone. Additional Medicaid savings from the proposal over 10 years are estimated to be about \$639 million.

#### SOCIAL SECURITY PROTECTION ACT

*Question.* According to the “Justification of Estimates for Appropriations Committees” for the fiscal year 2006 budget request, the LAE account includes resources needed to implement the Social Security Protection Act. How much funding is required to implement each activity required by the Act?

*Answer.* There are fifty-one sections of the SSPA enacted March 2, 2004. The fiscal year 2006 administrative budget includes \$14.7 million, and 211 workyears (WYs), to fund the following provisions:

- Expanding numbers of onsite representative payee reviews the Agency will need to conduct under Section 102(b).
- Processing suspensions of Title II benefits to persons fleeing prosecution, custody, or confinement, and/or those violating probation or parole as provided in Section 203. This section extends fugitive felon provisions currently applied to Title XVI beneficiaries to Title II beneficiaries.
- Issuing receipts to acknowledge submission of reports of changes in work or earnings status of disabled beneficiaries as provided in Section 202.

The SSPA also authorizes attorney fees to be paid directly out of individuals’ retroactive SSI benefits to the same extent and under the same processes as currently are in place for deducting attorney fees from retroactive OASDI benefits (Section 302). Additionally, it requires SSA to test the impact of establishing a fee payment process for non-attorney representatives that is similar to the current one for attorneys (Section 303).

#### RAILROAD RETIREMENT BOARD

##### PREPARED STATEMENT OF MICHAEL S. SCHWARTZ, CHAIRMAN

Mr. Chairman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board’s (RRB) fiscal year 2006 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit pay-



ments and Medicare coverage for railroad workers. During fiscal year 2004, the RRB paid \$9 billion in retirement/survivor benefits to about 649,000 beneficiaries, and \$83 million in unemployment/sickness insurance benefits to about 34,000 claimants.

We are respectfully requesting a total agency budget of \$103,398,240 in fiscal year 2006. This total includes \$102,543,040 for ongoing agency operations, which is the same as the amount included in the President's proposed budget for the year. In addition, we are requesting \$855,200 for critical elements of the RRB's Enterprise Architecture Capital Asset Plan.

#### ADMINISTRATIVE FUNDING ISSUES

The President's proposed budget would provide the same level of funding for the RRB's administrative expenses in fiscal year 2006 as the amount appropriated for fiscal year 2005. To operate at this level, RRB staffing has been significantly reduced. Early this fiscal year, 77 employees were separated from the agency through a program of voluntary separation incentives, and since that time, new hiring has been severely restricted. The agency's funded staffing level for fiscal year 2005 is currently 76 full-time equivalent staff years (about 7.3 percent) lower than fiscal year 2004.

Continuation of the same funding level from fiscal year 2005 to 2006 would effectively require the RRB to absorb all fiscal year 2006 cost increases for the goods and services required to administer the railroad retirement/survivor and unemployment/sickness insurance benefit programs. These rising costs include the January 2006 pay increase for the agency's employees, which would total approximately \$1.61 million at the currently estimated rate of 2.6 percent.

Under current law, the cost increases would require further cuts in agency staffing, because nearly 80 percent of the RRB's budget is used for employees' salaries and benefits. We estimate that the President's proposed budget would provide sufficient funding for a staffing level of 931 FTE's, which is 41 FTE's less than we expect to use in fiscal year 2005. In order to reach this level, we would need to conduct a reduction-in-force of about 18 employees at an estimated cost of \$233,000.

#### NONGOVERNMENTAL DISBURSEMENT AGENT

The President's proposed budget assumes that the RRB will contract with a nongovernmental agent for disbursement services, as provided under Section 107(e) of the Railroad Retirement and Survivors' Improvement Act of 2001 (Public Law 107-90). However, initial market research has indicated that the cost of doing so would be about three times the cost of having similar services provided by the Department of the Treasury. In addition, our Inspector General has questioned whether certain services provided by the Department of the Treasury, such as reclamations, would be provided as effectively by a nongovernmental disbursement agent.

We have concluded that outsourcing this function would be inconsistent with the President's policy of outsourcing only where the government would save costs. For fiscal year 2005, the Congress added language to our appropriations bill prohibiting this transfer: Section 516 of the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act, 2005 provides that none of the funds appropriated under the Act are to be used to contract with a nongovernmental disbursement agent. The RRB also submitted separate legislation to address this issue during the previous Congress, and we plan to again submit legislation on the subject during this Congress.

Current estimates indicate that the cost of contracting with a nongovernmental disbursement agent would be in excess of \$3 million for the first year and \$2.3 million in subsequent years. By comparison, the annual cost of having these services provided by the Department of the Treasury is about \$800,000. Enactment of legislation to remove this requirement would provide sufficient savings in fiscal year 2006 to enable the RRB to cover essential operating costs at the proposed budget level.

#### ENTERPRISE ARCHITECTURE CAPITAL ASSET PLAN

Our budget request includes funding for a key element of the RRB's Enterprise Architecture Capital Asset Plan, which addresses the major initiatives needed to implement the agency's target enterprise architecture. This request is highlighted separately because of its significance to the long-term, continued viability of agency programs, and the realization that movement toward the desired target architecture will be a multi-year effort involving special funding needs. We are requesting an additional \$855,200 in fiscal year 2006 to continue with an initiative to convert our processing systems to a relational database management system.

Gartner Consulting recommended that we investigate alternatives for our Computer Associates' Integrated Database Management System (IDMS) and prepare to actively retire the platform beyond 2006. The RRB's day-to-day operations are heavily dependent on application systems that are based on IDMS technology. Delaying the database management system conversion would create a high risk of loss for these systems, which would compromise the agency's ability to pay benefits and fulfill its mission in the future. For this reason, we have already begun project development for this initiative. We are currently developing specifications for contractual assistance, and we expect to release a request for proposals later in fiscal year 2005. Preliminary estimates indicate that a full conversion might be accomplished within 12 to 18 months, although our schedule will depend on the availability of resources.

In addition to the requests for administrative expenses, the Administration's budget includes \$97 million to fund the continuing phase-out of vested dual benefits, and \$150,000 for interest related to uncashed railroad retirement checks.

#### FINANCIAL STATUS OF THE TRUST FUNDS

*Railroad Retirement Accounts.*—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (NRRIT), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 to manage and invest railroad retirement assets. The RRB transferred \$586 million to the NRRIT in fiscal year 2004. This amount is in addition to the \$19.188 billion and \$1.502 billion transferred in fiscal years 2003 and 2002, respectively. In fiscal year 2004, the NRRIT transferred \$1.564 billion to the RRB for the payment of tier 2 benefits.

In June 2004, we released the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report, which reflects changes in benefit and financing provisions under the Railroad Retirement and Survivors' Improvement Act of 2001, addresses the 25-year period 2004–2028 and contains generally favorable information concerning railroad retirement financing. The report included projections of the status of the retirement trust funds under three employment assumptions. These indicated cash flow problems only under a pessimistic employment assumption, and then not until calendar year 2026. This is 4 years later than in the previous year's report.

*Railroad Unemployment Insurance Accounts.*—The equity balance of the railroad unemployment insurance accounts at the end of fiscal year 2004 was \$87.5 million, an increase of \$36 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system, issued in June 2004, was generally favorable. The report indicated that even as maximum daily benefit rates rise 35 percent (from \$55 to \$74) from 2003 to 2014, experience-based contribution rates are expected to keep the unemployment insurance system solvent. No loans are anticipated even under our most pessimistic assumption. The average employer contribution rate remains well below the maximum throughout the projection period, but a 1.5 percent surcharge is now in effect and is expected for calendar year 2006 and probably 2007. We did not recommend any financing changes based on this report.

In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. We recognize that fiscal year 2006 will be a tight budget year throughout the Federal government, and our budget request reflects our continued commitment to contain the RRB's administrative costs accordingly. Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

---

#### PREPARED STATEMENT OF MARTIN J. DICKMAN, INSPECTOR GENERAL

Mr. Chairman and Members of the Subcommittee: My name is Martin J. Dickman, Inspector General of the Railroad Retirement Board (RRB). I would like to thank you, Mr. Chairman, and the members of the committee for your continued support for the Office of Inspector General. I wish to describe our fiscal year 2006 appropriations request and our planned activities.

The Office of Inspector General requests funding of \$7,195,968 to ensure the continuation of its independent oversight of the RRB. The agency is responsible for managing benefit programs which paid \$9 billion in retirement and survivor benefits to approximately 649,000 beneficiaries in fiscal year 2004 and an additional \$83 million in net railroad unemployment and sickness insurance benefits to 32,000 claimants. The RRB also administers Medicare Part B, the physician services aspect

of the Medicare program, for qualified railroad retirement beneficiaries. Through this program, approximately \$923 million in annual Medicare benefits are paid to approximately 551,000 beneficiaries.

In fiscal year 2005, the Office of Inspector General will continue to concentrate its efforts on the performance of reviews of significant policy issues and program operational areas. We will coordinate our efforts with agency management to identify and eliminate operational weaknesses. We will also continue our investigation of allegations of fraud, waste and abuse, and refer cases for prosecution and monetary recovery action.

We also request the removal of the prohibition on the use of appropriated funds for any audit, investigation or review of the Railroad Medicare program. The RRB manages a nationwide contract for processing Medicare Part B claims for railroad beneficiaries. The agency is responsible for the enrollment of beneficiaries, premium collection, answering beneficiary inquiries and conducting the annual Carrier Performance Evaluation for the Medicare carrier.

The prohibition does not permit the OIG to fulfill its statutory oversight responsibilities for a major agency program. The prohibition is contrary to Federal government priorities to reduce fraud in one of the largest Federal programs.

We also request oversight authority to conduct audits and investigations of the National Railroad Retirement Investment Trust (NRRIT), the body responsible for the investment of approximately \$27 billion in trust funds used to support Railroad Retirement Act benefit programs. This office would ensure sufficient reporting mechanisms are in place and assess if the NRRIT members are fulfilling their fiduciary responsibilities. We have repeatedly expressed concerns about RRB management's passive relationship with the NRRIT, and identified the issue as a serious challenge for the RRB.

The OIG currently is required to reimburse the agency for office space, equipment, communications, office supplies, maintenance and administrative services. We are the only Federal OIG that cannot negotiate a service level agreement with its parent agency. We, therefore, request that the language in appropriation law be removed.

#### OFFICE OF AUDIT

Auditors will perform the audit of the RRB's 2005 financial statements and preliminary work for the 2006 financial statements to ensure the issuance of reliable financial information. The OIG will obtain the services of a consulting actuary to audit the statement of social insurance.

Audit staff will work with agency management to ensure detailed and verifiable financial information is available from the National Railroad Retirement Investment Trust (NRRIT). As discussed above, we believe RRB management should take a more active interest in NRRIT activities.

They will conduct the annual evaluation of the RRB's information systems security to meet the requirements of the Federal Information Security Management Act of 2002. We will also monitor the agency's information systems operations to determine if the agency is meeting the goals established in its Strategic Information Resources Management Plan and to ensure the agency is in compliance with the provisions of the Information Technology Management Reform Act.

Auditors will continue to monitor agency actions to address security deficiencies and complete corrective actions. They will ensure that network and system security safeguards are in place to protect the confidentiality of sensitive financial and personal information. Auditors will also perform assessments of the agency's e-government initiatives to identify and eliminate system vulnerabilities, and to ensure compliance with the E-Government Act of 2002. We will continue our monitoring efforts of the RRB's document imaging activities and the expansion of paperless processing to ensure the integrity of records.

Auditors will continue to review RRB benefit processes and procedures to identify ways to reduce administrative and adjudicative errors. They will offer recommendations to strengthen the agency's debt collection program to reduce the outstanding receivables.

#### OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) identifies, investigates and presents cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. In fiscal year 2006, OI will continue to focus its resources on the investigation of cases with the highest fraud losses. OI currently has approximately 500 active investigations involving fraudulent benefit payments and fraudulent reporting with fraud losses of approximately \$11 million. These cases involve all RRB pro-

grams that provide sickness and unemployment insurance benefits to injured or unemployed workers, retirement benefits, and disability benefits for workers who are disabled.

We will continue our efforts with program managers to address weaknesses in agency programs that allow fraudulent activity to occur, and will recommend changes to ensure program integrity.

We will concentrate our resources on cases with the highest fraud losses, those related to the RRB's retirement and disability programs as well as fraudulent reporting by railroad employers. OI will dedicate considerable resources to the investigation of nationwide schemes to defraud the RRB disability program. Disability cases currently constitute about 40 percent of our investigative caseload. These cases involve more complicated schemes and result in the recovery of substantial funds for the agency's trust funds.

In fiscal year 2006, we will continue to use the Department of Justice Affirmative Civil Enforcement (ACE) program for those cases which do not meet the criminal guidelines of U.S. Attorneys. Through this program, we are able to obtain civil judgements and recover trust fund monies for the RRB.

#### SUMMARY

In fiscal year 2006, the Office of Inspector General will continue to focus its resources on the review and improvement of RRB program operations and ensuring the integrity of agency trust funds. We will also continue to aggressively pursue individuals who engage in activities to fraudulently obtain RRB funds.

## NONDEPARTMENTAL WITNESSES

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

### DEPARTMENT OF LABOR

#### PREPARED STATEMENT OF MOTIVATION, EDUCATION AND TRAINING, INC.

Honorable Chairman, Senator Arlen Specter, and Honorable Committee Members: It is with sincere appreciation that I convey our gratitude for your efforts on behalf of all hard working Americans, and for granting us the opportunity to share information about the nation's migrant and seasonal agricultural workers and the importance of the National Farmworker Jobs Program.

I am the executive director of Motivation Education & Training, Inc. (MET), the authorized National Farmworker Jobs Program (NFJP) operator in Louisiana, Minnesota, North Dakota, and Texas, which are all funded through Section 167 of the Workforce Investment Act (WIA). MET is a community-based organization headquartered near Houston, Texas, and has been actively engaged serving low-income populations and communities for almost four decades.

Since the 1960s, the affirmative efforts of both Congress and various Presidential Administrations have created and preserved a modest, though vital, system to aid farmworkers and their family members who seek improved economic prospects through career training and stabilization services. As you may know, a typical American agricultural worker faces some of the harshest working conditions in the United States, and yet their compensation is neither commensurate with the risks taken, nor sufficient for the work performed. During the most recently completed Program Year, MET served more than 3,000 migrant and seasonal farmworkers with reported average annual earnings of \$5,855 per client. Despite this shockingly low income, very few farmworkers, only 6.3 percent, seek and receive public assistance, preferring instead the path of self-reliance and an extremely meager existence.

Uncertainty, which is inherent in the agricultural economy, ensures the perpetuation of a cruel paradox wherein extended periods of joblessness due to lack of available work, are interspersed with fleeting spikes in labor demand as crops mature or weather conditions permit activity in the fields. The long distances that many farmworkers and their families travel represents the desperate tradeoff between the mere hope of income and the likelihood that any semblance of stability can be achieved and maintained. But members of this community face severe challenges when seeking to exercise other career options, and for many families, reliance on agriculture is passed along from one generation to the next, thus ensuring the inheritance of work, subsistence, and poverty for decades to come.

Historically, migrant and seasonal farmworkers have had relatively limited access to the public workforce investment system. A number of factors have worked in concert to discourage their participation, and even in the recently expanded One-Stop network, farmworkers can expect little assistance outside of the local systems where NFJP programs consistently offer high caliber career development and stabilization services. Yet despite both the need for the program and the phenomenal performance of the NFJP with respect to all other workforce investment programs, the current leadership at the US Department of Labor fails to see any value in preserving this most basic form of individual, family, and community economic development. Though duly authorized in WIA we now face the regular threat of elimination, but MET and our partners across the country continue to strive for better employment options for farmworkers and increased earnings that can move families out of poverty and into progressively higher tiers of economic stability and security.

Within the last year, a series of DOL-sponsored community forums in three regions of the country reinforced the necessity of preservation of the NFJP. The dialogues brought together local workforce boards, local and regional One-Stop partners, state agencies, federal stakeholders, and NFJP representatives in a setting

that encouraged analysis and discussion related to improved One-Stop access for migrant and seasonal farmworkers. The forum in Texas that I attended primarily served as the central U.S. regional dialogue, and ultimately delivered two resounding messages: (1) preservation of the NFJP is crucial if farmworker clients can expect any type of appropriate workforce investment service; (2) expanded farmworker access to the One-Stop system is an improbable, if not impossible, prospect in the absence of the NFJP or a substantially similar nationally-administered initiative.

Workforce board representatives affirmed the necessity of our experienced and capable administration of workforce investment services for migrant and seasonal farmworkers. Citing the complexity of the challenge that farmworker clients represent to the general system's core, intensive, and training delivery operations, as well as our singular expertise in working with these constituents, boards and other key stakeholders candidly expressed their concerns about some of the limitations within the evolving One-Stop system. I did not hear one dialogue participant state, suggest, or even imply that passing responsibility to the states and local boards would do anything except dramatically reduce farmworker access to public workforce services.

A reasonable evaluation of NFJP performance clearly places this critical workforce component in the highest echelon of WIA authorized partners, achieving better results than programs that receive substantially more funds per client, as well as those serving populations that are better equipped than farmworkers upon program entry to secure sustainable employment. We work hard to place our clients in permanent positions that will afford an opportunity for consistent long-term upward mobility, and that provide compensation packages consistent with the needs of today's families. Few jobs are permanent in the strictest sense, and given the nature of the evolving global economy, an individual's ability to acquire and retain employment is only as promising as that person's capacity to satisfy emerging skill demands and their facility in utilizing available resources to promote their employment. Without the individual attention and highly intensive case management intervention that is available to farmworkers only through the NFJP, most of this population would be unable to matriculate or complete a workforce development training program of the type necessary to secure and retain higher wage and higher skill employment.

Belt-tightening and budget reductions are inevitable considerations in light of the current federal revenue shortfall; however, we would do immeasurable injustice to a worthy few and an extreme disservice to our national character if, in our attempt to reduce expenditures, we place a heavier load on the backs of our already overburdened and less fortunate citizens. I would respectfully request your favorable consideration of full restoration for the NFJP in fiscal year 2006, and if that proves altogether too ambitious, at least the maintenance of current federal support for this crucial component in the struggle for economic self-sufficiency among the poorest of America's workers.

---

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF HOME BUILDERS

On behalf of the more than 220,000 members of the National Association of Home Builders (NAHB), as well as our workforce development arm, the Home Builders Institute (HBI), we thank you for the opportunity to submit this statement for the record on the Responsible Reintegration of Youth Offenders program, and the Prisoner Re-entry Program.

NAHB members are involved in home building, remodeling, multifamily construction, property management, subcontracting, design, housing finance, building product manufacturing and other aspects of residential and light commercial construction. Known as "the voice of the housing industry," NAHB is affiliated with more than 800 state and local home builder associations around the country. NAHB's builder members will construct about 80 percent of the more than 1.6 million new housing units projected for 2005, making the housing industry one of the largest engines of economic growth in the country, and vital to the nation's overall economic growth and prosperity.

Throughout the past two decades, one of the most pressing problems confronting our industry has been a shortage of skilled workers. Record numbers in the construction of new homes, retirements and lackluster interest in the construction trades by younger generations, compounded by insufficient training opportunities for those interested in construction, are among the many factors contributing to the shortages. According to the Bureau of Labor Statistics, some 240,000 workers are needed each year to meet the nation's demand for housing, and they anticipate that

over 1 million new jobs in the residential construction industry will be created in the next decade as builders attempt to keep up with demand for affordable housing.

#### HOME BUILDERS INSTITUTE (HBI) PROGRAM BACKGROUND

Each year, the Home Builders Institute (HBI) works through various programs to train and place several hundred youth in residential construction jobs. Through real-life, hands-on training, some of our nation's most at-risk young people, learn a skill, and earn a second chance at a productive and successful life and career. Since 1994, HBI has focused a significant portion of its effort and resources on one particular targeted population, adjudicated youth, through its Project CRAFT (Community Restitution Apprenticeship-Focused Training) program. Piloted in 1994 through a Department of Labor demonstration grant, Project CRAFT is targeted solely to adjudicated youth and youthful offenders. This program has successfully combined employers, the juvenile justice system, workforce development and other systems, in one overall approach, and has since been implemented at 15 sites in ten states (Colorado, Ohio, Florida, Maryland, Mississippi, New Jersey, North Dakota, South Carolina, Tennessee, and Texas). Funding for HBI's implementation of this program in the state of Tennessee has come largely through funds provided under the Responsible Reintegration of Youth Offenders budget line.

Project CRAFT incorporates the apprenticeship concept of hands-on training and academic instruction, utilizing its Pre-Apprenticeship Certificate Training (PACT), numeracy, literacy and employability skills curricula. Under the supervision of journey-level trade instructors, students learn residential construction skills while completing community service construction projects. Nearly 85 percent of Project CRAFT graduates achieve success through industry jobs each year.

Since 1994, Project CRAFT has helped more than 2,000 high-risk youth, and in addition to offering adjudicated youth trade skills and job placement, community service projects by students saved taxpayers nearly \$400,000 in labor costs in 2003–2004 alone. During 2003–2004, Project CRAFT graduates were placed in jobs with an average wage of \$8.58/hour and graduates performed over 49,000 hours of community service as part of their programs. Recidivism rates for Project CRAFT have averaged between 10–15 percent, an impressive rate when compared to the national average of over 50 percent. Additionally, students in the program tend to evidence one grade level of improvement in math and language skills attributable largely to the formal education component that includes contextual learning. Math and communication skills are continually reinforced as students are challenged to apply these skills to everyday situations in the field and in the classroom.

Project CRAFT efforts were recognized by the Department of Labor and the National Youth Employment Coalition when in September 2002, the program received a PEPNet (Promising and Effective Practices Network) Award. We are also grateful to the Senate Subcommittee on Labor, Health and Human Services and Education for its acknowledgement of Project CRAFT in fiscal year 2005 Report Language, as well as Congress' years of dedicated support for the Responsible Reintegration of Youth Offenders program.

#### RESPONSIBLE REINTEGRATION OF YOUTH OFFENDERS PROGRAM

NAHB and HBI's encouraging experience with Project CRAFT is an example of the enormous success of the Responsible Reintegration of Youth Offenders pilot program, and the reason why we very strongly support the continuation of funding for a youth-focused program targeting adjudicated youth with training that provides this at-risk population with important job- and life-skills. The Responsible Reintegration of Youth Offenders Program has helped to bring together industry and government in a partnership with tangible positive outcomes. Since 1994 the program has earned a reputation as a worthwhile investment of taxpayer dollars, a significant and important resource to the nation's building industry, and a major contributor to the future success of thousands of young people. It is a demonstration model that works, and as such deserves to be touted and replicated. We hope that its proven success and recognition as an effective intervention will help enable it to receive continued funding, whether through a stand-alone program, or as part of a youth-focused component of the Prisoner Re-entry Program.

#### PRISONER RE-ENTRY PROGRAM

In its fiscal year 2006 budget proposal, the administration proposes to fund the Prisoner Re-entry Program through appropriations to three federal departments (Department of Labor, \$35 million; Department of Justice \$15 million, Department of Housing and Urban Development, \$25 million.) We hope this joint funding level will provide more opportunities to train the nation's at-risk youth. The Prisoner Re-

entry Program continues to focus on “helping individuals exiting prison make a successful transition to community life and long-term employment” through programs to help ex-offenders find and keep employment, obtain housing, and take advantage of mentoring programs.

NAHB and HBI support the goals of the Prisoner Re-entry program, and agree that there is enormous potential for successful programming targeting ex-offenders. NAHB and HBI continue to believe that an important targeted community within the Prisoner Re-entry program must be adjudicated juveniles and we support extending Prisoner Re-entry program eligibility to adjudicated juveniles and youthful offenders ages 16–24, in addition to other age groups served by the program. We have found that these young people in particular are energetic, interested and engaged in learning the skills taught through our Project CRAFT program. We believe that any funding targeted to training those who are re-entering society must include a component targeted to the youth offender population.

As we have stated, the Prisoner Re-entry program has significant potential for helping the adult offender community receive important training and job skills. And we believe that HBI is well-positioned to participate in an adult-focused program through its Project TRADE (Training, Restitution, Apprenticeship, Development and Education) program—which is the sister program to the youth-focused Project CRAFT. Designed to train and place adult offenders in employment in the home building industry, TRADE is currently being implemented in Colorado Springs and Sheridan, Ill. Project TRADE has trained over 500 adult offenders in the residential construction trade since 1995 through programs in Maryland, North Carolina, North Dakota, Oregon, Pennsylvania, Washington, Tennessee, Colorado and Illinois. We believe that Project TRADE’s emphasis on adults complements the work done by Project CRAFT with younger offenders.

#### CONCLUSION

NAHB and HBI continue to strongly support the goals of the Responsible Reintegration of Youth Offenders program. We also support the Department of Labor’s interest in targeting a program to ex-offenders and adjudicated individuals through the Prisoner Re-entry program, and we very strongly support the inclusion of youth offenders and adjudicated juveniles in this initiative.

We believe that the Responsible Reintegration of Youth Offenders demonstration program has been highly successful, as evidenced by our own accomplishments with Project CRAFT. We fervently hope that any proposal supported by congressional appropriators will take into account the needs of both the youth and adult ex-offender populations, and will clearly lay out congressional intent to continue serving the youth ex-offender population.

Again, we thank the subcommittee for this opportunity to share our views on the Responsible Reintegration of Youth Offenders program, and Prisoner Re-entry Initiative. We look forward to working with you to promote training programs that help America’s at-risk youth acquire the skills they need for successful and productive careers in the home building industry.

---

#### PREPARED STATEMENT OF THE NATIONAL COALITION FOR HOMELESS VETERANS

##### INTRODUCTION

The National Coalition for Homeless Veterans appreciates the opportunity to submit recommendations on fiscal year 2006 appropriations for and program management issues related to the U.S. Department of Labor (DOL).

The National Coalition for Homeless Veterans (NCHV), established in 1990, is a nonprofit organization with the mission of ending homelessness among veterans by shaping public policy, promoting collaboration, and building the capacity of service providers. NCHV’s nearly 250 member organizations in 46 states and the District of Columbia provide housing and supportive services to homeless veterans and their families, such as street outreach, drop-in centers, emergency shelter, transitional housing, permanent housing, recuperative care, hospice care, food and clothing, primary health care, addiction and mental health services, employment supports, educational assistance, legal aid and benefit advocacy.

More than 250,000 veterans are homeless on any given night; more than 500,000 experience homelessness over the course of a year. Conservatively, one of every three homeless adult males sleeping in a doorway, alley, box, car, barn or other location not fit for human habitation in our urban, suburban, and rural communities has served our nation in the Armed Forces. Homeless veterans are mostly males (2 percent are females). 54 percent are people of color. The vast majority are single,



although service providers are reporting an increased number of veterans with children seeking their assistance. 45 percent have a mental illness. 50 percent have an addiction.

America's homeless veterans have served in World War II, Korea, the Cold War, Vietnam, Grenada, Panama, Lebanon, anti-drug cultivation efforts in South America, Afghanistan, and Iraq. 47 percent of homeless veterans served during the Vietnam Era. More than 67 percent served our nation for at least three years and 33 percent were stationed in a war zone.

Male veterans are twice as likely to become homeless as their non-veteran counterparts, and female veterans are about four times as likely to become homeless as their non-veteran counterparts. Like their non-veteran counterparts, veterans are at high risk of homelessness due to extremely low or no income, dismal living conditions in cheap hotels or in overcrowded or substandard housing, and lack of access to health care. In addition to these shared factors, a large number of at-risk veterans live with post traumatic stress disorders and addictions acquired during or exacerbated by their military service. In addition, their family and social networks are fractured due to lengthy periods away from their communities of origin. These problems are directly traceable to their experience in military service or to their return to civilian society without appropriate transitional supports.

Contrary to the perceptions that our nation's veterans are well-supported, in fact many go without the services they require and are eligible to receive. One and a half million veterans have incomes that fall below the federal poverty level. Neither the VA, state or county departments of veteran affairs, nor community-based and faith-based service providers are adequately resourced to respond to these veterans' health, housing, and supportive services needs. The VA plays only a limited role in providing employment services to veterans, administering just one small supported employment program for veterans with serious disabilities.

The U.S. Department of Labor and state and local workforce agencies bear primary responsibility for ensuring that veterans are provided opportunities to prepare for and obtain productive employment. Accordingly, we urge Congress to provide full funding for the programs of the Department of Labor Veterans Employment and Training Service (VETS) in order to ensure that our nation's workforce services system is equipped to fulfill their obligations to our nation's veterans.

FISCAL YEAR 2006 APPROPRIATION RECOMMENDATION—HOMELESS VETERAN  
REINTEGRATION PROGRAM

The Homeless Veterans Reintegration Program (HVRP), within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer outreach, job placement and supportive services to homeless veterans. HVRP is the primary employment services program accessible by homeless veterans and the only targeted employment program for any homeless subpopulation. Homeless veterans have many additional barriers to employment than non-homeless veterans due to their lack of housing. HVRP grantees remove those barriers through specialized supports unavailable through other employment services programs. Grantees are able to place HVRP participants into employment for \$2,100 per placement, a tiny investment for moving a veteran out of homelessness, and off of dependency on public programs.

DOL estimates that 14,750 homeless veterans will be served through HVRP at the fiscal year 2005 appropriation level of \$21 million. This figure represents just three percent of the overall homeless veteran population, which the Department of Veterans Affairs estimates numbers more than 500,000 over the course of a year. An appropriation at the authorized level of \$50 million would enable HVRP grantees to reach approximately 24,000 homeless veterans.

Additionally, HVRP is being used as the account to fund a joint Department of Labor and Department of Veterans Affairs initiative authorized by Congress to assist veterans incarcerated in their reentry to the community. This decision essentially adds a new purpose to the HVRP program, for which additional funds are needed.

We urge Congress to appropriate at least \$50 million for HVRP in fiscal year 2006 Labor-HHS-Education appropriations legislation.

## FUNDING FOR HOMELESS VETERANS REINTEGRATION PROGRAM

[In millions of dollars]

Fiscal year	Amount
2004 .....	19
2005 .....	20.8
2006—Administration .....	22
2006—NCHV .....	50

## FISCAL YEAR 2006 APPROPRIATION RECOMMENDATION—VETERANS WORKFORCE INVESTMENT PROGRAM

The Veterans Workforce Investment Program (VWIP), within the Department of Labor's Veterans Employment and Training Service (VETS), provides grants to states and community-based, faith-based, and local public organizations to offer workforce services targeted to veterans with service connected disabilities, with active duty experience in a war or campaign, recently separated from the service, or facing significant barriers to employment (including homelessness). At least 80 percent of total VWIP funds are distributed via competition. VETS may reserve 20 percent of total VWIP funds for discretionary grants. VETS uses these discretionary funds for studies, demonstration projects, and additional funding to supplement competitive grants. The fiscal year 2005 appropriation for VWIP is \$8.5 million.

Both those agencies that receive VWIP funds and those hoping to apply face the problem of resource scarcity. Due to funding limitations, agencies and organizations in less than half of states receive VWIP funds. The need for the type of targeted assistance that VWIP offers is clearly needed by veterans in all states. Additionally, caps on the size of grant awards make it difficult for existing grantees to recruit and retain staff. This limits program effectiveness and the collaborative process. Sadly, the President's fiscal year 2006 request is a step backward, reversing the one million increase that Congress appropriated just last year.

We urge Congress to appropriate at least \$33.5 million for VWIP in fiscal year 2006 Labor-HHS-Education appropriations legislation.

## FUNDING FOR VETERANS WORKFORCE INVESTMENT PROGRAM

[In millions of dollars]

Fiscal year	Amount
2004 .....	7.5
2005 .....	8.5
2006—Administration .....	7.5
2006—NCHV .....	33.5

## CONCLUSION

NCHV appreciates the opportunity to submit recommendations to Congress regarding the resources and activities of the U.S. Department of Labor. We look forward to continuing to work with the Appropriations Committee in ensuring that our federal government does everything within its grasp to prevent and end homelessness among our nation's veterans. They have served our nation well. It is beyond time for us to repay the debt.

## PREPARED STATEMENT OF THE OPPORTUNITIES INDUSTRIALIZATION CENTER OF WASHINGTON

Honorable Chairman Specter and members of the Subcommittee: Opportunities Industrialization Center of Washington (OIC) has been providing employment and training, educational, nutritional and other community services in Central Washington for over 34 years. Since July of 1999, we have been the U.S. Department of Labor National Farmworker Jobs Program (NFJP) grantee for the state of Washington. Agriculture is one of Washington State's principal industries; the value of major crops alone is approximately \$5.5 billion per year.

Our NFJP program operates six regional offices and three satellite offices in central and western Washington. OIC provides a full range of core, intensive, training, and related assistance services to eligible farmworkers and dependents. From July of 1999 to June of 2004, we provided direct services to approximately 3,200 farm-

workers, most all of whom had substantial barriers to employment. Approximately 41 percent of our customers had less than an 8th grade education and an additional 29 percent had only up to an 11th grade education. Also, 58 percent of customers were limited English proficient, 79 percent lacked significant work history outside of agriculture, 34 percent lacked transportation, and 20 percent were single head of household with children. Over 80 percent were unemployed at the time they entered our program. In light of these obstacles, our staff did an excellent job in obtaining year-round employment for approximately 1,200 of our customers, which was 114 percent of program goals during this time period.

OIC has been a part of the development of our state's WorkForce Development System (the OneStop system) and are partners in each of the Workforce Development Councils within the areas that we provide services. This includes participation on key committees as the voice of the farmworker, as well as out-stationing of staff in each area's WorkSource Center. It is our experience that, while our state's WorkSource Centers provide quality services overall, they are not yet positioned to provide adequate services to the farmworker community.

Traditionally, farmworkers in our state have been reluctant to go to official/bureaucratic settings in order to receive services. This holds true for our WorkSource Centers, most of which are housed in what were formerly Washington State Employment Security Department Job Service Centers, and which continue to be managed by this agency. Most WorkSource Centers maintain traditional business hours, Monday through Friday from 8:00 a.m. to 5:00 p.m. Moreover, service delivery is designed around a self-service methodology and makes extensive use of computer-based systems. As a result migrant and seasonal farmworkers are prevented from accessing services due to hours of operation. Also, people with low levels of literacy and/or limited/non-existent computer skills such as our customers cannot make effective use of available resources.

A compounding problem is the lack of resources needed to adequately serve customers with substantial barriers to employment. Our state is currently working to develop its biennium budget, which currently has a \$2.1 billion shortfall. Major cutbacks are targeted for most all state agencies, including the Employment Security Department which operates the WorkSource centers.

For years, our WorkSource Centers have struggled to maintain adequate staffing due to budgetary constraints. With our state's current budget crisis, this problem will only worsen. Our NFJP program has helped to alleviate this problem by out-stationing staff on a regularly scheduled basis in the eight WorkSource Centers and affiliate sites. Our bilingual-bicultural staff provides direct services to customers and collaborating with our other WorkSource partners in serving the universal access needs of our customers in general, and farmworkers and agricultural employers in particular.

The National Farmworker Jobs Program has been a success both nationally and within the state of Washington. To our knowledge, there are no resources at the federal or state level to fill the void that will occur if its funding is reduced or eliminated. Thus, the vital services now provided through the NFJP to Washington State's migrant and seasonal farmworkers, as well as to our state's WorkSource system, will not be replaced.

#### OIC NFJP SUCCESS STORIES

The following illustrates both the value provided through the National Farmworker Jobs Program, and the perseverance and dedication of those whom we are entrusted to serve.

Mrs. P came to Washington State with her family, not knowing anyone here or having any family members. Over most of her 17 years of married life, Mrs. P had never worked outside the home, while her husband provided for their five children (ages range from 3 years to 16 years) and her. Things changed dramatically when her husband suffered a severe emotional trauma resulting from his involvement in a fatal accident, together with other negative incidents. He has since been unable to work and is on long-term disability.

Without a high school education, no driver's license or work experience, Mrs. P was only able to work in agriculture. She found her way to our office through the referral of a previous participant. Following assessment, an Individual Employment Plan was developed with Mrs. P to help her move out of the fields and into a good job that paid a livable wage. Mrs. P began work experience training in our Mount Vernon office as an Office Assistant and attended GED classes in the evenings. Later that fall she received training in our Office Technology course, a class developed specifically for our participants to teach them keyboarding, Microsoft office professional programs and prepare them for an office occupation (classes are held in

the evening to accommodate participant such as Mrs. P who have to work during the day to support families). Mrs. P was also provided with job search/resume assistance that lead to an OJT with Housing Authority of Skagit County as a full time General Office Clerk earning \$9.28 an hour. Mrs. P also worked hard to get her Washington State Driver's License and after three attempts she finally realized this goal. Through her diligence, and the opportunities provided through our program, Mrs. P is now working as a Section 8 Specialist earning \$11.15 an hour with Housing Authority of Skagit County.

Prior to coming to our program, Ms. A. was, in her words, "On the road to nowhere." Abused as a child, she attempted suicide at 11 and ran away from home at the age of 13. When she found her way to our Wenatchee office, she was unemployed and without any funds to support her 16 year old son and herself. Her only meaningful employment was 20 years spent working in the orchards since she was 13. As might be expected, she never attended high school, and her prospects for full-time employment were bleak.

Staff met with Ms. A to perform an assessment to address her immediate needs; identify her skills, interests, and goals; and put together a plan to meet those goals. Ms. A focused on two goals that had always eluded her: to earn her GED and obtain a permanent job through which she could support her son.

Staff immediately provided Ms. A with emergency services for food and shelter to stabilize her situation. They then enrolled her into an evening High School Equivalency program to provide the instruction and tutoring she needed to work towards her GED. Also, a work experience placement was developed to help her develop essential job-related skills, while also providing income to her household. Staff also provided Ms. A with ongoing counseling and support to help her attain success.

Through her hard work, Ms. A felt the pride of having her son watch as she received her GED in a graduation ceremony with 22 other farmworkers. She also realized her employment goal when she became a full-time receptionist and assistant to the housing director for the Wenatchee Women's Resource Center. In all, staff worked with Ms. A for approximately one year to assist her in moving back onto a "road to somewhere."

---

#### PREPARED STATEMENT OF THE NATIONAL JOB CORPS ASSOCIATION, INC.

On behalf of the National Job Corps Association (NJCA) we want to thank the Labor, Health and Human Services and Education Appropriations Subcommittee for its dedication to Job Corps and our country's most vulnerable youth. For 40 years, Job Corps has consistently demonstrated its relevance and positive results for employers and youth. The program's supporters represent a bipartisan and broad coalition of congressional leaders; employers and community organizations; and other key decision-makers. They all agree that Job Corps has adapted to America's economic changes by listening to local and national businesses. In turn, Job Corps has partnered with high demand, high growth businesses to develop innovative solutions to meet their workforce needs and find life-long careers for America's most economically disadvantaged youth.

We appreciate the Committee's strong support for the Job Corps program and urge you to provide Job Corps with \$1.6 billion in the fiscal year 2006 appropriations process. The NJCA is deeply concerned that President's budget request does not go far enough to efficiently maintain the effective job training and educational services and the requisite infrastructure necessary to serve Job Corps' estimated 68,000 students entering the 21st century workforce. While we encourage spending restraint by the United States Government, we also believe it is imperative to provide adequate funding to programs with proven positive results. We believe the work that Job Corps accomplishes on a daily basis goes hand-in-hand with the economic prosperity and security of our local communities and our nation.

#### JOB CORPS SUCCESSES

Job Corps is known as "America's first choice for a second chance" for a good reason. Job Corps works. Over the past 40 years, Job Corps has instilled in more than 2 million youth the skills and attitudes they need to become productive, contributing participants of the nation's workforce. For a moment, consider some of Job Corps' most shining examples and see for yourself why Job Corps is considered one of the most successful job training programs in the country.

Judge Sergio Gutierrez attended the Wolf Creek Job Corps Center (Oregon) in 1970 after he decided to drop out of high school to provide additional money for his family which was barely making ends meet at the time. The self proclaimed introvert proudly recalls how Job Corps enabled him to come into his own as a leader

of a carpentry crew. After graduating from Job Corps, Judge Gutierrez enrolled at Boise State University where he received his B.A. in Elementary Education. After teaching fifth grade and English as a Second Language for a few years, Judge Gutierrez went back to school to earn his Juris Doctor degree from the University of California. In 1993, Judge Gutierrez was selected to serve as the district judge for the 3rd Judicial District of Idaho. In 2002, he earned a higher judicial appointment, this time as a member of the Idaho Court of Appeals. Today, Judge Gutierrez takes his children to visit Job Corps centers. Judge Gutierrez said, "I wanted them to see where my success began."

Jasmine Small, a Licensed Practical Nursing (LPN) graduate from the Keystone Job Corps Center (Pennsylvania) graduated from the program and went on to pass the Pennsylvania State Board of Nursing Exam. The Tobyhanna, Pennsylvania native completed her clinical rotation at the Kingston HCR Manor Care facility, and in August 2004 accepted a job on-site. Small aspires to be a Registered Nurse (RN) one-day. "Job Corps helped me grow strong and determined to get things done," Small said. Thanks to employer partners like HCR Manor Care, Small will continue to advance her career within the health care field.

#### NJCA FISCAL YEAR 2006 REQUEST

The NJCA requests a total of \$1.6 billion for Job Corps in the fiscal year 2006 budget: \$1.486 billion for Job Corps' Operational account and \$115 million in the Construction, Rehabilitation and Acquisitions (CRA) account. The NJCA believes that Job Corps merits a \$54 million increase over the fiscal year 2005 appropriations. This increase would provide a modest cost-of-living increase over the fiscal year 2005 enacted levels that unfortunately have not been addressed over the last two fiscal cycles. The increase would allow Job Corps to maintain its existing student services and allotted slots with a full inflationary adjustment for the 122 centers, address infrastructure rehabilitation needs, continue to eliminate the \$350 million backlog of repairs, and provide second year funding for incremental expansion of Job Corps.

#### *Operational Funds*

As the nation's largest residential education and job training program, Job Corps is designed to serve our nation's at-risk youth who might otherwise "fall between the cracks." Job Corps succeeds by providing a safe place to learn the literacy, vocational, and employability skills youth need to become productive, taxpaying members of their community.

Job Corps' 24-hour-a-day, 7-day-a-week program of individualized attention, discipline, and support has produced long-term results that save taxpayer dollars. As a residential program, Job Corps operations are particularly vulnerable to fixed cost increases, including wholesale food, transportation, utilities/energy, and health care. As you are aware, the price of gasoline has spiked to all-time highs in the last three years; food and beverage costs have increased by 24 percent over the last ten years; and medical costs and health insurance premiums have risen at double-digit rates. These increases are costs Job Corps cannot control. While Job Corps has been implementing strategies to decrease costs—particularly energy costs—money has to be invested in the short-term to save money in the future. We all know that investing in our homes increases the property value. Investing in Job Corps increases the value of our local economies through an increased number of youth—32 percent of Job Corps youth come from families on public assistance—becoming well-positioned taxpaying members of their communities.

Job Corps continues to maintain a high placement rate. In fact, more than 90 percent of all Job Corps graduates get jobs, enlist in the military, or enroll in higher education, making Job Corps America's most effective job training programs for economically disadvantaged youth.

In fiscal year 2006 the NJCA requests the Committee provide \$1.486 billion for Job Corps' Operational account. This would allow Job Corps to:

- Maintain existing student services and allotted slots with a full cost-of-living increase for the 122 Job Corps centers across the country;
- Continue Job Corps' rigorous 24-hour-a-day, comprehensive residential services for approximately 68,000 economically disadvantaged youth per year;
- Provide funding necessary to cover the escalating costs of staff salaries, wholesale food, utilities/energy, transportation, medical, mental and dental services, and workers compensation insurance; and
- Develop Job Corps pilot and demonstration projects to strengthen academic and vocational offerings in high-growth and emerging occupations, including but not limited to health care, homeland security, and the military.

*Construction, Rehabilitation and Acquisition (CRA) Funds*

With respect to Job Corps' capital account, the NJCA requests \$115 million in fiscal year 2006. These funds would be targeted to: repair dorms, classrooms, and other student facilities on existing Job Corps centers; replace deteriorated structures, especially those that threaten safety and health or violate minimum building codes, including mechanical systems; continue to address the estimated \$350 million backlog in construction and/or repair needs; and provide second year funding for incremental Job Corps expansion.

As you know, Job Corps gives young people the opportunity to focus and learn in a safe, stable, and supportive environment. However, the average building on a Job Corps center is 46 years-old—20 years older than the industry standard. While the program is trying valiantly to address the backlog of construction and repair improvements, it needs more funding to allow students to learn in an auspicious setting. Over the past several years, the Committee has taken a proactive approach to provide the program with the funds necessary to maintain Job Corps' physical plant. We thank the Committee for its strong support and urge Members to continue that support in fiscal year 2006.

*Incremental Expansion*

Within Job Corps' CRA account, the NJCA strongly supports \$15 million for second year funding for the Congressional supported incremental expansion of Job Corps. As part of the NJCA's 10-year initiative—Job Corps: For the Nation and the Next Generation—to strengthen and improve Job Corps, the NJCA supports the Committee's past effort to designate centers as "High-Growth Centers," designed specifically to address the country's most vital workforce needs. The NJCA envisions these "High-Growth Centers" providing academic and vocational training in the following high growth, high demand industries such as: automotive, construction, financial services, health professions, hospitality, information technology, homeland security, and transportation. In Job Corps' most recent expansion process, more than 50 communities across the nation applied for new centers in their communities. Since that time, many other communities have expressed interest, including Las Vegas; Nevada; Ottumwa, Iowa; and the states of New Hampshire and Wyoming, the only states lacking a Job Corps center. The NJCA looks forward to working with the Committee to continue the incremental expansion of Job Corps.

*Preparing the Workforce for the 21st Century Job Corps: For the Nation and the Next Generation*

Increasingly, private and public employers have turned to the Job Corps program for qualified entry-level recruits. While they are enthusiastic about the employees they hire from the program, they commonly express one limitation: the number of trained and employment-ready graduates in these fields is too small. Although Job Corps is the nation's largest national residential training and education program, it currently can accommodate only about 68,000 students per year. Hospitals, pharmacies, nursing homes, the U.S. Army and Navy, civilian military support contractors, security firms, local police departments, and ambulance companies all say that they can hire as many qualified applicants as Job Corps can produce. Job Corps has beds, however, for only one percent of youth eligible to attend the program.

To address these demands, the NJCA has developed a decade-long initiative, Job Corps: For the Nation and Next Generation, to strengthen and expand Job Corps to help meet our nation's needs for trained, entry level workers in three areas: health care, homeland security, and military preparedness. This Initiative would leverage the contributions of private and public sector partners with federal appropriations to expand Job Corps' capacity to train entry-level employees in these three crucial areas of shortage. The Initiative would produce quantifiable results over 10 years: 60,000 graduates in health care occupations, 50,000 graduates defending homeland security, and 50,000 military personnel. To support this Initiative, the NJCA requests dedicated funds beyond the NJCA's \$1.6 billion request in the following federal programs and/or Departments:

*Addressing the Nation's Health Care Workforce Shortage*

The NJCA requests dedicated funding—\$5 million—for the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions to address the shortage of health care professionals and provide access to health care vocational opportunities for many disadvantaged young people enrolled in Job Corps. The NJCA strongly believes that Job Corps centers are uniquely qualified to utilize HRSA grant programs to train students to pursue health careers while generating more health care professionals to serve economically disadvantaged communities. The NJCA urges that HRSA funds be dedicated to Job Corps in two key grant pro-

grams: Pathways to Health Professions Demonstration Program and Health Careers Adopt-a-School Demonstration Program.

*Ensuring Safer Communities for the Nation*

Within the Department of Homeland Security (DHS) and building upon language in the fiscal year 2005 Omnibus Appropriations legislation, the NJCA requests funds—\$2 million—for a pilot demonstration program to establish local relationships between the Transportation Security Administration (TSA) at three designated Job Corps centers. The pilot program would study the needs of airports and attrition rates of airport security personnel and the feasibility of utilizing local Job Corps centers with security training programs as suppliers of qualified, eager-to-work homeland security and airport screener employees.

The NJCA also requests funds—\$3 million—from DHS in fiscal year 2006 budget to develop fully recognized Federal Emergency Management Agency (FEMA) training sites at three designated Job Corps centers. The partnership between FEMA and Job Corps would include Homeland Security and Fire Safety certifications that are currently incorporated into existing Safety/Security vocational programs on Job Corps campuses across the country.

*Enhancing America's Security and Readiness*

Building upon the mutually beneficial relationships that Job Corps has established with the U.S. Army, U.S. Navy, U.S. Coast Guard, and U.S. Army and Air National Guard, the NJCA requests \$5 million from the Department of Defense (DOD) to develop military-endorsed curriculum in order to establish six military preparation programs that would increase the number of Tier I high quality accessions recruits joining the military. These military preparation programs would be incorporated within a student's academic and vocational training. By providing these funds, Job Corps can significantly supplement the military's efforts to address unmet recruiting and retention needs through a 40-year successful residential education and training program for disadvantaged youth. Curricula would include the critical components valued by the military in grooming and advancing recruits to become high quality accession enlistments. Preference would be given to Job Corps centers located near military installations.

*President's Community College Initiative*

The NJCA requests that a minimum of \$10 million of President Bush's proposed \$250 million fiscal year 2006 Community College Initiative (also called the President's Community-Based Job Training Grants) be dedicated to community colleges partnerships with Job Corps centers. The NJCA requests this modest portion within the U.S. Department of Labor's Employment and Training Administration proposed budget be designated to: (1) develop strategic partnerships with community colleges, business and industry leaders, and Job Corps centers to train students in high, growth, high demand industries; and (2) design "dual enrollment" programs based on reciprocal agreements between Job Corps and adjacent community colleges.

The NJCA strongly believes it is fitting and proper for community colleges to work with Job Corps because both parties share the same basic goals of providing access and opportunity to disadvantaged Americans. Job Corps and community colleges also have the ability to partner with employers looking for higher-skilled workers. Numerous Job Corps centers have already established working relationships and participated with local community colleges to provide advanced career training, increased opportunity to pursue occupations in high-growth industries, and greater access to industry-recognized certification programs.

CONCLUSION

As Job Corps looks to the future, we hope you agree that it remains a federal program that is worthy of America's support. The NJCA looks forward to working with members of this Committee to define, expand and advance this decade-long effort to tie Job Corps' training more closely to our nation's most critical labor needs. Even in these tough budgetary times when no federal program can be above scrutiny, Job Corps shines through with versatility of purpose and a record of success that can help America address its most serious challenges. Job Corps remains a beacon of hope for many young Americans and an excellent example of our government's role in helping all sectors of our society. Thank you for your strong support.

The NJCA is a professional trade association comprised of business, labor, volunteer, advocacy, academic, and community organizations. All are joined in supporting the Association's mission "to unite the Job Corps community through activities and services that strengthen the program for the benefit of students, staff and employers."

## PREPARED STATEMENT OF RURAL OPPORTUNITIES, INC.

On behalf of the Migrant and Seasonal Farmworkers in Pennsylvania, Rural Opportunities, Inc. (ROI) extends a sincere thank you to the Sub-Committee for the opportunity to share our success as the statewide grantee funded by the United States Department of Labor under the Workforce Investment Act, Section 167—The National Farmworker Jobs Program (NFJP).

In providing services to migrant and seasonal farmworkers, ROI's 27 years of experience in Pennsylvania has clearly demonstrated that farmworkers are a "special population" that have unique needs that require not only basic skills, English-as-a-Second Language, and job training; but, access to services via outreach in rural communities at non-traditional hours of service provision where and when One-Stop services are virtually non-existent. Further, should these services be required, the language requirements to ensure access are often unavailable unless a ROI staff person is on site in the One-Stop.

In painting a personal picture, examples may be that if a farmworker were accessing services in Philadelphia County, they may speak Khmer. If a farmworker were accessing services in Franklin County or Chester County, he/she may speak Creole and Spanish respectively. ROI has continuously hired bilingual staff that is culturally sensitive and skilled at working with the predominant farmworker population in the specific service-provision area; thus, ensuring access.

With this said ROI has taken its responsibility seriously for the stewardship of the federal funds it is awarded by ensuring access to effective employment and training programs that not only ensure the transferability of skills, but future upward-mobility both within agriculture and out. ROI places a high priority on measuring and improving the efficiency and effectiveness of our program by collecting detailed data on our farmworker program participants through our Management Information System, by monitoring program results as they pertain to performance standards, and evaluating our net impact.

ROI has always been a strong training provider. Thus, again, having the NFJP Program "zeroed out" for funding, when we are a premiere program that truly provides training to the hardest-to-serve, is unconscionable. Perhaps, one can better understand the impact of the NFJP Program through the words of a program graduate. Alfonso Lua, of Dunmoyer Trucking, Inc., states, "When I came to the program several years ago, I had nothing. Rural Opportunities helped me get my Commercial Driver's License (CDL) and I became a truck driver. Now I own 13 rental properties. I am going to make almost \$70,000 this year. The program is like a ladder you can use to better yourself. If you want to have success, you have to educate yourself and learn something new. That's why the program is there to help with this. It is an alternative to staying where you are".

Alfonso Lua was a program participant who had been a farmworker for many years; yet, had always dreamed of becoming a truck driver. In the typical One-Stop setting, Alfonso may not have been able to access CDL Training because of his, then, language limitations. ROI worked hand-in-hand with Alfonso translating the parts of the truck from Spanish to English to ensure Alfonso clearly understood the translation. Further, ROI Staff provided on-site tutoring, ensuring a positive outcome. Another program participant, Madelyn Morales, a Department Manager at Wal-Mart, Inc. states, "Thank you to Rural Opportunities, Inc. who believed in me and opened possibilities for me to become someone in life". When program participants confront barriers in accessing employment that requires specialized training, ROI has the expertise to tailor a curriculum to an individual's needs. This is extremely important in working with the farmworker population.

ROI also has taken the initiative, as a NFJP Grantee, to work hand-in-hand with agricultural employers who often are overlooked in the One-Stop System. ROI has developed cross-training for agricultural upgrade taking harvesters into a variety of demand occupations. Without the services provided by ROI under the auspices of the NFJP program, these particular training services would be inaccessible. The significance of this can not be underestimated as an agricultural employer representative, Maria C. Serrano, Human Resource & Benefits Specialist of Giorgi Mushroom Company, states, "We at Giorgi Mushroom Company have the practice of employee development and we provide advancement opportunities to motivate employees. In our harvesting department it is often hard to promote within, since they lack the skills for advancement. That is where Rural Opportunities, Inc. comes in. They help tremendously, companies like ours to help and motivate employees to pursue a different position within the company. Their NFJP Program allows our employees the opportunity to advance by providing the necessary resources to develop new skills, where there is no economic drain to the company. Quite the contrary, it helps our company. We have enjoyed a very good relationship with ROI in allowing us the op-



portunity so that we can pass this program on to our employees. Their programs have helped not only our employees become a better people and gain a new position, but also our company as a whole. ROI offers remarkable programs that work for both the company and employees by giving them the chance. Without these programs, no one wins. We strongly agree that ROI Programs benefit both parties involved; and we deeply support their efforts.”

In closing, ROI believes our success speak volumes about the NFJP Program’s success. We are just one of the NFJP Grantees that the Department of Labor’s own assessment stipulates do excellent work every day. Let us not forget that Migrant and Seasonal Farmworkers already bring multiple barriers to the table. Let us not place another barrier in their path by eliminating the NFJP Program. We request the Sub-Committee recognize the enormous potential of this program by maintaining the NFJP Program in the Appropriations for the Department of Labor for 2006; thus, ensuring that the services this population so desperately needs is funded.

Thank you for this opportunity to present testimony today.

## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### PREPARED STATEMENT OF THE ACADEMIC FAMILY MEDICINE ADVOCACY ALLIANCE

Mr. Chairman, the Society of Teachers of Family Medicine, the Association of Departments of Family Medicine, the Association of Family Medicine Residency Directors, and the North American Primary Care Research Group, thank you for the opportunity to provide this statement for the record on behalf of funding for family medicine training, and the Agency for Health Care Research and Quality (AHRQ).

#### HEALTH PROFESSIONS: THE PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER

Mr. Chairman, the Academic Family Medicine Advocacy Alliance would like to thank you and this committee for your commitment to these programs. We very much appreciate the funding included in the fiscal year 2005 appropriations funding bill, especially in light of fiscal constraints. Family medicine training programs are funded under Section 747, the Primary Care Medicine and Dentistry cluster, of Title VII of the Public Health Service Act. We ask that you continue your support for family medicine training, and restore the appropriations level for section 747, the Primary Care Medicine and Dentistry Cluster, to fiscal year 2003 levels of \$92 million, a small increase of about \$3 million.

This statement is designed to show the committee how its investment is paying off. This statement will discuss the success of these programs and include recommendations about what still needs to be done. As you look at all the opportunities you have to fund domestic health programs you need to be able to make judgments about the value and utility of these programs. We have been asked in various venues to show proof that these funds actually do what they are designed to do. We must show that this money makes a difference. In this statement we intend to do just that. In addition, we believe Congress also needs to understand the unmet needs that exist in our nation—needs health professions programs can successfully help address.

#### *President’s Budget Request for Fiscal Year 2006 Once Again Zeros Out Primary Care Funding*

The President’s budget zeroes out funding for the Primary Care Medicine and Dentistry cluster. In addition, the proposal includes only \$11 million for all Title VII Health Professions programs, a sharp cut from current level funding of \$308 million.

#### *Family Medicine Training Programs Are A Success*

First, let’s take a look at health professions training—specifically family medicine training. These programs are producing the outcomes that Congress has requested. A recent study (Family Medicine, June 2002), by the Robert Graham Center For Policy Studies showed that federal funding through Title VII of family medicine departments, predoctoral programs, and faculty development hps made a difference. The study measured the differences in career choices made by students exposed to Section 747 funds compared to those who were not, both within the same school and in different schools. This research found that section 747 funding is associated with:

- 54 percent increase in students going into family practice
- 25 percent more into primary care
- 34 percent more into rural underserved counties

The increased number of family physicians associated with Title VII funding between 1978–1993 was found to be about 7,000. If the same continued for the next

decade, there would be 12,000 additional family physicians attributable to Section 747 funding in 2003. We must conclude from this data that this funding means that thousands of physicians are making different career choices, choices that positively affect millions of patients in underserved areas and in primary care. Moreover, if this money were to “go away” fewer students would be making these career choices.

*Funding primary care training programs improves the health of America*

A greater supply of primary care physicians is associated with positive health outcomes due to early detection and an increased integration of care and oversight. With the associated rise in primary care physicians cited above, we can extrapolate from other sources that this increase could mean:

- 4,600 cases of colon cancer prevented and 1,400 deaths from colon cancer prevented.
- 7,400 cases of cervical cancer prevented and 3,200 deaths from cervical cancer prevented.
- 24,000 individuals quit smoking.
- 7,700 additional physicians serving in rural areas and 970 additional physicians serving in HPSAs.
- 1.2 million deaths prevented.

*Primary care is cost effective*

A study in Health Affairs (April 2004) demonstrates that the associated measures in primary care physicians resulting from Title VII, section 747 leads to an estimated \$320 billion in saved health care expenses and 1.2 million lives saved over 26 years. For example, a study in the New England Journal of Medicine (Feb. 1996) looked at outcomes and costs of people who came to a primary care physician, a chiropractor, or an orthopedic surgeon for their back pain. It was determined that the patients all had the same outcome regardless of who provided care, but the primary care physicians’ care cost \$194 per person less. According to a study in the Journal of Family Practice (May 1998) because back pain is so common, a primary care physician can expect to see 82 cases per year; therefore, Title VII funds can be thought to have had an estimated overall health care cost savings of \$2.4 billion from back pain alone.

*Loss of funding for family medicine training would cause tremendous impact on service to the underserved*

A study by the Robert Graham Center looked at counties designated as HPSAs to determine the degree to which the United States relies on family physicians in comparison to more other specialty. Of the more than three thousand counties in the United States, 784 are designated HPSAs. In a hypothetical exercise, the study removed all family physicians from the U.S. counties. Without family physicians, there would be 1,184 HPSAs—a 43 percent increase.

*Family Physicians Staff the Nation’s Community Health Centers (CHCs)*

The President’s fiscal year 2006 budget would provide approximately \$2 billion to CHCs in fiscal year 2006, an increase of \$304 million. Since nearly one-half of the physicians who staff the nation’s CHCs are family physicians, support for Section 747 would mean more trained doctors for those centers.

*Family Physicians Have an Economic Impact on States*

On average, the income that comes into a community due to the presence of one family physician, and the additional jobs that result from his or her practice, amounts to approximately:

- \$1.2million in rural areas, and,
  - \$0.9 million in urban areas.
- (Oklahoma Physician Manpower Training Commission, October 2003.)

*What Is The Unmet Need? Why Must We Continue To Fund And Grow These Programs?*

According to a study by Politzer, et al (The Journal of Rural Health, Winter,1999) Title VII funding is key to ending HPSAs. This funding has led to the time needed for HPSA elimination to decrease to 15 years. Doubling the funding for these programs would decrease the time for HPSA elimination to as little as 6 years.

According to the study, without this funding, not only would HPSAs not be eliminated, but the number of shortage areas would continue to grow. Moreover, success has been attained by an allocation of funds more favorable to family medicine than the other two primary care specialties.

Title VII funding has indeed accomplished many of the objectives for which it was designed:

- Funding of innovative projects
- Providing “seed money” for the start-up of new projects
- The creation and maintenance of departments of family medicine in the nation’s medical schools
- The development of 3rd year clerkships in family medicine
- The increase in students selecting primary care residencies from those schools with funded family medicine departments and 3rd year clerkships
- The increased rate of graduates from Title VII funded projects entering practice in medically underserved areas (MUAs), with a resultant reduction in the time required for Health Professions Shortage Area (HPSA) elimination

*Section 747 Advisory Committee Recommends Higher Funding*

In 1998, Congress established an Advisory Committee to review and make recommendations on Section 747. The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recently released its recommendations to Congress and the Secretary of the Department of Health and Human Services. The first recommendation urges greatly expanding federal support for Section 747 to \$198 million. The Committee notes the growing need for primary care providers, as well as the success of Title VII funded programs.

The training enterprise that does not value primary care either financially or otherwise is a key part of the problem. Title VII funds that support the infrastructure and stability of family medicine departments in medical schools have to be sustained in order to keep producing the current levels of primary care physicians and, more specifically, those who will practice in rural and other underserved areas. Clearly, the programs of Title VII are on the right track toward meeting the health care challenges of the 21st century. So, while we believe that current funding must be maintained, more needs to be done.

*Proposed Performance Measures need to be redefined*

The current proposed performance measures are neither measurable nor appropriate. Consequently, assessments of effectiveness of the programs based on these measures are highly flawed.

For example, the target set for the proportion of underrepresented minorities (URMs) and disadvantaged students in health professions funded programs is set at 50 percent for 2005, even though only 12.5 percent of current medical school graduates are URMs, and data on disadvantaged backgrounds is not routinely, or accurately collected. The concept of disadvantaged background varies based on income related to family size, or is based on a vague—non-quantifiable—notion of persons growing up in environments that don’t prepare them to enter health professions schools.

In 2000 approximately 12.5 percent of the medical degrees awarded in the United States went to underrepresented minorities. For all of health professions minority representation has risen from 8.3 percent in 1985 to 11.7 percent in 2000. Given this data, it’s simply unrealistic to expect any program to increase its minority representation in one year from 12.5 percent to 25 or 50 percent.

*Primary Care Training Programs React Quickly to Emerging Health Challenges*

Title VII dollars have created an infrastructure that allows educational programs to respond to contemporary health care issues. Specifically, the ACTPCMD report states that:

“Investment in education to provide primary care has effects that touch the largest number of people in the country. No other group of health care providers can exert such a broad influence on the kind and quality of health care in the United States. Primary care training programs are ideally positioned to react quickly to meet ever-changing health care needs and issues, whether they are related to HIV/AIDS, growing numbers of elderly with chronic illnesses, implications of the modern genetics revolution, the threat of bioterrorism, or other issues that will continue to emerge and demand rapid educational intervention. Thus, this infrastructure is uniquely able to play a pivotal role in bringing emerging issues in health care to the population at large.”

Mr. Chairman, we know that this committee has to weigh the value of funding various programs against each other. We hope that the evidence we have presented here will bring the committee to the conclusion that funding spent on these programs would bring value for the money and would be money exceptionally well spent.

## FUNDING FOR THE AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

Mr. Chairman, once again, we thank you and this committee for funding this important agency. It is apparent that the key federal agency available to fund primary care research is the Agency for Healthcare Research and Quality (AHRQ). In its recent reauthorization, Congress established within the Agency a Center for Primary Care Research to “serve as the principal source of funding for primary care practice research in the Department of Health and Human Services.” The statute defined primary care research as research that “focuses on the first contact when illness or health concerns arise, the diagnosis, treatment or referral to specialty care, preventive care, and the relationship between the clinician and the patient in the context of the family and community.”

*Funding Request For AHRQ*

We recommend appropriations of \$440 million for the Agency for Healthcare Research and Quality (AHRQ) in fiscal year 2005. AHRQ conducts primary care and health services research geared to physician practices, health plans and policy-makers that helps the American population as a whole.

*President’s Budget Request for fiscal year 2006 AHRQ Funding*

The President’s budget includes \$316 million for AHRQ, which is the same as actual funding for fiscal year 2005. This figure does not recognize the \$53 million in authorization that Congress provided AHRQ in the Medicare Modernization Act to study “clinical effectiveness and appropriateness of specific health services and treatments.”

*What Does AHRQ Do?*

AHRQ’s three goals are to (1) improve physician practice and Americans’ health outcomes, (2) improve the quality of health care (e.g., patient safety), and (3) improve the health care system (e.g., increase access and reduce costs). In brief, AHRQ “helps to improve the health and health care of the American people . . .” (AHRQ report, March, 2001).

*How Does AHRQ Meet Its Goals?*

AHRQ translates research findings from basic science entities like the National Institutes of Health into information that doctors can use every day in their practice with their patients. Another key function of the agency is to support research on the conditions that affect most Americans.

*AHRQ Translates Research into Everyday Practice*

Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. AHRQ takes this basic science and produces information that physicians can use every day in their practices. AHRQ also distributes this information throughout the health care system. In short, AHRQ is the link between research and the patient care that Americans receive. An example of this link is basic science research showing that beta blockers reduce mortality. AHRQ supported research to help physicians determine which patients with heart attacks would benefit from this medication.

*AHRQ Supports Research on Conditions Affecting Most Americans*

Most Americans get their medical care in doctors’ offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals. AHRQ studies and supports research on the types of illness that trouble most people. AHRQ looks at the problems that bring people to their doctors every day—not the problems that send them to the hospital. For example, AHRQ supported research that found older antidepressant drugs are as effective as new antidepressant medications in treating depression, a condition that affects millions of Americans.

*Institute of Medicine Recommends \$1 Billion for AHRQ*

The Institute of Medicine’s report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001), recommended \$1 billion a year for AHRQ to “develop strategies, goals, and actions plans for achieving substantial improvements in quality in the next 5 years.” The report looked at redesigning health care delivery in the United States. AHRQ is a linchpin in retooling the American health care system.

## RECOMMENDATIONS FOR FAMILY MEDICINE TRAINING AND RESEARCH

The Academic Family Medicine Advocacy Alliance have two main recommendations for the fiscal year 2006 Labor/HHS Appropriations bill. They are as follows:

- We ask that you continue your support for family medicine training, and bring the appropriations level for section 747, the Primary Care Medicine and Dentistry Cluster, up to fiscal year 2003 levels of \$92 million, a small increase of approximately \$3 million.
- In order to support critical practice-oriented primary care research, and to ensure that existing grants and contracts will not be cut, we are asking that the Agency for Healthcare Research and Quality be funded at \$440 million.

---

PREPARED STATEMENT OF AIDS ACTION

I am pleased to submit this testimony to the members of this committee on the importance of adequate funding for the fiscal year 2006 HIV/AIDS portfolio. The federal government's commitment to funding research, prevention, and care and treatment for those living with HIV is critical. We would not be where we are today in responding to this epidemic without the federal government's 24-year commitment to funding HIV programs here at home. AIDS Action is dedicated to working with the federal government to make sure it sustains this commitment.

Since 1984, AIDS Action's goals have been clear: to ensure effective, evidence-based HIV care, treatment, and prevention services; to encourage the continuing pursuit of a cure and a vaccine for HIV infection; and to support the development of a public health system which ensures that its services are available to all those in need. Furthermore, our commitment to working toward these goals is constant: AIDS Action is here Until It's Over.

For over 20 years AIDS Action Council, through its member organizations and the greater public health community, has worked to enhance HIV prevention programs, research protocols, and care and treatment services. An important part of this collaborative effort has been working to secure comprehensive federal resources to address community needs.

It is therefore on behalf of AIDS Action Council's diverse membership, comprising community-based AIDS service organizations, public health departments, and other organizations concerned with HIV research, education, and advocacy, that I bring your attention to some of the issues impacting the funding picture for fiscal year 2006.

Despite the good news of improved treatments, which have made it possible for people with HIV disease to lead longer and healthier lives, stark realities remain:

- There is neither a cure nor a vaccine for HIV.
- Current treatments do not work for everyone, and some have debilitating side-effects.
- There are nearly 1 million people living with HIV in the United States.
- Access to health care is unequal.
- Half a million HIV positive Americans are not receiving regular medical care.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which is administered by the Health Resources and Services Administration (HRSA) and is funded by this subcommittee, provides services to more than 533,000 people living with and affected by HIV throughout the United States and its territories. It is the single largest source of federal funding solely focused on the delivery of HIV services; it provides the framework for our national response to the HIV epidemic. As such, CARE Act programs have been critical to reducing the impact of the domestic HIV epidemic. Yet, providers of HIV services are working from a deficit. In recent years, CARE Act funding has been decreased through across-the-board rescissions. The .80 percent rescission that was executed on all non-defense and non-homeland security discretionary spending during the final negotiations for the fiscal year 2005 bill had a devastating impact on the HIV/AIDS portfolio in general, and on the Ryan White CARE Act in particular. Moreover, President Bush's budget for fiscal year 2006 requests just one increase to the CARE Act—an additional \$10 million for the AIDS Drug Assistance Program (ADAP).

Now in its fifteenth year, the Ryan White CARE Act is scheduled for reauthorization in this session of the 109th Congress, a fact President Bush made known to all Americans in his State of the Union address, when he voiced his strong support for reauthorization. He stated, "Because HIV/AIDS brings suffering and fear into so many lives, I ask you to reauthorize the Ryan White Act to encourage prevention, and provide care and treatment to the victims of that disease. And as we update this important law, we must focus our efforts on fellow citizens with the highest rates of new cases, African American men and women."

In June 2004, while discussing the global HIV epidemic, our President stated with confidence, "There's no doubt we can bring hope in all parts of the world, not only

in Africa, but in neighborhoods in our own country where people wonder what the American Dream means.”

On this point, AIDS Action Council concurs with President Bush: hope can be brought to all parts of the world. However, we respectfully disagree with the President on what will be needed to ensure hope here at home. The delivery of hope relies on the delivery of health care to all neighborhoods in this great nation—an effort that will not be sufficiently supported by the funding levels the President has requested for the HIV/AIDS portfolio in his fiscal year 2006 budget request.

Clearly, it will take more than a \$10 million increase for ADAP, a single program within the Ryan White CARE Act, to ensure HIV positive Americans receive the care and services necessary to remain healthy and productive. It is my hope that the Congress, through the good work of this subcommittee, will recognize and address the true funding needs of the care programs within the domestic HIV/AIDS portfolio.

Last year, there was an overall increase of 14.5 percent in the estimated number of living AIDS cases among the fifty-one hardest hit eligible metropolitan areas (EMAs) in the United States, with increases as high as 22.6 percent in some areas. Yet fiscal year 2004 funding allocations for Title I of the Ryan White CARE Act, which is designed to provide services to these areas, were reduced. Forty of the fifty-one jurisdictions experienced a decrease in funding, with some decreases as high as 15 percent. Similar reductions continued in fiscal year 2005 when thirty-three of the EMAs experienced a funding decrease, the highest being 14 percent.

Some of the services provided under Title I include physician visits, laboratory services, case management, home-based and hospice care, nutrition services, and substance abuse and mental health services. According to the most recent data available from the Health Resources and Services Administration (HRSA), more than half (51.8 percent) of Title I funds are allocated to core health care services, and more than one-third (35.0 percent) are allocated to services closely associated with medical care (including medically-based housing and care coordination and referral). These services are critical to ensuring patients have access to, and can effectively utilize, life-saving therapies.

Title II of the CARE Act ensures a foundation for HIV related health care services in each state and territory, including the critically important AIDS Drug Assistance Program (ADAP) and Emerging Communities Program. Title II base grants (excluding ADAP and Emerging Communities) decreased from \$292,279,000 in fiscal year 2004 to \$282,597,700 in fiscal year 2005 for a total decrease of over \$9 million (\$9,681,300).

Funding for Emerging Communities remained stable at \$10 million, but it was divided among an increased number of communities. The \$5 million “tier one” award was divided among four cities in fiscal year 2004 and among five cities this fiscal year, which resulted in funding reductions. Funding cuts for the original four cities ranged from \$200,000 to \$264,000 so that a fifth could receive \$836,000. This type of funding variability is not conducive to providing consistent HIV care in emerging communities.

We applaud the President’s recommended increase of \$10 million for ADAP in his fiscal year 2006 budget. ADAP provides medications for the treatment of individuals with HIV who do not have access to Medicaid or other health insurance. According to the National ADAP Monitoring Project, approximately 85,825 clients received medications through ADAP in June 2003.

A single drug in the multiple-drug regimen of highly active anti-retroviral therapy (HAART), the standard of care for HIV disease, may cost as much as \$15,000 annually. Drugs to treat other infections may bring the annual cost for a single HIV patient to \$40,000 a year. With the increasing number of people living with AIDS, the number of newly diagnosed infections fixed at 40,000 per year, and cuts in funding to state Medicaid programs, pressures on ADAP are increasing. Over the years, ADAP has proven to be a remarkable program, allowing people to receive the care and treatment they need. Consequently, AIDS Action urges Congress both to fully fund ADAP and to consider restructuring ADAP to ensure universal access to all needed drugs, regardless of state of residence. Moreover, many of the medicines supplied through ADAP reach maximum efficacy only in conjunction with proper nutrition. Therefore, we urge Congress to continue funding for Ryan White CARE Act nutrition programs, funded predominantly through Titles I and II.

Funding for Title III of the Ryan White CARE Act is awarded under the Early Intervention Services program. Title III grant recipients include community-based clinics and medical centers, hospitals, public health departments, and universities in 22 states and the District of Columbia. The grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic. The Title III funds are particularly needed in rural areas where the availability of HIV care and treatment

is still relatively new. Urban areas also continue to need Title III funds to ensure that emerging populations within these areas are not shortchanged as grantees struggle to meet the needs of previously identified HIV positive populations.

The Title IV portion of the Ryan White CARE Act is awarded under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth, as well as their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families.

If we are to comprehensively address the HIV care and treatment crisis in the United States, we must never forget the smaller—but nonetheless significant—programs in the CARE Act: AIDS Education and Training Centers (AETC), dental reimbursement, and special projects of national significance (SPNS). Like nearly every other CARE Act program, AETC and SPNS have been affected by diminishing federal funding.

Given that the President continues to support increases in funding to, and a greater reliance on, community health centers nationwide to provide care to the uninsured and under insured, we now find ourselves simultaneously faced with a pool of community providers who need to be educated about proper HIV care. The role of the AETCs is invaluable in ensuring that such education is available to physicians who are being asked to treat the increasing numbers of HIV positive patients who depend on them for care. Dental care is another crucial part of the spectrum of services needed by people living with HIV disease. Oral health is one of the first aspects of health care to be neglected by those who cannot afford, or do not have access to, proper medical care. Furthermore, oral health problems are often one of the first manifestations of HIV disease. Reimbursement offered by this CARE Act program allows dental education institutions to offer their much needed services to people living with HIV.

As this testimony suggests, rising infections and strapped care systems necessitate the research and development of innovative models of care. The SPNS program is designed for this very purpose and must therefore receive sufficient funding.

AIDS Action believes the entire Ryan White CARE Act portfolio needs \$3.2 billion for fiscal year 2006 to address the true needs of the approximately 1 million people that the Centers for Disease Control and Prevention (CDC) estimates are living with HIV in the United States. President Bush has requested just over \$2 billion (\$2,083,342,088).

The Housing Opportunities for People with AIDS (HOPWA) program, administered by the U.S. Department of Housing and Urban Development (HUD), is another integral program in the HIV care system. Stable housing is absolutely critical to the ability of people living with HIV to access and adhere to an effective HIV treatment plan. Without housing, one cannot appropriately store medicine or food and often cannot consistently access clean water or clean bathrooms. Furthermore, when one has no housing, the need for shelter often rises above the need to take care of one's HIV infection, which places the individual at higher risk of becoming ill and infecting others.

AIDS Housing of Washington has estimated that approximately one-third to one-half of people living with HIV are homeless, cannot afford their current housing, or are at risk of becoming homeless. HOPWA is the only program that specifically addresses the housing needs of people living with HIV. Despite the importance of the program, HOPWA's funding has been dramatically cut. In fiscal year 2005, HOPWA was funded at \$281.7 million (\$281,728,000), down from \$294.8 million (\$294,800,000) in fiscal year 2004—a cut of more than \$13 million. In his fiscal year 2006 budget proposal, the President proposes an additional cut to the program of almost \$14 million, to \$268 million (\$268,000,000) total. AIDS Action believes that \$385 million should be appropriated to the HOPWA program for fiscal year 2006 to address the needs of HIV positive people requiring housing assistance.

HIV continues to be an ongoing public health crisis. Despite treatment advances, there was a 2 percent increase in progression from HIV to an AIDS diagnosis between 2001 and 2002—the first such increase in several years. AIDS-defining illnesses are the leading cause of death among African-American women between the ages of 25 and 34 and they are the third leading cause of death among all African Americans in this age group. They are the sixth leading cause of death for Latinos and whites in this age group.

According to CDC estimates contained in the agency's December 2003 HIV/AIDS Surveillance Report, 929,985 cumulative cases of AIDS have been diagnosed in the United States, with a total of 524,059 deaths since the beginning of the epidemic. The CDC also estimates that between 850,000 and 950,000 people are living with HIV/AIDS in the United States, and approximately one-quarter of them, or 180,000—

280,000 people, are unaware of their status and could unknowingly transmit the virus to another person.

For several years, estimates of new infections have remained at 40,000 per year, compared to an estimated 180,000 new infections in the mid 1980s: an extraordinary achievement in efforts against HIV.

To further reduce new infections, the CDC implemented a new initiative in April of 2003 called Advancing HIV Prevention: New Strategies for a Changing Epidemic (AHP), consisting of four key strategies:

- Make HIV testing a routine part of medical care.
- Implement new models for diagnosing HIV infection outside medical settings.
- Prevent new infections by working with persons diagnosed with HIV and their partners.
- Decrease mother-to-child transmission of HIV.

The Urban Coalition for HIV/AIDS Prevention (UCHAPS), which represents the six cities that are directly funded by the CDC for HIV prevention and is an AIDS Action member, has responded positively to the AHP Initiative. UCHAPS members are working with the CDC to implement the Initiative effectively in their respective communities.

This Initiative, however, does not supersede the HIV Prevention Strategic Plan that was published by the CDC in 2001, which stated a goal of reducing by half the number of new HIV infections by 2005. These strategies, though innovative, require additional funding for implementation. AIDS Action Council estimates that the CDC HIV/AIDS, STD, and TB prevention programs will need \$2.33 billion in fiscal year 2006 to address the true unmet needs of prevention in HIV/AIDS, STDs, and TB. AIDS Action Council therefore is concerned that the President limited his fiscal year 2006 request for the CDC HIV/AIDS, sexually transmitted disease (STD), and tuberculosis (TB) prevention programs to \$956,283,000—a request that is \$4,428,000 less than what the CDC received in fiscal year 2005.

How will we keep pace of the epidemic and meet—albeit belatedly—the goal of limiting new infections to 20,000 annually without an immediate infusion of new resources, new partnerships, and new funding? Without such an infusion, this country will continue to face significant challenges in providing urgent care and treatment to HIV positive people.

Research on the domestic HIV epidemic is vital to the control of the disease. Research that includes biomedical, behavioral, and social services is the cornerstone of HIV prevention research. The research agenda for HIV prevention science at the Office of AIDS Research (OAR), part of the National Institutes of Health (NIH), targets interventions to at-risk individuals, both infected and uninfected, to reduce HIV transmission. It is essential that OAR continue its groundbreaking research to secure a vaccine that will keep HIV negative people negative. It is equally important that this office continue to research promising treatment vaccines that may help HIV positive people maintain optimal health. The research on microbicides for vaginal and anal sexual intercourse is critical as well. The use of microbicides by the receptive partner will give them power over their personal health when they cannot negotiate condom use with their partner to protect themselves from HIV transmission.

The research at NIH on new medications for drug resistant strains of HIV is also critical. The current success of treatment for people living with HIV and AIDS is due in large part to early research investments in new drugs that now have improved the health of people living with HIV. The United States must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. Primary prevention of new HIV infections must remain a high priority in the field of research.

Behavioral research to help individuals delay the initiation of sexual relations, limit the number of sexual partners, limit the consumption of alcohol and drugs prior to sexual relations, and move from drug use to drug treatment are all critically important in finding a solution to the spread of HIV in the United States. NIH's Office of AIDS Research is critical in supporting all of these research arenas. Increased funding is necessary to ensure that the resources needed to address all the research concerns are available both now and in the future. Commitment in research will ultimately decrease the care and treatment dollars needed if HIV continues to spread at the current rate.

AIDS Action is concerned that President Bush has only requested \$2,932,992,000 for the AIDS portfolio at NIH. AIDS Action believes the National Institutes of Health AIDS portfolio must be funded at \$3.327 billion for fiscal year 2006.

On behalf of all HIV positive Americans, and those affected by the disease, AIDS Action Council asks that you carefully consider the ramifications of the President's



suggested cuts to the domestic HIV/AIDS portfolio. Help us save lives by allocating sufficient funds to address this nation's epidemic.

---

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 94,000-member American Academy of Family Physicians submits this statement for the record to the Senate Appropriations Subcommittee on Labor/Health and Human Services, Education and Related Agencies. Our statement is made in support of the Section 747 Primary Care Medicine and Dentistry Cluster. The Academy also supports the Agency for Healthcare Research and Quality (AHRQ) and rural health programs.

SECTION 747 PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER

*Family Medicine Training*

Section 747 is the only federal program that funds family physician training. The law requires the program to meet two goals: (1) increase the number of primary care physicians (family physicians, general internists and general pediatricians) and (2) boost the number of people to provide care to the underserved. Regarding family medicine specifically, Section 747 offers competitive grants for training programs in medical school and in residency programs.

The fiscal year 2005 spending bill provided \$89 million to Section 747, a figure that was \$3 million below the fiscal year 2003 levels, which is the highest figure the program has received in the last several years. Unfortunately, the President's fiscal year 2006 budget provided zero dollars for the program. In contrast, the congressionally established Advisory Committee on Training in Primary Care Medicine and Dentistry, which was set up solely to evaluate these programs, recommended significantly more funding: \$198 million.

Family physicians are the specialists trained to provide comprehensive, coordinated and continuing care to patients of both genders and all ages and ethnicities, regardless of medical condition. These residency-trained, primary care physicians treat babies with ear infections, adolescents who are obese, adults with depression and seniors with multiple, chronic illnesses. And because they focus on prevention, primary care, and integrating care for patients, they are able to treat illnesses early and cost-effectively and when necessary, they help patients navigate our complex health system and find the right subspecialists.

*Section 747 and Rural and Underserved Areas*

In the last few years, there has been a great deal of interest in whether Section 747 actually meets its statutory goals, and specifically whether or not more physicians are practicing in rural and underserved areas as a result of the program. Due to this concern, the Robert Graham Center for Policy Studies studied medical schools receiving Section 747 family medicine funds and concluded that these programs met the law's requirements. According to this research, the trainees exposed to Section 747 funding while in these schools were more likely to:

- Practice in family medicine or primary care;
- Practice in a rural area; or
- Practice in a whole county Primary Care Health Professions Shortage Area (HPSA) (i.e., a county with inadequate numbers of family physicians, general pediatricians, general internists or obstetrician/gynecologists).

More specifically, according to this research, students with any exposure to Section 747 were 25 percent more likely to go into a primary care HPSA and 34 percent more likely to go to a rural county to practice. Moreover, the exposure of students to Section 747 funding between 1978–1993 was associated with nearly 4,000 additional primary care physicians in rural areas and 500 additional physicians in HPSAs than would have otherwise occurred. This research showed that Section 747, was, in fact, meeting the goals of the law.

*Preventing HPSAs*

Along a similar vein, another study by the Robert Graham Center looked at counties designated as HPSAs. The research showed that the United States relies on family physicians more than any other medical specialty. For example, of the more than three thousand counties in the United States, 784 are designated HPSAs. In a hypothetical exercise, the study removed all family physicians from the U.S. counties and found that without these specialists, there would be 1,184 HPSAs—a 43 percent increase. Section 747 grants contribute to bringing health care to underserved areas.

*Family Physicians for Community Health Centers and NHSC*

Family physicians also play a major role in staffing the nation's Community Health Centers (CHCs) and National Health Service Corps (NHSC). The Academy strongly supports the Administration's commitment to funding increases for these programs. However, we believe that increasing funding for CHCs and the NHSC is only a partial solution. Without support for family physician training, there will be fewer physicians who work in these centers or practice in underserved areas. Thousands of family physicians will be needed if the necessary number of CHCs sites and NHSC staff is to be realized.

In fact, in 2003, Community Centers depended on primary care physicians for 95 percent of their physician staffing, over half of whom were family or general practice physicians. And, since 1971, the National Health Service Corps has placed more than 18,000 health care providers in underserved areas: almost half of the NHSC doctors were family physicians. Support for CHCs and the NHSC must go in tandem with funding for Section 747.

*Lower Health Care Costs and Improved Quality*

As the only federal program aimed at producing more generalists, Section 747 plays a role in lowering our nation's health care costs and increasing the quality of U.S. health care. For example, an article in *Health Affairs* (April 2004) demonstrated that states that spent more on Medicare had lower quality of care. There were two reasons for this result: states' expensive health care did not improve patient satisfaction, or, outcomes (e.g., people who were admitted to intensive care in the last 6 months of their life.)

The second reason was also important: the authors found the makeup of the health care workforce made a difference. In fact, more primary care doctors in a state meant higher quality care and lower cost. In contrast, more specialists and fewer generalists led to lower quality and higher costs. And, just a small increase in the number of generalists in a state was associated with a large boost in that state's quality ranking.

An article in a more recent edition of *Health Affairs* (March 2005), "The Effects of Specialist Supply on Populations' Health: Assessing the Evidence" went even further. This piece stated that there is a "negative relationship between the supply of primary care physicians and death from stroke, infant mortality and low-birth-weight, and all-cause mortality." The article went on to say that just one more primary care physician per 10,000 people was associated with a decrease of 34.6 deaths per 100,000 population.

The article also cited breast cancer research for the state of Florida, which indicated that "each tenth-percentile increase in primary care physician supply is associated with a statistically significant 4 percent increase in odd of early-stage breast cancer." Statistics were similar for other types of cancers: there was a relationship between early identification and the supply of primary care physicians. Numerous other research was included in the *Health Affairs* article indicating that a higher ratio of primary care physicians to populations led to better health outcomes. These data support the need for additional funding for Section 747, the only federal program that produces primary care physicians.

*Economic Impact*

In 2003, the Oklahoma Physician Manpower Training Commission studied the amount of income that comes into a community due to the presence of one family physician, and the additional jobs that result from his or her practice. Their research showed that the figure was approximately \$1.2 million in rural areas and \$0.9 million in urban areas.

*The Overspecialized U.S. Physician Workforce*

Unlike all other developed countries, the United States does not have a primary care-based health care system. While other developed countries have about equal numbers of primary care doctors and subspecialists, less than one-third of the U.S. physician workforce is primary care doctors (including family physicians). As a result, about two-thirds of the U.S. physician workforce is made up of subspecialists.

In addition, compared to those in other developed countries, the United States spends the most per capita on healthcare—but has the worst healthcare outcomes. More than 20 years of evidence have shown that a health system based on primary care produces greater health and economic benefits. Boosting support for Section 747, which funds training for family physicians and for other primary care disciplines, could improve the health of patients in the United States to enjoy those benefits.

## AGENCY FOR HEALTHCARE, RESEARCH AND QUALITY

The Academy recommends \$440 million for the Agency for Healthcare, Research and Quality (AHRQ). A major purpose of AHRQ is to conduct primary care and health services research geared to physician practices, health plans and policy-makers. What this means is that the agency translates research findings from basic science entities like the National Institutes of Health (NIH) into information that doctors can use every day in their practices. Another key function of the agency is to support research on the conditions that affect most Americans.

More recently, AHRQ has become the lead federal agency for research on comparative clinical effectiveness; information technology; and patient safety. For example, the Medicare Modernization Act asked AHRQ to study the "clinical effectiveness and appropriateness of specified health services and treatments," and to use this information to improve the quality and effectiveness of the costly Medicare, Medicaid and SCHIP programs. In fiscal year 2005, \$15 million was appropriated by Congress for this purpose, and the agency now has determined the top 10 conditions for initial research. This type of study on "what works" in clinical therapies is crucial in an era of skyrocketing health care costs and limited federal dollars.

Historically, however, AHRQ has been the lead agency to translate research into information for physicians and patients. Over the years, Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. However, AHRQ's role has been to take this basic science and produce understandable, practical materials for the entire healthcare system. In short, AHRQ is the link between research and the patient care that Americans receive.

In addition, AHRQ has long-supported research on conditions that affect most people. Most Americans get their medical care in doctors' offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals. AHRQ studies and supports research on the types of illness that trouble most people. In brief, AHRQ looks at the problems that bring people to their doctors every day—not the problems that send them to the hospital.

## RURAL HEALTH PROGRAMS

Continued funding for rural programs is vital to provide adequate health care services to America's rural citizens. We support the Federal Office of Rural Health Policy; Area Health Education Centers; the Community and Migrant Health Center Program; and the NHSC. State rural health offices, funded through the National Health Services Corps budget, help states implement these programs so that rural residents benefit as much as urban patients.

## CONCLUSION

The Academy urges Congress to increase funding for Section 747 family medicine training, at a minimum, to the fiscal year 2003 level of \$92 million; provide \$440 million for AHRQ and support rural health programs. Federal funding for these initiatives is vital to sustain and improve America's health care system.

## PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

This statement is submitted on behalf of the American Academy of Pediatrics (AAP) and the endorsing organizations, the Society for Adolescent Medicine (SAM) and the Ambulatory Pediatric Association (APA).

There have been numerous and significant successes in improving the health of America's children and adolescents. The number of 2-year-olds who have received the recommended series of immunizations is at an all-time high. Child death rates have fallen steadily over the past several years. And teen pregnancy rates continue to decline. However, despite these significant improvements, more than 9 million children and adolescents through age 18 remain uninsured. Moreover, racial and ethnic health disparities for many children and adolescents continue to exist, while the percent of children living in poverty continues to climb. Clearly there remains much work to do. As clinicians we must not only diagnose and treat our patients but also promote strong preventive interventions to improve the overall health and well-being of all infants, children, adolescents and young adults. Likewise, as policy-makers, you have an integral role to play in improving the health of the next generation through adequate and sustained funding of vital federal programs.

The AAP, SAM and APA has identified three key priorities within this Committee's jurisdiction key priorities that are at the heart of improving the health and

well-being of America's children and adolescents: access to health care, quality of health care, and immunizations.

#### ACCESS

We believe that all children and adolescents should have full access to health care. From the ability to receive primary care from a pediatrician trained in the unique needs of children and adolescents, to timely access to pediatric medical subspecialists and pediatric surgical specialists, America's children and adolescents deserve access to quality pediatric care.

*Maternal and Child Health Block Grant.*—The Maternal and Child Health (MCH) Block Grant Program at the Health Resources and Services Administration (HRSA) is the only federal program exclusively dedicated to improving the health of all mothers and children. Nationwide, the MCH Block Grant Program provides preventive and primary care services to over 28 million women, infants, children, adolescents and children with special health care needs. In addition, the MCH Block Grant Program supports community programs around the country in their efforts to reduce infant mortality, prevent injury and violence, expand access to oral health care, and address racial and ethnic health disparities. Moreover, the MCH Block Grant Program includes efforts dedicated to addressing interdisciplinary adolescent training and services and research for adolescents' physical and mental health care needs. HRSA also supports adolescent health programs for vulnerable populations, including health care initiatives for incarcerated and minority group adolescents, and violence and suicide prevention. It also plays an important role in the implementation of the State Children's Health Insurance Program (SCHIP), which is critically important at a time when states are continuing to suffer from ongoing deficits and shifting costs. One of the many successful MCH Block Grant programs is the Healthy Tomorrows Partnership for Children Program, a public/private collaboration between the MCH Bureau and the American Academy of Pediatrics. Established in 1989, Healthy Tomorrows has supported over 140 family-centered, community-based initiatives in over 40 states, including Ohio, Wisconsin, Texas, California, Kentucky, and Maryland. These initiatives have addressed issues such as access to oral and mental health care, abstinence, injury prevention, and enhanced clinical services for chronic conditions such as asthma. To continue to foster these and other community-based solutions for local health problems, in fiscal year 2006 we strongly support an increase in funding for the MCH Block Grant Program to \$755 million.

*Family Planning Services.*—The family planning program, Title X of the Public Health Services Act, ensures that all teens have confidential access to valuable family planning resources. The consequence of adolescent pregnancy, sexually transmitted infections (STIs), and HIV/AIDS demands that adolescents be able to make informed, responsible sexual decisions. Title X—which does not provide funding for abortion services—supports teens in making those decisions. According to a January 2005 report from the Henry J. Kaiser Family Foundation, the percentage of high school students who report ever having had sexual intercourse has declined over the past decade, while the rate of contraceptive use among those teens has increased. Nevertheless, teen pregnancy rates continue to vary widely over racial and ethnic groups, over 4 million teens still contract a sexually transmitted infection each year, and nearly half (48 percent) of all teens say that they want more information from—and increased access to—sexual health care services. Responsible sexual decision-making, beginning with abstinence, is the surest way to protect against sexually transmitted diseases and pregnancy. However, for adolescent patients who are already sexually active, confidential contraceptive services, screening and prevention strategies should be available. We therefore support a funding level in fiscal year 2006 of \$350 million for Title X of the Public Health Service Act.

*Mental Health.*—It is estimated that one in five children and adolescents has a mental health problem such as depression, ADHD, or an eating disorder, and for as many as six million this problem may be significant enough to disturb school attendance, interrupt social interactions, and impact quality of family life. Despite these startling statistics, the National Institute of Mental Health (NIMH) estimates that fewer than one in five of these children receives treatment, due in part to stigma and the lack of affordability of care and availability of specialists. One key point of access for helping these children receive the mental health care they need is the inclusion of mental health services—provided by qualified counselors, psychologists, and social workers—in the nation's schools. Grants through the Children's Mental Health Services program have been instrumental in achieving decreased utilization of inpatient services, improvement in school attendance and lower law enforcement contact for children and adolescents. To ensure the continued and growing success of this and other programs focusing on children and adolescents with mental health

problems, the AAP and the endorsing organizations recommend that \$114.7 million be allocated in fiscal year 2006 for the Mental Health Services for Children program.

*Health Professions Education and Training.*—Critical to building a pediatric workforce to care for tomorrow's children and adolescents are the Training Grants in Primary Care Medicine and Dentistry, found in Title VII of the Public Health Service Act. These grants are the only federal support targeted to the training of primary care professionals. They provide funding for innovative pediatric residency training, faculty development and post-doctoral programs throughout the country. For example, at the Cincinnati Children's Hospital, Title VII health professions programs have funded critically important programs in pediatric medical education. The Residency Training in Primary Care grant is designed to train physicians for a career in primary care pediatrics, and features a strong emphasis on behavioral and developmental pediatrics, pediatrics in a community setting, and care for under-represented minorities and medically underserved populations. The community settings in which the primary care training takes place—and, often, ultimately where the physicians chose to practice—are federally-designated HPSAs with diverse populations. This program is now an integral part of the Cincinnati Children's pediatric residency training program, and widely sought after by physicians entering training at Children's.

Through the enduring support of this subcommittee and Congress, the Title VII program has continued to finance critically important educational opportunities in a variety of settings that educate and train tomorrow's generalist pediatricians to be culturally competent and to meet the special health care needs of their communities. We recommend fiscal year 2006 funding of at least \$40 million for General Internal Medicine/General Pediatrics. We also join with the Health Professions and Nursing Education Coalition in supporting an appropriation of at least \$550 million in total funding for Titles VII and VIII. We further recommend and support the Administration's increase in funds in fiscal year 2006 for the National Health Service Corps, a key component to ensuring an adequate distribution of health care providers across the country, but emphasize the need for continued support of the training and education opportunities through Title VII for health care professionals who will work in these areas including community health centers.

*Independent Children's Teaching Hospitals.*—Equally important to the future of pediatric education and research is the dilemma faced by independent children's teaching hospitals. Children's hospitals across the country are critical to the care of the nation's children and play a significant role in research and training tomorrow's pediatricians and pediatric subspecialists. This is especially important at a time when pediatric neurologists, gastroenterologists, and many other specialists for children are in short supply nationally. The children's hospitals have the critical mass of patients, physicians, and services needed to train these specialists, and their ability to sustain their teaching programs contributes to their ability to maintain these services. However, these hospitals qualify for very limited Medicare support, the primary source of funding for graduate medical education in other inpatient environments. As a bipartisan Congress has recognized in the past several years, equitable funding for Children's Hospitals Graduate Medical Education is needed to continue the education and research programs in these child- and adolescent-centered settings. We therefore reject the Administration's reduction in funding for this vital program and join with the National Association of Children's Hospitals to request total funding of \$309 million for the CHGME program in fiscal year 2006 reflecting an adjustment for the cost of inflation. The support for independent children's hospitals should not come, however, at the expense of valuable Title VII and VIII programs, including grant support for primary care training.

#### QUALITY

Access to health care is only the first step in protecting the health of all children and adolescents. We must ensure that the care provided is of the highest quality. Robust federal support for the wide array of quality improvement initiatives is needed if this goal is to be achieved.

*Emergency Services for Children.*—One program that assists local communities in providing quality care to children is the Emergency Medical Services for Children (EMSC) grant program. There are 31 million child and adolescent visits to the nation's emergency departments every year. Children under the age of 3 years account for most of these visits. Up to 20 percent of children needing emergency care have underlying medical conditions such as asthma, diabetes, sickle-cell disease, low birthweight, and bronchopulmonary dysplasia. Providers must be educated and trained to manage these special health care needs in emergency situations, and

emergency systems must be equipped with the resources needed to care for this especially vulnerable population. In order to assist local communities in providing the best emergency care to children, we urge that the EMSC program be maintained and funded at \$20 million in fiscal year 2006.

*Agency for Healthcare Research and Quality.*—Quality of care rests on quality research—for new detection methods, new treatments, new technology and new applications of science. As the lead federal agency on quality of care research, the Agency for Healthcare Research and Quality (AHRQ) provides the scientific basis to improve the quality of care, supports emerging critical issues in health care delivery and addresses the particular needs of priority populations, such as children. Substantial gaps still remain in what we know about health care needs for children and adolescents and how we can best address those needs. Children are often excluded from research that could address these issues. The AAP and endorsing organizations strongly support AHRQ's objective to encourage researchers to include children and adolescents as part of their research populations. We also support increasing AHRQ's efforts to build pediatric health services research capacity through career and faculty development awards and strong practice-based research networks. Additionally, AHRQ is focusing on initiatives in community and rural hospitals to reduce medical errors and to improve patient safety through innovative use of information technology—an initiative that we hope would include children's hospitals as well. Through its research and quality agenda, AHRQ continues to provide policymakers, health care providers, and patients with critical information needed to improve health care; therefore, we join with the Friends of AHRQ to recommend funding of \$440 million for AHRQ in fiscal year 2006.

*National Institutes of Health.*—Since its inception, the National Institutes of Health (NIH) is an integral part of the public health continuum. NIH has served as a vital component in improving the nation's health through research, both on and off the NIH campus, and in the training of research investigators, including pediatric investigators. Over the years, NIH has made dramatic strides that directly impact the quality of life for infants, children and adolescents through biomedical and behavioral research. For example, NIH research has led to successfully decreasing infant death rates, increasing the survival rates from respiratory distress syndrome, and the transmission of HIV from infected mother to fetus and infant has dropped from 25 percent to just 1.5 percent. NIH is engaged in a comprehensive research initiative to address and explain the reasons for a major public health dilemma—the increasing number of obese and overweight adults and children in this country. Today U.S. teenagers are more overweight than young people in many other developed countries. There is also a need for ongoing and increased biomedical research and funding support to study pre-term delivery, etiology, prevention and treatment regimens. In 2002, more than 480,000 babies were born prematurely and the causes of nearly half pre-term births are unknown. The pediatric community applauds the prior commitment of Congress to maintain adequate funding for the NIH and we urge you to sustain this momentum of scientific discovery. We support the recommendation of the Ad Hoc Group for Medical Research Funding for a funding level in fiscal year 2006 of \$30 billion. In addition, to ensure ongoing and adequate child and adolescent focused research, such as the National Children's Study conducted at the National Institute for Child Health and Human Development (NICHD), we join with the Friends of NICHD Coalition in requesting \$1.35 billion in fiscal year 2006.

We commend this committee's ongoing efforts to make pediatric research a priority at the highest level of the NIH. We urge continued federal support of NIH efforts to increase pediatric biomedical and behavioral research, including such proven programs as targeted training and education opportunities and loan repayment. We recommend continued interest in and support for the Pediatric Research Initiative in the Office of the NIH Director and sufficient funding to continue the pediatric training grant and pediatric loan repayment programs enacted in the Children's Health Act of 2000. This would ensure that we have adequately trained pediatric researchers in multiple disciplines that will not come at the expense of other important programs.

Finally, as clinicians, we know first-hand the considerable benefits for children and society in securing properly studied and dosed medications. The benefits of pediatric drug testing are undisputed. Proper pediatric safety and dosing information reduces medical errors and adverse events, ultimately improving children's health and reducing health care costs. In a very conservative estimate, the FDA projected savings from pediatric testing of over \$228 million a year in reduced hospitalization expenses for just five diseases affecting children. But until now there has been little incentive for drug companies to study off-patent drugs—older drugs that are critically needed therapies for children. The Research Fund for the Study of Drugs, cre-

ated as part of the Best Pharmaceuticals for Children Act of 2002, provides support for these critical pediatric testing needs, but unfortunately is currently funded at an amount sufficient to test only a fraction of the NIH and FDA-designated “priority” drugs. Therefore, we urge you to provide the NIH with sufficient funding to fund the study of generic (off-patent) and selected on-patent drugs for pediatric use.

We believe that these requests represent the best and most reliable estimates of the level of funding needed to sustain the high standard of scientific achievement embodied by the NIH. However, we encourage Congress to explore all possible options to identify additional sources of funding needed to support these increases if we are to reach these funding goals while not weakening any other valuable component of the Public Health Service.

#### IMMUNIZATIONS

Immunization remains one of the greatest public health achievements of the 20th century and has saved millions of lives. Since the widespread use of vaccines, millions of children have avoided terrible diseases that can cause great suffering and, in some cases, death. For example before immunization, polio paralyzed 10,000–25,000 children and adults, rubella (German measles) caused birth defects and mental retardation in as many as 20,000 newborns, and measles infected millions of children, killing 400–500 and leaving thousands with serious brain damage. Immunizations have reduced by more than 95 to 99 percent the cases of vaccine-preventable infectious diseases in this country. And some, like rubella, are virtually eliminated from North America, thanks to successful immunization programs.

Pediatricians, working alongside public health professionals and other partners, have brought the United States its highest immunization coverage levels in history. As a result, disease levels are at, or near, record low levels. We attribute this, in part, to the Vaccines for Children (VFC) Program and encourage Congress to maintain its commitment to ensuring the program’s viability. The VFC program combines the efforts of public health and private pediatricians and other health care professionals to accomplish and sustain vaccine coverage goals for both today’s and tomorrow’s vaccines. It removes vaccine cost as a barrier to immunization for some and reinforces the concept of vaccine delivery in a “medical home.” However, we are concerned that once again the Administration’s fiscal year 2006 proposal to reduce funding for the Section 317 program to expand VFC is shortsighted. Additional section 317 funding is necessary to provide the pneumococcal conjugate vaccine (PCV-7), a vaccine that prevents an infection of the brain covering, blood infections and approximately 7 million ear infections a year, to those remaining states that currently do not provide it. Increased funding also is needed to purchase the influenza vaccine. It is now recommended that young children between the ages of 6 months and 23 months of age receive an annual influenza vaccine. This age cohort is increasingly susceptible to serious infection and the risk of hospitalization. And an increase in funding is needed to purchase the recently recommended meningococcal conjugate vaccine (MCV). Meningococcal disease is a serious illness, caused by bacteria, with 10–15 percent of cases fatal and another 10–15 percent of cases resulting in permanent hearing loss, mental retardation, or loss of limbs.

The public health infrastructure that now supports our national immunization efforts must not be jeopardized with insufficient funding. One of the conclusions of the 2000 Institute of Medicine report, *Calling the Shots*, was that unstable funding for state immunization programs threatens coverage levels for specific populations and age groups and vaccine safety. This continues to be true today. A strong and sufficient infrastructure is essential. For example, adolescents continue to be adversely affected by vaccine-preventable diseases (e.g., chicken pox, hepatitis B, measles and rubella). Comprehensive adolescent immunization activities at the national, state and local levels are needed to achieve national disease elimination goals. States and communities continue to be financially strapped and therefore, many continue to divert funds and health professionals from immunization clinics in order to accommodate anti-bioterrorism initiatives. Moreover, continued investment in the CDC’s immunization activities must be made to avoid the reoccurrence of childhood vaccine shortages by providing and adequately funding a national 6 month stockpile for all routine childhood vaccines—stockpiles of sufficient size to insure that significant and unexpected interruptions in manufacturing do not result in shortages for children.

While the ultimate goal of immunizations clearly is eradication of disease, the immediate goal must be prevention of disease in individuals or groups. To this end, we strongly believe that CDC’s efforts must be sustained. In fiscal year 2006, we recommend an overall increase in funding of \$232 million to ensure that the CDC’s National Immunization Program has the funding necessary to accommodate vaccine

price increases, new disease preventable vaccines coming on the market, global immunization initiatives—including funds for polio eradication and the elimination of measles and rubella—and to continue to implement the recommendations developed by the IOM.

#### CONCLUSION

We appreciate the opportunity to provide our recommendations for the coming fiscal year. As this Subcommittee is once again faced with difficult choices and multiple priorities we know that as in the past years, you will not forget America's children and adolescents.

#### OTHER RECOMMENDATIONS FOR FISCAL YEAR 2006

##### DEPARTMENT OF HEALTH AND HUMAN SERVICES

Agency	Amount
Centers for Disease Control and Prevention (total) .....	\$8,065,000,000
Global Immunization (including polio eradication) .....	153,000,000
Birth Defects, Disability and Health .....	135,000,000
Newborn Hearing Screening Technical Assistance .....	9,000,000
National Violent Death Reporting System .....	10,000,000
Folic Acid Education Campaign .....	4,000,000
Health Resources and Services Administration (total) .....	7,500,000,000
Newborn Screening (Title XXVI) .....	25,000,000
Newborn Hearing Screening Grants to States .....	10,000,000
Consolidated Community Health Centers .....	2,038,000,000
Substance Abuse and Mental Health Services Administration (total) .....	3,531,000,000

#### PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 55,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on fiscal year 2006 appropriations for Physician Assistant (PA) education programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the Academy supports the HPNEC recommendation to provide at least \$550 million to support the Titles VII and VIII programs in fiscal year 2006, including \$18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

The Academy believes that the recommended increase in funding for the Title VII health professions programs is well justified. The programs are essential to the development and training of primary health care professionals and contribute to the nation's overall efforts to increase access to care by promoting health care delivery in medically underserved communities.

The Academy is very concerned with the Administration's proposal to eliminate funding for most Title VII programs, including zero funding for training in primary care medicine and dentistry. As Members of the Subcommittee are aware, these programs are designed to help meet the health care delivery needs of the nation's Health Professional Shortage Areas (HPSAs). By definition, the nation's more than 3,800 HPSAs experience shortages in the primary care workforce that the market alone can't address. We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support for these important programs in fiscal year 2006.

#### OVERVIEW OF PHYSICIAN ASSISTANT EDUCATION

Physician assistant programs provide students with a primary care education that prepares them to practice medicine with physician supervision. PA programs are located at schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are intensive education programs that are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 111 weeks of instruction. The first phase of the program consists of intensive classroom and laboratory study, providing students with an in-depth understanding of the medical sciences. More than 400 hours



in classroom and laboratory instruction are devoted to the basic sciences, with over 70 hours in pharmacology, more than 149 hours in behavioral sciences, and more than 535 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours or 50–55 weeks to clinical education, divided between primary care medicine and various specialties, including family medicine, internal medicine, pediatrics, obstetrics and gynecology, surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

Physician assistant education is competency based. After graduation from an accredited PA program, the physician assistant must pass a national certifying examination jointly developed by the National Board of Medical Examiners and the independent National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education credits over a two-year cycle and reregister every two years. Also to maintain certification, PAs must take a recertification exam every six years.

#### PHYSICIAN ASSISTANT PRACTICE

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are within the physician's scope of practice and the PA's training and experience, and are allowed by law. Forty-eight states, the District of Columbia, and Guam authorize physicians to delegate prescriptive privileges to the PAs they supervise.

PAs are located in almost all health care settings and in every medical and surgical specialty. Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 41 percent of PAs work in urban and inner city areas. Approximately 44 percent of PAs are in primary care. Nearly one-quarter practice in surgical specialties. Roughly 80 percent of PAs practice in outpatient settings. In 2004, an estimated 206 million patient visits were made to PAs and approximately 250 million medications were prescribed or recommended by PAs.

#### CRITICAL ROLE OF THE TITLE VII, PUBLIC HEALTH SERVICE ACT, PROGRAMS

A growing number of Americans lack access to primary care, either because they are uninsured, underinsured, or they live in a community with an inadequate supply or distribution of providers. The growth in the uninsured U.S. population increased from approximately 32 million in the early 1990s to nearly 45 million today. Simultaneously, the number of medically underserved communities continues to rise, from 1,949 in 1986 to more than 3,800 today.

The role of the Title VII programs is to alleviate these problems by supporting access to quality, affordable, and cost-effective care in areas of our country that are most in need of health care services, specifically rural and urban underserved communities. This is accomplished through the support of educational programs that train more health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, and increase access to care in underserved communities.

The Title VII programs are the only federal education programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurses, and some allied health professions training has been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities. That is the purpose of the Title VII Public Health Service Act Programs, which support such initiatives as loans and scholarships for disadvantaged students, scholarships for students with exceptional financial need, centers of excellence to recruit and train minority and disadvantaged students, and interdisciplinary initiatives in geriatric care and rural health care.

Furthermore, now that there is compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations, increasing the diversity of health care professionals is essential. Title VII programs are unique in that they seek to recruit providers from a variety of back-

grounds. This is particularly important, as studies have found that those from disadvantaged regions of the country are three to five times more likely to return to those underserved areas to provide care versus other areas.

#### TITLE VII SUPPORT OF PA EDUCATION PROGRAMS

Targeted federal support for PA education programs is currently authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, Public Law 105-392, which streamlined and consolidated the federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

Public Law 105-392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants and faculty, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to an affordable education and encourage PAs, upon graduation, to practice in underserved communities. These goals are accomplished by funding PA education programs that have a demonstrated track record of: (1) placing PA students in health professional shortage areas; (2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and (3) recruiting and retaining students who are indigenous to communities with unmet health care needs.

The program works. A review of PA graduates from 1990-2003 reveals that students graduating from PA programs supported by Title VII are 65 percent more likely to be from underrepresented minority backgrounds and 29 percent more likely to practice in underserved settings, than students graduating from PA programs that were not supported by Title VII.

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, a PA educational program in Iowa uses Title VII funds to target recruitment efforts to disadvantaged students, providing shadowing and mentoring opportunities for prospective students, increasing training in cultural competency, and identifying new family medicine preceptors in underserved areas. PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of web based and distant learning technology and methodologies so students can remain at clinical practice sites. A PA program in New York, where over 90 percent of the students are ethnic minorities, uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the special, unmet needs of medically underserved areas or disadvantaged students. The need is very real, and Title VII is critical in meeting it.

#### NEED FOR INCREASED TITLE VII SUPPORT FOR PA EDUCATION PROGRAMS

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without the Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or the communities in which they attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 1994 report of a workgroup of the Council on Graduate Medical Education (COGME), "Physician Assistants in the Health Workforce," estimated that the anticipated med-

ical market demand and the estimated workforce requirements for PAs would exceed supply. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 49 percent between 2002 and 2012. Title VII funding has provided, and continues to provide, a crucial pipeline of trained PAs to underserved areas. One way to assure an adequate supply of physician assistants, especially PAs likely to practice in underserved areas, is to continue offering financial incentives, such as funding preferences, to PA programs that emphasize recruitment and placement of people interested in primary health care in medically underserved communities.

Despite the increased demand for PAs, funding has not proportionately increased for the Title VII programs that are designed to educate and place physician assistants in underserved communities. Nor has the Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2003 indicates an average annual increase of seven percent, a total increase of 245 percent over the past 19 years, yet federal support has remained relatively static.

RECOMMENDATIONS ON FISCAL YEAR 2006 FUNDING

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all the public health agencies and programs when determining funding for fiscal year 2006. For instance, while it is important to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (HRSA) is inadequately funded. HRSA administers the “people” programs, such as Title VII, that bring the cutting edge research discovered at NIH to the patients—through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The critically important programs administered by NIH, HRSA, and CDC are integral components within the nation’s public health continuum. One component is not more important than another, and no one component can succeed without adequate support from each of the other elements.

Furthermore, while the Academy applauds the Administration’s proposal to strengthen national security by increasing support for health emergency preparedness initiatives, it should not do so at the expense of Title VII programs. Training is the key to preparedness, and Title VII, section 747, is an ideal mechanism for educating primary care providers in public health competencies, facilitating population based and community-based skills and training, and increasing the alliance between public health and primary care providers. This is particularly important for our Nation’s most disadvantaged and underserved populations, because they are the most vulnerable during medical emergencies because of a lack of resources and access to care.

The Academy respectfully requests that the Title VII and VIII health professions programs receive \$550 million in funding for fiscal year 2006, including \$18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

Thank you for the opportunity to present the American Academy of Physician Assistants’ views on fiscal year 2006 appropriations.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS (AANA)

FISCAL YEAR 2006 APPROPRIATIONS REQUEST SUMMARY

	Fiscal year 2005 actual	Fiscal year 2006 budget	AANA request
HHS /HRSA /BHPr Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve.	Awaiting grant allocations \$3.5 MM fiscal year 2004.	Grant allocations not specified.	\$3,000,000
Title VIII HRSA BHPr Nursing Education Programs.	\$150,674,000 .....	\$150,471,000 .....	210,000,000

Chairman Specter, Ranking Member Harkin, and members of the Subcommittee: The AANA is the professional association for more than 30,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs are directly involved in approximately 65 percent of all anesthetics given to patients each year in the United States. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, as well as providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and are the sole anesthesia providers in almost 70 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Having provided anesthesia since the Civil War, masters' educated nurse anesthetists today have set for ourselves the most rigorous continuing education and recertification requirements in the field. We are humbled and honored that the Institute of Medicine reported in 1999 that anesthesia is 50 times safer than 20 years ago. And a recent study by Dr. Michael Pine of over 400,000 cases in 22 states involving CRNAs, anesthesiologists, or both together finds "the type of anesthesia provider does not affect inpatient surgical mortality." In addition, a recent AANA workforce study's data showed that CRNAs and anesthesiologists are substitutes in the production of surgeries. Through continual improvements in research, education, continuing education and practice, nurse anesthetists are vigilant to continue improving patient safety.

And CRNAs provide the lion's share of the anesthesia care required by our U.S. Armed Forces through active duty and the reserves, from here at home to the leading edge of the field of battle. In May 2003, at the beginning of "Operation Iraqi Freedom" 364 CRNAs had been deployed to the Middle East to ensure military medical readiness capabilities. For decades CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support.

#### IMPORTANCE OF TITLE VIII NURSE ANESTHESIA EDUCATION FUNDING

Our chief request before the Subcommittee today, for at least \$3 million to be reserved for nurse anesthesia education from Title VIII, is based on two facts. First, there is a 12 percent vacancy rate of nurse anesthetists in the United States impacting people's healthcare. And second, the Title VIII program supported strongly by members of this Subcommittee in the past is an effective means to help address the nurse anesthesia workforce demand. This demand for CRNAs is something we as a profession are addressing every day with success, and with the critical assistance of federal funding through HHS' Title VIII appropriation.

In 2003 the AANA conducted a nurse anesthesia workforce study, which concluded a 12 percent vacancy rate in hospitals for CRNAs, and a lower vacancy rate in ambulatory surgical centers for 2002. The supply has increased in recent years, stimulated by increases in the number of CRNAs trained. However, these increases had not been enough to offset the number of retiring CRNAs. This trend, as of 2003, will require raising the number of nurse anesthesia graduates to fill the growing vacancy rate. This is compounded by rising number of Medicare-eligible Americans, from about 34 million today, to more than 40 million in 2010, who will require the care that CRNAs provide.

The problem is not that our 94 accredited schools of nurse anesthesia are failing to attract qualified applicants. These CRNA schools are located all across the country including ten in Pennsylvania, five each in Ohio and Florida and Texas, four each in Illinois and New York, three each in California and Connecticut and Maryland, two in Rhode Island, and one in Wisconsin. It is that they are full. Each CRNA school continues to turn away qualified applicants—bachelor's educated nurses who had spent at least one year serving in a critical care environment. Recognizing the importance of nurse anesthetists to quality healthcare, the AANA has been working with its 94 accredited schools of nurse anesthesia to increase the number of qualified graduates, and to expand the number of CRNA schools. The Council on Accreditation of Nurse Anesthesia Educational Programs (COA) reports that in 1999, our schools produced 948 new graduates. By 2005, that number had increased to 1,628, a 72 percent increase in just five years. The growth is expected to continue. The COA projects CRNA schools to produce 1,800 graduates in 2005. But to meet the challenge, we simply must continue expanding the capacity and number of CRNA schools. With the help of competitively awarded Title VIII funding, we are

making significant progress, expanding both the number of clinical practice sites and the number of graduates.

We are pleased to report that this progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. And we know what the Pine study confirms, "the type of anesthesia provider does not affect inpatient surgical mortality." Yet, for what it costs to train just one anesthesiologist, eleven CRNAs may be educated for the same task at the same superlative level of safety. This represents an eleven to one educational cost/benefit for supporting CRNA educational programs with federal dollars vs. supporting other anesthesia providers' education. This also contributes to a three or four to one anesthesia delivery cost/benefit. These ratios represent a cost/benefit unprecedented in any other healthcare specialty.

So is this \$3 million Title VIII investment in nurse anesthesia education effective? In February 2003, AANA surveyed its CRNA school program directors, to gauge the impact of the Title VIII funding. Of those that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding, and there were eleven such schools from 1998 to 2003, they said they on average had increased their number of graduating CRNAs by more than 15 each per year. They reported on average more than doubling their number of CRNA graduates per school, who provide care to patients during and following their education. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas. Under both of these circumstances, an increased number of student nurse anesthetists and CRNAs are providing healthcare to the people of medically underserved America.

We believe it is important for the Subcommittee to allocate \$3 million for nurse anesthesia education for several reasons. First, as we have shown, the funding is cost-effective and well-needed. Second, the Title VIII authorization previously providing such a reserve expired in September 2002. The amount we request is consistent with what Title VIII provided in fiscal year 2001. Third, this particular funding is important because nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. And, last, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

#### TITLE VIII FUNDING FOR STRENGTHENING THE NURSING WORKFORCE

Mr. Chairman, the AANA joins a growing coalition of nursing organizations and others in support of the Subcommittee providing a total of \$210 million in fiscal year 2006 for nursing shortage relief through Title VIII. This amount is approximately \$60 million over the fiscal year 2005 level, and over the President's fiscal year 2006 budget. Every district in America is familiar with the importance of nursing.

I understand that this request is a significant increase over the President's request. Thanks to your leadership and that of the Subcommittee, Congress increased nurse education funding \$5 million over the President's request in fiscal year 2005 for which we are grateful, though we are concerned the Division of Nursing "expert panel" report that motivated requests to reduce Advanced Education Nursing is itself fraught with shortfalls, pitfalls and problems.

Another perspective is that America spends more than \$1.7 trillion on healthcare this year, paid by private and public sources. About \$298 billion of that is estimated to be Medicare outlays in 2005. About \$8.7 billion of that Medicare funds direct and indirect GME, with some 99 percent of that funding helping to educate physicians and allied health professionals, and about 1 percent to help educate nurses. \$301 million of the fiscal year 2005 appropriations bill supports a GME-type program for pediatricians through children's hospitals. These are all worthy things. But for every present and future healthcare patient, Congress must put some focus on nurses and nurse anesthesia care.

From each dollar America spends in healthcare our request is that the federal government should allocate at least 15 thousandths of a cent to ensure we have enough nurses, and at least two ten-thousandths of a cent to ensure we have the safe anesthesia care we need when we need it. This action will improve patients' healthcare, and strengthen seniors' Medicare, all at once.

Thank you.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF OBSTETRICIANS AND  
GYNECOLOGISTS

The American College of Obstetricians and Gynecologists (ACOG), on behalf of its 46,000 partners in women's health care, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Specter, Ranking Member Harkin, and the entire subcommittee for their leadership to continually address maternal and child health care services.

The Nation has made important strides to improve women and children's health over the past several years, and ACOG is grateful to this Committee for its commitment to research. We look forward to working with the Members of this Committee to ensure that vital research continues to eliminate disease and to ensure valuable new treatment discoveries are implemented. The NIH has examined and determined many disease pathways, while the Health Resources and Services Administration has been successful in translating research findings into valuable public health policy solutions. This dedicated commitment to elevate, promote and implement medical research faces an uncertain future at a time when scientists are on the cusp of new cures.

It is vital that the Committee provide strong support for current studies, and for future advances, as well. We urge the Committee to support a 6 percent increase for the National Institutes of Health (NIH) in fiscal year 2006, and a 6 percent increase for the National Institute of Child Health and Human Development (NICHD). We also continue to support efforts to secure adequate funds for important public health programs such as the Health Resources and Services Administration (HRSA). Continued appropriations to these agencies will ensure ongoing and new research initiatives continue to yield positive results for women and children's health.

NATIONAL INSTITUTES OF HEALTH—RESEARCH LEADING THE WAY

*Ob-Gyn Representation on the NICHD Advisory Council*

ACOG is most concerned that research conducted through the National Institute on Child Health and Human Development (NICHD) receives adequate funding, that the Institute can attract new ob-gyn researchers, and that individuals who have expertise and knowledge about its work guide NICHD.

NICHD has overseen tremendous advancements for women including improving pregnancy and childbirth outcomes, and identifying cures for diseases and conditions affecting women of all ages and at all stages in life. NICHD is, in fact, the Institute where the vast majority of ob-gyn related research takes place and the only Institute where ob-gyns have a prominent role. It's critical, then, to require that the NICHD Advisory Council include an adequate number of individuals who have distinguished themselves in ob-gyn clinical practice and research.

Currently, this important Council, which guides the Institute's research funding decisions, is composed of 17 appointed members, including pediatricians, ob-gyns, sociologists, biologists, media consultants, and nurses. The ob-gyns on the Council bring years of expertise and knowledge of women's health care needs, research priorities, and the impact of research discoveries on women's lives. In November 2004, the number of ob-gyns on the Council was reduced from 3 to 2.

ACOG worked actively with the NICHD to advocate the appointment of another ob-gyn to this position, and we are deeply troubled that NICHD filled this position with an attorney, rather than with another ob-gyn. Research conducted at NICHD helps shape the future of women's health care. Women across America and the world suffer from issues of maternal morbidity, uterine fibroids, vulvodynia and numerous other health care issues that are far from being understood and cured. The world faces global challenges, too, of the spread of sexually transmitted diseases, which have barely been acknowledged, much less challenged and defeated.

The NICHD Advisory Council must include an adequate number of ob-gyns who are experts in these clinical and research areas. We object strongly to any attempt to reduce the ability of our specialty to contribute to the research direction of this Institute which is obviously so critical to the area that we know better than any other group or medical specialty—women's health.

We look to Congress to amend the NICHD statute to require that its Advisory Council include no fewer than three experts in the field of ob-gyn. This action is necessary to ensure that decisions that will affect the future of women's health care are made by individuals with expertise and a deep level of commitment to the field. We hope to work actively with this Committee and the Congress to restructure the Council representation requirements.

*Research at the NICHD*

The NICHD conducts research that holds great promise to improve maternal and fetal health and safety. With the support of Congress, the Institute has initiated research addressing the causes of cerebral palsy, gestational diabetes and pre-term birth. However, much more needs to be done to reduce the rates of maternal mortality and morbidity in the United States. More research is needed on such pregnancy-related issues as the impact of chronic conditions during pregnancy, racial and ethnic disparities in maternal mortality and morbidity, and drug safety with respect to pregnancy.

A commitment to research in maternal health sheds light on a breadth of issues that save women's lives. Important research examining the following issues must continue:

*Reducing High Risk Pregnancies*

NICHD's Maternal Fetal Medicine Unit Network, working at 14 sites across the United States (University of Alabama, University of Texas-Houston, University of Texas-Southwestern, Wake Forest University, University of North Carolina, Brown University-Women and Infant's Hospital, Columbia University, Drexel University, University of Pittsburgh-Magee Women's Hospital, University of Utah, Northwestern University, Wayne State University, Case Western University, and Ohio State University), will help reduce the risks of cerebral palsy, caesarean deliveries, and gestational diabetes. This Network discovered that progesterone reduces preterm birth by one-third.

*Reducing the Risk of Perinatal HIV Transmission*

In the last 10 years, NICHD research has helped decrease the rate of perinatal HIV transmission from 27 percent to 1.2 percent. This advancement signals the near end to mother-to-child transmission of this deadly disease.

*Reducing the Effects of Pelvic Floor Disorders*

The Institute has made recent advancements in the area of pelvic floor disorders. The NICHD is investigating whether women that have undergone cesarean sections have fewer incidences of pelvic floor disorder than women who have delivered vaginally.

*Reducing the Prevalence of Premature Births*

NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial groups.

*Drug Safety During Pregnancy*

The NICHD recently created the Obstetric and Pediatric Pharmacology Branch to measure drug metabolism during pregnancy.

*The Challenge of the Future: Attracting New Researchers*

Despite the NICHD's critical advancements, reduced funding has made it difficult for this research to continue, largely due to the lack of new investigators. Congressional programs such as the loan repayment program, the NIH Mentored Research Scientist Development Program for reproductive health, and a small grant program, all attract new researchers, but low pay lines make it difficult for the NICHD to maintain these researchers. Due to the structure of the peer review system, previous grant recipients have an advantage because their grants require fewer funds. This makes it more difficult for new investigators to get into the system, jeopardizing the future of women's health research. We urge the Committee to significantly increase funding at the NICHD to maintain a high level of research innovation and excellence, in turn reducing the incidence of maternal morbidity and mortality and discovering cures for other chronic conditions.

HEALTH RESOURCES AND SERVICES ADMINISTRATION: TURNING RESEARCH INTO SOLUTIONS

It is critical that we rapidly transform women's health research findings into public health solutions. The Health Resources and Services Administration (HRSA) has created women and children's health outreach programs based on research conducted on prematurity, high risk pregnancies, gestational diabetes, and a variety of other health issues. The National Fetal Infant Mortality Review and the Provider's Partnership are two examples of the successful programs under the Healthy Start Initiative.

For example, research shows tobacco abuse and health disparities are risk factors for infant mortality. Healthy Start offers programs for states, which fund provider and community education programs that improve maternal health through tobacco

cessation programs, and finds ways to decrease the infant mortality rate by investigating cultural and institutional health disparities.

#### NATIONAL FETAL INFANT MORTALITY REVIEW

The Fetal and Infant Mortality Review (FIMR) is a cooperative federal agreement between ACOG and the Maternal Child Health Bureau at HRSA. FIMR uses the expertise of ob-gyns and local health departments to find solutions to problems related to infant mortality. In light of the recent increase in the infant mortality rate for 2002, the FIMR program is vital to develop community-specific, culturally appropriate interventions. Today 220+ local programs in 42 states are implementing FIMR and finding it is a powerful tool to bring communities together to address the underlying problems that negatively affect the infant mortality rate.

In order to meet the demand of the increasing number of FIMR programs, NFIMR must be able to continue its activities at an adequate funding level. A rigorous national evaluation of FIMR conducted by Johns Hopkins University has concluded that the FIMR methodology is an effective perinatal initiative. Based on that new research, FIMR can now be called an evidence based MCH intervention. All Healthy Start programs and every locality with disparities in infant outcomes should be actively encouraged to implement this FIMR process.

We urge this Committee to recognize the many positive contributions of the FIMR program and ensure it remains a fully funded program within HRSA.

#### PROVIDER'S PARTNERSHIP

Through May 2003, HRSA funded the Provider's Partnership, a cooperative agreement between the Federal Maternal and Child Health Bureau and ACOG. This Partnership includes a series of state-level projects initiated to address key women's health issues, while simultaneously building partnerships between ACOG Members and public health leadership.

The Partnership works specifically with psychosocial issues that greatly impact the health and well being of women. The morbidity and mortality attributed to issues such as a woman's depression, tobacco use, substance abuse and domestic violence are becoming increasingly apparent as they weigh on both the woman and her entire family. Without treatment, these psychosocial issues place a heavy financial burden on state and federal resources. Obstetrician-gynecologists play a critical role in addressing these problems within their current practice, however because of the complexity and the importance of promptly linking at-risk women with appropriate services, responsibility for full psychosocial assessment and treatment cannot fall solely on obstetrician-gynecologists. Partnerships between women's health care physicians and state and community programs are needed that allow for integration of medical care with psychosocial services. Partnerships increase coordination thereby minimizing demands on both the behavioral health care system and individual providers. Provider's Partnership enables stakeholders to improve prevention interventions, so that later complications can be avoided.

There are currently 30 state-level Partnership teams focused on depression in women, tobacco use, perinatal HIV transmission and oral health. These teams have been successful at surveying obstetric providers on their screening; counseling and referral practices for perinatal depression and tobacco use, the results of which have been the basis for the development of statewide legislative and practice policy guidelines; establishing pilot screening and intervention initiatives for depression in women; and instituting provider training and technical assistance for depression and tobacco use screening and intervention. Despite their successes, these teams still struggle for funds to offset administrative and program costs. Representatives from additional states have expressed an interest in developing an ACOG Provider's Partnership, however, any new efforts are being postponed until additional funding can be identified.

Interagency cooperation to address the multiple factors that affect maternal and child health will help us increase our Nation's overall health. By continuing to translate research done at the NICHD on high-risk pregnancies, drug metabolism, and preterm births, into positive outreach programs such as NFIMR and the Provider's Partnership, we can further improve maternal health and reduce infant mortality.

Again, we would like to thank the Committee for its continued support of maternal and child health research and programs. We strongly urge this Committee to support increased funding for the National Institute of Child Health and Human Development (NICHD), and renewed appropriations for the National Fetal Mortality Review (NFIMR) and the Provider's Partnership programs. This funding would significantly increase the number of women and families who benefit from smoking



cessation programs, depression screening, and community specific solutions to infant mortality. Through joint community and government efforts we can decrease the harmful consequences these issues have on the Nation's health.

We further urge the Committee and the Congress to pass a requirement that the NICHD Advisory Council include no fewer than three experts in the field of ob-gyn, to ensure a bright future for advancements in women's health.

---

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Heart disease, stroke and other cardiovascular diseases kill more Americans each year than the next 5 leading causes of death combined, putting people of all ages at risk. Cardiovascular diseases remain our nation's No. 1 killer and a major cause of disability. We are concerned that our government is still not devoting sufficient resources for research and prevention to America's No. 1 killer—heart disease—and to our country's No. 3 killer—stroke.

STILL NO. 1—AN UNHAPPY DISTINCTION

Cardiovascular diseases represent a continuing crisis of pandemic proportions. More than 70 million Americans suffer from these diseases, and risk factors are on the rise. About 65 percent of American adults are overweight or obese and an estimated 9.2 million children and adolescents ages 6–19 are overweight or obese. Also, an estimated 65 million Americans have high blood pressure, nearly 38 million adults have high cholesterol, and nearly 14 million have diagnosed diabetes. Cardiovascular diseases cost Americans more than any other disease—an estimated \$394 billion in medical expenses and lost productivity in 2005. Heart defects are the most common birth defect and cause more infant deaths than any other birth defect.

HEART DISEASE AND STROKE. YOU'RE THE CURE

Now is the time to capitalize on our progress in understanding heart disease, stroke and other cardiovascular diseases. Promising, cost-effective breakthroughs in treatment and prevention are available, and new ones are on the horizon. A continued, sustained investment in the NIH and appropriate funding for NIH heart disease and stroke will support critically needed new initiatives, especially in the translation of that research into useful clinical and state programs. For fiscal year 2006, we urge you to:

*Appropriate \$30 billion for the National Institutes of Health (NIH)—to provide a continued, sustained investment in life-saving medical research*

NIH research provides new treatment and prevention strategies, creates jobs, and maintains America's status as the world leader in the biomedical and biotechnology industries.

*Provide \$2.3 billion for NIH heart research and \$341 million for NIH stroke research*

Researchers are on the brink of advances to enhance prevention and to provide new treatments so you and your loved ones can be spared the pain and suffering of heart disease and stroke. For example, the impact of co-morbidities on the progression of atherosclerosis and on its prevention and treatment needs further study. In terms of the well-recognized epidemic of obesity, research is needed on the science of weight regulation, on both the genetic and environmental bases of obesity, and on nutrition and exercise science. Inter-Institute communication and joint programs, which have been encouraged by the Director, should continue to grow, particularly in areas such as growth and development, atherosclerosis, obesity and diabetes among others.

*Allot \$55.6 million for Heart Disease and Stroke for the CDC to expand, intensify and coordinate prevention initiatives such as the State Heart Disease and Stroke Prevention Program and the Paul Coverdell National Acute Stroke Registry*

Science must be translated into state programs that hearten Americans to make healthy lifestyle choices to avert and control heart disease and stroke and track and improve stroke care delivery.

*Allocate \$15 million to continue to help rural and community areas treat cardiac arrest in time to save lives by initiating automated external defibrillator (AEDs) programs*

The Rural Access to Emergency Devices Act (part of Public Law 106–505) and the Community Access to Emergency Defibrillation Act (part of Public Law 107–188)

help rural and community areas purchase AEDs and train emergency and lay responders in their use.

#### HEART AND STROKE RESEARCH BENEFITS ALL AMERICANS

Thanks to advances in addressing risk factors and in treating cardiovascular diseases, more Americans are surviving these often deadly and disabling diseases. Heart disease and stroke research, prevention and treatment breakthroughs are saving and improving lives. Several examples follow.

*Automated External Defibrillator.*—Each year, 250,000 Americans die from cardiac arrest. Training volunteers to perform cardiopulmonary resuscitation and to use an AED—a briefcase-size device that shocks the heart into a normal rhythm—distributed in shopping malls, sports venues and other public places can double the survival rate of cardiac arrest victims.

*Implantable Cardioverter Defibrillator.*—An ICD, which provides an electrical impulse to correct an often fatal irregular heart beat, notably reduces deaths in heart failure patients. So, the government announced an expansion of the number of Medicare recipients eligible to receive ICDs. They estimate that about 25,000 Medicare beneficiaries will receive ICDs in the first year, possibly saving up to 2,500 lives. These patients are required to share information about their condition, so medical professionals can assess which individuals are helped the most by ICDs.

*Women and Low-Dose Aspirin.*—A study found that low-dose aspirin on alternative days did not prevent first heart attacks or death from cardiovascular diseases in women, but clot-based strokes were significantly reduced, with the greatest benefit in women age 65 and older.

*Ultrasound in Combination with tPA Enhances Drug's Effectiveness Against Stroke.*—Tissue plasminogen activator (tPA) effectively dissolves clots that are causing an acute clot-based stroke. But, using ultrasonography, a non-invasive technique that uses sound waves, in combination with tPA improves the drug's clot busting abilities, leading to improved chances for a better recovery from stroke.

We join other members of the research community in advocating for a fiscal year 2006 appropriation of \$30 billion for the NIH to provide a continued, sustained investment in life-saving medical research and support investigation into new therapies. The NIH budget for heart disease and stroke remains disproportionately under-funded compared to the enormous burden of these diseases and the numerous promising scientific opportunities that could advance the fight against these disorders. Heart disease, stroke and other cardiovascular diseases meet the NIH's criteria for priority setting (public health needs, scientific quality of research, scientific progress potential, portfolio diversification and adequate infrastructure support), but the NIH continues to invest only 7 percent of its budget on heart research and a mere 1 percent on stroke research. We have a particular interest in individual NIH components that relate directly to our mission. Our funding recommendations for these Institutes follow.

#### HEART RESEARCH CHALLENGES AND OPPORTUNITIES FOR NHLBI

Advances have been made by more than 50 years of American Heart Association-funded research and more than a half-century of investment by Congress in the National Heart, Lung, and Blood Institute. While more people survive heart disease and stroke, they can cause permanent disability, requiring costly medical care and loss of productivity and quality of life.

We urge this Committee to appropriate funding for the NHLBI and for its heart disease and stroke-related efforts to support and expand current activities and to invest in promising and critically needed new initiatives to aggressively advance the battle against heart disease and stroke. To accomplish this goal, we advocate an appropriation of \$3.1 billion for the NHLBI, including \$1.9 billion for heart disease and stroke. This added investment is needed to focus on heart disease and stroke challenges and opportunities. Several of these follow.

*Heart Failure Clinical Research Network.*—Despite advances in treatment, the number of new cases and the number of Americans suffering from heart failure continue to grow. And, the long-term prognosis for patients remains poor. A planned research network with the capability of implementing multiple concurrent clinical studies would conduct clinical studies of new approaches to improve outcomes and would provide an infrastructure to enable rapid translation of promising research findings into patient care.

*Novel Targets and Therapy Development for Clot-based Stroke.*—There is only one FDA-approved emergency treatment for clot-based stroke: t-PA. However, fewer than 5 percent of patients receive it, largely because it must be given within three hours from the onset of symptoms. To address an urgent need to develop new thera-

pies, the NHLBI and the National Institute of Neurological Disorders and Stroke (NINDS) have planned a collaborative effort to identify new molecular targets, explore promising agents, and develop innovative therapies to quickly restore blood flow to the brain and limit stroke damage.

*Technologies for Engineering Small Blood Vessels.*—A need exists to develop alternatives to natural blood vessels for patients who require heart artery bypass surgery and for children born with complex heart defects because the supply of native blood vessels to use as grafts does not meet the demand and prosthetic grafts fail at an unacceptable rate. Planned research would address the development of functional, small blood vessel substitutes.

*Specialized Centers of Clinically Oriented Research for Vascular Injury, Repair, and Remodeling.*—The NHLBI has planned a new SCCOR program to conduct interdependent clinical and multidisciplinary basic research projects on the molecular and cellular mechanisms of vascular (blood vessel) injury, repair, and remodeling. This program would promote patient-oriented research to improve prevention, detection, and treatment of vascular diseases, such as stroke. The SCCORs would provide resources to enable new clinical investigators to develop skills and research capabilities to conduct relevant research in this area.

#### STROKE RESEARCH CHALLENGES AND OPPORTUNITIES FOR NINDS

Stroke is the No. 3 killer of Americans and a major cause of permanent disability. Many of America's 5.4 million stroke survivors face debilitating physical and mental impairment, emotional distress and huge medical costs. About 1 in 4 stroke survivors is permanently disabled. An estimated 700,000 Americans will suffer a stroke this year, and nearly 163,000 will die. In addition to the elderly, stroke also strikes newborns, children and young adults.

We urge you to provide sufficient funding for the NINDS to support and expand current activities and to invest in promising and critically needed new initiatives to aggressively prevent stroke, protect the brain during stroke and enhance rehabilitation. To accomplish this goal, we advocate for an fiscal year 2006 appropriation of \$1.6 billion for the NINDS, including \$183 million for stroke. Some challenges and opportunities follow.

*Strategic Stroke Research Plan.*—As a result of congressional report language during the fiscal year 2001 appropriations process, the NINDS convened a Stroke Progress Review Group (SPRG). Their report serves as a guide for a long-range strategic planning for stroke and includes 5 research priorities and 7 resource priorities to be addressed in the coming years. Multiple scientific programs initiated since the SPRG report are making impressive progress. But, more funding is needed to continue to implement these activities and other components of the plan.

*Emerging Stroke Risk Factors.*—Although more Americans are controlling major stroke risk factors, such as high blood pressure and smoking, the number of stroke victims continues to rise. Scientists are defining new risk factors and re-examining the role of existing ones. Researchers are studying the role of inflammation in damaging arteries, heart valve disease, irregular heartbeats, and the long-term effects of high blood pressure. Increased funding for new approaches in these areas may lead to new ways to prevent stroke.

*Therapeutic Strategies for Stroke.*—Several major clinical trials have identified new methods for preventing and treating stroke in high-risk populations, including stroke survivors. But, as the number of strokes increases and disparities in treatment persist, funding for translational and clinical studies is vital to providing cutting-edge stroke treatment and prevention.

*Stroke Education.*—As a member of the Brain Attack Coalition, organizations devoted to fighting stroke, we work with the NINDS to increase public awareness of stroke symptoms and the need to call 9-1-1. Together, we initiated a public education campaign, Know Stroke: Know the Signs, Act in Time, and we are striving to develop systems to make tPA available to appropriate patients. In partnership with the CDC, the NINDS extended this campaign to launch a grassroots program called Know Stroke in the Community to enlist the aid of "Stroke Champions" who educate communities about stroke signs and symptoms. A pilot phase of the program in 5 cities has just been completed. When these measures are implemented, stroke treatment will shift from supportive care to early brain-saving intervention. But more funding is needed to educate the public and health providers about stroke.

#### RESEARCH IN OTHER NIH INSTITUTES BENEFIT HEART DISEASE AND STROKE

Research seeking to prevent and find better treatments for heart disease, stroke and other cardiovascular diseases is supported by other NIH entities like the National Institute on Aging, the National Institute of Diabetes and Digestive and Kid-

ney Diseases, the National Institute of Nursing Research, the National Institute of Child Health and Human Development and the National Center for Research Resources. It is important to provide sufficient additional resources for these entities to continue and expand their critical work.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The AHRQ is a critical partner with the public and private health care sectors. They help develop evidence-based information needed by consumers, providers, health plans and policymakers to improve health care decision making. We join with the Friends of AHRQ in advocating for an appropriation of \$440 million for the AHRQ to advance health care quality, cut medical errors and expand the availability of health outcomes information.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

Prevention is the best way to protect Americans' health and ease the financial and human burden of disease. Resources must be made available to bring the benefits of research to places where heart disease and stroke strike—our towns and neighborhoods. The CDC builds a bridge between what we learn in the lab, translating findings into programs in the communities where we live. We advocate a fiscal year 2006 appropriation of \$8.7 billion for the CDC, with a 10 percent increase over current funding for state-based chronic disease prevention and health promotion programs.

Within that figure, we support an appropriation of \$55.6 million for the CDC's Heart Disease and Stroke line—which would bring per capita spending for heart disease, stroke and other cardiovascular disease prevention from 10 cents to about 12 cents. This would allow the CDC to better expand, intensify and coordinate prevention activities against these diseases, such as enhancing the State Heart Disease and Stroke Prevention Program and the Paul Coverdell National Acute Stroke Registry. It would also allow the CDC to begin the development of a state-based cardiac arrest registry, augment current health communication projects on heart attack and stroke signs and symptoms, as well as public and health care provider education; and support critical standardization of lipid and other measurements.

We commend Congress for encouraging the CDC to create a Heart Disease and Stroke Division. With ample resources and capacity, a Division would further enable CDC's efforts in this area. Thanks to this Committee's support since fiscal year 1998, the CDC's State Heart Disease and Stroke Prevention Program covers 33 states, allowing them to design and/or implement state-tailored prevention programs. But only 12 states receive funding to actually implement programs to prevent and control heart disease and stroke. The other 21 states were only provided funds to support program planning; which is now largely complete. Since cardiovascular diseases remain the No. 1 killer in every state, each state needs funding for basic implementation of a State Heart Disease and Stroke Prevention Program. With fiscal year 2005 funding, the CDC can only elevate up to two states from planning to program implementation.

An appropriation of \$55.6 million would allow the CDC to add up to 4 new states to the State Heart Disease and Stroke Prevention Program, allowing them to conduct a state-tailored prevention plan, and would elevate 4 more states to from planning to program implementation. It would enhance the Paul Coverdell National Acute Stroke Registry, which tracks and improves delivery of acute stroke care that can mean the difference between a fairly normal life and long-term disability. After developing and conducting 8 registry prototypes (fiscal year 2001–2003), the CDC funded 4 state health departments to implement registries in fiscal year 2004.

We recommend the following fiscal year 2006 funding levels for the following CDC programs:

- \$132 million for the Preventive Health and Health Services Block Grant;
- \$70 million for the Obesity, Physical Activity and Nutrition Program;
- \$50 million for the Youth Media Campaign;
- \$82.4 million for the School Health Education Program; and
- \$145 million for the Office of Smoking and Health.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION.

About 95 percent of cardiac arrest victims die before reaching a hospital. AEDs are small, easy-to-use devices that can shock a heart back into normal rhythm and restore life. The Rural Access to Emergency Devices Act and the Community Access to Emergency Defibrillation Act authorize funds for state and local governments to start AED programs. States, cities and towns nationwide eagerly await funds from these vital public health service grant awards, with available funds far below re-

quests. An appropriation of \$15 million is required to support these authorized programs.

DEPARTMENT OF EDUCATION

Physical inactivity is a key risk factor for heart disease and stroke. Yet, our youth have fewer chances for physical education. Congress has been appropriating money for the Carol M. White Physical Education Program (PEP) to provide funding for school-based physical education initiatives that teach life-long physical activity habits and thus prevent diseases, like heart disease and stroke. We advocate for an appropriation of \$100 million for PEP.

ACTION NEEDED

Despite progress, heart disease, stroke and other cardiovascular diseases remain America's No. 1 killer. Cardiovascular diseases meet the NIH's criteria for priority setting, but NIH continues to invest only 7 percent of its budget on heart research and a mere 1 percent on stroke research. Increasing funding for promising research opportunities and for proven prevention and treatment programs will allow continued strides against these diseases. Our government's response to this challenge will help define the health and well being of Americans for decades.

PREPARED STATEMENT OF THE AMERICANS FOR NURSING SHORTAGE RELIEF ALLIANCE

The ANSR Alliance (Americans for Nursing Shortage Relief) appreciates the opportunity to submit written comments for the record regarding funding for nursing workforce and research programs in fiscal year 2006. ANSR is a coalition of 48 nursing organizations representing a diverse cross section of healthcare and professional organizations, healthcare providers, and friends of nursing that have united to address the ever-growing nursing shortage.

To ensure that the nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century, ANSR and the nation's 2.7 million registered and advanced practice registered nurses (RNs and APRNs) advocate at least \$210 million for the nursing workforce programs within Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA) as well as \$160 million for the National Institute of Nursing Research (NINR) at the National Institutes of Health (NIH) in fiscal year 2006. ANSR stands ready to work with policymakers at the federal level to advance policies and programs that will sustain and strengthen the nation's nursing workforce.

NURSING SHORTAGE BACKGROUND

Nursing is the nation's largest healthcare provider group with an estimated 2.7 million licensed nurses. Nurses play a critical role in the health care system because they represent approximately 54 percent of all health care workers and provide patient care in virtually all locations in which health care is delivered. Our ability, as a nation to meet these projected workforce needs is complicated by a number of factors.

- The total nursing workforce is aging. By 2010, the average age of RNs is forecasted to be 45.4 years, an increase of 3.5 years over the current age, with more than 40 percent of the RN workforce expected to be older than 50 years.
- Approximately half of the RN workforce is expected to reach retirement age within the next 10 to 15 years. The average age of new RN graduates is 31 years; RNs are entering the profession older and will have fewer years to work than nurses traditionally have had.
- For the first time, registered nurses top the U.S. Bureau of Labor Statistics list of occupations with the largest projected 10-year job growth. Nurses have been on the list for some time but never as number one. The Bureau's latest projections put the demand for registered nurses at 2.9 million in 2012, up from 2.3 million in 2002.
- The national nursing shortage also is affecting our nation's 7.6 million veterans who receive care through the 1,300 Veterans Administration (VA) health care facilities.
- Nearly 1,800 faculty members leave their positions and fewer than 400 potential faculty candidates receive doctoral degrees each year.
- For the 2003–2004 academic year, an estimated 125,000 qualified applicants were turned away from nursing programs at all levels due largely to a faculty shortage.

## ADEQUATE NURSING WORKFORCE: HOMELAND SECURITY

Homeland security efforts try to prevent harm to our country, and nurses play a critical role. These efforts involve the health system, and nurses represent the largest group of health care providers who will be called on to respond to an emergency, disaster, or mass-casualty event. The estimates for the nurse workforce demand in 2010 do not take into account the healthcare system's ability to meet the healthcare needs of a surge of patients that could be expected from a mass-casualty event, whether natural or man-made. Given the findings of the bipartisan 9–11 Commission, it seems particularly relevant now to ensure an adequate supply of all levels of nurses, who are often front-line, first-responders in the case of tragedy. Unless steps are taken now, the nation's ability to respond to a natural or intentional disaster will be impeded by the growing nationwide nursing shortage. An investment in the nurse workforce is a step in the right direction to re-build the public health infrastructure and increase our nation's healthcare readiness and emergency response capabilities.

## GROWING UNMET NEED

Fortunately—after years of failing to have enough interested individuals to pursue nursing—our nation is finally seeing a slight upturn in nursing school applications. Many Americans, who have lost their jobs due to the economy, and others interested in a second career, find nursing attractive because of the job security, sufficient pay, and the opportunity it affords to help others. However, nursing organizations are hearing from prospective nursing students that they face waiting periods of up to 3 years before they can matriculate because there is not enough teaching faculty available. In many cases, students who have been accepted into programs face long waits to matriculate in nursing school due to these challenges. For example, in 2004, U.S. nursing schools turned away more than 32,000 qualified applicants to entry-level baccalaureate and graduate nursing programs due to insufficient faculty, clinical sites, classroom space, clinical preceptors, and budget constraints, including almost 3,000 students who could potentially fill faculty roles. When nursing programs of all levels are considered, the number of qualified applicants turned away during the 2003–2004 academic year grows to more than 125,000. Without sufficient support for current nursing faculty and adequate incentives to encourage more nurses to become faculty—our nation will fail to have the teaching infrastructure necessary to educate and train the next generation of nurses we need so desperately to care for our family and friends, neighbors, colleagues, and ourselves.

Enacted in 2002, the Nurse Reinvestment Act included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in fiscal year 2003, HRSA received 8,321 applications for the Nurse Education Loan Repayment Program, but only had the funds to award 7 percent (602) of all applications. Also in fiscal year 2003, HRSA received 4,512 applications for the Nursing Scholarship Program, but only had funding to support a mere 2 percent (94) of all applications.

Therefore, the ANSR Alliance strongly urges Congress to provide HRSA with a minimum of \$210 million in fiscal year 2006 to ensure that the agency has the resources necessary to fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications as well as implement other essential endeavors to sustain and boost our nation's nursing workforce.

## SUSTAIN AND SEIZE NURSING RESEARCH OPPORTUNITIES

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses such as cancer. The ANSR Alliance supports a fiscal year 2006 appropriation level of \$160 million for the NINR at the National Institutes of Health.

## CONCLUSION

The ANSR Alliance stands ready to work with policymakers to advance policies and support programs that will sustain and strengthen our nation's nursing workforce. We thank you for this opportunity to discuss the funding levels necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow.

Programmatic area	Final fiscal year 2005	President's budget fiscal year 2006	ANSR's request
Nurse Workforce Development Programs .....	\$151,889,000	\$150,000,000	\$210,000,000
National Institute of Nursing Research .....	138,000,000	139,000,000	160,000,000

ANSR Alliance Organizations that endorse this testimony: American Association of Critical-Care Nurses; American Association of Occupational Health Nurses, Inc.; American Academy of Nurse Practitioners; American College of Nurse Practitioners; American Nephrology Nurses Association; American Society of PeriAnesthesia Nurses; Association of periOperative Registered Nurses; Association of State and Territorial Directors of Nursing; Association of Women's Health, Obstetric and Neonatal Nurses; Emergency Nurses Association; Infusion Nurses Society; National Association Nurse Massage Therapists; National Association of Orthopaedic Nurses; National Association of Pediatric Nurse Practitioners; National Association of School Nurses; National Council of State Boards of Nursing; National League for Nursing; National Nursing Centers Consortium; National Student Nurses' Association; Nurses Organization of Veterans Affairs; Oncology Nurses Society; Society of Trauma Nurses; and Society of Urologic Nurses and Associates.

## PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates this opportunity to comment on fiscal year 2006 appropriations for nursing education, workforce development, and research programs. Founded in 1886, ANA is the only full-service national association representing registered nurses. Through our 54 constituent member associations, we represent registered nurses (RNs) across the nation in all practice settings.

The ANA gratefully acknowledges this Subcommittee's history of support for nursing education and research. We appreciate your continued recognition of the important role nurses play in the delivery of quality health care services. This testimony will give you an update on the status of the nursing shortage, its impact on the nation, and the outlook for the future.

## THE NURSING SHORTAGE TODAY

The nursing shortage is far from solved. Here are a few quick facts:

- On February 11, 2004, the Bureau of Labor Statistics reported that registered nursing will have the greatest job growth of all U.S. professions in the time period spanning 2002–2012. During this 10-year period, health care facilities will need to fill more than 1.1 million RN job openings.
- The Division of Nursing at the Health Resources and Services Administration projects that, absent aggressive intervention, the supply of nurses in America will fall 29 percent below requirements by the year 2020.
- The American College of Healthcare Executives reported in October, 2004 that 72 percent of hospitals were experiencing a nursing shortage at their facility.
- According to the National Council of State Boards of Nursing, the number of first-time, U.S. educated nursing school graduates who sat for the NCLEX-RN® (the national licensure examination for registered nurses) decreased by 20 percent from 1995–2003. A total of 19,820 fewer students in this category of test takers sat for the exam in 2003 as compared with 1995.

This growing nursing shortage is having a detrimental impact on the entire health care system. Numerous recent studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study based on a review of more than 6 million patients was published in the *New England Journal of Medicine* in May, 2002. The researchers found that hospitalized patients had better outcomes when the number of hours of RN care per day increased. Specifically, nursing shortages were found to correlate with longer lengths of stay, increased incidence of urinary tract infections and upper gastrointestinal bleeding, higher rates of pneumonia, shock and cardiac arrest. Increased hours of RN care resulted in fewer "failure-to-rescue" deaths from pneumonia, shock

or cardiac arrest, upper gastrointestinal bleeding, sepsis and deep venous thrombosis.

Research published in the October 23, 2002 Journal of the American Medical Association demonstrated that more nurses at the bedside could save thousands of patient lives each year. In reviewing more than 232,000 surgical patients at 168 hospitals, researchers from the University of Pennsylvania concluded that a patient's overall risk of death rose roughly 7 percent for each additional patient above four added to a nurse's workload.

A Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) study published in 2002 shows that nearly one-quarter of all unanticipated deaths or injuries result from a lack of adequate nursing care.

#### THE IMPACT ON PREPAREDNESS AND MILITARY HEALTH CARE

This growing nursing shortage has effects well beyond domestic health care. RNs are integral in everything from adequate terrorism preparedness, to veterans' health delivery, to disaster response. In the event of a terrorist attack, nurses will be needed to evaluate patients, administer vaccines and medications, perform disease surveillance, and to train non-licensed staff. The Agency for Healthcare Research and Quality has developed a model to determine the number of health staff needed for these activities. According to this model, a small-scale anthrax attack in New York City would require 18,981 trained staff working around the clock for four days to provide needed testing and antibiotics. A contained, small-scale smallpox attack in Columbus, OH would require 2,296 patient-care staff working around the clock for 4 days. The GAO reports that five out of 7 states have claimed that nursing shortages are hindering their bioterrorism preparedness efforts.

The nursing shortage is also stressing military health care delivery. Because the military holds the vast majority of its health care assets in the reserves, the reserve activation has been particularly hard on nursing. There are currently more than 19,000 RNs providing care through the military reserves. As these nurses are drawn out of the domestic labor pool, the shortage is exacerbated.

The Army, Navy, and Air Force are offering lucrative RN recruitment packages that include large sign-on bonuses, generous scholarships, and loan forgiveness packages. Yet, for the last 2 years the Army has not met its RN recruiting goals for either the active service or the reserves. The Air Force has not met its recruiting goals for the last 5 years. Therefore, this shortage impacts our very strength as a nation.

#### NURSING WORKFORCE DEVELOPMENT PROGRAMS

Federal support for the Nursing Workforce Development Programs contained in Title VIII of the Public Health Service Act is unduplicated and essential. In 2002, the 107th Congress recognized the detrimental impact of the developing nursing shortage and passed the Nurse Reinvestment Act (Public Law 107-205). This law improved the programs of Title VIII to meet the unique characteristics of today's shortage. This significant achievement holds the promise of recruiting new nurses into the profession, promoting career advancement within nursing and improving patient care delivery. This promise will not be met, however, without a significant investment.

In fiscal year 2004 this Subcommittee allocated \$142 million in funding for Title VIII, this supported 28,253 individual student nurses. In fiscal year 2005, the hard work of this Subcommittee resulted in \$151 million in funding for Title VIII programs. ANA strongly urges you to increase funding for Title VIII programs by at least \$24 million to a total of \$175 million in fiscal year 2006. The nursing shortage and its impact on the health care of the nation demand this continued investment.

In 1974, this Subcommittee invested \$153.6 million Title VIII. Inflated to today's dollars, this long-ago appropriation would equal \$592 million, approximately four times the current appropriation. Certainly, today's shortage is more dire and systemic than that of the 1970's; it deserves an equivalent response.

Title VIII includes the following program areas:

*Nursing Education Loan Repayment Program & Scholarships.*—This line item is comprised of the Nurse Education Loan Repayment Program (NELRP) and the Nursing Scholarship Program (NSP), the Secretary of HHS has the authority to allocate funds between the two areas. The NELRP repays nursing student loans in return for at least two years of practice in a facility with a critical nursing shortage. For the first two years of service, the NELRP will repay 60 percent of the RN's student loan balance. If the nurse elects to stay for another year, an additional 25 percent of the loan will be repaid. Within 3 years, a nurse can pay off 85 percent of his/her student loans.



The NELRP boasts a proven track record of delivering nurses to facilities hardest hit by the nursing shortage. HRSA has given NELRP funding preference to RNs who work in skilled nursing facilities, disproportionate share hospitals, and departments of public health. However, lack of funding has hindered the full implementation of this program. In fiscal year 2004, HRSA received more than 4,800 applications for the NELRP. Due to lack of funding, only 857 loan repayments were awarded. Therefore, 82 percent of the nurses willing to immediately begin practicing in facilities hardest hit by the shortage were turned away from this program.

The nursing scholarship program offers funds to nursing students who, upon graduation, agree to work for at least two years in a health care facility with a critical shortage of nurses. Preference is given to students with the greatest financial need. Like the loan repayment program, the nursing scholarship program has been stunted by a lack of funding. In fiscal year 2004, HRSA received more than 8,800 applications for the nursing scholarship. Due to lack of funding, a mere 126 scholarships were awarded. Therefore, 98 percent of the nursing students willing to work in facilities with a critical shortage of nurses were denied access to this program.

*Nurse Faculty Loan Program.*—This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a 4-year period. Loans can cover the costs of tuition, fees, books, laboratory expenses, and other reasonable education expenses.

This program is vital given the critical shortage of nursing faculty. America's schools of nursing can not increase their capacity without an influx of new teaching staff. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In fiscal year 2004, HRSA awarded 61 nurse faculty loan repayments.

*Nurse Education, Practice, and Retention Grants.*—This section contains grant areas designed to expand enrollments in baccalaureate nursing programs; develop internship and residency programs to enhance mentoring and specialty training, and; provide new technologies in education including distance learning. Practice grant areas are designed to expand practice arrangements in non-institutional settings to improve primary health care in medically underserved communities; provide care for underserved populations; provide skills necessary to practice in existing and emerging health systems, and; develop cultural competencies. Retention grant areas include career ladders and improved patient care delivery systems. The career ladders program supports education programs that assist individuals in obtaining the educational foundation required to enter the profession, and to promote career advancement within nursing.

Enhancing patient care delivery system grants are designed to improve the nursing work environment. It provides grants to facilities to enhance collaboration and communication among nurses and other health care professionals, and to promote nurse involvement in the organizational and clinical decision-making processes of a health care facility. These best practices for nurse administration have been identified by the American Nurse Credentialing Center's Magnet Recognition Program. These practices have been shown to double nurse retention rates, increase nurse satisfaction, and improve patient care.

*Nursing Workforce Diversity.*—This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds—including racial and ethnic minorities, as well as individuals who are economically disadvantaged. Racial and ethnic minorities currently comprise more than 25 percent of the nation's population and will comprise nearly 40 percent by the year 2020. Only 12 percent of the RNs in the United States come from diverse backgrounds. Increasing the number of RNs from diverse races helps to address the prevention, treatment, and rehabilitation needs of an increasingly diverse population. For fiscal year 2004, HRSA received 144 submissions for nursing workforce diversity grants. HRSA was only able to fund 20 (14 percent of applications).

*Advanced Nurse Education.*—Advanced practice registered nurses (APRNs) are RNs who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, mental health, midwifery, neonatology, and women's & adult health. Title VIII grants have supported the development of virtually all initial state and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas.

These grants also provide traineeships for masters and doctoral students. Title VIII funds more than 60 percent of U.S. nurse practitioner education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of advanced nursing graduates go on to practice in medically underserved communities, and in areas with large Medicaid populations. Many provide care to minority or disadvantaged patients. In fiscal year 2004, HRSA funded 82 advanced education nursing grants (78 percent of applications), 335 advanced education nursing traineeships (every application), and 73 nurse anesthetist traineeships (every application).

*Comprehensive Geriatric Education Grants.*—This authority awards grants to train and educate nurses in providing health care to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. The growing number of elderly Americans and the impending health care needs of the baby boom generation make this program critically important. In fiscal year 2004, HRSA continued 17 previously awarded grants.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

ANA also urges the Subcommittee to increase funding for the NINR, one of the institutes at the National Institutes of Health (NIH). Nursing research is an integral part of the effectiveness of nursing care. Advances in nursing care arising from nursing and other biomedical research improves the quality of patient care and has shown excellent progress in reducing health care costs. Research programs supported by NINR address a number of critical public health and patient care questions. The research is driven by real and immediate problems encountered by patients and families.

Recent studies have revealed the difference in heart attack symptoms in women versus men, the most effective means to prevent infectious diseases in inner city households, the incidence and risk factors for uterine rupture in pregnancies following cesarean section, and the means to help family caregivers provide high-quality long-term care for loved ones with chronic health care needs. NINR is leading the NIH research on end-of-life and palliative care. NINR is the lowest funded institute at NIH. ANA recommends \$160 million in fiscal year 2006 funding for the NINR.

#### CONCLUSION

While we appreciate the continued support of this Subcommittee, ANA is concerned by the fact that Title VIII funding levels have not been sufficient to assist qualified students enter the nursing profession. The nursing shortage will continue to worsen if significant investments are not made in nursing workforce development programs. Recent efforts have shown that aggressive and innovative recruitment efforts can help avert the impending nursing shortage—if they are adequately funded.

ANA asks you to meet today's shortage with a relatively modest investment of \$175 million in Title VIII programs. Additionally, an investment of \$160 million in the NINR will help assure that these nurses are equipped with the information needed to provide the best care possible.

---

#### PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION (APHA)

The American Public Health Association (APHA), the oldest organization of public health professionals, represents more than 50,000 members from over 50 public health occupations. We are pleased to submit our views on federal funding for public health activities in fiscal year 2006.

#### RECOMMENDATIONS FOR FUNDING THE PUBLIC HEALTH SERVICE

APHA's budget recommendation concurs with the estimate developed by the Coalition for Health Funding: we believe the Public Health Service needs an increase of \$3.5 billion in fiscal year 2006. This figure is based on the professional estimate of need and opportunity within each agency of the Public Health Service and would accommodate needed increases for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH), as well as agencies outside this subcommittee's jurisdiction—the Food and Drug Administration (FDA) and the Indian Health Service (IHS).

## CENTERS FOR DISEASE CONTROL AND PREVENTION

APHA supports a funding level for the Centers for Disease Control and Prevention that enables it to carry out its mission to protect and promote good health and to assure that research findings are translated into effective state and local programs. It is time to support CDC as an agency—not just the individual programs that it funds. In the best professional judgment of the American Public Health Association, in conjunction with the CDC Coalition—given the challenges of terrorism and disaster preparedness, new and re-emerging infectious diseases, the epidemic of obesity, particularly among children, and our many unmet public health needs and missed prevention opportunities—the agency will require funding of at least \$8.65 billion to support its mission for fiscal year 2006.

APHA is pleased with the support the Subcommittee has given to CDC programs over the years, including your recognition of the need to fund Severe Acute Respiratory Syndrome (SARS) response efforts, obesity prevention, chronic disease prevention, and solutions to the shortage of the flu vaccine. By translating research findings into effective intervention efforts in the field, the agency has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. From anthrax to West Nile to smallpox to avian flu, the Centers for Disease Control and Prevention is the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

In fiscal year 2002, Congress appropriated \$7.7 billion for CDC. In fiscal years 2003, 2004 and 2005, Congress appropriated \$7.1 billion, \$7.2 billion, and \$8.0 billion, respectively. Now the President's proposed budget for the agency in fiscal year 2006 is \$7.5 billion—a \$500 million cut from last year's funding, and \$200 million below the fiscal year 2002 funding level. We are moving in the wrong direction. Public health is being asked to do more, not less. As far as we can tell, in light of the current workload placed on the public health service—in addition to the threat of emerging diseases such as the avian flu—it simply does not make any sense to cut the budget for CDC at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability.

Furthermore, the President's budget proposes the elimination of two very important chronic disease prevention programs: the Preventive Health and Health Services Block Grant and the Childhood Obesity Prevention Program (COPP), also referred to as the VERB or CDC Youth Media campaign. As states use their Prevention Block Grant dollars to address high priority needs such as emerging and chronic diseases, child safety seat programs, suicide prevention, smoke detector distribution and fire safety programs, adult immunization, oral health, worksite wellness, infectious disease outbreaks, food safety, emergency medical services, safe drinking water, and surveillance needs—we can scarcely understand why the Prevention Block Grant should be eliminated. And the success of the COPP program shows that over 30 percent of the target audience, children ages 9 to 10 years, increased their physical activity as a direct result of the VERB media campaign. This type of success warrants continued funding of a program to empower our children to respond to the growing concerns of the obesity epidemic and improve the health of this nation. We encourage the Subcommittee to restore the cuts and fund the Prevention Block Grant at \$132 million and the COPP program at \$70 million.

Until we are committed to a strong public health system, every crisis will force trade offs. For instance, the Administration's recent reprogramming request to make up for the vaccine shortage with money originally appropriated by Congress for chronic disease prevention programs (COPP and the Preventive Health and Health Services Block Grant) and bioterror preparedness funds is the most recent concrete example of attention to one disease coming at the expense of another.

We also encourage the Subcommittee to provide \$10 million for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. As with the public health workforce, the environmental health workforce is declining. Furthermore, the agencies that carry out these services are fragmented and their resources are stretched. These services are the backbone of public health and are essential to protecting and ensur-

ing the health and well being of the American public from threats associated with West Nile virus, terrorism, *E. coli* and lead in drinking water.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA programs assure that all Americans have access to our nation's best available health care services. HRSA provides a health safety net for medically underserved individuals and families, including 45 million Americans who lack health insurance; African American infants, whose infant mortality rate is more than double that of whites; and the estimated 850,000 to 950,000 people living with HIV/AIDS. Programs to support the underserved place HRSA on the front lines in erasing our nation's racial/ethnic and rural/urban disparities in health status. HRSA funding goes where the need exists, in communities all over America. The agency's overriding goal is to achieve 100 percent access to healthcare, with zero disparities. In the best professional judgment of APHA, in conjunction with the Friends of HRSA Coalition, to respond to this challenge, the agency will require a funding level of at least \$7.5 billion for fiscal year 2005.

We are grateful to the Subcommittee for your consistent strong support for all of HRSA's programs, including the initiatives in terrorism preparedness and response in the past. Unfortunately, the president's budget overall recommends a massive \$838 million or over 12 percent cut to the agency for fiscal year 2006. We urge the members of the Subcommittee to restore the cuts and fund the agency at a level that allows HRSA to effectively implement these important programs.

APHA is pleased that the Administration has requested a significant 17.5 percent increase for Community Health Centers. More than 4,000 of these sites across the nation provide needed primary and preventive care to nearly 15 million poor and near-poor Americans. Health centers provide access to high-quality, family-oriented, culturally and linguistically competent primary care and preventive services, including mental and behavioral health, dental and support services. Nearly three-fourths of health center patients are uninsured or on Medicaid, approximately two-thirds are people of color, and more than 85 percent live below 200 percent of the poverty level.

However, we are once again very concerned that the HRSA health professions programs under Title VII and VIII have once again landed on the chopping block. Today our nation faces a widening gap between challenges to improve the health of Americans and the capacity of the public health workforce to meet those challenges. An adequate, diverse, well-distributed and culturally competent health workforce is indispensable to our national readiness efforts and to address critical health care needs. These programs help meet the health care delivery needs of the areas in this country with severe health professions shortages, at times serving as the only source of health care in many rural and disadvantaged communities. Therefore, the elimination of most funding for the Title VII health professions training programs and flat funding for Title VIII nurse training will only make certain that the needs of these medically underserved populations will not be met.

Furthermore, we believe the elimination of the Healthy Community Access Program, universal newborn hearing screening programs, and the Emergency Medical Services for Children Program, especially when coupled with the flat-funding of the Maternal and Child Health Block Grant, will further undermine the availability of health services for some that are most in need—especially children. The Healthy Community Access Program is an example in which communities build partnerships among health care providers to deliver a broader range of health services to their neediest residents. This program of coordinated service delivery is innovative, not duplicative of other available programs, and therefore its elimination is of grave concern. Also, the proposed zero funding of universal newborn hearing screening programs in the Administration's budget will likely cause many hearing impairments in infants to go undetected, which can negatively impact speech and language acquisition, academic achievement, and social and emotional development. The proposed elimination of the Emergency Medical Services for Children Program will hurt many children who are eligible for Medicaid and SCHIP, but not enrolled due to state enrollment limits and budgetary pressures, and therefore frequently use emergency health services.

We are very concerned that most programs under the Ryan White CARE Act, administered by HRSA's HIV/AIDS Bureau, would be flat-funded should the figures requested by the Administration be implemented. The CARE Act program is an important safety net program, providing an estimated 533,000 people access to services and treatments each year. At a time when HIV/AIDS is the fifth leading cause of death for people who are 25 to 44 years old in the United States, and the number

of new domestic HIV/AIDS cases is increasing, not decreasing, flat funding these critical Ryan White Act programs does not make much sense.

Through its many programs and new initiatives, HRSA helps countless individuals live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled change in the nation's health care delivery system. HRSA is well positioned to meet these new challenges as it continues to provide first-rate health care to the nation's most vulnerable citizens. We recommend growth in HRSA's budget to meet the needs of vulnerable populations served by the agency.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We request a funding level of \$443 million for the Agency for Healthcare Research and Quality for fiscal year 2006, an increase of \$124 million over last year. This level of funding is needed for the agency to fully carry out its Congressional mandate to improve health care quality, including eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities. The cuts proposed in the administration budget will severely hamper these efforts.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

APHA supports a funding level of \$3.5 billion for the Substance Abuse and Mental Health Services Administration for fiscal year 2006, an increase of \$262 million over last year. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

The budget of the Office of Minority Health has been decreased in the last several years. In fiscal year 2004, OMH received \$55 million; in fiscal year 2005, OMH received \$50 million; and the proposed budget in fiscal year 2006 is \$47 million. APHA is concerned that at a time when we have increasing evidence of disparities in health care delivery, access and health outcomes, the budget of OMH is getting cut. We support restoring OMH funding to the fiscal year 2004 level.

#### CONCLUSION

In closing, we emphasize that the public health system requires financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. While we have said this before, in the post-September 11th era, we need to apply this to our spending growth in terrorism preparedness as well. We must think in a broad and balanced way, leveraging homeland security programs and funding whenever possible to provide public health benefits as a matter of routine, rather than emergency.

We thank the subcommittee for the opportunity to present our views on the fiscal year 2006 appropriations for public health service programs.

---

#### PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

Mr. Chairman and members of the subcommittee, I am pleased to submit testimony on behalf of the Association of Maternal and Child Health Programs (AMCHP) regarding the critical need for funding of the Title V Maternal and Child Health Services Block Grant in fiscal year 2006. As AMCHP's President and the director of Iowa's Child Health Specialty Clinics program, which uses MCH block grant funds to serve Iowa's children and their families, I know these funds make a difference. Because of the MCH Block Grant, states are able to fund a variety of activities to improve the health of your constituents. I urge you to provide \$755 million for the MCH Block Grant this year.

AMCHP is a national non-profit organization representing the leaders of state public health programs for maternal and child health, and children with special health care needs in all 50 states, the District of Columbia, and eight additional jurisdictions. Every state health department receives Title V Maternal and Child Health Services Block Grant funds to improve the health of all mothers and children.

This modest increase to \$755 million (3 percent) is necessary to help states maintain current levels of service. Between 1999 and 2003, the number of women and children served by this program increased by almost 4 million (16 percent). Federal funding has declined since 2003. The President's request of \$723.9 million for fiscal year 2006 would be the fourth straight year of level or reduced funding. States are being called to do more with less and state MCH programs have done their best to make sure that the women and children we served are not adversely affected. However, maternal and child health programs in every state have reached a breaking point, with many states experiencing reductions in both state and federal funding; without additional funds, more severe cuts may have to be made.

I also urge you to reject the Administration's proposal to eliminate funding for HRSA's Emergency Medical Services for Children program, Universal Newborn Hearing Screening program, trauma program and CDC's preventive health and health services block grant. The budget request argues that states will be able to use their MCH Block Grant funds to support some of these activities. States already work with these programs to avoid duplication and to ensure that each federal dollar, whether obtained through the block grant or not, goes further. The reality is that states have less federal and state funds available for maternal and child health programs and would not be able to support the current activities without cutting funds for other health priorities. Eliminating Newborn Hearing Screening grants will force states to cut other worthy MCH programs in order to continue hearing screening or to scale back or not conduct newborn hearing screening activities. According to a recent report, thanks to the HRSA funding, over 86 percent of infants born in hospitals nationwide are screened for hearing loss, up from 25 percent in 1999. Additionally, continued funding (\$5 million) within the Special Projects of Regional and National Significance (SPRANS) set-aside for MCH oral health activities is critical. Most state dental programs for children are part of the state's maternal and child health program and are supported through the Maternal and Child Health block grant and support ongoing leadership to states to address long-term oral health problems.

The Title V Maternal and Child Health Block Grant is one of the nation's oldest health programs and plays a pivotal part in states' current maternal and child health policy. The authorization of funding for the Maternal and Child Health Block Grant goes back to the Social Security Act of 1935. The legislation represented one of the very first state "grant-in-aid" programs, allocating federal revenues to states that agreed to meet the program's basic conditions of participation, which revolved around two main goals. The first was to help states lessen the negative social and public health impact of the Great Depression through promotion of maternal and child health services and the development of a basic preventive and primary health care infrastructure for women and children. The second, and one directly tied to the terrible epidemic of polio, was to assist states through grants to develop services for "crippled children."

Today, Maternal and child health programs have expanded their roles and lead state efforts to increase immunization and newborn screening rates, reduce infant mortality, prevent childhood accidents and injuries, and reduce adolescent pregnancy. Each year, more than 27 million women, infants, children and adolescents, including those with special health care needs, are served by MCH Block Grant funds. Half of the 4 million women who give birth annually receive health services made possible by the MCH Block Grant.

While the block grant now represents a much smaller funding stream for states, it still remains one of the few resources that gives states' the ability to provide numerous services to meet needs identified by the states, to millions of women, children, and their families annually. And in every state, the MCH Block Grant still provides a health safety net for low-income women and children, by being a payor of last resort for needed medical services when other sources of payment (either public or private) are not available.

#### WHO DO WE SERVE? WHAT DOES THE TYPICAL TITLE V CLIENT LOOK LIKE?

Every year, over 4 million babies are born in this country. Many of them are healthy and families leave the hospital confident of a better future. I can discuss the many ways that MCH Block Grant dollars and state programs help in producing those healthy outcomes. However, I want to focus on the case of those families with children who may have special health care needs present at birth or shortly afterwards. Like the parent from Massachusetts with a son who was eventually diagnosed with congenital heart disease, abnormal heart rhythms, and is now pacemaker dependent. Immediately after birth, the parent made countless visits to the pediatrician sensing that something seemed wrong with her son, but she didn't

know what. He was jaundiced for weeks after he was born and didn't gain weight, as he should. Even on formula, her son still did not gain weight. In a span of two calendar years, her son was hospitalized for 134 consecutive days. For all the "I feel for you" visits she had from hospital social workers, no one ever told her son was eligible for SSI after the first 30 consecutive calendar days as an inpatient, or that her family could apply for Massachusetts Medicaid buy-in option to offset their exorbitant out-of-pocket costs for the healthcare services her son was receiving. This parent, like many others, continued to have great difficulty in coordinating health care services. She had to make thousands of phone calls to state agencies and search the Internet, plead with her insurance company to pay for things, call state agencies, surf the Internet late into the night looking for support services, for other parents, or for anything that would help.

Another family in Pennsylvania juggle 11 doctors who treat their son with special health care needs and who constantly struggle to navigate the health care system for as many options that are available to improve the quality of life for their son. These are just a few examples of what is unfortunately a very common occurrence throughout the country.

MCH Block Grant funds help assure that every state has the ability to connect families like the one described above to services and when those services are not otherwise available, to pay for that care. In Missouri, a child was born with an infection similar to a form of meningitis and was in the NICU for the first 8 weeks of his life. Within a day after mother and child went home, a nurse from the Bureau of Special Health Care Needs contacted the family. The support from the state's children with special health care needs program did not stop but continued and even now 16 years later, is available when the family needs it. Anything from adaptive equipment, to personal care attendant services have been provided when necessary.

State Maternal and Child Health Programs play a primary role in assuring health care for children with special health care needs and their families. The services that each state provides may vary but by law, 30 percent of each state's Maternal and Child Health Block Grant allocation must be used to provide services for these kids. Why? Because the experiences for families that I outlined above have occurred too often. Since 1935, Congress has provided funding to states to make sure that we put an end to stories like these. A recent national survey by the Maternal and Child Health Programs estimated 13 percent of children in the United States have a special health care need. Maternal and Child Health Block Grant funded programs are reaching slightly over 1 million but more can be done with increased funding for this important program.

In Iowa, Child Health Specialty Clinics is the designated Title V Children with Special Health Care Needs program. We operate a statewide program that works with families, service providers and communities to provide subspecialty health care and support to children, from birth through age 21, who have a chronic condition (physical, developmental, behavioral or emotional) or who have an increased risk of a chronic condition and need special services. Like similar programs in all states, the program is primarily funded through the Maternal and Child Health Block Grant. Each specialty clinic center can offer from one to four evaluation and planning clinics per month. These clinics are staffed by community pediatricians, nurses, and nutritionists and serve mostly children with behavioral and developmental problems. Clinics serve children with chronic health problems like heart disease, diabetes, sickle cell disease, and bone and joint disease. Fees for the clinics are based on a sliding scale that accounts for family size and income.

Besides the clinics, Iowa uses MCH block grant funds to provide other services for children and their families including making sure family support is available and organizing care plans for children. Through a statewide parent-to-parent network, we provide one-on-one emotional support, problem-solving assistance and help with understanding health insurance to families. The network connects parents new to the program with parents who have already been through many of the same experiences. When one child can have as many as 11 doctors, the burden on families to navigate the health care maze can be crushing. Another way we help is helping families navigate the health care system. Some children with complicated health problems require different services from varied agencies and we help coordinate needed care with local agencies within the family's community. These are provided as free services to families.

Child Health Specialty Clinics serve approximately 9,000 children yearly, including 800 infants and 1,500 preschoolers, including making phone, mail and face-to-face contacts with families and health care providers. A few years ago I had 14 of these centers throughout Iowa. Today, we have 13 centers and in most other locations are now open only four days a week. Funding reductions at the state and fed-

eral level mean less clinics, families have to travel farther, and no ability to address emerging needs such as care for children with special emotional and behavioral health needs, one of the largest needs that we are currently seeing in the state.

#### STATE BUDGET CUTS

More MCH Block Grant funds are needed. Below are specific examples of reductions in services that states have made due to declining federal and state funding for maternal and child health.

#### IOWA

Because of decreased state and federal funding along with increases in personnel costs (inflation), Iowa closed pediatric mobile clinics, eliminated nutrition services for children, closed the Waterloo center and reduced services at other centers. Without increased funding, we are looking at:

- Closing centers in Burlington, Council Bluffs, Sioux City
- Consolidating the Dubuque and Davenport with other centers
- Increased waiting time up to 12 months for families and their kids to get the services they need
- Ending behavioral pilot programs, a medical home project and other activities to make sure these children and their families get the right services when they need them.

#### OHIO

Ohio received one of the steepest cuts in federal MCH block grant funding, losing \$1.5 million (or 6 percent) between fiscal year 2003 and fiscal year 2004. Combined with a \$7.5 million decline in the state funds available to support MCH, the ability for the program to maintain services to the 266,000 women, infants, and children who received services in 2002 has been severely compromised. Ohio's Children with Special Health Care Needs (CSHCN) program, because of both state cuts and cuts in the Ohio MCH Block Grant, has had to decrease the number of diagnoses covered by the CSHCN Treatment Program and to change the eligibility rules to reduce the services provided. Three diagnosed conditions were eliminated from coverage, affecting almost 600 children.

Other changes may affect up to 5,000 children who rely on the program. Co-payments are increased for families. Raising co-payments can significantly impact the financial and physical health of these families and their children if they are unable to pay them. These families turn to Title V when insurance (either private or public) cannot provide the services. The Ohio Specialty Field Clinic Program received a 20 percent decrease in MCH block grant and other funding support. The Specialty Clinic Program provides access to pediatric specialists for children in Ohio. The number of clinics will be cut, all in rural Ohio where the greatest need for services exists. This will affect the access to care for 300 children in Ohio's rural areas. Cardiac Specialty Clinics will be closed as of July 1, 2004. Funding reductions also slow the ability to respond to emerging issues, such as an increase in Ohio's infant mortality rate, which rose from 7.5 per 1,000 births in 2000 to 7.9 in 2002.

#### TEXAS

Texas received a reduction of \$753,000 (3 percent) in federal MCH funds. That reduction along with a reduction in state funds for MCH in 2004–2005 will drastically increase the unmet needs of the MCH population in Texas. Currently, the MCH program addresses less than 10 percent of the MCH population-in-need. For example, Title V MCH fiscal year 2004 contracts for services (i.e., initiatives directed toward teen pregnancy, childhood obesity, immunization, etc) decreased by 33 percent and by 13 percent for direct services (prenatal care, child well-check visits, dental, family planning, etc.). In 2001, the Texas Children with Special Health Care Needs program instituted a waiting list that has grown to 1,200 families and is expected to continue to increase.

#### CONCLUSION

Since its creation, the Title V Maternal and Child Health Block Grant has grown from a \$2.7 million program in fiscal year 1936 to a \$723.9 million program in fiscal year 2005, and despite its relatively modest size, it has been revisited by Congress repeatedly over the years as new maternal and child health related concerns become evident. Even with the enactment of Medicaid in 1965, the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program in 1967 (which simultaneously amended Medicaid and Title V to increase support for primary care) and



SCHIP in 1997, Title V continues as a source of flexible funding that allows states to invest in the child health “infrastructure” for both basic and specialty care. Increased funding is crucial to helping state MCH programs navigate the changing maternal and child health world. Please provide \$755 million for the Maternal and Child Health Block Grant in fiscal year 2006. Again, thank you for this opportunity to testify.

---

PREPARED STATEMENT OF THE ASSOCIATION OF WOMEN’S HEALTH, OBSTETRIC AND NEONATAL NURSES

The Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) appreciates the opportunity to comment on the fiscal year 2006 appropriations for nursing education, research, and workforce programs as well as programs designed to improve maternal and child health. AWHONN is a membership organization of 22,000 nurses whose mission is to promote the health of women and newborns. AWHONN members are registered nurses, nurse practitioners, certified nurse-midwives, and clinical nurse specialists who work in hospitals, physicians’ offices, universities, and community clinics across North America as well as in the Armed Forces around the world.

AWHONN appreciates the support that this Subcommittee has provided for nursing education, research and workforce programs as well as maternal and child health programs in the past. We realize that there are many competing priorities for the Subcommittee members, and we appreciate your consistent support.

GROWING NURSING SHORTAGE

AWHONN supports the advancement of quality care through an adequate nurse workforce. Data from the Bureau of Health Professions, Division of Nursing’s National Sample Survey of Registered Nurses—February 2002, confirm that of the approximately 2.7 million registered nurses in the nation, only about 82 percent of these nurses were working full-time or part-time in nursing. In addition to the shrinking pipeline of nurses coming into the program, the dominant factor in this shortage is the impending retirement of up to 40 percent of the workforce by 2010 or soon thereafter. This will occur at the same time that the needs of the aging baby boomer population will markedly increase demand for health care services and the services of registered nurses.

This critical demand is reinforced by the fact that in February 2004, the U.S. Bureau of Labor released statistics detailing how registered nurses have the largest projected 10-year job growth in the United States, with about 1 million new job openings by 2010. In addition to the care provider shortage, nursing faculties are also decreasing in number, requiring universities to decline acceptance to qualified nursing school applicants. The Southern Regional Education Board states that with faculty vacancies and newly budgeted positions, there has been a 12 percent shortfall in the number of nurse educators needed to train nursing applicants. The entire nursing workforce needs strengthening. As a result, it will take long-term planning and innovative initiatives at the local, state and federal level to assure an adequate supply of a qualified nurse workforce for the nation.

NURSE WORKFORCE DEVELOPMENT PROGRAMS

*AWHONN recommends a total of \$210 million for fiscal year 2006 to fund the Nurse Workforce Development programs in Title VIII*

The Nurse Education Act (Public Health Service Act, Title VIII), enacted in 1964, represents the only comprehensive federal legislation to provide funds for nursing education. The programs authorized in this portion of Public Law 105–392 help schools of nursing and nursing students prepare to meet patient needs in a changing health care delivery system, favoring programs in institutions that train nurses for practice in medically underserved communities and Health Professional Shortage Areas.

Reauthorized as the Nursing Workforce Development section in 1998, the new NEA gives the Department of Health and Human Services more discretion over the focus of federal spending. In 2002, Congress enacted the Nurse Reinvestment Act, which provides funding for new and expanded programs. These programs include scholarships, career ladders, internships and residencies, retention programs, and faculty loans designed to encourage students to consider nursing, keep nurses in the field, and ensure that nurse educators are plentiful enough to educate future nurses that we desperately need. The new programs received an initial appropriation of \$20 million in fiscal year 2003, which was in addition to \$93 million in funding provided

for existing Title VIII programming. Unfortunately, due to limited funding in the first 2 years of the new authorization, the loan and scholarship programs have not been successful in providing support to students in nursing schools. In the first year, only 574 loan repayment contracts were made nationally, averaging roughly 11 loan repayment agreements per state, and less than 2 percent of all scholarship applicants were funded.

The shortage of registered nurses and the effect of the shortage on nurse staffing and patient safety demand a significant increase in funding for these programs. Nursing is the largest health profession with over 2.7 million nurses, yet only one-fifth of 1 percent of federal health funding is directed to nursing education. A significant increase in funding for these programs would lay the groundwork to expand the nursing workforce, through education and clinical training and retention programs, in order to address some of the serious shortage issues.

The nursing shortage is not confined solely to care providers; there is also a growing, significant shortage of nurse faculty. The American Association of Colleges of Nursing (AACN) reports that the average age of nursing professors is 52, and for associate professors the average age is 55. The impending retirement of these seasoned educators will impact the ability of our schools and universities to meet the educational health care needs of the nation. According to AACN, U.S. nursing schools turned away almost 16,000 qualified applicants to baccalaureate nursing programs in 2003 due to insufficient faculty, clinical sites, classroom space, and budget constraints. Additionally, 125,000 qualified applicants were turned away from nursing programs at all levels across the United States in 2004 according to the National League for Nursing.

While the capacity to implement faculty development is currently available through Section 811 and Section 831, adequate funding and direction is needed to ensure that these programs are fully operational. Options to provide support for full-time doctoral study are essential to rapidly prepare the nurse educators of the future. AWHONN recommends that a portion of the funds be allocated for faculty development and mentoring.

Further, AWHONN recognizes the importance of appropriate investments in advanced practice nursing programs. As in other professions the advanced degree has become a necessary achievement for career advancement, and registered nurses who pursue the MSN degree are a part of the cadre of nurses who go on to become faculty. Our nation needs more nurses with basic training to enter the field, but focusing only on these nurses addresses just half of the problem. The nursing shortage encompasses nursing faculty; both advanced practice nursing and basic nursing must receive additional funding but not one at the expense of the other.

#### MATERNAL AND CHILD HEALTH BUREAU

*AWHONN recommends \$850 million in funding in fiscal year 2006 for the Maternal and Child Health Bureau*

This program provides comprehensive, preventive care for mothers and young children, as well as an array of coordinated services for children with special needs. In fact, the Maternal Child Health Block Grant (MCH) serves over 80 percent of all infants in the United States, half of all pregnant women, and 20 percent of all children.

MCH programs are facing increased demands for services due to continued growth in the Children's Health Insurance Program, which in turn identifies more children who are eligible for other MCH Services. Title V complements Medicaid and the State Children's Health Insurance Program by providing "wrap-around" services and enhanced access to care in underserved areas. Additional funding would give states the resources they need to expand prenatal and infancy home visitation programs, an approach that has been shown, in NINR research, to improve the prenatal health-related behavior of women and reduce rates of child abuse and neglect as well as maternal welfare dependence.

#### INDIAN HEALTH SERVICE

*AWHONN recommends an fiscal year 2006 appropriation of \$5.54 billion for IHS*

The Indian Health Service (IHS) is the principal federal health care provider and health advocate for Indian people with the goal of "ensur[ing] that comprehensive, culturally acceptable personal and public health services are available and accessible to all American Indian and Alaska Native people." IHS is tasked with an enormous responsibility in providing care to over half of the American Indian population.

The American Indian and Alaska Native people have long experienced lower health status when compared with other Americans. Lower life expectancy and the

disproportionate disease burden exist perhaps because of inadequate education, poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality of life issues rooted in economic adversity and poor social conditions.

A recent study of federal health care spending per capita found that the United States spends \$3,803 per year per federal prisoner, while spending about half that amount for a Native American: \$1,914. Per capita health care spending for the U.S. general population is \$5,065 per year. A significant increase in funding over fiscal year 2005 spending levels is necessary for the federal government to fulfill its responsibility to Indian Country and achieve its stated goals.

While the nursing shortage continues nationwide, IHS has been disproportionately affected by the lack of RNs. IHS nurses are older, with an average age of 48, and nearly 80 percent of RNs are over the age of 40. Further, the average vacancy rate for RNs is 14 percent. IHS administers three interrelated scholarship programs designed to meet the health professional staffing needs of IHS and other health programs serving Indian people. These programs are severely under-funded. Targeted resources need to be invested in the IHS health professions programs in order to recruit and retain registered nurses in Indian Country.

Additionally, Section 112 of the Indian Health Care Improvement Act, Public Law 94-437, authorizes grants to public or private schools of nursing, tribally-controlled community colleges and tribally-controlled post secondary vocational institutions for the purpose of recruiting, training and increasing the number of professional nurses who deliver health care services to Indian people. On average, Section 112 programs provide five undergraduate scholarships per year and two master's program scholarships. This important program should be expanded to provide many more scholarships, both at the undergraduate and graduate levels, in an effort to offer meaningful relief to the nursing shortage for IHS healthcare providers and the patients they serve.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

*AWHONN recommends an increase of \$22 million over fiscal year 2005 funding levels for the NINR, resulting in an fiscal year 2006 appropriation of \$160 million*

NINR engages in significant research affecting areas such as health disparities in ethnic groups, training opportunities for management of patient care and recovery, and telehealth interventions in rural/underserved populations. This research allows us to refine the practice and provide quality patient care in its current challenging environment.

NINR research contributes to or results in improved health outcomes for women. Recent public awareness campaigns target differences in the manifestation of cardiovascular disease between men and women. The differing symptoms are the source of many missed diagnostic opportunities among women suffering from the disease, which is the primary killer of American women. In a study funded by NINR, researchers were able to qualitatively analyze the intensity of pain and limitation of activity experienced by women suffering from angina, both of which were found to be of greater intensity than that experienced by men. The study concluded that the gender variation could significantly impact diagnosis and treatment of female patients suffering from related cardiovascular problems.

Because of the emphasis on biomedical research in this country, there are few sources of funds for high-quality behavioral research for nursing other than NINR. It is critical that we increase funding in this area in an effort to optimize patient outcomes and decrease the need for extended hospitalization.

#### NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

*AWHONN supports an increase in funding for NICHD for fiscal year 2006, bringing the appropriation to \$1.35 billion*

NICHD seeks to ensure that every baby is born healthy, that women suffer no adverse consequences from pregnancy, and that all children have the opportunity for a healthy and productive life unhampered by disease or disability. With increased funding, NICHD could expand its use of the NICHD Maternal-Fetal Medicine Network to study ways to reduce the incidence of low birth weight. Prematurity/low birthweight is the second leading cause of infant mortality in the United States and the leading cause of death among African American infants. AWHONN, like many organizations directly involved in programs to improve the health of women and newborns, looks to NICHD to provide national initiatives, such as the Maternal-Fetal Medicine Network that assists with the care of pregnant women and babies.

Recently NICHD released research indicating they may have found a test to predict preeclampsia in patients before the life-threatening complication, affecting five percent of all pregnancies, occurs. Abnormal levels of placental growth factor (PlGF) were found in the urine of pregnant women who later developed preeclampsia. Once NICHD screens for women who are high risk for developing preeclampsia, this group can be studied to prevent or cure this complication. This finding is a promising lead in the effort to prevent and cure preeclampsia.

NATIONAL INSTITUTES OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS)

*AWHONN supports an increase in funding for NIEHS for fiscal year 2006, bringing the appropriation to \$680 million*

Research conducted by the NIEHS plays a critical role in what we know about the relationship between our environmental exposures and disease onset. Through the research sponsored by this Institute, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases and ailments have confirmed environmental triggers. Our expanded knowledge, as a result, allows both policy makers and the general public to make important decisions about how to reduce toxin exposure and reduce the risk of disease and other negative health outcomes.

One impressive collaborative research project spearheaded by the NIEHS is the recent partnering of public and private funding agencies that will examine how better community design encourages people to be more physically active in their daily lives. Researchers will identify how our built environment contributes to obesity and how environmental changes can combat a growing public health problem. The NIEHS will examine the program's impact on physical activity, obesity, and other health indicators.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

*AWHONN recommends an fiscal year 2006 appropriation of \$8.65 billion for the CDC*

For nearly 60 years, the Centers for Disease Control and Prevention (CDC) has evolved to assume responsibility for programs in infectious disease surveillance, control and prevention, injury control, health in the workplace, prevention of heart disease, cancer, stroke, obesity and other chronic diseases, improvements in nutrition and immunization, environmental effects on health, prevention of birth defects, laboratory analyses, outbreak investigation and epidemiology training, and data collection and analysis on a host of vital statistics and other health indicators. Now more than ever, CDC's role in protecting the nation's health through prevention has become evident as we address issues of terrorism, emergency preparedness and health system capacity and infrastructure. Increased funding for CDC is critical.

#### *Birth Defects*

For over 30 years, CDC has been deeply involved in the prevention of birth defects through programs like the Folic Acid Education Campaign and the new National Center on Birth Defects and Developmental Disabilities (NCBDDD). The public health impact of birth defects is tremendous. Of the four million babies born each year in the United States, approximately 120,000 are born with a serious birth defect. According to CDC, the lifetime costs of caring for infants born in 1992, with at least one birth defect<sup>1</sup> or cerebral palsy was about \$8 billion. The emotional and financial burden for the families with affected children is devastating. CDC funds several programs critical to reducing the number of children born with birth defects, including funding to states for birth defects tracking systems. Due to lack of funds, CDC is only able to fund 15 states in fiscal year 2005, which is down from 28 states in fiscal year 2004. Additional funding for these grants is needed to fund all of the states seeking CDC assistance for these critical surveillance programs.

#### *Cardiovascular Disease*

Cardiovascular disease is the leading cause of death in the United States, causing one death every 34 seconds and \$393.5 billion a year in direct and indirect healthcare costs, according to the American Heart Association. The CDC reports that almost one-fourth of the U.S. population has some form of cardiovascular dis-

<sup>1</sup> These birth defects include: Spina bifida, truncus arteriosus, single ventricle, transposition/double outlet right ventricle, Tetralogy of Fallot, tracheo-esophageal fistula, colorectal atresia, cleft lip or palate, atresia/stenosis of small intestine, renal agenesis, urinary obstruction, lower-limb reduction, upper-limb reduction, omphalocele, gastroschisis, Down syndrome, and diaphragmatic hernia.

ease. Additionally, 65 percent of American adults are overweight or obese and nearly 16 percent of children and adolescents are overweight. Obesity is considered a major public health problem because it serves as the gateway disease for many other illnesses including but not limited to: depression, type 2 diabetes, hypertension, stroke, and poor female reproductive health and pregnancy complications.

These are but two examples of illnesses with programmatic public health funding through CDC. Any cuts to these programs will potentially leave millions of Americans without primary prevention programs that ultimately save lives and money. AWHONN urges \$8.65 billion in funding for CDC chronic disease prevention and health promotion programs to ensure that these programs have the resources necessary to translate preventive health research into practice. This investment will save lives and billions in health care costs and productivity.

#### SUMMARY RECOMMENDATIONS

A summary of AWHONN formal funding recommendations for these and other federal health programs:

Programmatic area	Final fiscal year 2005 <sup>1</sup>	President's budget fiscal year 2006	AWHONN's request
Nurse Workforce Development Programs .....	\$151,889,000	\$150,000,000	\$210,000,000
Maternal & Child Health Block Grant .....	729,817,000	724,000,000	850,000,000
Indian Health Service .....	2,985,000,000	3,048,000,000	5,540,000,000
Title X—Family Planning .....	288,283,000	286,000,000	350,000,000
Newborn Hearing Screening .....	9,872,000	.....	13,000,000
AHRQ .....	319,000,000	319,000,000	440,000,000
NIH .....	28,649,000,000	28,845,000,000	30,368,000,000
NINR .....	138,000,000	139,000,000	160,000,000
NICHD .....	1,271,000,000	1,278,000,000	1,350,000,000
NIHES .....	645,000,000	648,000,000	680,000,000
CDC .....	4,572,000,000	4,017,000,000	8,650,000,000

<sup>1</sup> Fiscal year 2005 numbers taken from conference report on omnibus bill do not reflect a further .8% across-the-board rescission.

Thank you for the opportunity to submit testimony on these critical areas of funding.

#### PREPARED STATEMENT OF THE BLUE CROSS AND BLUE SHIELD ASSOCIATION

The Blue Cross and Blue Shield Association (BCBSA), which represents 40 independent, locally operated Blue Cross and Blue Shield Plans throughout the nation, is pleased to submit written testimony to the subcommittee on fiscal year 2006 funding for Medicare contractors.

Blue Cross and Blue Shield Plans play a leading role in administering the Medicare program. Many Plans contract with the federal government to run much of the daily work of paying Medicare claims accurately and timely. Blue Cross and Blue Shield Plans serve as Part A Fiscal Intermediaries (FIs) and/or Part B carriers and collectively process most Medicare claims.

This testimony focuses on three areas:

- Background, including a description of Medicare contractor functions;
- Current financial challenges facing Medicare contractors; and
- BCBSA recommendations for Medicare contractor fiscal year 2006 funding.

#### BACKGROUND

Blue Cross and Blue Shield Medicare contractors are proud of their role as Medicare administrators. While workloads have soared, operating costs—on a unit cost basis—have declined about two-thirds from 1975 to 2005. In fact, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Medicare contractors have four major areas of responsibility:

1. *Paying Claims.*—Medicare contractors process all the bills for the traditional Medicare fee-for-service program. In fiscal year 2006, it is estimated that contractors will process over 1.1 billion claims, nearly 4 million every working day.

2. *Providing Beneficiary and Provider Customer Services.*—Contractors are the main points of routine contact with Medicare for both beneficiaries and providers. Contractors educate beneficiaries and providers about Medicare and respond to over 50 million inquiries annually.

3. *Handling Hearings and Appeals.*—Beneficiaries and providers are entitled by law to appeal the initial payment determination made by carriers and FIs. These contractors handle nearly 8 million annual hearings and appeals.

4. *Special Initiatives to Fight Medicare Fraud, Waste, and Abuse.*—All contractors have separate fraud and abuse departments dedicated to assuring that Medicare payments are made properly. Few government expenditures produce the documented, tangible savings of taxpayers' dollars generated by Medicare anti-fraud and abuse activities. For every \$1 spent fighting fraud and abuse, Medicare contractors save the government \$14.

#### CURRENT FINANCIAL CHALLENGES

Of utmost importance to attaining outstanding performance is an adequate budget. Medicare contractors have been underfunded since the early 1990's, however, and the largest portion of the contractor budget—Medicare operations—faces particularly severe funding pressures. Medicare operations activities include claims processing, beneficiary and provider education and communications, hearings and appeals of claims initially denied, and systems maintenance and security.

The underfunding of CMS and its Medicare contractors has gotten even more acute since the passage of the Health Insurance Portability and Accountability Act (HIPAA), the Benefits Improvement and Protection Act (BIPA), and the Medicare Modernization Act (MMA), which places new responsibilities on contractors, without sufficient resources to perform those duties. For example, between 1992 and 2002, Medicare benefits outlays increased 97 percent; claims volume increased 50 percent; yet Medicare operations funding increased a mere 26 percent. Contractor staffing only increased by 6 percent during this time even though many new responsibilities were added and claims volume continued to rise. Clearly funding has not kept pace with additional work. In addition, the Medicare reform legislation includes significant changes that will require additional resources on an ongoing basis for contractors to implement.

Whenever possible, contractors respond to reduced funding by achieving significant efficiencies in claims processing, but it is not enough to keep pace with rising Medicare claims volume and diminishing funding levels. It should be noted that contractors are already extremely efficient. Currently, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Inadequate budgets for Medicare operations also impact Medicare's fight against fraud and abuse. While many think of Medicare operations activities as simply paying claims, these activities are Medicare's first line of defense against fraud and abuse and are critically linked to activities under the separately-funded Medicare Integrity Program (MIP). As an example, many of the front-end computer edits (e.g., preventing duplicate payments and detecting inaccurately coded claims or claims requiring additional screening) are funded through Medicare operations.

Inadequate funding impacts different functions at different times, but always disrupts the integration of all the functional components needed to "get things right the first time." It thus results in inefficiency and higher costs.

#### BCBSA FISCAL YEAR 2006 FUNDING RECOMMENDATIONS FOR MEDICARE CONTRACTORS

BCBSA is pleased that many Members of this subcommittee recognize the need for adequate administrative resources at CMS. We are concerned the Administration's fiscal year 2006 budget would significantly cut Medicare operations funding by nearly \$43 million. BCBSA urges Congress to take the following steps to allow Medicare contractors to meet increased workloads as well as beneficiary and provider needs:

##### A. *Increase Medicare Contractor Operations Funding to \$2,240 Million for fiscal year 2006*

Medicare contractors continue to face increases in Medicare claims volume. Further reductions in administrative costs, as proposed in the President's budget, would seriously jeopardize contractors' ability to administer Medicare. BCBSA recommends:

1. *Claims processing funding must be maintained at \$812 million (\$10 million more than President's budget).*—The President's budget would decrease claims processing funding by \$10 million under the assumption that beneficiary movement to Medicare Advantage plans will decrease contractor workloads, particularly in claims processing, appeals and inquiries. BCBSA disagrees with this assumption.

While BCBSA recognizes a slight reduction in claims, appeals, and inquiries could occur, the amount is highly uncertain. In fact, data suggests claims volume will increase by 4 percent in fiscal year 2006. Congress must ensure funding is available

should volume and costs be higher than anticipated. Otherwise, contractors will be faced with budget shortfalls that will result in reduced services for beneficiaries and providers.

2. *Appeals funding must be restored to \$109 million (\$12.5 million more than the President's budget).*—The President's budget would decrease appeals funding by \$25 million under the assumption that the new Qualified Independent Contractors (QICs) will take on certain appeals responsibilities, lessening the load for contractors. BCBSA disagrees with this assumption.

Appeals workloads and costs are on the rise for several reasons. First, implementation of the QICs is behind schedule, requiring contractors to continue some of this work. Second, contractor interfaces with QICs require funding to prepare the case and transfer information. Third, CMS recently announced it will eliminate provider phone appeals, which cost \$10 compared to \$19 for written appeals, and require separate written notification of favorable determinations.

3. *Inquires funding must be increased to \$232 million (\$27 million more than the President's budget).*—The President's budget would decrease inquiries funding by \$17 million under the assumption that CMS' 1-800-MEDICARE call volume will continue to increase, diminishing work at the contractor site. BCBSA disagrees with this assumption.

While Medicare contractor call volume may decrease, the complexity and length of the call is increasing significantly. CMS often refers complex beneficiary and provider inquiries to the Medicare contractor that originally processed the claim. Further, CMS implemented a new Provider Customer Service Program required by the Medicare Modernization Act, but did not account for its costs in the fiscal year 2006 budget.

*B. Increase Flexibility and Funding for the Medicare Integrity Program (MIP)*

Congress created MIP in 1996 to provide a permanent, stable funding authority for the portion of the Medicare contractor budget that is explicitly designated as fraud and abuse detection activities. Despite the continued rise in claims, MIP funding has been capped at \$720 million since fiscal year 2003. In fact, claims volume increased by more than 16 percent (158 million claims) since MIP was last increased. Clearly, benefit integrity activities cannot keep pace with rising claims volumes without additional funding. BCBSA recommends Congress:

- Authorize an automatic yearly increase in MIP consistent with the rate of inflation and increase in claims volume;
- Direct a portion (\$20 million) of the new Part D oversight funding toward MIP Part A and B activities; and
- Urge CMS to give contractors greater flexibility to manage their Medicare Integrity budgets.

The following chart highlights BCBSA's request compared to fiscal year 2005 and the President's fiscal year 2006 request.

[In millions of dollars]

Medicare contractor budget	Fiscal year 2005	President's fiscal year 2006 recommendation	BCBSA fiscal year 2006 recommendation
Medicare Operations .....	2,233	2,190	2,240
Medicare Integrity Program .....	720	720	740
<b>Total Contractor Budget .....</b>	<b>2,953</b>	<b>2,910</b>	<b>2,980</b>

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to provide this testimony for the record to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding fiscal year 2006 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors appreciate the Subcommittee's consistent support for the LIHEAP program, and we recognize the difficult decisions facing the Subcommittee in this time of severe fiscal constraints. However, in light of sharply higher home energy prices, we request the Subcommittee provide \$3.4 billion in regular fiscal year 2006 LIHEAP funding as well as the authority to release emergency contingency funds for unforeseen circumstances, such as price spikes in home heating fuels, severe weather and other potential emergencies.

LIHEAP is a vital tool in making home energy more affordable for almost 5 million of the nation's very low-income households—the elderly and disabled on fixed incomes and families with young children. The percentage of income spent on total home energy by these low-income households can be four times higher than average households. For many of these households, annual income is simply not sufficient to pay high winter heating bills, even in periods of economic growth. Even after taking constructive actions to reduce their home energy use, too many low-income residents are forced to make dangerous choices between heating their homes, paying the full rent or mortgage, seeking medical attention, or purchasing food or vital medications.

The substantial rise in home heating fuel prices hits these vulnerable citizens especially hard. The Northeast is heavily dependent on deliverable home heating fuels such as home heating oil, kerosene, and propane. In addition, price volatility in these fuels adversely affects the low-income households who, without the disposable income to purchase fuels off-season, typically enter the market when both the demand for and price of fuels are high.

The Energy Information Administration predicts that the price of home heating oil, propane, and natural gas will continue to rise this year. Compared with 2001 to 2002, households can expect this winter to pay 55 percent more to heat a home with natural gas, 93 percent more for those heating with home heating oil, and 51 percent more for those heating with propane. However, within this same time period, the annual LIHEAP appropriation has increased modestly. In spite of the welcomed increase in LIHEAP funding, only a fraction—approximately 15 percent of eligible households—can be served at current LIHEAP funding. As a result, states across the country in recent years have seen significant increases in their regular LIHEAP caseloads, as well as in requests for emergency assistance from those households in imminent danger of a utility or fuel service cut-off. At current funding levels, states may be faced with the prospect of serving even fewer eligible households, reducing benefits, or curtailing the duration of the program. Clearly, the projected need far outweighs the available funding.

Higher energy prices diminish the purchasing power of available LIHEAP funding assistance. In addition, without funds to carryforward to the new heating season, state LIHEAP programs lack the capability to undertake the “pre-buy” programs that help stabilize heating fuel prices for low-income households and expand the reach of limited program funds. An increased federal appropriation would allow states to manage the program resources in a manner to better take advantage of market opportunities.

The current uncertainty of world energy markets underscores the importance of states being able to prepare for rising and potentially volatile energy prices. These preparedness activities, while critical, cannot fully shield our lowest-income citizens from the impacts of higher heating fuel prices. An increase in the regular LIHEAP appropriation to \$3.4 billion in fiscal year 2006 will enable states across the nation to reach more of those vulnerable citizens in need of assistance and more fully implement cost-effective measures to meet their continuing energy needs.

Your support for fiscal year 2006 LIHEAP appropriations at the \$3.4 billion level, as well as the authority to release emergency contingency funds for unforeseen circumstances, is urgently needed to enable our states to help mitigate the potential life-threatening emergencies and economic hardship that confront the nation's most vulnerable citizens.

We thank the Subcommittee for this opportunity to share the views of the Coalition of Northeastern Governors, and we stand ready to provide you with any additional information on the importance of the Low Income Home Energy Assistance Program to the Northeast.

---

PREPARED STATEMENT OF THE COMMUNITY MEDICAL CENTERS

Mr. Chairman and Members of the Subcommittee: My name is Dr. Philip Hinton and I am the Chief Executive Officer of Community Medical Centers in Fresno, California. Community Medical Centers is a not-for-profit, locally owned health care corporation that is committed to improving the health of the community. I am pleased to provide the subcommittee with a request for assistance in securing federal monies for a critical project in the Central San Joaquin Valley that would improve access to health care to the uninsured in Fresno County.

The challenges and struggles facing our nation's public hospitals and health systems are ever-increasing. The nation's uninsured population continues to grow while there are significant reductions in state and federal government support. Hence, it is imperative for public hospitals to maximize their public funding sources while



being proactive and creative in its strategies to deliver care to those who need it most.

Community Medical Centers serves as the “safety net” provider for Fresno County. In its 1996 partnership with the County of Fresno, Community assumed the obligations of indigent care. In order to fulfill this obligation, last year Community provided over \$90 million in uncompensated care. However, as Community looks to the future, it has determined the need for a more bold and aggressive strategy to meet the tremendous need for health care services in Fresno County.

In its efforts to make health care available to the over 30 percent of the County’s residents who are uninsured, Community has planned an Outpatient Care Center on the campus of the Regional Medical Center in downtown Fresno. This proposed facility will provide primary and specialty care including a children’s clinic, a women’s clinic focusing on prenatal, obstetrical and gynecological needs, asthma treatment and education, diabetes education and treatment, and surgical follow-up. This facility addresses the need for primary care services to the underinsured and uninsured population while attempting to reduce the number of unnecessary visits to local emergency departments. Although the overcrowding of emergency departments by the uninsured is a national problem, the Fresno area is particularly impacted with a larger percentage of uninsured.

In addition to a high percentage of uninsured, the region boasts some equally sobering statistics:

- An unemployment rate hovering at 15 percent
- Over 25 percent of the residents living below the poverty line
- The third highest asthma mortality rate in the nation
- The highest rates of teen pregnancy in the state
- Late or no prenatal care for pregnant women

We believe that an Outpatient Care Center is critical to begin addressing these challenges, and we would like to ask for your assistance in securing \$1 million towards the construction of this facility. We at Community Medical Centers are working diligently to secure significant private foundation monies for this facility as well. We understand that this request would require a special earmark under the Health Resources Services Administration account in the Labor/Health and Human Services/Education appropriations bill. We know that funds are limited, but feel that this project merits funding. It is a project which will improve the quality of life in the Central San Joaquin Valley.

---

PREPARED STATEMENT OF THE COUNCIL OF STATE AND TERRITORIAL  
EPIDEMIOLOGISTS

The Council of State and Territorial Epidemiologists (CSTE) is pleased to provide the Subcommittee with its fiscal year 2006 funding recommendations for nine priorities all of which are programs and activities administered by the Centers for Disease Control and Prevention.

CSTE is a professional association with over 850 public health epidemiologists working in all 50 states as well as local and territorial health agencies to detect, prevent and control conditions that impact the public’s health. CSTE members possess expertise in surveillance and epidemiology in a broad range of areas including communicable diseases, immunization, environmental health, chronic diseases, occupational health, injury control, maternal and child health and oral health.

PUBLIC HEALTH WORKFORCE: INCREASING STATE AND LOCAL EPIDEMIOLOGY AND  
LABORATORY CAPACITY

- \$4 million increase for CDC’s Office of Workforce and Career Development in fiscal year 2006 to support 65 CDC/Council of State and Territorial first year applied epidemiology fellows at a cost of \$60,000 per year;
- \$2 million in increased funding for CDC’s National Center for Infectious Diseases in fiscal year 2006 to support 35 CDC/Association of Public Health Laboratory applied research training fellows.

The disciplines of epidemiology and laboratory science are the pillars and backbone of public health practice. States and local communities have come to rely on well trained public health epidemiologists and laboratory scientists to investigate, monitor, and respond aggressively to public health threats. Every state’s residents have become familiar with the “disease detectives” who they know will be in the lead for communicating risks and recommending preventive action for outbreaks of SARS, flu, West Nile virus, Monkeypox and epidemics of obesity, diabetes, HIV/AIDS and a host of other serious threats the public has experienced during recent years. These are the “go to” professionals in every state. Yet, a new 2004 epidemi-

ology capacity survey shows the number and the level of training of epidemiologists is perceived as seriously deficient in most states. Federal funding has increased the number of epidemiologists engaged in bioterrorism preparedness since 2002, but has done so at the expense of state environmental health, injury and occupational health activities—shifting epidemiologists from these activities to federal bioterrorism preparedness priorities. Those engaged in chronic disease activities have increased since 2002, but are still viewed as too low in number and training and the number of epidemiologists engaged in infectious disease activities has stagnated.

Efforts under the leadership of CDC have been made to begin addressing these gaps at both the federal and state level. In addition to expanded CDC Epidemic Intelligence Service and Career Epidemiology Field Officers for state and local health departments, CDC is supporting training fellowship programs for epidemiologists and laboratory scientists who are expected to increase state capacity and provide future leadership in these professions. CSTE applauds these efforts and proposes aggressive expansion of existing state-focused programs to increase the number of epidemiologists and public health laboratory scientists at state and local health departments. The proposed fiscal year 2006 increase will provide CSTE and APHL with the resources to accelerate much needed expansion of the state and local workforce in these critical disciplines to approximately 75 epidemiologists and 75 laboratory scientists in training during fiscal year 2006.

The overall benefits to the states and localities will be additional well trained epidemiologists and laboratory scientists entering employment through training programs that include the following characteristics:

- national recruiting through a partnership between CSTE and the Association of Schools of Public Health
- orientation and training course with CDC and CSTE and APHL faculty
- a ready-made applicant pool for state and local positions with adequate time to evaluate job performance
- a structured, individualized training curriculum for each fellow
- technical and administrative support for fellows and state mentors

#### PUBLIC HEALTH INFRASTRUCTURE ENHANCEMENT AND TERRORISM PREPAREDNESS

CSTE supports \$927 million, at a minimum, for CDC's State and Local preparedness grants to enhance capacity to prepare for and respond to terrorist attacks. The President's fiscal year 2006 request for CDC's State and local terrorism preparedness grants cuts funding by \$130 million and appears to shift this funding to National Stockpile activities, including a new \$50 million Federal Mass Casualty Initiative. CSTE opposes this cut to on-going efforts to build strong state and local capacity which means, in many cases, eliminating personnel already hired. New federal initiatives, if they are deemed needed, should be funded from new resources.

After decades of neglect of governmental public health systems, documented in numerous Institute of Medicine (IOM) reports, and Reports to Congress (The Future of the Public's Health in the 21st Century, IOM, 2003; Emerging Microbial Threats to Health in the 21st Century, IOM, 2003; Report to Congress, Public Health's Infrastructure: a Status Report, CDC, 2001; Emerging Infectious Diseases: Consensus on Needed Laboratory Capacity could Strengthen Surveillance, GAO, 1999), Congress and the Administration began a substantial effort to repair the damage following the events of 9/11 and the ensuing anthrax attacks. This effort to restore and enhance the system to protect the public against terrorist attacks, as well as naturally occurring disease threats, such as SARS, pandemic influenza, and West Nile virus, is beginning to have positive effect, but progress can only continue with sustained support.

Reasons for maintaining funding levels in fiscal year 2006:

- No single State, and no community in any State, has reached a full level of national security preparedness to address the health consequences of a terrorist event.
- Few public health preparedness investments are one-time expenses. State and local health departments have been strongly urged to use preparedness funding to increase their personnel capacity in epidemiology, laboratory science, communications and logistics. Personnel are on-going expenses.
- State and local health departments are in the third year of expanded funding for terrorism preparedness. The effect of reducing the amount of available funding by 14 percent will seriously jeopardize their momentum in addressing critical capacity needs.
- The CDC cooperative agreement guidance listed several new eligibility areas for State spending, including mental health, chemical preparedness, and food security and newly expanded guidance is expected for fiscal year 2005. In addition,

States are being asked to help administer several new federal programs such as BioWatch, BioSense, ChemPack, additional smallpox vaccination program activities, and consequence management for postal facility Biohazard Detection Systems. This requires spreading funding over increased areas of responsibility.

Now is not the time to reduce our national commitment to State and local health departments. Building a strong public health infrastructure, particularly a trained public health workforce with sufficient epidemiologists and public health laboratory scientists, core public health professionals, will take a sustained commitment of resources over a long period of time, but will reap critical benefits in protected health.

#### CSTE SUPPORTS \$132 MILLION FOR THE PHHS BLOCK GRANT IN FISCAL YEAR 2006

The Preventive Health and Health Services Block Grant, currently funded at \$132 million, is proposed to be eliminated in the President's fiscal year 2006 budget. CSTE urges Congress not to cut this important prevention program for states, but maintain funding at the fiscal year 2005 level. When this proposed cut is considered alongside the \$130 million cut in the state and local Bioterrorism grant program, the net result is to seriously undermine support for developing state public health capacity and activities, a strong Congressional goal leading up to and following the attacks of 9/11.

The Block Grant was created to help states focus on achieving the health objectives identified in Healthy People 2010—a nationally conceived effort to set and achieve national health goals. To receive block grant funding, states must develop health plans, report to the federal government about their activities, and target public health interventions to populations in need. The flexibility of the grant allows each state to address their own unique challenges in exciting and innovative ways.

Examples of this include a program in Idaho to prevent falls for older adults. Falls are the leading cause of injury death for Idaho adults age 65 and older, with hip fractures alone costing the United States \$20 billion annually. The Idaho program funds a curriculum and provides training to individuals who lead senior fall prevention exercise programs throughout the state. Another example is in Alabama where the Community Waterborne Disease Program, funded solely with PHHS Block Grant dollars protects 340,000 Alabamians who reside in rural areas against waterborne disease outbreaks from contaminated wells and septic tanks. Other Block Grant funds are used to combat newly emerging public health threats, such as West Nile virus, distribute smoke detectors, counter the growing epidemic of obesity and ensuing chronic diseases, improve cancer screening, conduct disease surveillance and infectious disease outbreaks, such as Hepatitis A and E.coli O157:H7. While Block Grant funds sometimes complement existing categorical programs, they DO NOT DUPLICATE other CDC funded programs.

#### CSTE SUPPORTS \$250 MILLION FOR INFECTIOUS DISEASES CONTROL IN FISCAL YEAR 2006

Infectious diseases are the leading cause of death worldwide, and the number of deaths from infectious diseases had been increasing in the recent past and remains substantial in the United States today. New challenges in the growth of resistance to commonly used antibiotics, emerging disease threats such as avian flu, SARS, the rapid spread of West Nile virus across the United States, and the rising number of food borne disease outbreaks, including increased monitoring of mad cow disease, make increased resources for infectious diseases control essential to the nation's health and well-being.

CSTE's fiscal year 2006 recommendation for infectious diseases control is \$25 million more than the fiscal year 2005 appropriation level of \$225.5 million. CSTE urges that the additional \$25 million in funding target the following critical areas:

- Expand the Emerging Infections Program (EIP) from its current funding level of about \$20 million to allow more than the current 11 States (CA, CO, CT, GA, MD, MA, NM, NY, OR, TN, TX) to join this program that provides a population-based network of surveillance for infectious diseases, applied epidemiologic and laboratory research, as well as capacity for flexible public health response.
- Provide support for epidemiology fellowship programs to expand the number of trained public health epidemiologists, particularly at the State level, where shortages in these essential public health professionals are severe.
- Expand the Epidemiology and Laboratory Capacity (ELC) cooperative agreement program which provides the 50 States, plus six large local health departments (Chicago, Houston, Los Angeles, New York City, Philadelphia, Washington, D.C.) and Puerto Rico, with support to strengthen the collaboration between epidemiologic and laboratory science at the State and local level to meet the demands placed upon the country by emerging and re-emerging infectious disease threats.

- Ensure that funding for CDC's new initiative in global infectious diseases supports the International Emerging Infections Program, which is modeled on the U.S. EIP program.

CSTE SUPPORTS \$50 MILLION FOR CDC'S HEALTH TRACKING GRANT PROGRAM IN FISCAL YEAR 2006

Researchers have linked specific diseases with exposures to some environmental hazards, such as the link between exposure to asbestos and lung cancer. Other links remain unproven, such as the suspected link between exposure to disinfectant by-products and bladder cancer. As the Pew Environmental Health Commission's report, "America's Environmental Health Gap: Why the Country Needs A Nationwide Health Tracking Network" noted, there is currently no national surveillance system to investigate the possible links between these environmental exposures and a number of diseases and conditions. Most states have little environmental health capacity. The Environmental Public Health Tracking Program is designed to increase state and local environmental health capacity by providing resources to conduct surveillance of health effects, exposures and hazards and their possible linkages.

*Program Accomplishments*

Since fiscal year 2002, CDC has supported 20 state and local health departments to:

- Build environmental health capacity
- Increase collaboration between environmental and health agencies
- Identify and evaluate existing data systems
- Build partnerships with non-governmental organizations and communities
- Develop model systems that link data

Additional funding would be used to:

- Fund additional state health departments to increase their environmental health capacity
- Fund technical development activities to support a nationwide network
- Expand training and education activities
- Expand collaboration with national partners to coordinate technologic standards development efforts for the network

*Surveillance: Four Priorities—Behavioral Risk Factor Surveillance Survey (BRFSS).*—Among the many important chronic disease programs within CDC's Center for Chronic Disease Prevention, Health Promotion, and Genomics which CSTE supports, a priority is the Behavioral Risk Factor Surveillance Survey (BRFSS). CSTE urges continued progress toward achieving a funding level of \$18 million (+\$10 million)—the base amount needed to fully implement the survey. CSTE is very pleased that Congress increased funding for the survey from \$1.8 million where it had remained for many years, to \$6.9 million in fiscal year 2003 and to \$7.2 million in fiscal year 2004 and \$7.6 million in fiscal year 2005. The BRFSS is a primary source of information to guide intervention, policy decision, and budget direction at the local, state and federal level for a host of health problems, especially chronic diseases. It is the source of data for 24 of the 73 chronic disease indicators, six areas of the Healthy People 2010 leading health indicators and serves as the core source of surveillance for multiple public health programs across the CDC. The additional funding provided in fiscal year 2004 and fiscal year 2005 will significantly improve data collection infrastructure, timeliness, and analysis that will not only improve guidance for state-based public health activities, but allow state to state comparisons, state to national comparisons, and a more solid foundation for national resource and other decisions with regard to a range of public health activities.

*HIV/AIDS Surveillance.*—Within a total recommendation of \$1,049.2 million (+\$386.6 m) for CDC's HIV/AIDS prevention activities, CSTE urges an increase of \$35 million in fiscal year 2006 for HIV/AIDS surveillance cooperative agreements with state and local health departments to strengthen HIV case reporting. Surveillance activities are critical to the goal of preventing new HIV infections which can save an estimated \$195,000 in lifetime treatment costs per individual. Persistent, significant funding gaps between what state and local health departments have requested and what CDC can provide impede attainment of national prevention goals. CSTE recommends, at minimum, an additional \$35 million for HIV/AIDS core surveillance, enhanced perinatal surveillance, incidence surveillance, behavioral surveillance and morbidity monitoring.

*National Violent Death Reporting System.*—Within a total recommendation of \$168 million (+\$30 m) for CDC's National Center for Injury Prevention and Control, CSTE urges \$10 million in funding for fiscal year 2006 (+\$6.8 million) to continue building a fully implemented violent death reporting system in every state. Information from the reporting system can be used to target prevention and early

intervention efforts to prevent a significant number of the 50,000 annual deaths in the United States due to violence. Increased resources in fiscal year 2006 would be used to create uniform reporting systems in more states and build capacity to both collect and analyze data; ensure leadership and assistance; establish strong partnerships among federal, state, and non-governmental organizations; and research potential barriers to data collection. As of August, 2004, CDC is funding 17 states: AK, CA, CO, GA, KY, MA, MD, NC, NJ, NM, OK, OR, RI, SC, UT, VA, WI.

*State-Based Occupational Safety and Health Surveillance.*—Within a total recommendation of \$335 million (+\$49 m) for CDC's NIOSH activities, CSTE urges that \$10 million be provided in fiscal year 2006 to fully fund this program to prevent workplace injuries, diseases and death.. Both the CDC and CSTE believe that programs should be established within State Health departments as one of the most effective ways to build a nationwide system to prevent major causes of injuries and illnesses that are caused by hazardous conditions at work. The CDC and CSTE have established 13 occupational health indicators that every State should use to measure the burden of workplace injuries and illnesses, and then determine where they need to act to reduce preventable disease and disability in the population. In fiscal year 2005, NIOSH has funded the first 12 States to establish programs to use these indicators to count workplace injuries and illnesses, and make recommendations about how to prevent a few important health conditions (such as asthma, pesticide illness, silica lung diseases, and needlesticks). This program should be expanded to all 50 States to assure that every State has the capacity to track work-related health problems and take steps to prevent work-related injury, disease and death. Professional judgment assesses that \$10 million is needed to expand this program to all 50 States.

---

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES  
ADMINISTRATION (HRSA)

The Friends of HRSA is an advocacy coalition of more than 100 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. Our member organizations strongly support programs that assure Americans' access to health services.

HRSA programs assure that all Americans have access to our nation's best available health care services. Through its programs in thousands of communities across the country, HRSA provides a health safety net for medically underserved individuals and families, including 45 million Americans who lack health insurance; 49 million Americans who live in neighborhoods where primary health care services are scarce; African American infants, whose infant mortality rate is more than double that of whites; and the estimated 850,000 to 950,000 people living with HIV/AIDS. Programs to support the underserved place HRSA on the front lines in erasing our nation's racial/ethnic and rural/urban disparities in health status. HRSA funding goes where the need exists, in communities all over America. The Friends support a growing trend in HRSA programs to increase flexibility of service delivery at the local level, necessary to tailor programs to the unique needs of America's many varied communities. The agency's overriding goal is to achieve 100 percent access to health care, with zero disparities. In the best professional judgment of the members of the Friends of HRSA, to respond to this challenge, the agency will require a funding level of at least \$7.5 billion for fiscal year 2006.

Through its many programs and new initiatives, HRSA helps countless individuals live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled change in the nation's health care delivery system. HRSA is well positioned to meet these new challenges as it continues to provide first-rate health care to the nation's most vulnerable citizens. We are grateful to the Subcommittee for your consistent strong support for all of HRSA's programs, including the initiatives in terrorism preparedness and response in the past. Unfortunately, the president's budget overall recommends a massive \$838 million or over 12 percent cut to the agency for fiscal year 2006. We urge the members of the Subcommittee to restore the cuts and fund the agency at a level that allows HRSA to effectively implement these important programs.

Community-based health centers and National Health Service Corps-supported clinics form the backbone of the nation's safety net. More than 4,000 of these sites across the nation provide needed primary and preventive care to nearly 15 million poor and near-poor Americans. HRSA primary care centers include community health centers, migrant health centers, health care for the homeless programs, public housing primary care programs and school-based health centers. Health centers provide access to high-quality, family-oriented, culturally and linguistically com-

petent primary care and preventive services, including mental and behavioral health, dental and support services. Nearly three-fourths of health center patients are uninsured or on Medicaid, approximately two-thirds are people of color, and more than 85 percent live below 200 percent of the poverty level. Additional primary care is provided by 2,700 clinicians in the National Health Service Corps. Corps members work in communities with a shortage of health professionals in exchange for scholarships and loan repayments. The Friends of HRSA are pleased that the president has requested a significant 17.5 percent increase for Community Health Centers for a total of \$2.038 billion.

The Friends are concerned about a number of programs slated for deep cuts or elimination under the Administration's fiscal year 2006 budget proposal. An adequate, diverse, well-distributed and culturally competent health workforce is indispensable to our national readiness efforts. We are concerned with the president's proposed cut for hospital preparedness. In the post 9/11 era, all responders, providers and facilities must be ready to detect and respond to complex disasters, including terrorism, and HRSA must continue to support these vital programs.

HRSA Health Professions Programs under Title VII and VIII address the need for an adequate national workforce in the face of projected nationwide shortages of nurses, pharmacists, and other professionals. Graduates of these programs are up to 10 times more likely to practice in underserved areas, and they are up to 5 times more likely to be minorities. These programs provide support to students, programs, departments, and institutions to improve the accessibility, quality, and racial and ethnic diversity of the health care workforce. In addition to providing unique and essential training and education opportunities, these programs help meet the health care delivery needs of the areas in this country with severe health professions shortages, at times serving as the only source of health care in many rural and disadvantaged communities. The Friends are greatly concerned about the elimination of most funding for the Title VII health professions training programs and flat funding for Title VIII nurse training.

The Healthy Community Access Program is an example in which communities build partnerships among health care providers to deliver a broader range of health services to their neediest residents. Grantees are public or private entities that demonstrate a commitment to bridging service gaps and improving health outcomes for uninsured and underserved people. The Friends are very concerned that the Administration's budget proposal once again recommends eliminating this program of coordinated service delivery, an innovative program that does not duplicate other available programs.

Another vital program administered by HRSA is newborn screening. Newborn screening is a public health activity used for early identification of infants affected by certain genetic, metabolic, hormonal or functional conditions for which there is effective treatment or intervention. Screening detects disorders in newborns that, left untreated, can cause death, disability, mental retardation and other serious illnesses. Parents are often unaware that while nearly all babies born in the United States undergo newborn screening tests for genetic birth defects, the number and quality of these tests vary from state to state. Screening programs coordinated through the HRSA Bureau of Maternal and Child Health will assure that every baby born in the US receive, at a minimum, a universal core group of screening tests regardless of the state in which he/she is born.

Title 26 of the Children's Health Act of 2000 authorized funding for grants and programs to improve state-based newborn screening. This provision also called for an advisory committee to provide advice and recommendations to the Secretary for the development of grant administration policies and priorities, and to enhance the ability of the Secretary to reduce mortality or morbidity from heritable disorders. The Secretary appointed 15 members to this committee in February 2004. HRSA, together with this committee, recently published a report to be considered by the Secretary, which makes recommendations on the number and types of conditions that should be required by state programs. The Friends are very concerned that the Administration's budget did not include additional funding for such activity and that once again, the President's budget zeroed-out existing funding for the universal newborn hearing screening program. The newborn screening program is vital to ensuring that newborns are screened and treated for conditions that, if left alone, disability, mental retardation and even death.

HRSA programs improve health care service for the more than 61 million people who live in rural America. Although almost a quarter of the population lives in rural areas, only an eighth of our doctors work there. Because rural families earn less than urban families, many health problems associated with poverty are more serious, including high rates of chronic disease and infant mortality. While the recently passed Medicare prescription drug bill included several enhancements for

Medicare reimbursement for rural hospitals, this does not justify the elimination of small, targeted programs designed to improve access to health care services in rural areas. The deep \$115 million cut proposed for rural health programs has the potential to only exacerbate rural/urban health disparities seen today.

In light of many states experiencing budget crises, HRSA's State Planning Grants Program provides one-year grants to States to develop plans for providing access to affordable health insurance coverage to all their citizens. Considering that 45 million Americans are uninsured, with many individuals simultaneously being dropped from Medicaid and SCHIP rolls, there is a need for states to explore alternative approaches that provide health insurance benefits to its residents that are affordable in nature. The potential for states to share best practices as a result of this program is enormous, and therefore the Friends of HRSA is gravely concerned with this program's proposed elimination in the president's budget request.

Also, the proposed elimination of the Emergency Medical Services for Children Program is of concern considering many children who are eligible for Medicaid and SCHIP cannot enroll due to state enrollment limits and budgetary pressures. Therefore, these uninsured children will likely increasingly utilize emergency health services, as they are less likely to have a usual source of care. Not investing in improving the quality of emergency health services to children, especially at this time, may result in higher rates of death and disability among this population. Also, this program, as outlined in the midcourse review of the EMSC Five-Year Plan, 2001–2005, has been shown to make significant progress in meeting stated objectives to improve emergency health service delivery to children.

The Friends of HRSA are also concerned with the proposed flat funding of programs that make a difference in thousands of communities across the United States, and ultimately affect the lives of millions. The Maternal and Child Health Block Grant is another source of flexible funding for states and territories to address their unique needs, and remains in great need of increased, not flat, funding. The Block Grant is one of several HRSA Maternal and Child Health programs. Each year, more than 26 million pregnant women, infants and children nationwide are served by a MCH program. Of the nearly 4 million mothers who give birth annually, almost half receive some prenatal or postnatal service from a MCH-funded program. MCH programs increase immunizations and newborn screening, reduce infant mortality and developmentally handicapping conditions, prevent childhood accidents and injuries, and reduce adolescent pregnancy. Although states in theory could use MCH block grant funds to continue the universal newborn hearing screening and Emergency Medical Services for Children programs, two programs that have been proposed for elimination, in reality this is not a viable alternative. With the proposed flat funding of the block grant, funding additional programs under its auspices would mean that programs currently funded would have to be cut.

Title X of the Public Health Service Act was enacted to provide high-quality, subsidized contraceptive care to those who need but cannot afford such services, to improve women's health, reduce unintended pregnancies, and decrease infant mortality and morbidity. Title X programs provide comprehensive, voluntary and affordable family planning services to millions of low-income women and men—many of whom are uninsured—at more than 4,600 clinics nationwide. People who visit Title-X funded clinics receive a broad package of preventive health services, including breast and cervical cancer screening, blood pressure checks, anemia testing, and STD/HIV screening.

The Ryan White CARE Act programs, administered by HRSA's HIV/AIDS Bureau, are the largest single source of federal discretionary funding for HIV/AIDS health care for low-income, uninsured and underinsured Americans. We are very concerned that most programs under the Act would be flat-funded should the figures requested by the Administration be implemented, which will not be enough to meet the growing need and demand for services. The CARE Act program is an important safety net program, providing an estimated 533,000 people access to services and treatments each year. In addition to primary health care, CARE Act programs support the dissemination of drug therapies, home-based care, early intervention services, treatment adherence, case management and support. The CARE Act also funds a dental reimbursement program and the AIDS Education and Training Centers that offers specialized clinical education on the latest in HIV/AIDS care. Only the State AIDS Drug Assistance Program (ADAP), which provides medications to over 120,000 individuals those living with HIV/AIDS who would otherwise fall through the cracks, lacking private health insurance, but ineligible for Medicaid, receives an increase of \$10 million over fiscal year 2005.

Cross-cutting HRSA programs continually respond to new public health challenges. Tooth decay remains the single most chronic childhood disease in the nation. About 125 million Americans have no dental insurance; lack of access to dental care

is especially severe among children of poor, rural and minority families. A quarter of the nation's school-age children have 80 percent of all dental disease, putting them at risk for a host of related illnesses. And as new drugs help people with HIV/AIDS live longer, healthier lives, their need for regular oral health care will continue to climb. HRSA can help both groups by increasing the number of dentists in community and school-based centers and by providing greater reimbursements to hospital dental clinics and dental schools for the growing costs of treating people living with HIV/AIDS.

The members of the Friends of HRSA are grateful for this opportunity to present our views to the Subcommittee.

---

## PREPARED STATEMENT OF THE INTERTRIBAL BISON COOPERATIVE

### INTRODUCTION AND BACKGROUND

My name is Ervin Carlson, a Tribal Council member of the Blackfeet Tribe of Montana and President of the InterTribal Bison Cooperative. Please accept my sincere appreciation for this opportunity to submit testimony to the honorable members of the Appropriations Sub-Committee on Labor, Health and Human Services and Education. The InterTribal Bison Cooperative (ITBC) is a Native American non-profit organization, headquartered in Rapid City, South Dakota, comprised of 54 federally recognized Indian Tribes located within 18 States across the United States.

Buffalo thrived in abundance on the plains of the United States for many centuries before they were hunted to near extinction in the 1800s. During this period of history, buffalo were critical to survival of the American Indian. Buffalo provided food, shelter, clothing and essential tools for Indian people and insured continuance of their subsistence way of life. Naturally, Indian people developed a strong spiritual and cultural respect for buffalo that has not diminished with the passage of time.

Numerous tribes that were committed to preserving the sacred relationship between Indian people and buffalo established the ITBC as an effort to restore buffalo to Indian lands. ITBC focused upon raising buffalo on Indian Reservation lands that did not sustain other economic or agricultural projects. Significant portions of Indian Reservations consist of poor quality lands for farming or raising livestock. However, these wholly unproductive Reservation lands were and still are suitable for buffalo. ITBC began actively restoring buffalo to Indian lands after receiving funding in 1992 as an initiative of the Bush Administration.

Upon the successful restoration of buffalo to Indian lands, opportunities arose for Tribes to utilize buffalo for tribal economic development efforts. ITBC is now focused on efforts to assure that tribal buffalo projects are economically sustainable. Federal appropriations have allowed ITBC to successfully restore buffalo the tribal lands, thereby preserving the sacred relationship between Indian people and buffalo. The respect that Indian tribes have maintained for buffalo has fostered a serious commitment by ITBC member Tribes for successful buffalo herd development. The successful promotion of buffalo as a healthy food source will allow Tribes to utilize a culturally relevant resource as a means to achieve self-sufficiency.

### FUNDING REQUEST FOR PREVENTATIVE HEALTH CARE INITIATIVE

The InterTribal Bison Cooperative respectfully requests an appropriation for fiscal year 2006 in the amount of \$2,000,000 in the form of an earmark to the Department of Health and Human Service Department's budget. ITBC intends to utilize the funds to conduct a national demonstration project focused on the delivery of bison meat to Native Americans suffering from diet related diseases.

The Native American population currently suffers from the highest rates of Type 2 diabetes. The Indian population further suffers from high rates of cardio vascular disease and various other diet related diseases. Studies indicate that Type 2 diabetes commonly emerges when a population undergoes radical diet changes. Native Americans have been forced to abandon traditional diets rich in wild game, buffalo and plants and now have diets similar in composition to average American diets. More studies are needed on the traditional diets of Native Americans versus their modern day diets in relation to diabetes rates. However, based upon the current data available, it is safe to assume that disease rates of Native Americans are directly impacted by a genetic inability to effectively metabolize modern foods. More specifically, it is well accepted that the changing diet of Indians is a major factor in the diabetes epidemic in Indian Country.

Approximately 65-70 percent of Indians living on Indian Reservations receive foods provided by the USDA Food Distribution Program on Indian Reservation (FDPIR) or from the USDA Food Stamp Program. The FDPIR food package is com-



posed of approximately 58 percent carbohydrates, 14 percent proteins and 28 percent fats. Studies have shown that the FDIPIR food package has not been compatible with the genetic compositions of Native Americans and has been a major factor in the high incidence of diet-related disease among Native Americans. Indians utilizing Food Stamps generally select a grain based diet and poorer quality protein sources such as high fat meats based upon economic reasons and the unavailability of higher quality protein food sources.

Buffalo meat is low in fat and cholesterol and is compatible to the genetics of Indian people. ITBC intends to develop a health care initiative that would educate Indian Reservation families of the benefits of incorporating buffalo meat into their diets. In conjunction with educating Reservation families on the benefits of buffalo meat, ITBC intends to develop methods to make buffalo meat accessible for Indian families and to promote incorporation of buffalo into their diets. ITBC intends to coordinate with Reservation health care providers in nutritional studies of Reservation populations that incorporate buffalo meat into diet packages.

ITBC believes that incorporating buffalo meat will positively impact the diets of Indian people living on Reservations. A healthy diet for Indian people that results in a lower incidence of diabetes and other diet related illnesses will reduce Indian Reservation health care costs and result in a savings for taxpayers.

#### FUNDING REQUEST FOR ITBC TRAINING AND LABOR PROGRAM

The InterTribal Bison Cooperative respectfully requests an appropriation for fiscal year 2006 in the amount of \$500,000. This amount is \$400,000 above the fiscal year 2005 appropriation for ITBC and is critical to maintain last years funding level and to develop ITBC's training and labor program.

In fiscal year 2005, the ITBC and its member Tribes were funded at \$100,000, a decrease of \$200,000 from the previous year. ITBC is now requesting \$500,000 for fiscal year 2006 for job training as part of ITBC's labor initiative. To insure the success of ITBC's buffalo restoration efforts to Indian lands, training for the various jobs related to the buffalo projects is essential. Most member Tribes of ITBC have reservation unemployment rates of 72 percent. Jobs opportunities on most Indian Reservations are limited, low-paying, and often seasonal and temporary. The jobs created by buffalo restoration to Indian lands will positively impact Tribal unemployment rates and the overall Reservation poverty levels. Raising buffalo as an economic development effort requires skilled labor in permanent employment. ITBC has developed a job training program incorporating on-the-job training and work experience for youth that specifically addresses the unique needs of managing and maintaining buffalo. ITBC's training program further focuses on strengthening the economic development opportunities of buffalo restoration with training specific to meat processing, veterinary science, wildlife and biological services, infrastructure development, business and management training, and the overall development of a skilled workforce.

Sufficient funding for job training is critical to the success of the buffalo restoration projects. The increase in funding will ensure that ITBC can provide job training, job growth training to ITBC member tribes. Without funding at the requested level, the buffalo restoration projects have less assurance of success.

#### ITBC GOALS AND INITIATIVES

In addition to developing a preventative health care initiative, ITBC intends to continue with buffalo restoration efforts and the Tribal buffalo marketing initiative.

In 1991, seven Indian Tribes had small buffalo herds, with a combined total of 1,500 animals. The herds were not utilized for economic development but were often maintained as wildlife only. During ITBC's relatively short 10-year tenure, it has been highly successful at developing existing buffalo herds and restoring buffalo to Indian lands that had no buffalo prior to 1991. Today, through the efforts of ITBC, over 35 Indian Tribes are engaged in raising over 15,000 buffalo. All buffalo operations are owned and managed by Tribes and many programs are close to achieving self-sufficiency and profit generation. ITBC's technical assistance is critical to ensure that the current Tribal buffalo projects gain self-sufficiency and become profit-generating. Further, ITBC's assistance is critical to those Tribes seeking to start a buffalo restoration effort.

Through the efforts of ITBC, a new industry has developed on Indian reservations utilizing a culturally relevant resource. Hundreds of new jobs directly and indirectly revolving around the buffalo industry have been created. Tribal economies have benefited from the thousands of dollars generated and circulated on Indian Reservations.

## CONCLUSION

ITBC has proven highly successful since its establishment to restore buffalo to Indian Reservation lands to revive and protect the sacred relationship between buffalo and Indian Tribes. Further, ITBC has successfully promoted the utilization of a culturally significant resource for viable economic development.

ITBC has assisted Tribes with the creation of new jobs, on-the-job training and job growth in the buffalo industry resulting in the generation of new money for tribal economies. ITBC is also actively developing strategies for marketing Tribally owned buffalo. Finally, and most critically for Tribal populations, ITBC is developing a preventive health care initiative to utilize buffalo meat as a healthy addition to Tribal family diets to reduce the incidence of diet-related illnesses.

ITBC strongly urges you to support its request for a \$2,000,000 earmark to the Department of Health and Human Service Department's budget to develop the critically needed preventative health care initiative utilizing Tribally produced buffalo.

---

 PREPARED STATEMENT OF THE LUMMI INDIAN NATION

## WHO WE ARE

The Lummi Nation is a party to the Point Elliot Treaty of 1855. Under this Treaty we understand that the Lummi Nation has secured the protection of the United States of America and has reserved the right to govern our own lands, people and the people who enter these lands voluntarily. The Lummi Nation is a federally recognized Indian tribal government located in what is now called the State of Washington. The Lummi Nation includes a population of nearly 5,000 people. The Lummi Nation land base includes over 12,500 upland acres and 5,000 acres of tidelands. The Lummi are a fishing people with fishing rights in the San Juan Islands and much of Puget Sound and its associated waterways extending for hundreds of miles.

*Self-governing Status*

The Lummi Nation is one of the first self-governance Tribes. Although many thought the Lummi Nation was seeking to establish a new relationship with the Federal government, it was really seeking to re-establish the relationship that it started in 1855; to affirm the government-to-government relationship that began back then and reshape it into a relationship that fits today's realities, needs and goals. Each generation must continue the unbroken promise to take responsibility for the welfare of our people that began in the past and extends into the future.

*Health Disparities Index*

Over the past several years there has been growing concern over the disparities in Health care funding that is available to disadvantaged populations within the United States. Unfortunately this concern has not generated additional funding for health care services. Instead the information that there are substantial and verifiable disparities in the level of funding provided to minority population. New funding has been appropriated to study the problem and to make recommendations that will most likely include a recommendation for additional service funding.

*U.S. Civil Rights Commission Report*

The Civil Rights Report "A Quiet Crisis" was issued last year. In this report, the federal government provides a devastating indictment of the level of funding for Indian Country. This situation did not occur during the current administration, nor did it occur during the previous administration. This is not about politics. It is about human beings.

## INDIAN HEALTH CARE IMPROVEMENT ACT

The Lummi Nation wants the Congress and the Department to support that section of the proposed Indian Health Care Improvement Act which enables tribes to not only participate but to operate Medicaid Program services consistent with the need for health care service needs of their people. This proposal is budget neutral. These costs are already included in the current expenditure. This is simply re-routing a existing expenditures through the Tribal governments, which are closest to the people who are being served. This proposal enables Tribal governments to develop their own Medicaid Services plans instead of simply participating in the State's plan.

## HEAD START BUREAU—NEW HEAD START FACILITY

The Lummi Nation is proud to have operated a Head Start Program since 1969. Our Head Start Program now serves one hundred and eighteen children (118) and their families. However, the Lummi Nation Head Start Program needs to serve over two hundred (200). The limitations of the existing facility have limited the expansion of the program and its badly needed services. The Lummi Nation has completed construction of a new school facility with Bureau of Indian Affairs funding. In the process of constructing this facility the Lummi Nation planned for the construction of a new Head Start Facility adjacent to the new School Facility. Water, sewer and electrical services have been stubbed out to the site, thereby reducing the cost of constructing the facility. The first phase of construction will cost approximately \$500,000.

## ADMINISTRATION FOR CHILDREN AND FAMILIES

*Tribal Social Services Demonstration Projects*

ACF staff have informed Tribal Leadership the Department was considering a demonstration project to provide Tribes with direct access to Title IV (b) and Title IV (e) Social Services and Foster Care Services. The Lummi Nation supports the idea of a demonstration project and would eagerly participate in such a project. The Lummi Nation would support legislation that enables tribal governments to work directly with DHHS to access funding for Title IV (b), (c), (d), and (e) while maintaining their service relationship with the State services for the benefit of all Indian children.

*Unemployment and Poverty*

The Lummi Nation approaches the problems of poverty and welfare through its own experience. The Lummi Nation economy is unique. It had remained a traditional fishing economy in the 21st century. The strength of the annual salmon runs had supported the Lummi Nation economy since time immemorial. However, these runs have finally succumbed to combination of farm fish competition, over-fishing and disappearing habitat.

*Increasing Welfare Case Load*

The experience of the Lummi Nation is that TANF caseloads are increasing not decreasing. Due to the failure of the last 5 years fishing seasons the Lummi Nation fishers are being added into the existing welfare base case loads for the TANF and BIA General Assistance Programs. Each Lummi fisher person supports an additional four to five families that worked on their boat and received a share of the total income. These fishing boats have reduced by 53 percent from 700 to 373. What community in the United States could sustain this level of economic disaster? For the Lummi Nation this is the bankruptcy of nearly all its small businesses owners/operators within a short period of time.

*Funding for Tribes to Build Social Services/TANF Infrastructure*

The existing TANF funding for Tribes fails to recognize the long-term investment in the development of the State Welfare infrastructure. Therefore, Tribes are presented a less than level playing field when they seek to develop and implement welfare service programs that meet the needs of their people. The Lummi Nation urges the Committee to consider earmarking a portion of the funding provided to States for their administrative costs to support the development of Tribal TANF infrastructure. This funding should be provided directly to Tribes who have assumed the responsibility for operating TANF.

## SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

*Tribal Substance Abuse Block Grant*

The Lummi Nation has been able to have several meetings with the senior management of the Substance Abuse and Mental Health Services Administration over the past year. During one of these meetings we suggested that they re-program just one year's increase in the funding that is available to "States under the Substance Abuse Block Grant funding. Currently only the Red Lake Band of Chippewa is receiving an allocation directly from the Substance Abuse Block Grant administered by the Substance Abuse and Mental Health Services Administration. The Tribal specific Block Grant Program could be started using only the increases that are appropriated for the general population re-programmed as a Tribal only Substance Abuse Block Grant. Then Congress would subsequently appropriate enough funds for annual inflationary increases for both the State Block Grant and the Tribal Block Grant.

*Alcohol and Substance Abuse Program Infrastructure Funding*

SAMHSA has been able to support the development of State Alcohol and Substance abuse program infrastructure. While Tribal governments face the same data challenges that are posed by the operation of the Alcohol and Substance Abuse Treatment, Prevention and After-care activities. Apparently tribal governments can achieve what State governments who have access to tax bases of their own, cannot do without Federal assistance.

## DEPARTMENT OF LABOR

*Jobs Now—Job Creation and Economic Development*

In response to the economic fishing disaster for the Lummi people, of past 5 years, the Lummi Nation has created the JOBS NOW Initiative and is in the process of developing a long-term economic stimulus plan. These initiatives utilize all of the Lummi Nation projects, services, and resources to address the internal, social and economic needs of Lummi Nation families. Through this initiative the Lummi Nation has been able to register its membership in a job skills bank and identified area of job training that are in demand by the local labor market and consistent with the employment preferences of the membership.

*Lummi Nation Families Need 500 Jobs to Replace Lost Fishing Industry Jobs*

The goal of the Lummi Nation Salmon Recovery Initiative is to create 500 jobs that provide a family wage to confront the current and long-term effects of the fishing economic disaster that is facing Lummi Nation members. Therefore the Lummi Nation urges the Committee to support additional job training program funding earmarked to address the economic crisis that is facing the members of the Lummi Nation.

*Lummi Nation Dislocated Fishers Project*

The Lummi Nation is fully aware of how different, how culturally specific this economic dislocation is. The Lummi Nation expects the federal government including the Department of Labor to recognize the unique relationship that exists between the Lummi Nation and the United States of America through the Point Elliot Treaty of 1855.

The Lummi Nation anticipated that it would be afforded the full discretion allowed under the law. Instead we believe that we have been held hostage to the past experiences of the Dislocated Worker Program. Past practices are not useful guides to new situations. We are disappointed with the reaction of the Department of Labor to the needs of our community members. The situation at Lummi Nation is a real economic dislocation, not just a profit dislocation. This is not a company failure. This is not simply a matter of mismanagement and plant failure. We are not working with workers but with small businessmen who were previously successfully self-employed. The service models that are imposed by the Department of Labor are based on the plant failure model.

It is clear that the intent of the legislation is to assist workers to get jobs when the industry that supported them is no longer operable. Our situation is clearly within the intent of the authorizing legislation. The fishing industry to which our people have devoted their lives and invested their fortune has changed, due to no action or inaction on the part of the workers for whom assistance is sought.

*Negotiated Standard*

During negotiations with the Department of Labor the Lummi Nation sought and received a promise that funding would be available to meet the needs of all eligible members of the Lummi Nation. The Lummi Nation expects the Department to honor this standard and continue funding of this project until all eligible Lummi Nation members have been provided services such that they are able to secure and maintain comparable permanent employment.

*+ \$420,000.—Additional funding for Lummi Nation WIA Programs and Services*

The Lummi Nation allocation for funding under the WIA Comprehensive and Youth Programs is less than one third of what it needs to be. The Lummi Nation is requesting that the Committee review its allocations and increase the funding that is available to the Lummi Nation by three (3) times. The Lummi Nation receives \$140,000 annually to meet the needs of 5,000 people, with multiple needs including basic reading and writing skills, physical therapy, other personal issues to address prior to job training and eventually employment. The Lummi Nation needs an allocation of \$420,000.

## DEPARTMENT OF EDUCATION

*Funding for Tribal Education Departments*

This is needed by all of Indian Country. Those tribes that do not operate their own schools need the infrastructure to support their youth in the public schools. Those Tribes that do operate schools need the Department format to insure that educational services are connected to the Tribal government.

*No Child Left behind*

The United States of America has left behind Indian children. While we are supportive of many provision of the Act we are not aware of any benefits that it has brought to us. Indian children are still left behind by the lack of adequate school and preschool facilities, teachers and operating resources. While the 2006 Presidents budget Request does includes requests to maintain the 2004 funding level it is woefully inadequate. The leading cause of death in our community is abuse of alcohol and/or drugs. Children who live in such a community have significant social, developmental needs that must be addressed so that basic educational services can be of any value. The current funding level mean that Indian Children will continue to be left behind as the rest of America is catapulted into the 21st Century.

*Vocational Rehabilitation*

The Lummi Nation is a long-standing grantee of the Department's Indian Vocational Rehabilitation. We are grateful for the support of the Department for the development of the Lummi Nation Vocational Rehabilitation Program as well as the funding to provide much needed services for our membership. The Department needs to insure that the full amount of this allocation is available for the benefit of Indian people.

*477 Program*

The Lummi Nation along with other who are participating in the 477 Program are seeking to consolidate all employment and training programs, services functions and activities. The Education Department needs to fully participate in this program. The Lummi Nation urges the Committee to require the Department to meet with Tribal leadership and members of the Committee staff to identify the barriers to full participation and develop appropriate administrative and or legislative remedies.

---

 PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

## SUMMARY

The proposed cuts in the fiscal year 2006 budget of the Centers for Disease Control and Prevention (CDC) fall disproportionately on local and state public health departments. The two largest proposed program cuts for CDC are a reduction of \$130 million in funding for state and local bioterrorism preparedness and elimination of the \$131 million Preventive Health and Health Services block grant program. Such funding cuts would seriously compromise the ability of the nation's governmental public health system to fulfill its mission of protecting and promoting health.

Local public health departments work every day on the front lines to combat threats to the health of their communities. They can ill afford substantial reductions in federal support for their roles as first responders to bioterrorism and other public health emergencies. Moreover, local public health departments receive about 40 percent of the Preventive Health and Health Services block grant (PHHS) funds. These enable them to carry out programs ranging from prevention of heart attack and stroke to combating West Nile virus. In states where local health departments rely on these funds to run prevention programs for which no other sources of funding are available, activities to reduce the burdens of preventable disease will be reduced.

At a time when the nation is engaged in urgent work to protect the homeland from terrorists, as well as to stop an epidemic of obesity, it is profoundly counterproductive and irrational to reduce support for local programs that are the first line of defense against the greatest threats to the health of communities. NACCHO urges Congress to continue funding these two CDC programs at levels no less than that of the current fiscal year. Those levels are \$932 million for state and local bioterrorism preparedness and \$131 million for the Preventive Health and Health Services block grant.

STRENGTHENING THE GOVERNMENTAL PUBLIC HEALTH SYSTEM TO IMPROVE HOMELAND SECURITY REQUIRES SUSTAINED FUNDING

Congress recognized in 1997 an unmet need to strengthen the nation's capacity to respond to an act of bioterrorism and initiated funding for bioterrorism preparedness in fiscal year 1999. The initial funding of about \$121 million (which included \$51 million solely for stockpiling medications) assisted CDC and state and local health departments to begin examining what plans and resources were necessary. After 9/11 and the anthrax outbreaks in the fall of 2001, Congress increased bioterrorism funding markedly and included \$940 million for building state and local capacities, of which about \$870 million was actually made available to states and localities. The Department of Health and Human Services got these funds out to states and three large cities via cooperative agreements very promptly, far ahead of other homeland security funds for states and localities.

Substantial bioterrorism preparedness funds for improving all aspects of preparedness have actually been in the hands of state health departments since August 2002, less than three years. Local public health departments, many of which have been funded for much less time, are justifiably proud of the progress they have made.

Extensive response plans, developed in collaboration with local emergency management systems, have been made. Numerous "tabletop" and real field exercises have tested local capabilities. Mass vaccination clinics have taken place, some in conjunction with the actual requirement to provide smallpox vaccine to selected first responders, others as a real response to this year's flu vaccine shortage. Communications systems and equipment that enable rapid electronic information exchange among health departments and by health departments to their communities are operational. Improved systems for disease detection are in place.

Local health departments have engaged hospitals, physicians, and other individuals and organizations in the private sector in developing their roles in responding to a serious disease outbreak. Complex logistical arrangements needed to distribute medications or equipment from the Strategic National Stockpile to stricken populations have been developed.

In some locations, genuine public health crises, such as suspected SARS cases or flu vaccine shortages, have demanded a response. In the act of the responding, local health departments and their community partners continually identify new challenges and new ways to improve their ability to respond. Improving a locality's ability to detect a disease outbreak promptly and to contain it swiftly is a continuous process. Interrupting that process through funding cuts would take the nation's bioterrorism preparedness backwards, not forward. New capacities that are now in place cannot be sustained without sustained funding.

The Administration has proposed to fund more medicines and supplies for the Strategic National Stockpile and to purchase portable medical treatment units, instead of sustaining funding for state and local capacities. Yet the acquisition of vaccines or equipment is useless unless there are trained people and established systems in place to get the vaccines or treatment to stricken populations. According to a recent report by the Government Accountability Office ("Bioterrorism: Information on Jurisdictions' Expenditure and Reported Obligation of Program Funds," February 2005), state and local governments are taking action responsibly to prepare for bioterrorism and there are not large surpluses of unspent funds. It is wholly irrational to suggest that more vaccines and supplies can improve national preparedness, if funding to sustain health departments' capacity to use those vaccines and supplies is simultaneously cut back.

The nation has a long way to go before every citizen enjoys the best possible protection by disease detection and response systems that work as quickly as humanly possible. Providing this protection is the job of the governmental public health system. No other entity can do it. NACCHO urges Congress not to cut back funds available to local public health departments, the nation's first responders to bioterrorism.

THE PHHS BLOCK GRANT IS A LINCHPIN FOR PREVENTION

Local public health departments receive approximately 40 percent of the Preventive Health and Health Services block grants nationally. The proportion varies among states from less than 5 percent to almost 100 percent. The block grant funds fulfill three critical purposes. First, they enable states to address critical unmet public health needs. The coexistence of other federal categorical public health funds does not mean that available categorical funds are sufficient or available to address all problems. They are not. Improving chronic disease prevention through screening programs and programs that promote healthy nutrition and physical activity are prime examples of activities to which many jurisdictions devote PHHS funds. Forty

percent of fiscal year 2004 block grant funds were spent on chronic disease prevention, including prevention of obesity, stroke, heart disease, cancer, diabetes, and dental caries.

Second, PHHS funds provide some flexible funding to address unexpected problems or problems that are unique to a particular geographic area. West Nile virus, a fully preventable disease spread to humans by mosquitoes, is one good example. Third, PHHS funds provide leverage for more funds and in-kind resources from non-federal sources. In one southern state, local health departments collectively used \$2.77 million in block grant funds to establish new prevention programs and generate \$5 million in additional resources for those programs.

States are fully accountable to the Department of Health and Human Services for their expenditures of block grant funds and report how much money they spend by specific program area. In those states where local health departments receive a significant amount of PHHS funds from the state, local prevention efforts will diminish. Local and state health departments are key leaders and providers of population-based prevention programs. They work to keep prevention in the public eye and they build on programs that have been proven effective in reducing disease and preventing premature death. As health care costs escalate, reducing the nation's commitment to prevention by eliminating the PHHS block grant and weakening state and local public health departments is unwise and uneconomic.

The National Association of County and City Health Officials (NACCHO) is the organization representing the almost 3,000 local public health departments in the United States.

---

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF FOSTER GRANDPARENT  
PROGRAM DIRECTORS

INTRODUCTION

I am honored to testify in support of fiscal year 2006 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNS).

Good morning Mr. Chairman. My name is Brenda Lax and I have been the Foster Grandparent Program Director with the City of Kansas City, Missouri for the past 17 years. I am here in my capacity as President of the National Association of Foster Grandparent Program Directors (NAFGPD). NAFGPD is a membership-supported professional organization whose roster includes the majority of more than 350 directors who administer Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP. This year we will celebrate our 40th Anniversary of engaging low-income seniors in service to children with special needs with a reception on September 21, 2005 here in Washington, DC. On behalf of NAFGPD members across the country, I would like to extend an invitation to you and your staff to join us for this special occasion.

Mr. Chairman, I would like to begin by thanking you and the distinguished members of the Subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this Subcommittee has always been there to protect the integrity and mission of our programs. Our volunteers and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. I also want to acknowledge your outstanding staff for their tireless work and very difficult job they have to "make the numbers fit"—an increasingly difficult task in this budget environment.

Last year I had the great privilege of testifying before the House Subcommittee about the fiscal year 2005 budget request for FGP. While it was a great honor to be there, I was compelled to deliver some very disappointing news—a cut of some \$3.5 million was proposed for our programs across the country. Well, Mr. Chairman under your leadership the Subcommittee not only rejected this misguided cut, but provided an increase of nearly \$2 million over the fiscal year 2004 enacted level. NAFGPD was very glad to see this ill-conceived cut rejected, and we believe your action sent a message about our programs—they are alive and well and quite worthy of scarce federal resources.

Thanks to your action in the fiscal year 2005 appropriations process, Mr. Chairman, the fiscal year 2006 budget request for FGP does not suggest another significant cut to our programs. Instead, the fiscal year 2006 budget provides an increase of \$634,000 (.5 percent) for headquarters-based administrative functions such as training and technical assistance. While NAFGPD was pleased to see our programs

not slated for a cut, we remain concerned that the Corporation's request does not provide any new funding where it is needed most—in the field. All of us recognize the spending constraints placed on the President and, most importantly on you and the Appropriations Committee, Mr. Chairman. However, in a time of such scarce federal resources, NAFGPD believes strongly that any new funding should flow to our programs in the field where it is most urgently needed, not CNCS headquarters.

NAFGPD respectfully requests the subcommittee to provide \$116.440 million for the Foster Grandparent Program in fiscal year 2006, an increase of \$5.016 million over the fiscal year 2005 level. This critical funding will ensure the continued viability of the Foster Grandparent Program, and allow for important expansion of this unique program. Specifically, this proposal would fund a 3 percent cost of living increase for every Foster Grandparent Program and expansion grants to existing programs that would add 372 new low-income senior volunteers to serve children.

#### FGP: AN OVERVIEW

Established in 1965, the Foster Grandparent Program was the first federally funded, organized program to engage older volunteers in significant service to others. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises nearly 350 programs in every state and the District of Columbia, Puerto Rico, and the Virgin Islands. All of these programs are now primarily based in community volunteer sites—where most special needs children can be found today—and are administered locally through a non-profit organization or agency and Advisory Council comprised of community citizens dedicated to FGP and its mission. FGP represents the best in the federal partnership with local communities, with federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. There are currently 38,700 Foster Grandparent volunteers who give over 36 million hours annually to more than 277,000 children.

The Foster Grandparent Program is unique for several reasons. We are one of only two volunteer programs in existence that enable seniors living on very limited incomes to serve their communities as volunteers by providing a small non-taxable stipend and other support which allow volunteers to serve at little or no cost to themselves. Our volunteers provide intensive, consistent service—15 to 40 hours every week, usually 4 hours every day. FGP provides intensive pre-service orientation and at least 48 hours of ongoing training every year to keep volunteers current and informed on how to work with children who have special needs. And our volunteers provide one-to-one service to their assigned children, exactly what is required to help prepare our nation's neediest children to become self-sufficient adults.

#### FGP: THE VOLUNTEERS

The Foster Grandparent Program is a versatile, dynamic, and uniquely multi-purpose program. First, we give Americans 60 years of age or older who are living on incomes at or less than 125 percent of the poverty level the opportunity to serve 15 to 40 hours every week and use the talents, skills and wisdom they have accumulated over a lifetime to give back to the communities which nurtured them throughout their lives. Seniors in general are not valued or respected in today's society, and low-income seniors are particularly devalued because of their economic status. They are rarely asked by their communities to contribute through volunteering, because they are not traditionally those who participate in community activities.

FGP actively seeks out these low-income seniors. We dare to ask them to serve, to give something back. And we help them to develop the additional skills they may need to function effectively in settings unfamiliar to them, like public schools, hospitals, childcare centers, and juvenile detention facilities. We also provide them with ongoing training and support throughout their tenure as Foster Grandparents. Through their service, our older volunteers say they feel and stay healthier, that they feel needed and productive. Most importantly, they leave to the next generation a legacy of skills, perspective and knowledge that has been learned the hard way—through experience.

Within budgetary constraints, FGP is engaging older people who are not usually asked to serve and those usually considered as needing services rather than being able to serve: 86 percent are 65 or older and 45 percent come from various ethnic groups.

#### FGP: THE CHILDREN

Through our volunteers, the Foster Grandparent Program also provides person-to-person service to children and youth under the age of 21 who have special or exceptional needs, many of whom face serious, often life-threatening challenges. With



the changing dynamics in family life today, many children with disabilities and special needs lack a consistent, stable adult role model in their lives. The Foster Grandparent is very often the only person in a child's life who is there every day, who accepts the child, encourages him no matter how many mistakes the child makes, and focuses on the child's successes.

Special needs of children served by Foster Grandparents include AIDS or addiction to crack or other drugs; abuse or neglect; physical, mental, or learning disabilities; speech, or other sensory disabilities; incarceration and terminal illness. Of the children served, 7 percent are abused or neglected, 26 percent have learning disabilities, and 11 percent have developmental delays. FGP focuses its resources in areas where they will have the most impact: early intervention services and literacy activities. Nationally, 85 percent of the children served by Foster Grandparents are under the age of 12, with 39 percent of these children age 5 or under. Foster Grandparents work intensively with these very young children to address their problems at as early an age as possible, before they enter school. Nearly one-half of FGP volunteers serve nearly 12 million hours annually addressing literacy and emergent-literacy problems with special needs children.

Activities of the FGP volunteers with their assigned children include teaching parenting skills to teen parents; providing physical and emotional support to babies abandoned in hospitals; helping children with developmental, speech, or physical disabilities develop self-help skills; reinforcing reading and mathematics skills; and giving guidance and serving as mentors to incarcerated or other youth.

#### FGP: THE VOLUNTEER SITES

The Foster Grandparent Program provides agencies and organizations providing services to special-needs children with a consistent, reliable, invaluable extra pair of hands 15 to 40 hours every week to assist in providing these services. Seventy-one percent of FGP volunteers serve in public and private schools as well as sites that provide early childhood pre-literacy services to very young children, including Head Start.

#### FGP: COST-EFFECTIVE SERVICE

The Foster Grandparent Program serves local communities in a high quality, efficient and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and out of expensive in-home or institutional care. Using the Independent Sector's 2003 valuation for one hour of volunteer service (\$17.19/hour), the value of the service given by Foster Grandparents annually is over \$618 million, and represents a 5-fold return on the federal dollars invested in FGP. The annual federal cost for one Foster Grandparent is \$3,800—less than \$4.00 per hour.

The value local communities place on FGP and its multifaceted services is evidenced by the large amount of cash and in-kind donations contributed by communities to support FGP. For example, FGP's fiscal year 2001 federal allocation was matched with \$40 million in non-federal donations from states and local communities in which Foster Grandparents volunteer. This represents a non-federal match of 42 percent, or \$.42 for every \$1.00 in federal funds invested—well over the 10 percent local match required by law.

#### NAFGPD'S FISCAL YEAR 2006 BUDGET REQUEST

Given the dramatically expanding number of low-income seniors eligible to serve and the staggering number of troubled and challenged children in America today, we respectfully request that the Subcommittee provide \$116.440 million for the Foster Grandparent Program in fiscal year 2006, an increase of \$5.016 million over fiscal year 2005. This critical funding will ensure the continued viability of the Foster Grandparent program, and allow for an expansion of this important program.

The requested increase would be allocated for the following purposes, in order of priority:

1st.—Award an administrative cost increase of 3 percent to each existing Foster Grandparent Program in order to maintain quality, enable recruitment and sustain the important work already being done by programs.

2nd.—In accordance with the Domestic Volunteer Service Act (DVSA), designate one-third of the increase over the fiscal year 2005 level to fund Program of National Significance (PNS) expansion grants to allow existing FGP programs to expand the number of volunteers serving in areas of critical need as identified by Congress in the DVSA.

This funding proposal will generate opportunities for approximately 372 new low-income senior volunteers contributing in excess of 400,000 hours of service annually to more than 2,000 additional children.

The message is clear: (1) the population of low-income seniors available to volunteer 15 to 40 hours every week is increasing; (2) communities need and want more Foster Grandparent volunteers and more Foster Grandparent Programs. FGP respectfully requests increased funding that will address our most pressing need: a 3 percent administrative cost increase that will enable the program to expand its reach across the nation. The Subcommittee's continued investment in FGP now will pay off in savings realized later, as more seniors stay healthy and independent through volunteer service, as communities save tax dollars, and as children with special needs are helped to become contributing members of society.

Mr. Chairman, in closing I would like to again thank you for the subcommittee's support and leadership for FGP over the years. NAFGPD takes great comfort in knowing you and your colleagues in Congress appreciate what our low-income senior volunteers accomplish every day in communities across the country.

---

#### PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing (NLN)—representing more than 1,200 nursing schools and health care agencies, some 18,000 individual members composed of nurses, educators, administrators, public members, and 18 constituent leagues—appreciates the Subcommittee's past support for nursing education and your continued recognition of the important role nurses play in the delivery of health care services. We are concerned, however, that the advancements made by Congress to help alleviate the nursing shortage will be lost during the fiscal year 2006 appropriations process unless additional resources are expended. NLN urges your continued support for Title VIII—Nursing Workforce Development Programs by ensuring that these programs are funded at a minimum level of \$210 million for fiscal year 2006. To put this funding request into perspective, in 1974, during the last serious nursing shortage, Congress appropriated \$153 million for nurse education programs. In today's dollars that would equate to \$592 million, approximately four times what the federal government is spending now.

Today's nursing shortage is very real and very different from any experienced in the past. The current shortage is evidenced by an aging workforce and an inadequate number of people entering the profession. Schools of nursing are suffering from a continuing and growing shortage of faculty, which prevents these institutions from admitting many qualified students who are applying to their programs. A recent NLN survey of nursing programs at all levels shows that an estimated 125,000 qualified applicants were turned away from nursing programs for the academic year 2003–2004 because of the severe faculty shortage. The supply of appropriately prepared nurses and nursing faculty is inadequate to meet the needs of a diverse, aging population, and this shortfall will grow more serious over the next 5 years.

Congress did an admirable job of passing the Nurse Reinvestment Act in 2002. The new monies used to fund loans and scholarships are appreciated. However, it has become abundantly clear that significantly more funding is required to even minimally meet the existing need.

NLN's Faculty Survey conducted in 2002 concludes that not enough qualified nurse educators exist to teach the number of nurses needed to ameliorate the nursing shortage. Subsequent information indicates that this situation is getting more serious and is not expected to improve in the near future, since an inadequate number of nurse educators are currently in the education pipeline.

The NLN Survey found three trends influencing the future of nursing education over the next decade:

—*The aging of the nurse faculty population.*—An average of 1.3 full-time faculty members per program left their positions in nursing education in 2002. About half the Survey respondents had at least one unfilled budgeted full-time faculty position and some have as many as 15 such positions. 36.5 percent of faculty who left their positions in the preceding year did so because of retirement; 8.6 percent of faculty were 61 years of age or older; and 75 percent of the current faculty population is expected to retire by 2019.

Approximately 1,800 full-time faculty members leave their positions each year. About 10,000 master's level nurses graduate per year, 15 percent of whom would have to go into teaching just to maintain the status quo. Since this is highly unlikely, the gap between unfilled positions and the candidate pool will widen significantly.

—*The increasing number of part-time faculty.*—The number of part-time faculty has increased notably since 1996—nearly 17 percent in baccalaureate programs and 14 percent in associate degree programs. Part-time faculty now provides approximately 23 percent of the estimated number of faculty FTEs.

Part-time employees are often not an integral part of the design, implementation, and evaluation of the overall nursing education program. Many may hold other positions that often limit their availability to students. Further, many part-time faculty have not been prepared for the faculty role.

—*The large number of nursing faculty who are not prepared at the doctoral level.*—Approximately half the full-time faculty in baccalaureate and higher degree programs hold a doctoral degree. In associate degree programs, doctorally prepared faculty account for only 6.6 percent of the total faculty and the number is slightly more than 5 percent in diploma programs. Only 350 to 400 nursing students receive doctoral degrees each year and the pool of doctorally prepared candidates for full-time nursing professorships is very limited.

Educators without doctoral degrees may lack credibility within a university setting and have limited opportunities to assume leadership positions. Institutions with low numbers of doctorally prepared educators may be less likely to get funds to support research or educational innovations.

As important as educational incentives are for future practicing nurses, the scholarships for doctoral students who will instruct the next generation of nurses are even more critical. Please do not allow us to lose ground in the fight against the nursing shortage. Fund Title VIII—Nursing Workforce Development Programs at a level commensurate with the severity of the health care crisis facing the nation today.

Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care. If you have any questions about NLN's position or we can be of further assistance to you, please feel free to contact Kathleen Ream, NLN Manager of Government Affairs, at 703-241-3974.

---

#### PREPARED STATEMENT OF THE NATIONAL MENTAL HEALTH ASSOCIATION

Thank you for this opportunity to submit testimony to the Subcommittee and to address the important issue of mental health. The National Mental Health Association (NMHA), the country's oldest and largest advocacy organization addressing all aspects of mental health and mental illness, represents over 340 affiliates throughout the country. NMHA is uniquely positioned to speak to the entire mental health and substance abuse portfolio including prevention, early intervention, treatment, and research.

NMHA would like to thank Chairman Regula and Reps. Obey and Kennedy for your leadership and for your strong support in winning increases last year for mental health programs. However, we are deeply troubled by the Administration's current proposal to cut mental health services at the Center for Mental Health Services (CMHS) by a dangerous 7 percent (from \$901 to \$837 million) and to increase funding for the National Institutes of Health (NIH) by less than 1 percent. We hope to highlight the tremendous need for mental health services in communities throughout the country and why it is imperative that we make an investment not cuts in mental health.

#### CALL TO MAKE MENTAL HEALTH A NATIONAL PRIORITY

NMHA strongly urges you to make mental health a national priority. In creating the Commission on Mental Health, President Bush emphatically declared that "Our country must make a commitment: Americans with mental illness deserve our understanding, and they deserve excellent care. I look forward to . . . fixing the [mental health] system, so that Americans do not fall through the cracks."

These are not cracks; these are, at this time, unbridgeable chasms. As we know and as corroborated in a December 2004 New York Times editorial, the robust community-based mental health system that national leaders envisioned would replace the country's reliance on warehoused institutional care never materialized. As a result, an astounding 80 percent of children entering the juvenile justice system have mental disorders, and prisons and jails have become de facto mental hospitals, but without the treatment that would allow individuals with a mental illness to control their symptoms and organize their lives.

The President's New Freedom Commission on Mental Health, the first such commission in over 25 years, recommended a fundamental transformation of the Nation's approach to mental health care. This transformation must ensure that mental

health services and supports actively facilitate recovery, and build resilience to face life's challenges—with consumers active participants in designing and developing their plans of care. The Commission also found that our nation's failure to make mental health a priority is a national tragedy. A measure of the scope of that tragedy is the disproportionately high number of individuals with mental illness in the corrections system as well as over 30,000 lives lost annually to suicide—a loss, the Commission states, that is largely preventable.

#### UNTENABLE FISCAL YEAR 2006 MENTAL HEALTH BUDGET CUTS

Although mental illness (the chronic disease of the young) ranks first in the United States in terms of causing disability, the proposed fiscal year 2006 budget for the Center for Mental Health Services at SAMHSA would shrink funding for the federal government's lead mental health agency to virtually the level of support provided the agency for fiscal year 2002. Cutting a mental health budget to fiscal year 2002 levels at a time that more than 67 percent of adults and nearly 80 percent of children who need mental health services do not receive treatment is hardly a formula for making mental health a national priority.

NMHA strongly urges the Subcommittee to reverse the proposed 7 percent cut or loss of nearly \$70 million to mental health services at the Center for Mental Health Services (CMHS).

In particular, we urge you to reverse the following proposals in the Administration's budget for the Substance Abuse and Mental Health Services Administration:

- The proposed cut in funding for a successful youth-violence prevention program by nearly a third, from \$94 to \$67 million;
- The proposed cut in funding for jail diversion program by nearly 50 percent, from \$7 to \$4 million;
- The proposed cut in funding of an additional \$40 million in CMHS' important Programs of Regional and National Significance account—in essence slashing funding from an account aimed at much needed priority programming; and
- The proposed cut in funding for substance abuse prevention by 7 percent, from \$198 to \$184 million.

In addition, we urge you to build on the Administration's proposal to:

- Level fund critical youth suicide-prevention efforts, the children's systems-of-care, the homelessness (PATH), PAIMI and elderly programs, the mental health and substance abuse block grants, as well as the Consumer TA Centers; and
- Provide an increase of only 0.4 percent, on average, for research activities at the National Institutes of Mental Health, Drug Abuse, and Alcohol Abuse and Alcoholism.

Lastly, we support the Administration's \$6 million increase request for the State Infrastructure Grants, which will likely fund 11 grants with the proposed new total of \$26 million, to assist States with planning and implementing the Commission's call for transformation of state mental health services across multiple service systems.

#### YOUTH VIOLENCE PREVENTION: A WHOLLY UNWARRANTED BUDGET CUT

Recent tragic events illustrate what we believe are critical failures in priority-setting in the SAMHSA budget. This month's horrible shootings at Minnesota's Red Lake High School, the most violent school slaying since Columbine, is a reminder that youth violence is still prevalent and underscores the need for every school house to be prepared to deal with traumatic, tragic events. Surely this incident is emblematic of the shortsightedness of the Administration's proposed devastating cut of nearly 33 percent or \$27 million to youth violence prevention—the Safe Schools/Healthy Students (SS/HS) program—at CMHS.

As CMHS' major school violence prevention program, the SS/HS initiative addresses school violence prevention through a wide range of early childhood development, early intervention and prevention, suicide prevention, and mental health treatment services. The primary objective of this grant program is to promote healthy development, foster resilience in the face of adversity, and prevent violence. The President's Commission report highlighted the need for the mental health system to coordinate better with other federal agencies. This landmark program, administered jointly with the Department of Education (Safe and Drug Free Schools Office) and the Department of Justice (Office of Juvenile Justice and Delinquency Prevention), does just that.

The Red Lake School shooting and other such shootings underscore the tremendous mental health needs of young people that too often go unmet. One in ten children suffers from a mental disorder severe enough to cause some level of impairment. Even more children experience psychiatric trauma, or emotional harm, which

is essentially a normal response to an extreme event that may or may not happen with some regularity.

This Subcommittee should make investments not only in the area of youth violence prevention, but also invest in Jail Diversion programs designed to keep young people at home and in their communities as they get care. This is not the time to cut funding for programs that help to protect our nation's youth.

#### LACK OF COMMUNITY MENTAL HEALTH SERVICES

While we call on the Subcommittee to reverse the alarming cuts proposed in the SAMHSA budget, we urge that the Subcommittee also provide needed increases in funding. To illustrate the magnitude of needs that plead for attention, we urge that you take steps to address the shocking findings highlighted by Sen. Susan Collins (R-ME) whose hearing last year spotlighted the devastating reality that, every day, about 2,000 children and adolescents are warehoused in juvenile detention centers around the country simply because community mental health services are unavailable. An estimated \$100 million of taxpayers' money is spent on the detention of these youth awaiting community mental health services. Shouldn't that \$100 million and other precious resources be invested in the community rather than in the corrections system to provide cost-effective, quality mental health services? Consider the outrage that would be heard if 2,000 young people with ANY other illness not only went without treatment, but were involuntarily institutionalized as well.

NMHA agrees with Senator Collins that "another consequence of our tattered 'safety net' for children with mental illness [is] the inappropriate use of juvenile detention centers as 'holding areas' for young people who are waiting for mental health services. Like custody relinquishment [of children with mental disorders], these inappropriate detentions are a regrettable symptom of a much larger problem, the lack of available, affordable, and appropriate mental health services and support systems."

With this tragic situation in mind, we urge you to consider, for example, a greater investment in the Children's Mental Health Services program that would allow CMHS to expand beyond the 92 grants in 46 States that have provided services to approximately 54,343 children from 1993–2004. This program, which scored highly in the OMB PART review/evaluation, has only served children in 274 or 9 percent of the 3,142 counties in the United States.

#### NEEDS ARE INCREASING, AND APPROACHING A MENTAL HEALTH STATE OF EMERGENCY

The need for mental health services is ever-escalating for both young people and adults, and gaining ever-wider recognition. To illustrate, a February 2005 study found that U.S. hospital emergency departments greatly under-diagnose psychiatric disorders. Investigators from Louisiana State University examined records of more than 33,000 patients and discovered an overall psychiatric disorder rate among patients of 5.27 percent—far below the national rate of 20 percent to 28 percent. The researchers believe this points to large numbers of missed diagnoses. Last July a county in Nevada declared a "State of Emergency" after many individuals with mental illness overcrowded the state's hospitals. In Nebraska, the state last February reported its mental health system to be in crisis. And with the fifth-highest suicide rate in the nation, West Virginia's Gazette-Mail concluded earlier this year that the state is in the midst of a "mental health crisis."

Broad societal mental health needs too often go unrecognized. As the nation grapples with an obesity epidemic, for example, there has been insufficient recognition of the link to mental health. Yet mental health issues are often closely intertwined with other chronic illness. In the case of obesity, for example, we can expect individuals who suffer from obesity to be at risk for heart disease. Two decades of NIMH research have shown that people with heart disease are more likely to suffer from depression than otherwise healthy people, and conversely, that people with depression are at greater risk for developing heart disease. With sharp cutbacks in the already modest (PRNS) funding available to the Center for Mental Health Services to address priority needs, any opportunity that might exist to address such comorbidities appears futile. Yet such a focus could pave the way for the one in three people who have survived a heart attack and experience major depression in a given year to improve their overall health and lessen the fiscal burden on the nation's health care system.

#### RETURNING SOLDIERS

It has been reported that through the end of September 2004, nearly 900 troops had been evacuated from Iraq by the Army for psychiatric reasons, included attempts or threatened attempts at suicide. And a study of members of combat infan-

try units deployed to Iraq in 2003 published in the *New England Journal of Medicine* (July 1, 2004), researchers found evidence of major depression, anxiety, or PTSD after combat duty in approximately one of every six of these troops. Dr. Stephen C. Joseph, an assistant secretary of defense for health affairs from 1994 to 1997, declared that “the mental health consequences are going to be the medical story of [the Iraqi] war.” We should not assume, however, that those bearing the psychic scars of this war will necessarily seek treatment from the Defense Department or the Department of Veterans Affairs. The study in *New England Journal* was particularly troubling in that regard in finding that most veterans who appeared to have combat-related mental health problems avoided seeking the treatment available in the military, due principally to stigma. That finding suggests that for many veterans war-related mental health problems may go unaddressed for a period of time. In many instances, an already overburdened public mental health system may be called on to meet their needs.

At a minimum, this problem calls for a robust, multi-pronged campaign to renew and more fiercely combat the enormous stigma in key sectors of American society, such as among service-members. Where stigma and misperceptions regarding mental health problems fuel resistance to early intervention, one can foresee that these problems will simply persist and worsen. Yet with a sharply diminished budget, it is highly unlikely that SAMHSA could even consider a new anti-stigma effort.

#### SUICIDE

Yet another very troubling dimension of the SAMHSA budget is its “status quo” approach to public health crisis. Both the Institute of Medicine and the President’s New Freedom Commission on Mental Health have highlighted that mental illness plays a major role in the over 650,000 attempted suicides in America every year—30,000 suicides are completed. Almost twice as many individuals die from suicide than homicide yet hundreds of millions are spent on law enforcement and corrections facilities to prevent and protect Americans from homicides while suicide prevention funding under the proposed CMHS budget would be held to a mere \$16.5 million. We urge the Subcommittee to heed this disparity and bring funding for suicide prevention efforts more closely in line with the scope of this public health crisis.

The tragedy that befell Sen. Gordon Smith and his family when his son took his life did shine a spotlight on this unspeakable crisis. Last year, Congress enacted the Garrett Lee Smith Memorial Act to: (a) support the planning, implementation, and evaluation of organized activities involving statewide youth suicide intervention and prevention strategies; (b) authorize grants to institutions of higher education to reduce student mental and behavioral health problems; and (c) authorize funding for the national suicide prevention resource center. The program will provide early intervention and assessment services, including screening programs, to youth who are at risk for mental or emotional disorders that may lead to a suicide attempt, and that are integrated with school systems, educational institutions, juvenile justice systems, substance abuse programs, mental health programs, foster care systems, and other child and youth support organizations.

Suicide is a problem of enormous scope and demands a response commensurate with its enormity. The truly tragic aspect to suicide is how largely preventable this crisis is. It is not just young people at risk of suicide deaths, older Americans are also at great risk. We urge the Subcommittee to increase both youth-suicide prevention funding and support for the Elderly program at CMHS to deal with suicide and other issues endemic to an aging population.

#### CLOSING

Shrinking CMHS program funding to fiscal year 2002 dollar levels is a very troubling response to a landmark Presidential commission’s call to make mental health a national priority. But a budget decline of this magnitude would have concrete implications in communities across this country. It would, for example, mean closing the door to states and communities that badly need help to improve mental health service-delivery. It would mean no help to anguished school systems that are struggling to achieve the twin goals of school-safety and healthy-students in the face of the threat of more Columbines and Red Lakes. It would mean despair for young people languishing in juvenile detention facilities across the country while they wait for community mental health treatment and families forced to relinquish custody of their children to secure desperately needed mental health services.

Without a seismic shift in the level of priority the Federal government gives to mental health, and a corresponding investment in research, supports and services, we can expect to see a disproportionate numbers of individuals with mental illness who attempt and complete suicide or languish in corrections facilities.

By making mental health a more robust funding priority, this Subcommittee could dramatically change the lives of millions of Americans, improving not only their well-being but our nation's productivity. And by investing in early intervention services and in an array of other mental health services and supports, precious resources at the state and federal level would be saved by stemming the flow of resources being spent in corrections or other systems that deliver mental health services that are not as cost-effective and at a lower quality than providing those services in the community.

---

#### PREPARED STATEMENT OF THE NATIONAL NURSING CENTERS CONSORTIUM

The NNCC (National Nursing Centers Consortium) appreciates the opportunity to submit written comments for the record regarding funding for nursing workforce and research programs in fiscal year 2006. This testimony does not include a monetary request. Instead, the NNCC requests that this subcommittee support the creation of a new grant program under the jurisdiction of the Health Resources and Services Administration's (HRSA's) Bureau of Health Professions (BHP) that would enable the Centers for Medicare and Medicaid Services (CMS) to issue nurse-managed health centers (NMHCs) prospective payment reimbursement for their Medicare and Medicaid patients.

#### NNCC BACKGROUND

The NNCC is the first nation wide association of nurse-managed health centers (NMHCs) in the United States. The organization currently represents over 100 NMHCs and individual members in 35 states. These centers are typically community-based non-profit organizations or are affiliated with university-based schools of nursing. The fact that many NNCC member centers are affiliated with schools of nursing allows them to act as teaching centers for new nurses entering the workforce. Along with fulfilling this important role with regard to nursing education, these centers also provide a host of primary care, health promotion and disease prevention services to medically underserved patients living in both urban and rural communities. NNCC member centers are run by nurse practitioners in partnership with the communities they serve. Many NMHCs have established community advisory boards that give the community a role in determining the future of the center and the services provided. Along with nurse-practitioners, these services may also be provided clinical nurse specialists, registered nurses, health educators, community outreach workers, health care students and collaborating physicians.

The vision of the NNCC is to improve the health of communities through neighborhood-based health care services that are accessible, acceptable, and affordable. The mission is to strengthen the capacity, growth, and development of nurse-managed health centers to provide quality health care services to vulnerable populations and to eliminate health disparities in underserved communities.

#### THE FINANCIAL CRISIS FACED BY NURSE-MANAGED HEALTH CENTERS

Many NMHCs were initially established with the help of Nurse Practice and Retention grants from the BHP. However, of the 70 grantees that received Division of Nursing (DON), grants to establish nurse-managed health centers between 1993-2001, 27 or 39 percent have been forced to close. There are two main reasons why such a high percentage of DON funded NMHCs are no longer in operation. The first reason is that DON has shifted its funding priorities to nurses working in acute care settings, and is no longer funding NMHCs. The second reason is that even though a recent study conducted by the NNCC and sponsored CMS found that NMHCs are safety-net providers, they do not have access to the prospective payment system (PPS), which is offered to other safety-net providers such as Community Health Centers (CHCs) and Federally Qualified Health Centers (FQHCs).

Under PPS, CHCs/FQHCs are able to offset the cost of caring for the uninsured because they receive a higher level of reimbursement for their Medicare and Medicaid patients. Even though NMHCs also see a high percentage of uninsured patients they cannot offset these costs through PPS. Without PPS, NMHCs are forced to depend on low capitation payments from managed care organizations (MCOs) and unreliable private grants. These payments and grants are not sufficient to cover the costs of operating NMHCs.

For example, the average cost of caring for a Medicaid recipient at a NMHC is about \$540 per year. However, Medicaid MCOs pay an average annual capitation payment of about \$144 for each Medicaid patient. This means that capitation payments only cover about 26 percent of the costs associated with caring for Medicaid

patients. NMHCs are forced to seek outside funding to recover the other 74 percent of these costs. Assuming the NMHC is able to cover these costs, the center must then take into account the costs associated with caring for their uninsured clients that are and not eligible for capitation payments. About 46 percent of the clients receiving care at NNCC member centers around the nation are uninsured.

In contrast, CHCs and FQHCs with access to PPS are able to recover about 89 percent of the costs associated with their Medicaid clients. This increased revenue allows these centers to direct a higher percentage of their resources to covering the cost of caring for their uninsured patients. In addition, CHCs receive an average payment of \$250 for each uninsured patient. PPS helps to ensure that CHCs/FQHCs remain financially viable. If NMHCs do not also gain access to PPS reimbursement many more of these centers will be forced to close leaving thousands of medically underserved and uninsured clients without access to critical primary care services. Congress itself has recognized the tremendous financial challenges faced by NMHCs, and has published language, "encouraging HRSA to provide alternative means to secure cost-based (or PPS) reimbursement for NMHCs" (Senate Report 108-345 (2005) p.37).

Earlier this year the Senate Appropriations Committee praised NMHCs for the important work they are doing to reinforce America's health care safety-net. The committee stated, "Nurse-Managed Health Centers (NMHCs) serve a dual function in strengthening the health care safety-net by providing health care to populations in underserved areas and by providing the clinical experiences to nursing students that are mandatory for professional development." (Senate Report 108-345 (2005) p.37). If Congress truly values NMHCs this subcommittee should move to ensure that they have access to PPS reimbursement.

NNCC requests that this subcommittee support the creation of a new grant program under which HRSA's BPHr would be allowed to distribute grants through which CMS could issue NMHCs PPS reimbursement. The most likely place for BPHr to find the authority to issue such grants would be under Title VIII of the Public Health Service Act (PHSA). Placing the new grant program under Title VIII of the PHSA would allow NMHCs to retain their emphasis on education and nursing workforce development. The NNCC also requests that any NMHCs, which previously received start up funding through DON, be automatically granted access to the newly created PPS. As mentioned above, there are still about 48 NMHCs in operation around the country which were established with the help of DON grants. However, shifting funding priorities at DON have left these centers in need of a stable source of funding. Granting them automatic access to PPS would make them financially viable and allow them to provide a full range of primary care, health promotion and disease prevention services to their patients. These centers record close to 600,000 client encounters each year. Lastly, CHCs receive approximately \$250 every year for each of their uninsured patients. BPHr should be given the discretion to provide similar grant funding to NMHCs that provide care to a high percentage of uninsured clients.

#### CONCLUSION

We thank you for this opportunity to discuss the financial crisis faced by NMHCs and the significance of maintaining their financial sustainability. The NNCC is ready to assist policy makers in granting NMHCs PPS reimbursement, and has already drafted a model bill that would accomplish this goal. If the above steps are taken the NNCC believes the future of these important safety-net providers will be secure for years to come.

---

#### PREPARED STATEMENT OF THE NATIONAL ORGANIZATIONS RESPONDING TO AIDS (NORA) COALITION

##### RECOGNIZING THE CHALLENGES AND LOOKING TO THE FUTURE

The year 2005 brought with it a new Congress and a new Administration, yet for people living with, and at risk for, HIV and the organizations and agencies that serve them, things have remained much the same. For the fourth year in a row federal funding for the domestic HIV/AIDS portfolio remains level, and for the past two years funding has been reduced through funding rescissions. For the fifth consecutive year, the Centers for Disease Control and Prevention (CDC) maintains that there are 850,000-950,000 people living with HIV in the United States, despite a



minimum of 40,000 new infections each year.<sup>1</sup> And once again we find ourselves challenged to make a noticeable difference in the course of the HIV epidemic.

Since 2000, the CDC has estimated that there were 850,000–950,000 people living with HIV in the United States. Since that time, the CDC has reported that there are approximately 40,000 new HIV infections, and 15,000 deaths from AIDS related causes, in the United States each year.<sup>2</sup> (This is a minimum number; recent data suggests that we may be actually seeing 43,000–44,000 additional new infections each year.) Thus, by simply doing the math it would seem that today, in 2005, there are roughly 125,000 more people living with HIV in this country than there were just five years ago—for a total of 975,000–1,075,000 HIV positive Americans. In other words, 1 million people.<sup>3</sup>

Twenty-four years after the start of the HIV epidemic one million people are living in the United States with HIV—and that number continues to grow each and every day. Despite all the progress that has been made, from the development of new treatments and therapies to increased availability of testing and counseling services, the epidemic here at home is still far from over.

The U.S. domestic response has historically been a patchwork of services, ranging from the work of community-based organizations to that of agencies of the federal government, each of which continues to play a critical role in addressing the epidemic. Since the beginning the thread that has bound all of these pieces together has been the financial support of Congress and the White House. Unfortunately, recent fiscal constraints have caused that thread to fray—to the point where some of the pieces are threatening to come undone. It is increasingly clear that unless we reengage ourselves in the real work of responding to this epidemic we will no longer be able to maintain the public health systems that have until now have been the true successes in addressing HIV in the United States.

Of special note, of the 1 million people who are currently living with HIV in the United States, CDC and the Health Resources and Services Administration (HRSA) estimate that roughly one half are accessing regular medical care.<sup>4</sup> On one level that is a very important accomplishment. 500,000 people are receiving the live-saving treatment and medical support that they need because our government made an investment and a commitment to help through the establishment of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and through the commitment of additional resources to existing programs. However, the fact remains that the other half—another 500,000—are not in care, either because they are unaware of their HIV status or because of financial and/or other barriers that are keeping them from getting the care and treatment that they need. This grim statistic has remained unchanged for the past five years. The challenge before us now is to find a way to tip the balance.

If we are going to provide care and support services for those 500,000 Americans currently not in care we must first face up to the reality of the challenge that lies before us. Most of the programs within the domestic federal HIV portfolio have been level-funded and/or cut for the past four fiscal years. Many are now facing their lowest funding levels in recent memory—despite the fact that they are seeing an increasing demand for services. We are now finding ourselves straining to meet the needs of the 500,000 we already serve, all the while aware of the need to reach an additional 500,000 whose needs we have not even begun to assess or address. Despite all of our best efforts we are still not reaching the people who need us most. Without access to testing and counseling, and subsequently care and treatment, these people remain unaware of the realities of their HIV infection, and thus unable to maintain their own health and prevent further transmission of the virus. This is simply unacceptable.

Both CDC and HRSA have recently identified the half a million HIV positive people not in care as a top priority for their HIV programs. Beginning with the 2000 reauthorization of the Ryan White CARE Act, HRSA has focused attention on what it has termed “unmet need,” individuals who are HIV positive and aware of their status, but not in care. CARE Act grantees have received instructions from HRSA to prioritize this population in the delivery of services in an attempt to successfully connect these individuals to care. However, no additional resources have been allocated to grantees for this task, and many report that they are already overburdened

<sup>1</sup>Centers for Disease control and Prevention, “Basic Statistics,” 2003. <<<http://www.cdc.gov/hiv/stats.htm#hivest>>>

<sup>2</sup>Fleming, P., et al., “HIV Prevalence in the U.S. 2000,” 9th Conference on Retroviruses and Opportunistic Infections, February 2002.

<sup>3</sup>Ovadiya, Iris, and Tytel, Jessica, AIDS Action.

<sup>4</sup>Fleming, P., et al., “HIV Prevalence in the U.S. 2000,” 9th Conference on Retroviruses and Opportunistic Infections, February 2002.

by their current client load. For example, in the Washington, D.C. metro area newly diagnosed HIV positive clients are being placed on 3 month long waiting lists for doctor's appointments.

In 2003, CDC launched Advancing HIV Prevention (AHP), a new initiative "aimed at reducing barriers to early diagnosis of HIV infection and, if positive, increasing access to quality medical care, treatment, and ongoing prevention services."<sup>5</sup> One of the primary goals of this national initiative is to increase access to HIV counseling, testing, and referral to care. Since the first funds were awarded in 2003, AHP has shown success in linking people to testing through the use of new rapid test technologies; however, it remains to be seen whether or not the CDC can successfully link these people to care—and whether or not HRSA's already overburdened care system can maintain them in services.

Last year NORA chose to focus on building upon our past successes. This year we must look to what we still have left to do. The AHP and unmet need initiatives are working, but we can not expect them to be the definitive solution. The HIV epidemic in this country continues to evolve, and we continue to face unanticipated policy and program challenges. In the past year alone we have seen the initial phases of implementation of the Medicare Modernization Act, the expansion of rapid testing technologies, and emerging concerns about the Food and Drug Administrations (FDA) drug approval process. At the same time the Department of Health and Human Services has committed itself to the goal of reducing by half annual HIV infections in this country by 2010, after realizing that the 2005 goal was out of reach. The federal government must commit to fund, manage, and monitor the domestic response, or else we will find ourselves falling even farther behind in our response to the epidemic.

The challenge before us today is significant, but it is not insurmountable. If we commit to funding that truly meets the needs of people living with, and at risk for, HIV infection then we can change the course of the epidemic.

We know how to provide care.

We know what it takes to link people to medical treatment.

We know how to support its communities living with HIV.

Now is the time to turn knowledge into action.

The chart that follows is NORA's funding recommendations for fiscal year 2006.

---

<sup>5</sup>Centers for Disease Control and Prevention, "Advancing HIV Prevention: New Strategies for a Changing Epidemic," September 2003. <<<http://www.cdc.gov/hiv/partners/AHP-brochure.htm>>>

NORA FISCAL YEAR 2006 APPROPRIATIONS REQUESTS FOR FEDERAL HIV/AIDS PROGRAMS

Program	Fiscal year 2006 need	Fiscal year 2005 appropriation	President's fiscal year 2006 request	Change from fiscal year 2005	Fiscal year 2006 NORA recommendations	Change from fiscal year 2005
<b>DEPARTMENT OF HEALTH AND HUMAN SERVICES</b>						
Minority HIV/AIDS Initiative (To be added across multiple HHS programs and included in fiscal year 2002 program totals as indicated).	\$855 million	\$399 million <sup>1</sup>	\$399 million	.....	\$610 million	+ \$411 million
ACF: Runaway and Homeless Youth Act Programs	.....	104 million	114 million	+ \$10 million	140 million	+ 36 million
Agency for Healthcare Research and Quality	.....	319 million	319 million	.....	440 million	+ 121 million
CDC: Total—HIV, STD, TB line	2.33 billion	961.2 million	957.3 million	- 4 million	2.33 billion	+ 1.27 billion
CDC: HIV Prevention and Surveillance	.....	662.6 million	686.6 million	- 4 million	1.5 billion	+ 813.4 million
CDC: STD Prevention	.....	159.7 million	159.7 million	.....	351 million	+ 191.3 million
CDC: TB Prevention	.....	138.9 million	138.9 million	.....	287.3 million	+ 148.4 million
CDC: Viral Hepatitis (Infectious Disease Control line)	.....	17.36 million	17.36 million	.....	100.24 million	+ 82.88 million
CDC: DASH (Chronic Disease Prevention and Health Promotion line)	.....	56.75 million	56.76 million	+ 0.1 million	88.25 million	+ 31.49 million
FDA	.....	1.45 billion	1.5 billion	+ 50 million	1.57 billion	+ 116 million
HRSA: Ryan White CARE Act Total	3.2 billion	2,048 billion	2,058 billion	+ 10 million	2.56 billion	+ 513 million
Title I	.....	610 million	610 million	.....	725 million	+ 115 million
Title II: Care	.....	334 million	334 million	.....	384 million	+ 50 million
Title II: ADAP	.....	787 million	797 million	+ 10 million	1,09 billion	+ 303 million
Title III	1.5 billion (non-add)	196 million	196 million	.....	236.6 million	+ 41 million
Title IV	.....	72.53 million	72.53 million	.....	113.25 million	+ 40.72 million
Part F: AETCS	.....	35 million	35 million	.....	45 million	+ 10 million
Part F: Dental Reimbursement	.....	13.3 million	13.3 million	.....	19 million	+ 5.7 million
HRSA: Consolidated Health Centers	.....	1,733 billion	2,038 billion	+ 304.2 million	2,038 billion	+ 304.2 million
HRSA: Title V	.....	724 million	724 million	.....	755 million	+ 31 million
HRSA: Title X	.....	286 million	286 million	.....	350 million	+ 66 million
Indian Health Service: HIV/AIDS Program	.....	2.68 million	2.79 million	+ 0.1 million	10 million	+ 7.32 million
NIH Office of AIDS Research	3.327 billion	2.92 billion	2.93 billion	+ 12 million	3.1 billion	+ 200 million
Office of the Secretary: Office of HIV/AIDS Policy	5 million	.....	.....	.....	2 million	+ 2 million
SAMHSA: Center for Substance Abuse Treatment Block Grant <sup>2</sup>	.....	1.78 billion	1.78 billion	.....	1.85 billion	+ 71 million
SAMHSA: Center for Substance Abuse Treatment—other	.....	422.4 million	447.1 million	+ 24.7 million	472 million	+ 50 million
SAMHSA: Center for Substance Abuse Prevention <sup>3</sup>	.....	198.7 million	184.3 million	- 14.4 million	210 million	+ 11 million
SAMHSA: Mental Health Block Grant <sup>4</sup>	.....	432.8 million	432.8 million	.....	471.5 million	+ 38.9 million
SAMHSA: Center for Mental Health Services—other <sup>4</sup>	.....	176.7 million	144.1 million	- 32.6 million	191.8 million	+ 15.1 million
SAMHSA: GBHI	.....	40.1 million	34.4 million	- 5.7 million	42.5 million	+ 1.7 million
SAMHSA: PATH	.....	54.8 million	54.8 million	.....	59.8 million	+ 5 million

NORA FISCAL YEAR 2006 APPROPRIATIONS REQUESTS FOR FEDERAL HIV/AIDS PROGRAMS—Continued

Program	Fiscal year 2006 need	Fiscal year 2005 appropriation	President's fiscal year 2006 request	Change from fiscal year 2005	Fiscal year 2006 NORA recommendations	Change from fiscal year 2005
DEPARTMENT OF EDUCATION (DOE)						
Protection and Advocacy for Human Rights	.....	16.6 million	16.6 million	.....	22 million	+ 5.4 million
DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)						
HOPWA	2.8 billion	282 million	268 million	- 14 million	385 million	+ 103 million
McKinney-Vento Homelessness Assistance Grant Program	.....	1,241 billion	1.44 billion	+ 199 million	1,572 billion	+ 331 million
GLOBAL HIV/AIDS PROGRAMS						
<i>President's Emergency Plan for AIDS Relief (PEPFAR)</i>	6.7 billion	2.9 billion	3.16 billion	+ 265 million	4.61 billion	+ 1.7 billion
HIV/AIDS Programs	.....	.....	.....	.....	.....	.....
<i>Global Fund to Fight AIDS, Tuberculosis and Malaria (non-add)</i>	1.5 billion	435 million	300 million	- 135 million	1.5 billion	+ 1.06 billion
Global Fund	.....	.....	.....	.....	.....	.....

<sup>1</sup> NOTE.—All fiscal year 2004 amounts include the .80 percent rescission.  
<sup>2</sup> The numbers in this chart reflect the entire budget of SAMHSA for Substance Abuse Treatment; HIV/AIDS programs are included in this total.  
<sup>3</sup> The numbers in this chart reflect the entire budget of SAMHSA for Substance Abuse Prevention; HIV/AIDS programs are included in this total.  
<sup>4</sup> The numbers in this chart reflect the entire budget of SAMHSA for Mental Health Services; HIV/AIDS programs are included in this total.

## PREPARED STATEMENT OF THE NORTH AMERICAN BRAIN TUMOR COALITION

I am Gary L. Kornfeld, a nine-year survivor of a grade 3 oligoastrocytoma and Chair of the North American Brain Tumor Coalition (NABTC). On behalf of the Coalition, I am pleased to offer these comments regarding brain tumor research for the record of the Labor, Health and Human Services, and Education Appropriations Subcommittee. The NABTC, a network of 12 brain tumor organizations, is dedicated to improving treatments for brain tumors and ensuring individuals with brain tumors access to high quality care. The volunteers who comprise the NABTC are survivors, family members, friends, and caregivers, and we know firsthand the devastating effects that brain tumors can have. We are working hard to reduce the suffering from brain tumors and improve the outlook for all who receive this diagnosis.

Each year, approximately 190,000 people in the United States and 10,000 in Canada will be diagnosed with a primary or metastatic brain tumor. Approximately 40,000 individuals in the United States will be diagnosed with primary brain tumors; of this total, more than 18,000 will be diagnosed with malignant brain tumors. Brain tumors are a leading cause of death from childhood cancer, accounting for almost a quarter of cancer deaths in children up to 19 years of age. Brain tumors are the second leading cause of cancer death in young adults ages 20–39.

These numbers, as frightening as they are, do not convey the complete story. The treatment of brain tumors is very difficult, and factors that contribute to these treatment challenges are the location of these tumors and the fact that there are more than 120 different kinds of tumors. Standard therapies for brain tumors include surgery, radiation therapy, and chemotherapy, used either individually or in combination.

## RECENT ADVANCES IN TREATMENT

There have been recent advances in the treatment of glioblastoma multiforme (GBM), or grade IV malignant glioma, which usually causes death in a year. Researchers have found that concurrent administration of a chemotherapy drug, temozolomide, and radiation therapy results in a clinically meaningful survival benefit of two and one-half months for newly diagnosed glioblastoma patients.

These findings were published in the *New England Journal of Medicine* on March 10, 2005.<sup>1</sup> Temozolomide with radiation can be a very significant development for patients with GBM, and the brain tumor community applauds this development. However, much more must be done to extend and improve the lives of those affected by brain tumors. Progress against brain tumors still comes much too slowly.

The NABTC believes treatment strides will come through an enhanced investment in brain tumor research and improved dissemination of information about the best available care for brain tumors. Researchers in the Glioma Outcomes Project recently reported troubling gaps in care of individuals with brain tumors, suggesting that more work needs to be done to guarantee that the best possible therapies are available to all with brain tumors.<sup>2</sup>

## ENHANCE THE INVESTMENT IN BRAIN TUMOR RESEARCH

In 2000, the National Cancer Institute (NCI) and National Institute of Neurological Disorders and Stroke (NINDS) published the report of a brain tumor research advisory panel, called the Brain Tumor Progress Review Group. This report included an aggressive and thoughtful plan for moving brain tumor research and treatments forward. In 2000, the NABTC endorsed the Progress Review Group plan and urged implementation of its key research recommendations. In 2005—half a decade after the report's publication—the NABTC finds that the report still describes a valid and vital plan for brain tumor research. While the continuing relevance of the report is in part a testament to the vision of the Progress Review Group, it is primarily a testament to the troubling lack of progress in brain tumor research and treatment and the failure to implement the report's recommendations.

To advance brain tumor research, the NABTC recommends that:

—NCI and NINDS implement the recommendations of the Brain Tumor Progress Review Group. To ensure that we do not look back from 2010 and observe limited progress on the Progress Review Group plan, the NABTC requests that NCI and NINDS submit to Congress a brain tumor research plan, including timelines and a budget for implementation of the PRG report.

<sup>1</sup>Stupp, et al., "Radiotherapy Plus Concomitant and Adjuvant Temozolomide for Glioblastoma," *New England Journal of Medicine*, March 10, 2005.

<sup>2</sup>Chang, et al., "Patterns of Care for Adults With Newly Diagnosed Malignant Glioma," *Journal of the American Medical Association*, February 2, 2005.

- The Directors of NCI and NINDS appoint leaders of their extramural brain tumor programs without delay. Strong scientific management is necessary to ensure that the nation's financial investment in brain tumor research is utilized as effectively as possible. Extramural research coordinators should be appointed at each institute to ensure that there is proper leadership on brain tumor research issues.
  - Congress provide adequate funding for existing brain tumor research efforts. There are several structures or systems for clinical research on brain tumors, including the brain tumor consortia and the brain tumor specialized programs of research significance (SPOREs), but these programs are not adequately funded to allow investigation of all promising brain tumor treatments and to ensure correlative studies as part of trials.
  - NINDS and NCI convene a special workshop on brain tumor research. Brain tumor research is an area where cross-disciplinary research approaches are absolutely critical, and a workshop on a cutting-edge brain tumor research topic would likely stimulate innovative research efforts. A workshop is an activity that could be undertaken by NINDS in collaboration with NCI.
- For individuals with brain tumors and their families, friends, and caregivers, the NABTC urges a greater sense of urgency among the leaders of NCI and NINDS regarding brain tumor research.

#### ELIMINATE THE TWO-YEAR WAITING PERIOD FOR MEDICARE

Although we realize Medicare is not in the jurisdiction of this Subcommittee, we nevertheless would like to direct your attention to important legislation, introduced by Senator Jeff Bingman (D-NM) and Representative Gene Green (D-TX), that would eliminate the two-year waiting period for Medicare benefits for those who have established eligibility for Social Security Disability benefits. For many individuals with brain tumors, the current 24-month waiting period can result in delays in access to care that extends or improves life.

Thank you again for the opportunity to offer this brief statement on brain tumor research and care.

---

#### PREPARED STATEMENT OF THE ONCOLOGY NURSING SOCIETY

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding funding for cancer and nursing related programs in fiscal year 2006. ONS, the largest professional oncology group in the United States composed of more than 31,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

This year more than 1.37 million Americans will be diagnosed with cancer and more than 570,000 will lose their battle with this terrible disease. Despite these grim statistics, significant gains in the War Against Cancer have been made through our nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless unless we can deliver them to all Americans in need. Recent studies have reported 126,000 registered nurse vacancies in hospitals and 13,900 registered nurse vacancies in nursing homes. These statistics create a sizeable barrier to ensuring that all people benefit from breakthroughs in cancer research.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates on-going and significant federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. The Society stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the nation's nursing workforce.

#### SECURING AND MAINTAINING AN ADEQUATE ONCOLOGY NURSING WORKFORCE

Over the last 10 years, the setting in which treatment for cancer is provided has changed dramatically. An estimated 80 percent of all Americans receive cancer care in community settings including cancer centers, physicians' offices, and hospital outpatient departments. Treatment regimens are as complex, if not more so, than regimens given in the inpatient setting a few years ago. Oncology nurses are on the

front lines in the provision of quality cancer care for individuals with cancer—administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing counseling to patients and family members, and engaging in myriad other activities on behalf of people with cancer and their families.

Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older. Currently, Medicare beneficiaries account for more than 50 percent of all cancer diagnoses and 64 percent of cancer deaths. Over the next 10 to 15 years the number of Medicare beneficiaries with cancer is estimated to double while more than 1.1 million registered nursing vacancies will need to be filled by 2012 to meet growing patient demand and replace retiring nurses. With an increasing number of people with cancer needing high quality health care, coupled with an inadequate nursing workforce, our nation could quickly face a cancer care crisis of serious proportion with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the *New England Journal of Medicine* found that nursing shortages in hospitals are associated with a higher risk of complications—such as urinary tract infections and pneumonia, longer hospital stays, and even patient death. Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need and patient health and well being could suffer.

Further, of additional concern is that our nation also will have a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of nurses in cancer research, the War against Cancer will take longer because of unfulfilled staffing needs coupled with the reality that in some practices and cancer centers resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, our nation will falter in its delivery—or application—of the benefits from our federal investment in research.

ONS has joined with others in the nursing community in advocating \$210 million as the fiscal year 2006 funding level necessary to support implementation of the Nurse Reinvestment Act and the range of nursing workforce programs housed at the U.S. Health Resources and Services Administration (HRSA). Enacted in 2002, the Nurse Reinvestment Act included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in fiscal year 2004 HRSA received 4,873 applications for the Nurse Education Loan Repayment Program, but only had funding to award 857—a rate of 17.6 percent. Also in fiscal year 2004, the agency received 8,806 applications for the Nursing Scholarship Program, but only could fund 126—a rate of 1.4 percent. Further exacerbating the current situation is that nursing programs turned away more than 125,000 qualified students last year, in part due to a shortage of faculty. If funded sufficiently, the components and programs of the Nurse Reinvestment Act would help address the multiple factors contributing to the nationwide nursing shortage, including the shortage of faculty, decline in nursing student enrollments, and poor public perception of nursing as a viable and worthwhile profession.

ONS strongly urges Congress to provide HRSA with a minimum of \$210 million in fiscal year 2006 to ensure that the agency has the resources necessary to fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications as well as implement other essential endeavors to sustain and boost our nation's nursing workforce. Nurses—along with patients, family members, hospitals, and others—have joined together in calling upon Congress to provide this essential level of funding. One Voice Against Cancer (OVAC)—a collaboration of more than 45 national nonprofit organizations representing millions of Americans—has added a request of \$210 million for the Nurse Reinvestment Act funding to its fiscal year 2006 appropriations advocacy agenda. ONS and its allies have serious concerns that without full funding, the “Nurse Reinvestment Act” will prove an empty promise; the current and expected nursing shortage will worsen and people will not have access to the quality cancer care they need and deserve.

BOOST OUR NATION'S INVESTMENT IN CANCER PREVENTION, EARLY DETECTION, AND AWARENESS

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential

for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our nation does not invest sufficiently in these strategies. While as a nation we spend almost a trillion dollars a year on our health care system, we only allocate about one percent of that amount for population-based prevention. By the year 2020, cancer and other chronic disease expenditures will reach one trillion dollars or 80 percent of health care costs. The nation must make significant and unprecedented federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our nation both for today and tomorrow.

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering at the community level what is learned from research—especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research. Therefore, ONS joins with our partners in the cancer community—including OVAC—in calling on Congress to provide additional resources for physical activity, nutrition, and tobacco control programs and other cancer-related screening, prevention, and public health education efforts supported through the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the appropriation of \$404 million in fiscal year 2006 for the Centers for Disease Control and Prevention's (CDC) comprehensive cancer, ovarian cancer, breast and cervical cancer early detection, cancer registries, prostate cancer, colorectal cancer, and skin cancer programs. ONS also urges an increase funding for the CDC's physical activity, nutrition, and tobacco-control programs to help reduce risk factors for developing cancer and other chronic diseases, diminish suffering from cancer, and decrease the demand on the healthcare system.

- \$250 million for the National Breast and Cervical Cancer Early Detection Program;
- \$65 million for the National Cancer Registries Program;
- \$25 million for the Colorectal Cancer Prevention and Control Initiative;
- \$25 million for the Comprehensive Cancer Control Initiative;
- \$20 million for the Prostate Cancer Control Initiative;
- \$5 million for the National Skin Cancer Prevention Education Program;
- \$9 million for the Ovarian Cancer Control Initiative;
- \$5 million for the Geraldine Ferraro Blood Cancer Program;
- \$145 million for the National Tobacco Control Program; and
- \$70 million for the Nutrition, Physical Activity, and Obesity Program.

#### SUSTAIN AND SEIZE CANCER RESEARCH OPPORTUNITIES

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joins with the entire cancer community in advocating \$30.1 billion for the NIH in fiscal year 2006. This will allow NIH to sustain and build on its research progress resulting from the recent NIH budget doubling effort while avoiding the severe disruption to that progress that would result from a minimal increase.

Cancer research is producing extraordinary breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for cancer patients. We have seen extraordinary advances in cancer research resulting from our national investment that have produced effective prevention, early detection and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate \$5.21 billion to the National Cancer Institute (NCI) in fiscal year 2006 to continue our battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses such as cancer. ONS joins with the nursing community in advocating an allocation of \$160 million for NINR in fiscal year 2006.



## CONCLUSION

ONS stands ready to work with policymakers to advance policies and support programs that will reduce and prevent suffering from cancer this year and sustain and strengthen our nation's nursing workforce. Moreover, ONS maintains a strong commitment to working with Members of Congress, other nursing societies, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face as the baby boom generation ages. We thank you for this opportunity to discuss the funding levels necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

## PREPARED STATEMENT OF THE PROCTER &amp; GAMBLE COMPANY

Procter & Gamble appreciates the opportunity to provide testimony in support of funding for the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM) and pain and distress research under the jurisdiction of the Labor, Health and Human Services, Education and Related Agencies Subcommittee in fiscal year 2006.

As a leader in the development of alternatives to animal testing, P&G is committed to eliminating animal testing for products intended for human use. We are working on a global basis with governments and academia to eliminate regulations that require unnecessary animal testing and to promote the acceptance of alternatives. To date, P&G has devoted significant resources to this effort and helped to develop more than 50 proven alternative methods. Despite these advances, it is acknowledged that state-of-the-art science cannot replace animal research at present and far more research is needed, by governments, academia and the private sector, for the development, promotion and validation of alternative test methods.

## INTERAGENCY COORDINATING COMMITTEE ON THE VALIDATION OF ALTERNATIVE METHODS (ICCVAM)

We were very pleased that Congress enacted Public Law 106-545 by unanimous voice vote in both chambers in 2000. This legislation, introduced by Senator Mike DeWine (R-OH) and Representatives Ken Calvert (R-CA) and Tom Lantos (D-CA), strengthened and made permanent the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM). The statute has already begun to enhance the federal government's capacity to evaluate and adopt chemical testing methods that are often faster, cheaper, and more scientifically sophisticated than current methods, as well as more responsive to the public's concerns about the welfare of animals used in toxicity testing. Public Law 106-545 has streamlined the process by which these better methods are validated and assessed, and has eased institutional barriers within federal agencies that discourage their use.

ICCVAM performs an invaluable "win-win" function for regulatory agencies and stakeholders in industry, public health, and animal protection by assessing the suitability of new toxicological test methods that have interagency application. These new (and newly revised) methods include alternative methods that can limit animal use or suffering in testing. After appropriate independent peer review of a new test method, ICCVAM provides its assessment of the new test to the federal agencies that regulate the particular endpoint that the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test method as appropriate for the agencies' regulatory mandates. This streamlined approach to assess the validation status of new test methods has reduced the regulatory burden of individual agencies, provided "one-stop shopping" for industry, animal protection, and public health advocates to consider test methods, and set uniform criteria for what constitutes a validated test method.

ICCVAM arose from an initial mandate in the NIH Revitalization Act of 1993 for the National Institute of Environmental Health Sciences (NIEHS) to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established an ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from 14 regulatory and research agencies developed NIH Publication No. 97-3981, Validation and Regulatory

Acceptance of Toxicological Test Methods. This report has become the “sound science” guide for consideration of new test methods by the federal agencies and interested stakeholders. After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS’ National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Methods (NICEATM). Representatives from federal regulatory and research agencies have continued to meet, with advice from NICEATM’s Scientific Advisory Committee and independent peer review committees, to assess the validation of new toxicological test methods.

Since its inception, ICCVAM has conducted rigorous evaluations of several test methods and has concluded that these methods are scientifically valid, i.e., have been adequately validated, and are acceptable for specific purposes. These methods include Corrositex, Epiderm, Episkin, and Transcutaneous Epithelial Resistance assays for assessing skin corrosivity; the 3T3 NRU Phototoxicity assay for assessing phototoxicity; the Local Lymph Node Assay for assessing skin sensitization; and the Up and Down Method and various cytotoxicity assays for assessing acute systemic toxicity. In turn, the appropriate regulatory agencies have incorporated these methods into their regulatory practices.

The open public comment process, input by interested stakeholders, and the continued commitment by various federal agencies have all enhanced the ICCVAM process. Now, under Public Law 106–545, ICCVAM is poised to go beyond its largely passive role of assessing the validation status of test methods that have been developed and validated by industry and others. ICCVAM should adopt a more proactive role in developing and validating promising tests methods in partnership with outside stakeholders, to ensure that a steady stream of new test methods are available for review and adoption by the federal government. Such a proactive stance and partnership with stakeholders will enable the federal government to better harness the potential of emerging technologies to meet the challenge of efficiently testing large numbers of chemicals with minimal cost in terms of money and animal lives. With a more proactive approach, ICCVAM could, for example, explore the potential of investigator-initiated and small business grant programs to further its mission.

Adequate funding should be provided for ICCVAM to put the resources in place to ensure the federal government and industry have the best available tools with which to assess the toxic properties of chemicals in commerce. To accomplish this, we respectfully request an earmark of \$3.6 million for fiscal year 2006 and the following Committee Report language:

“In order for the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) to carry out its responsibilities under the ICCVAM Authorization Act of 2000, the Committee strongly urges NIEHS to strengthen the resources provided to ICCVAM for methods validation reviews in fiscal year 2006. ICCVAM and NIEHS activities must include up-front validation study design, execution, and review to ensure that new and revised test methods, non-animal test methods, and alternative test methods (such as QSARs, mechanistic screens, high throughput assays, and toxicogenomics) are deemed scientifically valid before they are recommended or adopted for use by federal agencies or used in implementing the National Toxicology Program’s Road Map and Vision for NTP’s toxicology program in the 21st century.”

#### PAIN AND DISTRESS RESEARCH

An estimated 40 percent of the National Institutes of Health (NIH) budget—or currently more than \$11 billion—is devoted to some aspect of animal research. At this time, no funding is set aside specifically for research into alternatives that reduce the amount of pain and distress to which research animals are subjected, nor methods that replace or reduce the use of vertebrate animals in research. NIH may receive \$28.8 billion in fiscal year 2006 if Congress fulfills the President’s budget request. Out of this funding, we seek \$2.5 million (0.009 percent) for research and development focused on identifying and alleviating animal pain and distress. In addition to our request for a specific funding amount, we also urge the Committee to specify in report language that this research should be conducted in conjunction with, or “piggy-backed” onto, ongoing research that already causes pain and distress. Infliction of pain and distress on additional animals is unnecessary, given the volume of existing research (we estimate a minimum of 20–25 percent of all animal research) that is believed to involve moderate to significant pain and/or distress.

The large extent to which animals are used in federally-funded research underscores the importance of earmarking funds for pain and distress research. NIH has a statutory mandate to conduct or support research into alternative methods that produce less pain and distress in animals. This was specified in the NIH Revitalization Act of 1993 regarding a plan for the use of animals in research. Earmarked

funding will assist NIH in meeting this mandate. Additionally, researchers themselves often comment publicly at scientific meetings about the urgent need for funding in order to properly understand and mitigate pain and distress in research animals and to follow Animal Welfare Act and Public Health Service policy requirements to minimize pain and distress.

It is well known that uncontrolled, undetected, and unalleviated pain and distress has adverse effects on animal welfare, which leads to adverse effects on the quality of science. Ultimately, the lack of information on pain and distress leads to misinterpretation of research results that could result in harmful effects in human beings when pre-clinical animal research results are applied to humans in clinical trials.

A 2001 survey conducted by an independent polling firm indicates that concern about animal pain and distress strongly influences public opinion about animal research in general. Seventy-five percent of the American public opposes research that causes severe animal pain and/or distress, even when it is health-related. Despite this public concern, NIH has failed to sponsor research and development aimed at determining how to minimize animal suffering and distress in the laboratory.

During the past several years, our organization has been reviewing institutional policies and practices with respect to pain and distress in animal research. We have found that research institutions have inconsistent policies due to the lack of information on this subject, and that standards vary greatly from one institution to another. The federal standard for determining laboratory animal pain specifies that, if a procedure causes pain or distress to humans, it should be assumed to cause pain and distress to animals. Furthermore, while human experience can and should provide a useful guide in some cases, there are others in which humans are never subjected to the conditions facing laboratory animals. Information on pain and distress that animals themselves actually experience is important.

Our nation takes pride in leading the world in biomedical research, yet we lag behind many other countries in our efforts to minimize pain and distress in animal subjects. For example, the United Kingdom, Sweden, Switzerland, Germany, the Netherlands and the European Union all have committed funds specifically for the "three R's" (replacing the use of animals, reducing their use, and refining research techniques to minimize animal suffering).

We urge the Committee to make this small investment of \$2.5 million to promote animal welfare and enhance the integrity of scientific research. We also respectfully request this accompanying committee report language:

"The Committee provides \$2.5 million to support research and development focused on improving methods for recognizing, assessing, and alleviating pain and distress in research animals. No pain and distress should be inflicted solely for the purpose of this initiative, since the investigations can and should be conducted in conjunction with ongoing research that is believed to involve pain and distress under Government Principle IV of Public Health Service Policy, which assumes that procedures that cause pain and distress in humans may cause pain and distress in animals."

Again, we appreciate the opportunity to share our views regarding priorities for the Labor, Health and Human Services, Education and Related Agencies Appropriation Act of fiscal year 2006. We hope the Committee will be able to accommodate these modest requests that will benefit animals, enhance effectiveness of toxicological testing, and improve the quality of research. Thank you for your consideration.

---

#### PREPARED STATEMENT OF THE SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

On behalf of the Society for Animal Protective Legislation (SAPL) and Doris Day Animal League I would like to discuss several important issues within the jurisdiction of this committee. In addition, SAPL endorses the funding request by the Doris Day Animal League for fiscal year 2006 to operate the National Institute of Environmental Health Sciences' (NIEHS) National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) activities for fiscal year 2006.

#### CRIMINAL ANIMAL CRUELTY CHARGES FILED AGAINST NIH'S ALAMOGORDO PRIMATE FACILITY

For years, the NIH funded the New Mexico-based Coulston Foundation primate testing lab with millions of taxpayer-funded dollars despite the lab's continued violations of the Animal Welfare Act. Compliance with federal animal welfare laws is a

requirement for receipt of federal funds. The Coulston situation resulted in unprecedented regulatory action by the U.S. Department of Agriculture, international media interest, and intense Congressional scrutiny. The NIH's actions at Coulston prompted the House Committee on Energy and Commerce to launch a broad investigation of the mismanagement of billions of dollars in taxpayer-funded grants by NIH.

Under the intense pressure from Congress, the NIH eventually stopped funding the Coulston lab. The agency assumed ownership of the facility located on Holloman Air Force Base, renamed it the Alamogordo Primate Facility (APF), and in June 2001 awarded Charles River Laboratories with a 10-year, \$42 million contract to operate the lab, which houses approximately 265 government-owned chimpanzees. The NIH is legally responsible for the "day-to-day management" of the APF including its "associated animal activities." The APF is an intramural NIH lab and is listed under the agency's Animal Welfare Assurance.

One would think that after the years of Coulston abuses—and the accompanying NIH malfeasance that prompted a Congressional investigation—the agency would be that much more careful to ensure that the lab it now directly owns and manages would comply with the most basic precepts of animal welfare and simple human decency.

One would be wrong.

In September 2004, New Mexico District Attorney Scot Key filed multiple counts of criminal animal cruelty, accusing the NIH's handpicked contractor, Charles River Laboratories, and APF Director, veterinarian Rick Lee, of institutional negligence in the deaths of two chimpanzees and the near-death of a third. The D.A.'s independent criminal investigation found that it was "standard practice" for Charles River to leave critically ill chimpanzees in the "care" of security guards after trained animal care staff repeatedly walked off, clocking out at the end of the workday around 4:00 p.m.

Because the APF is a federal research facility, it is required to comply with the Animal Welfare Act, but the USDA has no jurisdiction to enforce it. In 2001, the New Mexico legislature, prompted by the continuing abuses at Coulston and the federal government's inability to stop them, amended the state's animal cruelty statute to remove the blanket exemption for research facilities.

In September 2003, the NIH was informed that the D.A. had initiated a criminal investigation against Charles River; that APF Director Lee had illegally threatened employees with lie detector tests in an attempt to find out who had leaked information about the treatment of the chimpanzees; and that the allegations were worse than anything ever documented at the Coulston lab. On October 1, 2003, an ad hoc NIH consultant, veterinarian Thomas Butler, conducted a one-day site visit along with the NIH official, Dr. Raymond O'Neill, in charge of overseeing the contract with Charles River. Butler's "site visit" report—compiled in less than one day by an ad hoc NIH consultant with no law enforcement authority—was neither thorough nor an investigation. Indeed, it completely failed to address the heart of the criminal charges: Charles River's abandonment of the three chimpanzees—including Rex, who was unconscious and vomiting—to security guards. In stark contrast to the NIH consultant's report, multiple eyewitnesses named in the D.A.'s months-long independent criminal investigation corroborated the criminal charges.

On March 23, 2005, New Mexico judge Jerry Ritter accepted Charles River's argument that it was engaged in the practice of veterinary medicine, and dismissed the charges; he issued no written opinion regarding the other legal technicalities. By making this argument, Charles River and the NIH have conceded that for them, the "practice of veterinary medicine" constitutes intentional and repeated abandonment of critically ill or injured chimpanzees to once-per-hour observation by untrained security guards.

Charles River never denied the facts alleged by the D.A. in the criminal charges, and the judge's decision did not deny the merits of the case. For now, Charles River and the NIH are accountable to absolutely no legitimate law enforcement authority. Neither the D.A., the USDA, nor the New Mexico Veterinary Board have any jurisdiction over the APF. The only "oversight" is provided by the NIH—the very definition of a conflict of interest—whose malfeasance at this very same facility when it was operated by the Coulston Foundation prompted a Congressional investigation of the entire agency.

After the years of abuse at Coulston, the situation at this government-owned facility descended into alleged criminal animal cruelty while the agency was paying Charles River millions of tax dollars annually, including \$175,000 in maximum bonus incentives. Charles River and the NIH have never denied the cold, cruel facts alleged by the D.A. in criminal charges resulting from a months-long independent criminal investigation conducted by a 24-year police veteran.

Charles River and the NIH cannot be allowed to evade their culpability by hiding behind legal technicalities, half-truths and the typical NIH whitewash. This small-town District Attorney was attempting to uphold the law and do the job that a \$28 billion federal agency has refused to do. We urge Congress to step into this gaping void of oversight and hold accountable the perpetrators of this unconscionable cruelty and their violation of the most basic standards of simple human decency. Congress should continue to actively investigate NIH's mismanagement of the APM and hold public hearings into the situation.

NIH FAILS TO ADDRESS THIS SUBCOMMITTEES CONCERN ON ILLEGALLY ACQUIRED DOGS AND CATS

Approximately 90,000 dogs and cats are used for experimentation in the United States each year. The vast majority of these animals are obtained from breeders who raise the animals under controlled conditions and have extensive information on their genetic background and health and vaccination status. In addition, some dogs and cats are being bred for experimentation at research facilities like the University of Texas, and in some cases, inexpensive random type animals are purchased directly from animal pounds.

Despite extensive documentation strongly discouraging the practice, some research facilities are foot-dragging by continuing to buy dogs and cats from random source dealers. These dealers, with a Class B license designation by the U.S. Department of Agriculture (USDA), are notorious for selling animals to laboratories that have been acquired illegally and for their widespread failure to comply with other minimum requirements under the Animal Welfare Act.

The saga of C.C. Baird is a prime example of the problem. Baird was a licensed dealer who sold random source dogs and cats for experimentation for about 15 years. More than a year and a half ago, 126 animals were seized by federal authorities because their health was in jeopardy. And shortly thereafter USDA finally filed charges against him for hundreds of violations of the Animal Welfare Act stating, "The violations alleged in this complaint are of the utmost seriousness, and include severe mistreatment and neglect of a multitude of animals in respondents' custody, falsification of health certificates for dogs and cats that respondents sold to research facilities, multitudinous record-keeping deficiencies and instances of noncompliance with the barest standards of care, husbandry and housing for dogs and cats." The charges against Baird included failure to provide adequate veterinary care and illegal acquisition of animals.

—Dog Dealer's Day of Reckoning: <http://www.awionline.org/pubs/Quarterly/03-52-4/524p1011.htm>

—A Glimpse Behind the Kennel Door: <http://www.awionline.org/pubs/Quarterly/04-53-3/533p16.htm>

—Random Source Dealer Surrenders: <http://www.awionline.org/pubs/Quarterly/05-54-1/541p2.htm>

Despite all of this, several registered research facilities including the University of Missouri continued to purchase animals from him. Unless NIH gives proper direction, some institutions will continue to place a higher priority on a cheap, ready supply of dogs than ensuring that animals are legally acquired and properly cared for. Thankfully, Baird has finally been put out of business. In fact, less than 20 Class B dealers remain, but the problems will persist until their number is reduced to zero.

NIH has told this Subcommittee that it is "committed to ensuring the appropriate care and use of animals in research." However, NIH has left the decision of whether or not to buy dogs and cats from random source dealers "to the local level on the basis of scientific need." NIH defends the use of Class B dealers arguing that these dealers are needed to obtain "animals that may not be available from other sources, such as genetically diverse, older, or larger animals." In fact, in the rare circumstance that a researcher asserts the need for such animals, they can be obtained directly from pounds as noted previously.

The distinction between non-purpose-bred animals from pounds versus Class B dealers must be made. By using Class B dealers (middlemen) instead of pounds, researchers are contributing to the problem. In their search to fill researchers' demands for "genetically diverse, older or larger animals," random source dealers and their suppliers may be stealing pets from backyards and farms or they are acquiring animals through fraud by collecting animals offered "free to a good home."

All animals used in research should be obtained from legitimate sources.

Taxpayer dollars, in the form of NIH extramural grants, must not continue to fund purchase of dogs and cats from dealers whose modus operandi are pet theft, acquisition of pets by fraud, payments made under the table and other illegal activi-

ties. Proper oversight of NIH's dispersal of extramural grants is urgently needed. We respectfully request that this Subcommittee include the following language in the HHS appropriations bill: "None of these funds shall be used for research which utilizes dogs and/or cats obtained from random source dealers."

---

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing is an alliance of four national nursing organizations—the American Association of Colleges of Nursing (AACN), the American Nurses Association (ANA), the American Organization of Nurse Executives (AONE), and the National League for Nursing (NLN). Focused on leadership and excellence in nursing, the Tri-Council represents the breadth of the nursing profession including practicing nurses, nurse executives, nurse educators, and nurse researchers.

The Nursing Workforce Development Programs under Title VIII of the Public Health Service Act strive to meet the health needs of the nation by assuring an adequate supply and distribution of qualified nursing personnel. These Programs increase access to quality care through improved composition, diversity, and retention of the nursing workforce; improved quality of nursing education and practice; and the identification of and use of data, and program performance measures and outcomes to make informed decisions on nursing workforce issues. The Tri-Council for Nursing urges Congress to ensure that adequate funding is available to address the critical nursing shortage through the Nursing Workforce Development Programs authorized by Title VIII of the Public Health Service Act.

This testimony highlights the fundamental importance of the Nursing Workforce Development Programs as they relate to an adequately prepared nursing workforce. As an example, we would like to bring the public health role of nurses and the vital services they are providing to this nation today to the forefront of your attention.

Nurses are a critical, but often unrecognized, component of the federal medical response to major emergencies and disasters, both natural and manmade. In the case of a major emergency, nurses have and will continue to be called upon to assist with chemoprophylaxis (oral or injectable medications/vaccinations) of hundreds of thousands or millions of Americans. The Office of Public Health Preparedness at the Health Resources and Services Administration (HRSA) estimates that a population of 100,000 people attacked by biological weapons would require 200 personnel working 100 hours just to deliver chemoprophylaxis. This effort would require approximately 16,171 trained persons for a city the size of New York. Nurses will also be called upon to assist with the planned use of "special needs shelters" during disasters. People in special needs shelters may include an insulin-dependent diabetic who requires frequent monitoring, epileptic persons with a history of unstable seizure activity, and persons with disabilities requiring assistance with activities of daily living.

Today's nursing shortage is very real and very different from any experienced in the past. It is evidenced by acute shortages of registered nurses (RNs) who are adequately prepared to meet patient care needs in a changing health care environment across the country. Although applications and enrollments for nursing programs have increased due to the major marketing efforts of corporations and health care providers, a serious nursing faculty shortage prevents the expansion of nursing programs to educate the number of nurses needed now and in the future. Studies have shown that unless dramatic steps are taken, the supply of appropriately prepared nurses will fall far short of what is needed to meet the needs of a diverse population and that this shortfall will grow more serious over the next 20 years. Since RNs represent the largest portion of our health care workforce, the shortage threatens the very essence of our health care system.

In February 2004, the Bureau of Labor Statistics reported that registered nursing would have the greatest job growth of all professions in the United States in the years spanning 2002 to 2012. During this ten-year period, health care facilities will need to fill more than 1.1 million RN job openings. HRSA projects that, absent aggressive intervention, the RN workforce will fall 29 percent below requirements by the year 2020.

The increasing health care demands of an aging population and changes in the country's nursing work-force have combined to create a shortage unlike any other. A fundamental shift has occurred in the RN workforce over the last two decades. As occupational opportunities for young women have expanded, and the changing health care environment has increased stresses on nursing, the number of young people entering the profession has declined resulting in a steady and dramatic increase in the average age of the nurse. Today, the average working RN is more than 43 years old.

## NURSES—INCREASING ACCESS TO QUALITY PATIENT CARE

Studies have shown that insufficient numbers of nurses contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the May 30, 2002, *New England Journal of Medicine* reported that higher levels of nursing care correlate with better patient care. Another study published in the October 23, 2002, *Journal of the American Medical Association* found that among the surgical patients studied, a pronounced correlation existed between nursing shortages and both patient mortality and failure to rescue.

By the year 2025, 68.3 percent of the current nursing workforce will be among the first of 78 million baby boomers reaching retirement age and enrolling in the Medicare program. By 2030, 20 percent of the population—70 million—will be older Americans, more than twice their number in 1999. The emerging complex health and social conditions of an aging population demonstrate the need for more and experienced nurses to care for this special population. Funding to support additional research and education in this area is needed.

Nurses can increase the public's access to quality primary health care through advanced practice registered nurses (APRNs), RNs who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Practice areas include, but are not limited to, anesthesiology, family medicine, gerontology, pediatrics, mental health, and midwifery. APRNs include:

Nurse Practitioners (NPs) who diagnose and treat common illnesses and injuries; provide immunizations; manage high blood pressure, diabetes, and other chronic problems; order and interpret lab tests; and counsel patients on adopting healthy lifestyles. Research confirms that NPs improve the public's access to high quality care at a cost savings to the system while a landmark study published in 2000 in the *Journal of the American Medical Association* indicates that NP quality of care is equal to that of physicians.

Clinical Nurse Specialists (CNSs) who provide care in a range of specialty areas, such as oncology, neonatal, and obstetric/gynecological nursing, pediatrics, and psychiatric/mental health while working in hospitals and other clinical sites. CNSs develop quality assurance procedures and serve as educators and consultants. An estimated 69,000 CNSs are currently in practice.

Certified Nurse-Midwives (CNMs) who provide prenatal and gynecological care to normal healthy women; deliver babies in hospitals, private homes, and birthing centers; and continue with follow-up postpartum care. Of all visits to CNMs, 90 percent are for primary, preventive care that includes gynecologic care such as annual exams and reproductive health visits.

Certified Registered Nurse Anesthetists (CRNAs) who administer more than 65 percent of all anesthetics given to patients each year, and are the sole anesthesia providers in approximately two-thirds of all rural hospitals.

As more acute public health needs exist in our communities, nurses, through their professional qualifications and sheer numbers, are at the very core of the nation's public health infrastructure.

"Nurse managed centers" (NMCs) play an important role in the health services delivery system and offer a unique approach to primary care that emphasizes health promotion and disease prevention, particularly in underserved communities. They often serve at-risk persons who might not otherwise receive health care. About half of all their patients are uninsured and many are unable to turn elsewhere for medical care. In the Philadelphia region, for example, nurses at nurse-managed health centers see their patients almost twice as often as other providers see theirs; their patients are hospitalized 30 percent less and use the emergency department 15 percent less often than those patients of other health care providers. Unfortunately, NMCs often struggle or fail to remain financially viable; the centers themselves need a safety net to survive financially.

The Nursing Workforce Development Programs of Title VIII provide the ability to maintain and expand the availability of a qualified nursing workforce and facilitate the integration of underrepresented populations into nursing.

*Section 811.*—The Advanced Education Nursing Program—funds traineeships for individuals preparing to be nurse practitioners, nurse midwives, nurse administrators, and public health nurses. In addition, grants are awarded to nursing schools to support education and training of APRNs.

*Section 821.*—The Nursing Workforce Diversity Program—funds grants to increase nursing education opportunities for individuals who are from disadvantaged backgrounds by providing student stipends, pre-entry preparation, and retention activities. These opportunities ensure a culturally diverse workforce to provide health care for a culturally diverse patient population.

*Section 831.*—The Nurse Education, Practice and Retention Program—provides grant support for academic and continuing education projects designed to strengthen the nursing workforce. Several of this program’s priorities apply to quality patient care including developing cultural competencies among nurses and providing direct support to establishing or expanding NMCs in non-institutional settings to improve access to primary health care in medically underserved communities. It also serves to provide grants to eligible entities to improve retention of nurses and enhanced patient care.

*Section 846.*—The Loan Repayment and Scholarship Programs—is divided into two primary components. The Nursing Education Loan Repayment Program assists individual registered nurses by repaying up to 85 percent of their qualified educational loans over three years in return for their commitment to work at health facilities with a critical shortage of nurses. Similarly, the Nurse Scholarship Program provides financial aid to individual nursing students in return for working a minimum of two years in a health care facility with a critical nursing shortage.

*Section 855.*—The Comprehensive Geriatric Education Grant Program—focuses on training, curriculum development, faculty development, and continuing education for nursing personnel caring for the elderly.

#### NURSES—EDUCATING THE FUTURE

At nursing schools across the nation, a surge of qualified applicants, who could ease the worsening shortage of nurses, is being turned away because schools of nursing are suffering from a continuing and growing shortage of faculty. This situation is not expected to improve in the near term, since an adequate number of nurse educators are currently not in the education pipeline.

The nursing faculty shortfall is driven by health care jobs that offer better pay than faculty positions and by fewer nurses pursuing the doctorate required for full-time teaching positions. Just as with the nursing workforce, the faculty is graying and a wave of retirements is expected about the same time when more care will be needed for aging baby boomers. An insufficient faculty was the top reason cited by nursing schools for not accepting all qualified applicants into entry-level programs for the 2004–2005 academic year. Just as important as educational incentives are for future practicing nurses, the scholarships for doctoral students who will instruct the next generation of nurses are even more critical.

Title VIII funding bolsters existing programs to increase the number of qualified nurse faculty.

*Section 846A.*—The Nurse Faculty Loan Program—supports the establishment and operation of a loan fund within participating schools of nursing to assist RNs to complete their education to become nursing faculty. The Program provides a cancellation provision in which 85 percent of the loan may be cancelled over four years in return for serving full time as faculty in a school of nursing.

*Section 811.*—The Advanced Education Nursing Program—provides trainee support for individuals preparing to be nurse educators. These funds support master’s and doctoral programs, combined RN/master’s degree programs, and post-nursing master’s certificate programs.

#### SUMMARY

While the Tri-Council for Nursing is encouraged by a recent resurgence of interest in the nursing profession, we are concerned that the funding levels for the Title VIII—Nursing Workforce Development Programs are insufficient to assist qualified students to enter, advance, and remain within the nursing profession. The nursing shortage will continue to worsen if significant investments are not made in these Title VIII programs. Recent efforts have shown that aggressive and innovative strategies can help avert the impending nursing shortage—if they are adequately funded. The contributions of nurses in our health care system are complex and multifaceted, and are directly impacted by the level of federal funding that supports nursing programs.

---

#### PREPARED STATEMENT OF PATIENT SERVICES INCORPORATED (PSI)

##### PATIENT SERVICES INCORPORATED MEDICAL INSURANCE AND CO-PAYMENT ASSISTANCE CASE MANAGEMENT PROGRAM FOR HEPATITIS C

PSI believes that its 16 years of proven patient assistance and results can and will translate into providing successful solutions to two major challenges in healthcare policy that the United States is currently facing:



- Providing standard comprehensive health insurance coverage for the uninsured and the underinsured in this country.
- Developing a public-private partnership to solving this problem in light of the tightening budget constraints at the federal and state government levels.

With our goals and vision in mind, PSI would use the federal resources to further develop and augment the Medical Insurance and Co-payment Assistance Case Management Program for Hepatitis C to save federal and state government resources in this era of fiscal austerity. PSI intends to do this by:

- Assisting Medicaid eligible patients affected with the Hepatitis C virus (HCV) by transitioning these patients into the private insurance market. According to our research, 10 percent to 15 percent of the Hepatitis C patient population on Medicaid who are responding positively to the Pegylated Alpha Interferon/Ribavirin Combination treatment regimen can return to work. A positive response to the regimen can be defined as having such a low amount of the virus in your cell system that the viral load is undetectable. This portion of the population can re-enter the workforce, thus returning to the status of taxpayer and transition off the Medicaid roles.
- PSI will use a portion of the federal funds to purchase health insurance premiums through State High-Risk policies, Guaranteed Issue policies, and/or Open Enrollment policies for these patients thus freeing up Medicaid dollars. These patients will then be eligible to re-enter the workforce, and ultimately be covered by an employer funded benefits package.
- Assisting the segment of the Hepatitis C patient population not eligible for Medicaid, such as those patients enrolled in the Medicare program, state assistance programs, as well as those patients underinsured or uninsured.
  - PSI can assist patients on Medicare by satisfying the co-payment for the expensive, but life-altering treatment regimens.
  - PSI can assist those patients receiving treatments through state assistance programs by transitioning them into the private insurance market.
  - PSI can assist those patients who are uninsured and underinsured by transitioning them into the private insurance market.

Over the last 9 years, PSI has proven that as an organization it can be an effective steward of taxpayer's dollars. For a \$1 million investment by the federal government, PSI believes it can assist 1,200 to 1,500 patients. This investment could have the potential once fully implemented to save the federal and state governments \$10 million a year.

*Is your project a labor, health and human services, or education request?*

Health and Human Services

*Within the Labor, Health and Human Services, Education Appropriations Bill, the specific account within which funding is sought*

Centers for Medicare and Medicaid Services (CMS): Research, Demonstration and Evaluation Program.

*Amount Requested*

\$1,000,000 for fiscal year 2006; \$1,000,000 for fiscal year 2007; \$1,000,000 for fiscal year 2008.

*How, specifically the federal funds will be spent, if obtained?*

PSI asks Congress to establish a demonstration project through the Department of Health and Human Services, Centers for Medicare and Medicaid Services, which will assist Medicare and Medicaid eligible individuals, who are infected with the Hepatitis C virus (HCV) and desiring assistance, to identify and subsidize individual health insurance policies. By providing premium and co-payment assistance, PSI will save federal Medicare and Medicaid dollars.

PSI will begin the Medical Insurance and Co-payment Assistance Management Program for Hepatitis C by the Summer of 2005.

*Federal funding history of the organization*

This is the first year that Patient Services Incorporated has made a federal funding request.

*List the amount state, local and private funds being used to support the project. Indicate the proposed federal share of the project*

PSI is in the final stages of development of a co-payment assistance program with private sector industry. The industry support will provide PSI with funds to develop a disease management program for patients infected with Hepatitis C. This program

would provide PSI with key funds to launch this pilot program, which would provide pharmacy co-payment assistance for the treatment regimen of Hepatitis C.

The private funds provided to PSI will initially assist 100 patients nationwide. PSI will also continue to reach out to other manufacturers of Hepatitis C treatments for further development of this program. The infusion of federal resources will assist in developing the PSI Medical Insurance and Co-payment Assistance Case Management Program for Hepatitis C into a more comprehensive program.

Proposed federal share: \$1 million per year, for 3 years.

*Report language requested*

Recommend Report Language Centers for Medicare and Medicaid Services, Program Management of the Medicare and Medicaid Research, Demonstration and Evaluation program.

The committee has included \$1,000,000 for a demonstration project/pilot program with Patient Services Incorporated of Midlothian, Virginia to save federal health care costs by subsidizing private health insurance coverage for individuals suffering from the Hepatitis C virus (HCV). The committee requests a report on the results of this unique and potentially cost-saving program.

*Members of Congress are you working with on this request*

Senator John Warner (R-VA) and Senator George Allen (R-VA).

*Please share any additional information you deem important*

Currently there is authorization for programs such as PSI's proposal under the following bills:

(1) Centers for Medicare and Medicaid Research, Demonstration and Evaluation Program is an existing, statutory program.

(2) The Medicare Modernization Act authorizes demonstration projects for innovative programs to reduce federal health care costs, and for chronic care improvement pilot projects.

Pertinent background information and justification for this appropriations request:

*Patient Services Incorporated Demonstration Project/Pilot Program: Covering the Uninsured with Chronic and Catastrophic Illness*

PSI is a national, non-profit organization committed to supporting people with specific chronic illnesses and conditions by locating and securing solutions with health insurance by paying health insurance premiums and pharmacy co-payments in order to help improve their quality of life. PSI's vision for the future is to become the premier national non-profit organization in developing strategies and programs through collaboration with federal and state governments, corporations and individuals to address gaps in public and private health care coverage.

PSI asks Congress to establish a demonstration project through the Department of Health and Human Services, Centers for Medicare and Medicaid Services, which will assist Medicare and Medicaid eligible individuals, who are infected with the Hepatitis C virus (HCV) and desiring assistance, to identify and subsidize individual health insurance policies. By providing premium and co-payment assistance, PSI will save federal Medicare and Medicaid dollars.

*Background on PSI*

Founded in 1989, PSI has spent the last fifteen years working with patients from the chronic disease community. PSI currently assists patients nationwide with the expensive costs of seventeen chronic illnesses and acute conditions. A few examples are those with Hemophilia, Alpha 1, Rheumatoid Arthritis, Crohn's Disease, Immune Deficiencies, Psoriasis and Multiple Sclerosis. PSI saves families from becoming financially devastated when a member is diagnosed with an expensive chronic illness. The PSI model provides the means for patients to become insured and have choices of treatments and providers.

Private contributors, foundations, and corporate sponsors donate resources to PSI. PSI uses these resources to help families avoid turning to government sponsored social service programs. Families are offered assistance based upon the severity of their medical and financial needs, which is determined through an application process, a procedure that is unique to PSI. PSI has developed a sliding scale formula specifically designed to capture the working middle class person, providing the family with a safety net from financial ruin and assuring a successful return to work outcome. PSI does this by working with patients to gain access to insurance through State High Risk Insurance Pools, Open Enrollment, and Guaranteed Issue health insurance policies. PSI also assists patients in maintaining COBRA policies for

those who qualify. PSI is committed to working with the chronically ill to ensure that they have the resources to meet their specific and costly health care needs.

PSI is in the unique position of tackling head-on the acute problem of locating and ultimately paying for health insurance for the uninsured population in the United States. Currently the United States Census Bureau reports that there are over 44 million Americans who have no health insurance for a time period of one year or more. However, over 80 million Americans are without health insurance for some period of time during any given year. PSI can assist individuals in both categories. Since 1996, PSI also has successfully worked with State Health Department Title V programs, such as, Children With Special Health Care Needs and Childrens Rehabilitative Services (Medicaid). The PSI model has saved the Commonwealth of Virginia over \$12 million since 1996 and the state of Kentucky over \$5 million in program costs since 2000.

In 2002, the U.S. Department of Health and Human Services' Office of the Inspector General issued a positive opinion endorsing the PSI model of premium assistance and sanctioning the co-payment assistance for Medicare patients. The Centers for Medicare and Medicaid Services acknowledged in its recent 641 Replacement Drug Demonstration Project that charitable organizations, like PSI, can assist patients with the out of pocket expenses associated with certain replacement drugs.

It is no secret the chronic illnesses are both financially and emotionally draining for patients and families to cope with. Treating chronic conditions also accounts for the largest percentage of spending within the Medicare budget. The costliest five percent of Medicare beneficiaries account for about half of all Medicare spending each year. PSI has developed programs to help many of the families afflicted by these costly diseases; their Medical Insurance and Co-payment Assistance Case Management Program for Hepatitis C holds a great deal of promise for individuals and families who are affected by this virus and the accompanying complications.

#### *Hepatitis C*

The Hepatitis C virus (HCV) is a disease of the liver that has potentially fatal outcomes. In the majority of Hepatitis C cases, infection becomes chronic and slowly damages the liver over many years. During this time, the liver damage can lead to cirrhosis (scarring) of the liver, end-stage liver disease, and liver cancer. In the United States, Hepatitis C affects close to 4 million people, making the disease more prevalent than HIV/AIDS infection. The costs for providing care for patients with HCV-associated liver disease in the United States are estimated to range from \$758 million to several billion dollars annually. Hepatitis C infections are expected to increase to 10.8 million Americans in the next decade, leading to a major drain on government health resources and increased health costs.

Hepatitis C can be treated; early diagnosis and treatment are crucial to being able to control the progression of the disease and reduce the chances of further liver damage. There are instances where the treatment has taken a protracted time to show any positive results in lowering the viral load of patients, and in certain cases the treatment may not change the progression of the disorder. Currently, the National Institutes of Health (NIH) recommends that Hepatitis C patients receive pegylated alpha interferon treatment in combination with the antiviral drug, Ribavirin. Three different agents are used in this treatment approach:

—*Alpha Interferons*.—A protein made naturally by your body to boost your immune system and to regulate other cell functions. All of the currently approved treatments for chronic Hepatitis C include some form of natural or synthetic alpha interferon.

—*Pegylated Alpha Interferon*.—Made by attaching a large water-soluble molecule call polyethylene glycol (PEG) to the alpha interferon molecule. These modified alpha interferons stay in the body longer and studies show they are more effective in producing a sustained viral response in patients with chronic Hepatitis C.

—*Ribavirin*.—An antiviral drug that is used with manufactured forms of alpha interferon for the treatment of chronic Hepatitis C. Ribavirin by itself has not been shown to be effective against the Hepatitis C virus, but in combination with forms of alpha interferon is a much more successful treatment than alpha interferon alone.

The Pegylated Alpha Interferon/Ribavirin Combination treatment regimen is expensive; according to the 2003 Red Book Update, the costs range from \$24,000 to \$48,000 for the drug alone. These costs do not include fees for administering the drugs, laboratory visits, and medical tests associated with HCV. Hepatitis C is an expensive chronic illness; PSI is able to work with the federal government to assist this community to ensure that it receives quality care in an economically efficient way.

## PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

## INTRODUCTION

Mr. Chairman and members of the subcommittee, I am Dr. Carol Barnes of the University of Arizona and President of the Society for Neuroscience (SfN). I am here today in my capacity as the President of SfN to urge your support of biomedical research. SfN represents the entire range of scientific research endeavors aimed at understanding the nervous system and translating this knowledge to the treatment and prevention of nervous system disorders. It fosters the broad interdisciplinarity of the field, which uses multiple perspectives to study the nervous system of organisms ranging from invertebrates to humans across various stages of development, maturation, and aging.

## WHAT IS THE SOCIETY FOR NEUROSCIENCE?

The Society for Neuroscience is a nonprofit membership organization of basic scientists and physicians who study the brain and nervous system. Neuroscience includes the study of brain development, sensation and perception, learning and memory, movement, sleep, stress, aging, and neurological and psychiatric disorders. It also includes the molecules, cells, and genes responsible for nervous system functioning and human behavior.

The 36,000 members of SfN include basic researchers studying the many neuroscience disciplines and clinicians specializing in neurology, neurosurgery, psychiatry, ophthalmology, and related fields. In 1970, neuroscience barely existed as a separate discipline. Today, there are more than 300 training programs in neuroscience alone. The field of neuroscience has made startling discoveries that have transformed our understanding of the healthy brain and helped to deliver treatments of disorders affecting millions.

## NATIONAL INSTITUTES OF HEALTH'S NEUROSCIENCE BLUEPRINT

The NIH Neuroscience Blueprint is a framework to enhance cooperation among 15 NIH Institutes and Centers that support research on the nervous system. Over the past 10 years, driven by the science, the NIH neuroscience Institutes and Centers have increasingly joined forces through initiatives and working groups focused on specific disorders. The Blueprint builds on this foundation, making collaboration an everyday part of how the NIH does business in neuroscience. By pooling resources and expertise, the Blueprint can take advantage of economies of scale, confront challenges too large for any single institute, and develop research tools and infrastructure that will serve the entire neuroscience community.

Last year, the Blueprint participants developed a set of initiatives focused on tools, resources, and training with immediate impact because they would build on existing programs. These initiatives include an inventory of neuroscience tools funded by the NIH and other government agencies, enhancement of training in the neurobiology of disease for basic neuroscientists, and expansion of ongoing gene expression database efforts, such as the Gene Expression Nervous System Atlas (GENSAT).

Advances in the neurosciences and the emergence of powerful new technologies offer many opportunities for Blueprint activities that will enhance the effectiveness and efficiency of neuroscience research. Blueprint initiatives for fiscal year 2006 will include systematic development of genetically engineered mouse strains of critical importance to research on the nervous system and its diseases and training in critical cross cutting areas such as neuroimaging and computational biology.

Several of the most common causes of death and disability, as well as hundreds of rare disorders, affect the brain, spinal cord, or nerve cells in the eye, ear, or elsewhere in the body. The vast array of nervous system disorders encompasses mental illness, neurological disease, drug and alcohol abuse, chronic pain conditions, developmental disorders, and dementias of aging. Numerous problems of hearing, vision, and other senses also include a brain component, and are serious health issues.

In fiscal year 2006, NIH intends to allocate \$26 million, with \$14 million contributed by collaborating institutes and centers, for Blueprint initiatives as follows:

- Neuromouse Project*.—developing genetically engineered mouse strains specifically for nervous system disease research;
- Cross-Institute Neuroscience Training Programs*.—training in critical cross-cutting areas such as neuroimaging and computational biology;
- Neuroscience Core Grants*.—supporting specialized, interdisciplinary “core” centers that might focus on areas such as animal models, cell culture, computer modeling, DNA sequencing, drug screening, gene vectors, imaging, microarrays, molecular biology, or proteomics and their applications to neuroscience research;

—*Translation of Discoveries*.—accelerating the translation of basic neuroscience discoveries into better ways to treat and prevent nervous system diseases; and  
 —*Analytical Methods and Conceptual Models*.—spurring the development of new analytical methods and conceptual models to study disease and allow for increased coordination among public education and outreach campaigns involving the brain and nervous system.

#### ACCOMPLISHMENTS

The Society for Neuroscience would like to thank you for your past support. In the last 10 years, funding from the NIH and the Department of Veterans Affairs has helped scientists make great progress in helping people in many areas, including:

1. *Bipolar disorder*.—Also known as manic depression, bipolar disorder is a serious brain disease that causes extreme mood swings, from intense feelings of euphoria (mania) to deep depression. Past funding from NIH and the Department of Veterans Affairs has helped scientists make great progress in understanding bipolar disorders and, thus, in diagnosing and treating the illness. Using the latest brain imaging technologies, scientists have also discovered that brain function and structure in people with bipolar disorder differs markedly from that in people without the illness. Researchers have found a significant decrease in the size of the amygdala, a part of the brain that governs emotions, in people with bipolar disorder. Other studies have found a decrease in the density of gray matter in the brains of people with bipolar disorder. These and other exciting new findings are helping to pave the way for the design of new drugs that directly target specific genes or areas of the brain.

2. *Alzheimer's Disease & Normal Aging*.—Alzheimer's disease, one of the most frightening memory-robbing disorders, hampers the lives of some 4 to 5 million older Americans, costing the United States at least \$100 billion in medical care and lost productivity each year. Fortunately, NIH-funded research has helped to generate new treatments that can aid memory loss. These medications slow memory deterioration in some patients and allow others to resume normal lives. Additional gains can and must be made in the field of memory research in order to benefit a wider range of people, and to reduce the financial burden of care. Recent studies on animal models suggest that the outlook could improve with treatments that target brain mechanisms to enhance memory. Additionally, research into Alzheimer's disease and its effects on memory have also led to important advances in how memory can be optimized in normal aging. This would clearly benefit the remaining millions of Americans who are looking toward successful aging.

3. *Depression & Heart Disease*.—Depression is a biologically based brain disorder that affects about 10 percent of Americans over the age of 18. Depressed people feel intensely sad and worthless and have a diminished sense of emotional well-being. Among other diseases such as alcoholism and stroke, people with depression have an increased risk for heart disease, particularly coronary artery disease. In otherwise healthy people, depression doubles the risk for coronary artery disease. Furthermore, for those with coronary artery disease, there is evidence that depression influences outcomes, particularly mortality, following a heart attack. Additionally, for those undergoing coronary artery bypass grafting, there is increasing evidence that depression is associated with poorer outcomes. Studies from Johns Hopkins University reveal that patients with severe depression are up to five times more likely to have poorer outcomes such as the return of chest pain, heart attacks, or death. Despite much progress in understanding the biology of depression in the past decade, much remains to be done. The mechanisms of the interaction between depression and outcomes with cardiac disease are not clear. Nor is it known if treatment of depression, even mild depression, would lead to more favorable outcomes for those with cardiac problems. NIH-funded research might help us answer these complicated questions in order to save lives and money.

#### THE AMERICAN BRAIN COALITION

Last year, the Society for Neuroscience, along with the American Academy of Neurology, started the American Brain Coalition (ABC). ABC is a nonprofit organization that brings together patients with disabling brain disorders, the families of those that suffer, and the professionals that research and treat diseases of the brain. The mission of the ABC is to reduce the burden of brain disorders, and advance the understanding of the brain.

Because the brain is the center of human existence and the most complex living structure known, ABC advocates for collaboration among researchers and doctors who treat disorders of the brain. As seen with depression and heart disease, the

brain plays a vital role in conditions once believed to be unrelated to the brain. It is only through more research that we will begin to further understand, prevent, and treat neurological and psychiatric diseases.

FISCAL YEAR 2006 BUDGET REQUEST

The Society for Neuroscience supports the Ad Hoc Group for Medical Research Funding request of a 6 percent increase for NIH in fiscal year 2006. This will help NIH to carry out its Blueprint initiatives and help people affected by neurological disorders lead healthier, productive lives. Furthermore it will help sustain the infrastructure for innovative discoveries necessary to compete as a worldwide leader in biomedical research.

The request is based on the following information:

- \$1 billion is needed to cover biomedical research inflation, which is projected to be 3.5 percent;
- \$560 million is needed to replace the evaluation set-aside (an amount taken from each institute), which this year amounted to 2.4 percent (it used to be 1 percent); and
- The total number of research project grants (RPGs) is declining by 402 from what it was in fiscal year 2005.

Mr. Chairman, thank you for the opportunity to testify before this committee.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

On behalf of The Humane Society of the United States (HSUS) and our more than 8.6 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priorities for the Labor, Health and Human Services, Education and Related Agencies Subcommittee in fiscal year 2006.

INTERAGENCY COORDINATING COMMITTEE ON THE VALIDATION OF ALTERNATIVE METHODS (ICCVAM)

We were very pleased that Congress enacted Public Law 106–545 by unanimous voice vote in both chambers in 2000. This legislation, introduced by Senator Mike DeWine (R-OH) and Representatives Ken Calvert (R-CA) and Tom Lantos (D-CA), strengthened and made permanent the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM). The statute has already begun to enhance the federal government’s capacity to evaluate and adopt chemical testing methods that are often faster, cheaper, and more scientifically sophisticated than current methods, as well as more responsive to the public’s concerns about the welfare of animals used in toxicity testing. Public Law 106–545 has streamlined the process by which these better methods are validated and assessed, and has eased institutional barriers within federal agencies that discourage their use.

ICCVAM performs an invaluable “win-win” function for regulatory agencies and stakeholders in industry, public health, and animal protection by assessing the suitability of new toxicological test methods that have interagency application. These new (and newly revised) methods include alternative methods that can limit animal use or suffering in testing. After appropriate independent peer review of a new test method, ICCVAM provides its assessment of the new test to the federal agencies that regulate the particular endpoint that the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test method as appropriate for the agencies’ regulatory mandates. This streamlined approach to assess the validation status of new test methods has reduced the regulatory burden of individual agencies, provided “one-stop shopping” for industry, animal protection, and public health advocates to consider test methods, and set uniform criteria for what constitutes a validated test method.

ICCVAM arose from an initial mandate in the NIH Revitalization Act of 1993 for the National Institute of Environmental Health Sciences (NIEHS) to “(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use.” In 1994, NIEHS established an ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from 14 regulatory and research agencies developed NIH Publication No. 97–3981, Validation and Regulatory Acceptance of Toxicological Test Methods. This report has become the “sound science” guide for consideration of new test methods by the federal agencies and in-

terested stakeholders. After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Methods (NICEATM). Representatives from federal regulatory and research agencies have continued to meet, with advice from NICEATM's Scientific Advisory Committee and independent peer review committees, to assess the validation of new toxicological test methods.

Since its inception, ICCVAM has conducted rigorous evaluations of several test methods and has concluded that these methods are scientifically valid, i.e., have been adequately validated, and are acceptable for specific purposes. These methods include Corrositex, Epiderm, Episkin, and Transcutaneous Epithelial Resistance assays for assessing skin corrosivity; the 3T3 NRU Phototoxicity assay for assessing phototoxicity; the Local Lymph Node Assay for assessing skin sensitization; and the Up and Down Method and various cytotoxicity assays for assessing acute systemic toxicity. In turn, the appropriate regulatory agencies have incorporated these methods into their regulatory practices.

The open public comment process, input by interested stakeholders, and the continued commitment by various federal agencies have all enhanced the ICCVAM process. Now, under Public Law 106-545, ICCVAM is poised to go beyond its largely passive role of assessing the validation status of test methods that have been developed and validated by industry and others. ICCVAM should adopt a more proactive role in developing and validating promising tests methods in partnership with outside stakeholders, to ensure that a steady stream of new test methods are available for review and adoption by the federal government. Such a proactive stance and partnership with stakeholders will enable the federal government to better harness the potential of emerging technologies to meet the challenge of efficiently testing large numbers of chemicals with minimal cost in terms of money and animal lives. With a more proactive approach, ICCVAM could, for example, explore the potential of investigator-initiated and small business grant programs to further its mission.

Adequate funding should be provided for ICCVAM to put the resources in place to ensure the federal government and industry have the best available tools with which to assess the toxic properties of chemicals in commerce. To accomplish this, we respectfully request an earmark of \$3.6 million for fiscal year 2006 and the following Committee Report language:

“In order for the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) to carry out its responsibilities under the ICCVAM Authorization Act of 2000, the Committee strongly urges NIEHS to strengthen the resources provided to ICCVAM for methods validation reviews in fiscal year 2006. ICCVAM and NIEHS activities must include up-front validation study design, execution, and review to ensure that new and revised test methods, non-animal test methods, and alternative test methods (such as QSARs, mechanistic screens, high throughput assays, and toxicogenomics) are deemed scientifically valid before they are recommended or adopted for use by federal agencies or used in implementing the National Toxicology Program's Road Map and Vision for NTP's toxicology program in the 21st century.”

#### PAIN AND DISTRESS RESEARCH

An estimated 40 percent of the National Institutes of Health (NIH) budget—or currently more than \$11 billion—is devoted to some aspect of animal research. At this time, no funding is set aside specifically for research into alternatives that reduce the amount of pain and distress to which research animals are subjected, nor methods that replace or reduce the use of vertebrate animals in research. NIH may receive \$28.8 billion in fiscal year 2006 if Congress fulfills the President's budget request. Out of this funding, we seek \$2.5 million (0.009 percent) for research and development focused on identifying and alleviating animal pain and distress. In addition to our request for a specific funding amount, we also urge the Committee to specify in report language that this research should be conducted in conjunction with, or “piggy-backed” onto, ongoing research that already causes pain and distress. Infliction of pain and distress on additional animals is unnecessary, given the volume of existing research (we estimate a minimum of 20–25 percent of all animal research) that is believed to involve moderate to significant pain and/or distress.

The large extent to which animals are used in federally-funded research underscores the importance of earmarking funds for pain and distress research. NIH has a statutory mandate to conduct or support research into alternative methods that produce less pain and distress in animals. This was specified in the NIH Revitalization Act of 1993 regarding a plan for the use of animals in research. Earmarked funding will assist NIH in meeting this mandate. Additionally, researchers themselves often comment publicly at scientific meetings about the urgent need for fund-

ing in order to properly understand and mitigate pain and distress in research animals and to follow Animal Welfare Act and Public Health Service policy requirements to minimize pain and distress.

It is well known that uncontrolled, undetected, and unalleviated pain and distress has adverse effects on animal welfare, which leads to adverse effects on the quality of science. Ultimately, the lack of information on pain and distress leads to misinterpretation of research results that could result in harmful effects in human beings when pre-clinical animal research results are applied to humans in clinical trials.

A 2001 survey conducted by an independent polling firm indicates that concern about animal pain and distress strongly influences public opinion about animal research in general. Seventy-five percent of the American public opposes research that causes severe animal pain and/or distress, even when it is health-related. Despite this public concern, NIH has failed to sponsor research and development aimed at determining how to minimize animal suffering and distress in the laboratory.

During the past several years, our organization has been reviewing institutional policies and practices with respect to pain and distress in animal research. We have found that research institutions have inconsistent policies due to the lack of information on this subject, and that standards vary greatly from one institution to another. The federal standard for determining laboratory animal pain specifies that, if a procedure causes pain or distress to humans, it should be assumed to cause pain and distress to animals. Furthermore, while human experience can and should provide a useful guide in some cases, there are others in which humans are never subjected to the conditions facing laboratory animals. Information on pain and distress that animals themselves actually experience is important.

Our nation takes pride in leading the world in biomedical research, yet we lag behind many other countries in our efforts to minimize pain and distress in animal subjects. For example, the United Kingdom, Sweden, Switzerland, Germany, the Netherlands and the European Union all have committed funds specifically for the "three R's" (replacing the use of animals, reducing their use, and refining research techniques to minimize animal suffering).

We urge the Committee to make this small investment of \$2.5 million to promote animal welfare and enhance the integrity of scientific research. We also respectfully request this accompanying committee report language:

"The Committee provides \$2.5 million to support research and development focused on improving methods for recognizing, assessing, and alleviating pain and distress in research animals. No pain and distress should be inflicted solely for the purpose of this initiative, since the investigations can and should be conducted in conjunction with ongoing research that is believed to involve pain and distress under Government Principle IV of Public Health Service Policy, which assumes that procedures that cause pain and distress in humans may cause pain and distress in animals."

Again, we appreciate the opportunity to share our views and top priorities for the Labor, Health and Human Services, Education and Related Agencies Appropriation Act of fiscal year 2006. We hope the Committee will be able to accommodate these modest requests that will benefit animals, enhance effectiveness of toxicological testing, and improve the quality of research. Thank you for your consideration.

---

#### PREPARED STATEMENT OF VOICES FOR NATIONAL SERVICE

Mr. Chairman and Members of the Subcommittee, Voices for National Service, formerly known as the Save AmeriCorps Coalition, is a coalition of community-based organizations, faith-based groups, state commissions, private sector partners, institutions of higher education, and others interested in promoting national service through AmeriCorps and other vehicles. We look forward to working with you to strengthen AmeriCorps and national service as you oversee the entire budget of the Corporation for National and Community Service for the first time.

In light of AmeriCorps 10th Anniversary, it is appropriate to review some of the goals Congress set for AmeriCorps in 1993: "to meet the unmet human, educational, environmental and public safety needs of the United States; to renew the ethic of civic responsibility and the spirit of community throughout the United States; to expand educational opportunity by rewarding individuals who participate in national service with an increased ability to pursue higher education or job training; to encourage citizens of the United States, regardless of age, income, or disability, to engage in full-time or part-time national service; and, to provide tangible benefits to the communities in which national service is performed."



We believe that those who do service through AmeriCorps, as part of school or community-based service-learning, or senior volunteer programs, through their churches synagogues and mosques, and community-based organizations are part of one of the great currents of American history: working with one's neighbor to build a better community and a better nation. President Bush captured this theme when, in his State of the Union Address in 2002, he said:

“My call tonight is for every American to commit at least 2 years—4,000 hours—over the rest of your lifetime to the service of your neighbors and your nation. . . . Our country [also] needs citizens working to rebuild our communities. We need mentors to love children, especially children whose parents are in prison. And we need more talented teachers in troubled schools.”

#### GOVERNMENT SPONSORED SERVICE IS DEEPLY ROOTED IN OUR HISTORY

It was almost a century ago that philosopher William James spoke of service as “the moral equivalent of war” and said if there “were a conscription of the whole youthful population to form for a certain number of years a part of the army enlisted against Nature, the injustice would tend to be evened out . . . .”

Since that speech in 1906, Presidents from Franklin D. Roosevelt to George W. Bush have proposed that Americans serve both here and abroad to improve conditions for those who need support. They recognized that serving made better citizens and better Americans, that government—in conjunction with community-based institutions—has a role to play in solving our most intractable problems and that service must be real, not make-work.

In 1933, President Roosevelt spoke to Civilian Conservation Corps (CCC) members in Warm Springs, Georgia and told them that “You are rendering a real service, not only to this community but to this part of the State and the whole State. It is permanent work, it is work that is going to be useful for a good many generations to come. That is why, one reason why, the people of this country as a whole believe in the Civilian Conservation Corps . . . .”

It is difficult to believe that nearly half a century has passed since President Kennedy challenged a new generation by saying “And so, my fellow Americans: ask not what your country can do for you—ask what you can do for your country.” Kennedy’s Peace Corps proposal included many of the principles embodied in AmeriCorps:

“In establishing our Peace Corps we intend to make full use of the resources and talents of private institutions and groups. Universities, voluntary agencies, labor unions and industry will be asked to share in this effort . . . making it clear that the responsibility for peace is the responsibility of our entire society. . . . We will only send abroad Americans who are wanted by the host country—who have a real job to do—and who are qualified . . . . Programs will be developed with care, and after full negotiation . . . . Life in the Peace Corps will not be easy. There will be no salary and allowances will be at a level sufficient only to maintain health and meet basic needs.”

#### NATIONAL SERVICE HAS BROAD BIPARTISAN SUPPORT

The roots of AmeriCorps are contained in national service legislation enacted in 1990 and signed by President George H.W. Bush. It reflected his belief, articulated in his Inaugural address, that “America is never wholly herself unless she is engaged in high moral principle. We as a people have such a purpose today. It is to make kinder the face of the Nation and gentler the face of the world. My friends, we have work to do.” To address these issues, he said “we will do the wisest thing of all: We will turn to the only resource we have that in times of need always grows—the goodness and the courage of the American people.” He called for:

“A new engagement in the lives of others, a new activism, hands-on and involved, that gets the job done. We must bring in the generations, harnessing the unused talent of the elderly and the unfocused energy of the young. For not only leadership is passed from generation to generation, but so is stewardship. And the generation born after the Second World War has come of age. The old ideas are new again because they are not old, they are timeless: duty, sacrifice, commitment, and a patriotism that finds its expression in taking part and pitching in.”

Exactly seven years less one day before September 11, President Clinton swore in the first class of AmeriCorps members. Reflecting many of the themes articulated by President Bush, he told them that “Service is never a simple act, it’s about sacrifice for others and about accomplishment for ourselves, about reaching out, one person to another, about all our choices gathered together as a country to reach

across all our divides. It's about you and me and all of us together—who we are as individuals and what we are as a nation. Service is a spark to rekindle the spirit of democracy in an age of uncertainty.”

Like Presidents Roosevelt, Kennedy, and Bush, President Clinton also understood that each generation owes something to the nation for what it has received as well as to those who follow:

“And your generation is no exception. We look at you now. And we know you are no generation of slackers. Instead you are a generation of doers. And you want to give something back to the country that has given so much to you. The only limit to our future is what we're willing to demand of ourselves today. Generations of Americans before us have done the groundwork. Now, it falls to all of us to build on their foundations.”

Two years ago, AmeriCorps was in crisis; its very survival in doubt. At that time, virtually every governor, more than 150 mayors, hundreds of university presidents, and corporate and civic leaders publicly recognized the good that AmeriCorps had accomplished since its creation 10 years ago. More than 100 editorials in large and small newspapers throughout the nation provided ample evidence of how AmeriCorps members improved their communities.

President George W. Bush's support, important bipartisan legislative initiatives to improve the management of the Corporation for National and Community Service, installation of a new leadership team, and the rulemaking process still underway not only helped to save AmeriCorps but to remind us that service is the responsibility of all Americans.

#### STRENGTHENING COMMUNITIES

AmeriCorps members serve in more than 900 local and state nonprofit organizations, public agencies, and faith-based organizations funded by the Corporation for National and Community Service through both state commissions as well as national nonprofit AmeriCorps programs including Teach for America, the National Association of Community Health Centers, the Red Cross, Habitat for Humanity, City Year, Public Allies, the National Association of Service and Conservation Corps, Jumpstart for Young Children, the Sisters of Notre Dame, and the Experience Corps.

They serve to address problems within four broad categories: “unmet human, educational, environmental, or public safety needs.” Communities identify their needs and choose the model that is most appropriate to meeting those needs. This is a bottom up, not a top-down program.

AmeriCorps members also help strengthen Homeland Security and prevent or mitigate the effects of natural disasters. Recently, AmeriCorps members from Minnesota and Washington State joined colleagues serving in Florida to bring a measure of relief to victims of devastating hurricanes. They helped mobilize the largest volunteer disaster response in American history, repaired damaged homes, and distributed food and water to victims and community volunteers. Indeed, since September 11, 2001 the AmeriCorps program has expanded its work in public safety, public health, disaster relief, and homeland security.

AmeriCorps members teach in underserved schools, tutor and mentor youth including the children of prisoners, run after-school programs, build affordable housing, provide public health services, prevent forest fires and do disaster relief, run after-school programs, and help communities respond to disasters. Hundreds of AmeriCorps state programs clean rivers and streams, enrich after school programs, support local law enforcement by providing meaningful alternatives to gangs, deliver services to the elderly, and meet other needs defined by the communities in which they serve.

This year, for example, AmeriCorps members are serving more than 2 million children and youth, providing valuable resources to reach the President's goal of having all children able to read by third grade. They are also helping to recruit and train more than 600,000 community volunteers.

AmeriCorps members leverage community resources as well as perform direct service. In fiscal year 2003, AmeriCorps members recruited more than 529,000 community volunteers an increase of almost 275,000 (from the previous year when the Corporation stopped recruiting new members and new volunteers because of its self-imposed recruitment freeze). Last year, AmeriCorps programs generated more than \$165 million from non-Corporation partners, \$70 million more than in the previous year.

## ACCOMPLISHMENTS

According to the State Profiles and Performance Report 2002–2003 published by the Corporation for National and Community Service (December 2004), examples of what AmeriCorps members accomplished include (but are not limited to):

- In Alaska, members tutored almost 6,000 students in grades 1 through 12 and assessed 485 homes for energy efficiency.
- In Florida, members recruited 2,000 community volunteers to provide education services, maintained and expanded 200 acres of habitat for threatened and endangered species, and built 40 homes for low-income families.
- In Georgia, almost 7,500 homeless individuals received referrals to permanent or transitional housing.
- In Indiana, 2,400 juveniles participated in career development activities for offenders or ex-offenders.
- In Iowa, more than 4,800 elementary and middle students received tutoring and mentoring support, and 32,000 received education and training about the environment.
- In Kentucky, members staged eight forums to educate more than 1,000 at-risk elderly about home safety and conducted 265 Home Safety Assessments for seniors.
- In Maine, members made 600 presentations on disaster preparedness, benefiting more than 36,000 people and almost 1,300 people participated in after-school activities designed to reduce violence in public housing.
- In Maryland, members removed 453 tons of trash, improving the quality of storm water run-off into the Chesapeake Bay and 1,900 homeless families received food, clothing, or furniture.
- In Minnesota, members constructed 151 housing units for low income seniors or people with disabilities, planted almost 142,000 trees, and conserved more than 10,000 acres of habitat and land.
- In Mississippi, members trained 715 people with disabilities in life skills, helped train mentally, or developmentally, disabled adults for employment, and mentored 1,100 low income and underachieving middle school students.
- In Montana, members constructed 54 miles of fence to protect wild- or park lands, maintained 309 miles of trails, roads, and other public areas, and increased access to technology for more than 1,100 youth, parents, and members of the community.
- In Nevada, 3,200 students in grades 1 through 12 received tutoring, 577 homeless veterans received employment-related counseling, and almost 1,000 women benefited from anti-victimization counseling and workshops on preventing domestic violence.
- In New Mexico, almost 24,400 people participated in after-school sports and violence avoidance activities, 400 adults received instruction in basic skills development and GED training, and 138 homeless families found homes.
- In New York, members transported 1,000 children to medical appointments, delivered meals and snacks to about 58,000 children and seniors, and provided literacy activities to almost 17,000 children.
- In Ohio, members trained more than 9,000 youth in conflict resolution, built repaired, or rehabilitated 364 housing units, and provided educational support services to 1,500 students during the summer months.
- In Oregon, 7,000 students benefited from updating high school Career Centers with college, military, apprenticeship, and trade school information, planted almost 5,000 trees, and grew and distributed more than 900 pounds of produce.
- In Pennsylvania, members tutored almost 14,600 elementary and high school students and more than 6,800 citizens received either needs assessment or support in the areas of domestic violence, foster care, mental health, and housing for homeless veterans.
- In Tennessee, more than 900 people received access to health care, almost 200 children had their immunizations ensured, and more than 1,300 senior women received informational materials about breast cancer.
- In Washington, almost 37,000 students benefited from out of class enrichment activities like field trips, about 6,600 peer tutors were recruited, and more than 19 miles of rivers, river banks, beaches, and fish habitat were restored or conserved, benefiting local salmon runs.
- In Wisconsin, members organized or packed 290 tons of food to be distributed to community agencies and provided after-school tutoring or mentoring services to more than 1,200 students.

—In West Virginia, more than 3,200 children received tutoring in a six-week summer literacy program, helping to realize an average four month gain in literacy skills.

According to the Corporation's National Performance Benchmarking Survey, "57 percent of organizations' AmeriCorps partners reported that AmeriCorps members 'considerably' helped them increase their involvement in partnerships and coalitions. (29 percent reported 'moderately' helped)." Also, three quarters of grantees said that "AmeriCorps had increased 'by a considerable amount' the number of end beneficiaries served." About "83 percent of grantees reported that AmeriCorps members helped their organization either 'considerably' (53 percent) or 'moderately' (30 percent) in leveraging additional volunteers." And, "more than 75 percent of organizations receiving disaster and emergency readiness and preparedness training from AmeriCorps programs have become better prepared by conducting emergency drills, changing organization operations, or preparing emergency kits."

With your support, in the next fiscal year, approximately 40,000 AmeriCorps members will provide tutoring to students, help operate after-school programs, increase Americans' access to health care, and provide support for families in crisis. In addition, more than 5,000 children of prisoners will receive services provided by AmeriCorps members.

In 2004, the Corporation for National and Community Service celebrated its tenth anniversary. In the last decade, more than 400,000 young Americans dedicated themselves to either full or part-time service through AmeriCorps to improve their communities and their country. At the same time, AmeriCorps members earned Education Awards worth more than \$1 billion.

#### SERVICE CHANGES THOSE WHO SERVE

Serving in AmeriCorps also changes those who serve. According to the recent study conducted by Abt Associates "Serving Country and Community: A Longitudinal Study of Service in AmeriCorps" participation in AmeriCorps "resulted in statistically significant positive impacts on members' connection to community, participation in community-based activities, and personal growth through service. While AmeriCorps members increased their level of civic engagement . . . scores for comparison group members typically showed little or no change. . . ." "Additionally, there was a positive and significant effect of AmeriCorps participation on volunteering for members without prior volunteering experience. These results are important because they reflect the capacity of AmeriCorps to strengthen existing beliefs in and commitments to civic engagement and community service, and to awaken new ones."

The Abt study also reported that service in AmeriCorps "had a meaningful impact on both attitudinal and behavioral employment outcomes." It increased "the work skills of AmeriCorps members" and motivated "members to choose public service careers, such as teaching, social work, and military service."

Thus, AmeriCorps proves its value everyday in communities across the country and by changing the lives of AmeriCorps members.

#### THE FISCAL YEAR 2006 REQUEST

We are hopeful that under your leadership local communities throughout the nation will continue to be served by as many as 75,000 AmeriCorps members. At the same time, we want to make clear that we are as committed to the quality of the service as to reaching a specific number of AmeriCorps members.

We very much appreciate the increase in funding that Congress provided in fiscal year 2004 to save AmeriCorps. It must be noted, however, that funding for AmeriCorps grants has declined from the fiscal year 2004 enacted high of \$312 million to the proposed \$275 million, a cut of more than 10 percent. At the same time funding for the Trust has increased from \$129 to a proposed \$146 million.

The Voices for National Service Coalition believes that it will require \$442 million to achieve the number of AmeriCorps members proposed by the Corporation for National and Community (75,000) while maintaining the historical balance between full-time, part-time, and Education award only AmeriCorps members. To sustain this level of service, we urge you to fund AmeriCorps at the level proposed by President Bush in his fiscal year 2005 budget. We are very concerned that with operating costs increasing, recruiting the same number of AmeriCorps members with \$20 million fewer dollars than the President proposed just last year may force the Corporation to make programmatic compromises that will undermine the historic nature and fundamental character of AmeriCorps. While we support the Corporation's desire to increase the number of "effective, lower cost programs, such as professional

and teacher corps” we remain convinced that responsiveness to local needs requires the Corporation to support a mix of higher, as well as lower, cost programs.

We also want to call the Committee’s attention to two other elements of the Corporation’s request. First, we support the Corporation’s proposal to eliminate the cap on National Direct grants. We share its concern that “capping funding for National Direct grants may prevent [it] from supporting outstanding service programs.” Second, we are concerned about the Corporation’s failure to seek funds for the Challenge Grant program. Challenge grants promote competition and are an important tool which programs can use to leverage additional private sector funds. If the Corporation truly wants to achieve program sustainability by reducing dependence on federal grants, it ought to increase Challenge Grant funds rather than eliminate them. The response to Challenge Grants has been overwhelming and we believe the program’s success justifies its continuation.

#### PROMOTING QUALITY AND INCREASING EFFICIENCY

As you begin your difficult work this year, Voices for National Service urges you to consider the following themes that will further increase the Corporation’s effectiveness and meet its goal of “put [ting] the customer first”:

1. Education Award Only slots should be a tool for state flexibility and cost-effectiveness. They should not become a way to increase the number of AmeriCorps members “on the cheap.” We believe that the current ratio between full- and part-time members and recipients of Education Awards should be maintained and that no more than 40 percent of the AmeriCorps portfolio should be allocated to Education Award Only programs. This will allow states to reduce cost per member, and be responsive to both local resources and local needs.

2. The Corporation must continue to affirm its commitment to diversity of AmeriCorps members and be sensitive to geographic diversity as well as racial, ethnic, and socio-economic diversity. Corporation policy should reflect an understanding of the difficulties that programs in rural areas and inner-cities have in recruiting private sector and philanthropic dollars and the fact that programs whose enrollment focus is on low-income, out of school and minority young people are likely to have greater difficulty recruiting and retaining members than programs that recruit more affluent members.

3. The Re-fill Rule should be fully restored. While we appreciate the Corporation’s effort to reintroduce its slot refill policy, the present one-to-one, one-time-only policy is not sufficient to ensure that programs can meet local needs. AmeriCorps programs that enroll significant numbers of economically and educationally disadvantaged corps members are likely to experience higher rates of attrition and lower rates of retention. Reverting to its prior practice of allowing programs to completely re-fill vacated slots at any time during the year would allow greater participation in AmeriCorps, encourage participants with a broad array of backgrounds to participate, and ultimately allow programs—and AmeriCorps as a whole—to provide deserving people, often highly disadvantaged, the opportunity to pursue their educational goals.

#### CONCLUSION

For the last 70 years, Presidents of both parties, and their Congressional champions, have recognized that service programs with government support, the active support of community-based organizations, faith-based institutions, and the private sector can play an important role in strengthening communities, teaching the virtues of civic engagement, and strengthening the bonds that connect us as a people. Service is not only an effective strategy for attacking our problems, it is a way to remind Americans of all ages that we have a responsibility to give something back to our country.

We believe that AmeriCorps has made substantial progress in meeting these ambitious goals and look forward to working with you to improve the lives of all Americans through service.

Thank you for the opportunity to provide this testimony.

#### NATIONAL INSTITUTES OF HEALTH

#### PREPARED STATEMENT OF THE ALPHA-1 FOUNDATION

#### SUMMARY OF RECOMMENDATIONS

The Alpha-1 Foundation requests an allocation in the budget to enable the CDC, National Center for Birth Defects and Developmental Disabilities to implement a

national targeted Alpha-1 detection program. The Foundation recommends that CDC receive \$2 million in fiscal year 2006 for implementation.

The Foundation recommends that NHLBI enhance its portfolio of research and education on the fourth leading cause of death in the United States, Chronic Obstructive Pulmonary Disease (COPD), including genetic risk factors such as Alpha-1 Antitrypsin Deficiency.

The Foundation commends NIH on the roadmap and recommends that NHLBI, NIDDK, NHGRI, NIEHS, and other institutes establish an Alpha-1 inter-institute coordinating committee to facilitate collaboration on this genetic lung and liver disease.

The Foundation encourages HRSA to collect additional data to evaluate the impact of the new lung transplant organ allocation system being implemented by the Organ Procurement and Transplantation Network/United Network for Organ Sharing.

The Foundation supports the request of the Ad Hoc Group for Medical Research Funding for a \$30 billion appropriation for NIH in fiscal 2006.

Mr. Chairman and members of the Subcommittee thank you for the opportunity to submit testimony for the record on behalf of the Alpha-1 Foundation.

#### THE ALPHA-1 FOUNDATION

The Alpha-1 Foundation is a national not-for-profit organization dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1 Antitrypsin (Alpha-1) Deficiency. The Foundation has built the research infrastructure with private investment, funding over \$15,000,000 in grants from basic to social science, establishing a national patient registry, tissue and DNA bank, translational laboratory, assisting in fast track development of new therapeutics, and stimulating the involvement of the scientific community. The Foundation has invested the resources to support clinical research which follows the roadmap established by the NIH; uniquely positioning it for a perfect private public partnership. There is a lack of awareness of the insidious nature of the early symptoms of the lung and liver disease associated with this genetic condition by both medical care providers and the public. It is our hope that the federal government will leverage the Foundation's investment with support for a national Alpha-1 targeted detection program.

#### ALPHA-1 IS SERIOUS AND LIFE THREATENING

Alpha-1 is the leading genetic risk factor for Chronic Obstructive Pulmonary Disease (COPD) and is often misdiagnosed as such. Alpha-1 afflicts an estimated 100,000 individuals in the United States with fewer than 5 percent accurately diagnosed. These are people who know they are sick and as yet have not put a name to their malady. Although Alpha-1 testing is recommended for those with COPD this standard of care is not being implemented. In addition, an estimated 20 million Americans are the undetected carriers of the Alpha-1 gene and may pass the gene on to their children. Of these 20 million carriers, 7–8 million may be at risk for lung or liver disease.

The pulmonary impairment of Alpha-1 causes disability and loss of employment during the prime of life (20–40 years old), frequent hospitalizations, family disorganization, and the suffering known only to those unable to catch their breath. Fully half of those diagnosed require supplemental oxygen. Lung transplantation, with all its associated risks and costs, is the most common final option. Alpha-1 is the primary cause of liver transplantation in infants and an increasing cause in adults. Alpha-1 liver disease currently has no specific treatment aside from transplantation. The cost to these families in time, energy and money is high and often devastating. Alpha-1 also causes liver cancer.

Alpha-1 is a progressive and devastating disorder that in the absence of proper diagnosis and therapy leads to premature death; in spite of the availability of therapeutics for lung disease and preventative health measures that can be life-prolonging. It is estimated that untreated individuals can have their life expectancy foreshortened by 20 or more years. Yet early detection, the avoidance of environmental risk factors and pulmonary rehabilitation can significantly improve health.

#### THE MEDICAL NEEDS OF THE ALPHA-1 COMMUNITY HAVE GONE UNMET

Alpha-1 is a hidden killer that desperately needs new therapies. There is a lack of awareness of the insidious nature of the early symptoms of the lung and liver disease associated with this genetic condition by both medical care providers and the public.

Currently, the only specific therapy for Alpha-1 lung disease is intravenous augmentation therapy produced from pooled human plasma at an average annual cost of \$50,000–\$100,000. This therapy increases the plasma levels of the deficient protein and appears to slow or halt the progression of the pulmonary disease described above. There is currently nothing available to regenerate lung tissue and restore lung function.

In addition, Alpha-1 liver disease is equally life threatening, as is the case with many chronic liver conditions, often reaching an advanced stage with few symptoms and little warning. Advanced liver disease is often untreatable, and many with Alpha-1 have erroneously been told they have alcoholic liver disease because of the lack of physician awareness.

#### ALPHA-1 AND COPD

As the fourth leading cause of death, COPD is a major public health concern. Data indicates that not all individuals who smoke develop lung disease leading many to conclude that COPD has significant genetic and environmental risk factors. As the most significant genetic risk factor for COPD, Alpha-1 has much to tell us about the pathogenesis of lung disease. Discoveries and advances made in Alpha-1 will impact the larger 10–24 million individuals living with COPD.

#### DETECTION

The Alpha-1 Foundation conducted a pilot program in the state of Florida where we garnered the knowledge and experience necessary to launch an awareness and National Targeted Detection Program (NTDP). The goals of the NTDP are to educate the medical community and people with COPD and liver disease, alerting them that Alpha-1 may be an underlying factor of their disease; and stimulating testing for Alpha-1. This effort will uncover a significant number of people who would benefit from early diagnosis, treatment and preventative health measures.

The Foundation distributes the American Thoracic Society/European Respiratory Society (ATS/ERS) “Standards for the Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency” to physicians, nurses and respiratory therapists. Additionally, health care practitioners and the COPD community are being targeted through press releases, newsletter articles and various website postings.

The national implementation of the NTDP is enhanced through the 7 Clinical Resource Network Centers of the National Heart, Lung, Blood Institute of the National Institutes of Health; 51 Foundation affiliated Clinical Resource Centers; large pulmonary practices and various teaching hospitals and universities. The NTDP also employs a direct to consumer approach targeted to people with COPD.

The Alpha-1 Foundation’s Ethical Legal and Social Issues (ELSI) Working Group endorsed the recommendations of the ATS/ERS Standards Document which recommends testing symptomatic individuals or siblings of those who are diagnosed with Alpha-1. Early diagnosis in Alpha-1 can significantly impact disease outcomes by allowing individuals to seek appropriate therapies, and engage in essential life planning. Unfortunately, seeking a genetic test may lead to discrimination against individuals who have no control over their inherited condition. The absence of federal protective legislation has caused the ELSI to recommend against population screening and genetic testing in the neonatal population. The Foundation commends the Senate for passing the Genetic Non-Discrimination Act of 2005 and is working to ensure that the House takes the same positive action.

The Alpha-1 Coded Testing (ACT) Trial, funded by the Alpha-1 Foundation and conducted at the Medical University of South Carolina offers a free and confidential finger-stick test that can be completed at home. The results are mailed directly to the participants. The ACT Trial has offered individuals the opportunity to receive confidential test results since September of 2001, to date over 2,400 test kits have been requested.

#### ALPHA-1 RESEARCH

The Alpha-1 Foundation believes that significant federal investment in medical research is critical to improving the health of the American people and specifically those affected with Alpha-1. The support of this Subcommittee has made a substantial difference in improving the public’s health and well-being.

The Foundation requests that the National Institutes of Health increase the investment in Alpha-1 Antitrypsin (AAT) Deficiency and that the Centers for Disease Control and Prevention initiate a federal partnership with the Alpha-1 community to achieve the following goals:

- Promotion of basic science and clinical research related to the AAT protein and AAT Deficiency;

- Funding to attract and train the best young clinicians for the care of individuals with AAT Deficiency;
- Support for outstanding established scientists to work on problems within the field of AAT research;
- Development of effective therapies for the clinical manifestations of AAT Deficiency;
- Expansion of awareness and targeted detection to promote early diagnosis and treatment.

#### SPECIFIC AREAS OF CONCERN AND RECOMMENDATIONS

1. The Foundation requests an allocation in the budget to enable the CDC, National Center for Birth Defects and Developmental Disabilities to implement a national targeted Alpha-1 detection program. The Foundation recommends that CDC receive \$2 million in fiscal year 2006 for implementation.

2. The Foundation recommends that NHLBI enhance its portfolio of research and education on the fourth leading cause of death in the United States, Chronic Obstructive Pulmonary Disease (COPD), including genetic risk factors such as Alpha-1 Antitrypsin Deficiency.

3. The Foundation commends NIH on the roadmap and recommends that NHLBI, NIDDK, NHGRI, NIEHS, and other institutes establish an Alpha-1 inter-institute coordinating committee to facilitate collaboration on this genetic lung and liver disease.

4. The Foundation encourages HRSA to collect additional data to evaluate the impact of the new lung transplant organ allocation system being implemented by the Organ Procurement and Transplantation Network/United Network for Organ Sharing.

5. The Foundation supports the request of the Ad Hoc Group for Medical Research Funding for a \$30 billion appropriation for NIH in fiscal 2006.

#### ALPHA-1 FAST FACTS

Alpha-1 Antitrypsin Deficiency (Alpha-1) is one of the most common fatal genetic diseases, 95 percent of those with Alpha-1 are undiagnosed.

Alpha-1 is commonly misdiagnosed as asthma and Chronic Obstructive Pulmonary Disease (COPD) as symptoms are similar. It usually takes seven years and five physicians to be accurately diagnosed after the onset of symptoms.

The World Health Organization (WHO) and the American Thoracic Society/European Respiratory Society recommends that all individuals with chronic obstructive pulmonary disease (an estimated 10–24 million Americans) as well as adults and adolescents with asthma (an estimated 14.6 million Americans) be tested for Alpha-1.

Alpha-1 is more prevalent than Cystic Fibrosis. An estimated 20 million Americans are undetected carriers of the Alpha-1 gene and may be at risk for lung and/or liver disease and may pass the gene on to their children.

Alpha-1 is a life-threatening adult onset lung disease that is progressive and irreversible. It is a major reason for lung transplantation. Nothing repairs lung tissue damage but early diagnosis allows individuals to engage in preventative health strategies and receive appropriate therapy which saves health care dollars.

Alpha-1 can also manifest as liver disease (5–10 percent) in adults as well as newborns for which the only treatment is a liver transplant. Alpha-1 is a leading cause of liver transplants in newborns.

#### COMMON SYMPTOMS OF ALPHA-1 INCLUDE

- Recurring respiratory infections
- Shortness of breath or awareness of one's breathing
- Non-responsive Asthma or Year-Round Allergies
- Rapid deterioration of lung function without a history of significant smoking
- Decreased exercise tolerance
- Chronic liver problems
- Elevated liver enzymes

---

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to present its recommendations on issues related to fiscal year 2006 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older



Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP would like to thank the Subcommittee for its continued strong support for increased funding for the National Institutes of Health (NIH) over the last several years, particularly the additional funding you have provided for the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

There are serious concerns, shared by AAGP and researchers, clinicians, and consumers that there exists a critical disparity between appropriations for research, training, and health services and the projected mental health needs of older Americans. This disparity is evident in the convergence of several key factors:

- demographic projections inform us that, with the aging of the U.S. population, there will be an unprecedented increase in the burden of mental illness among aging persons, especially among the baby boom generation;
- this growth in the proportion of older adults and the prevalence of mental illness is expected to have a major direct and indirect impact on general health service use and costs;
- despite the fact that effective treatment exists, the current mental health needs of many older adults remain unmet;
- the number of physicians being trained in geriatric mental health research and clinical care is insufficient to meet current needs, and this workforce shortfall is projected to become a crisis as the U.S. population ages over the next decade;
- a major gap exists between research, mental health care policy, and service delivery; and
- despite recent significant increases in appropriations for support of research in mental health, the allocation of NIMH and CMHS funds for research that focuses specifically on aging and mental health is disproportionately low, and woefully inadequate to deal with the impending crisis of mental health in older Americans.

#### DEMOGRAPHIC PROJECTIONS AND THE MENTAL DISORDERS OF AGING

With the baby boom generation nearing retirement, the number of older Americans with mental disorders is certain to increase in the future. By the year 2010, there will be approximately 40 million people in the United States over the age of 65. Over 20 percent of those people will experience mental health problems. A national crisis in geriatric mental health care is emerging and has received recent attention in the medical literature. Action must be taken now to avert serious problems in the near future. While many different types of mental and behavioral disorders can occur late in life, they are not an inevitable part of the aging process, and continued research holds the promise of improving the mental health and quality of life for older Americans.

The current number of health care practitioners, including physicians, who have training in geriatrics is inadequate. As the population ages, the number of older Americans experiencing mental problems will almost certainly increase. Since geriatric specialists are already in short supply, these demographic trends portend an intensifying shortage in the future. There must be a substantial public and private sector investment in geriatric education and training, with attention given to the importance of geriatric mental health needs. We will never have, nor will we need, a geriatric specialist for every older adult. However, without mainstreaming geriatrics into every aspect of medical school education and residency training, broad-based competence in geriatrics will never be achieved. There must be adequate funding to provide incentives to increase the number of academic geriatricians to train health professionals from a variety of disciplines, including geriatric medicine and geriatric psychiatry.

Current and projected economic costs of mental disorders alone are staggering. The direct medical expense to care for a patient with Alzheimer's disease ranges from \$18,000 to \$36,000 a year per patient, depending on the severity of the disease. In addition, there are substantial indirect costs associated with caring for an Alzheimer's disease patient including social support, care giving, and often nursing home care. It is estimated that total costs associated with the care of patients with

Alzheimer's disease is over \$100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and family burden. These psychiatric symptoms, associated with Alzheimer's disease, can increase the cost of treating these patients by more than 20 percent. Although NIA has supported extensive research on the cause and treatment of Alzheimer's, treatment of these behavioral and psychiatric symptoms has been neglected and should be supported through NIMH.

Depression is another example of a common problem among older persons. Approximately 30 percent of older persons in primary care settings have significant symptoms of depression; and depression is associated with greater health care costs, poorer health outcomes, and increased mortality. Of the approximately 32 million Americans who have attained age 65, about five million suffer from depression, resulting in increased disability, general health care utilization, and increased risk of suicide. Older adults have the highest rate of suicide rate compared to any other age group. Comprising only 13 percent of the U.S. population, individuals age 65 and older account for 19 percent of all suicides. The suicide rate for those 85 and older is twice the national average. More than half of older persons who commit suicide visited their primary care physician in the prior month—a truly stunning statistic.

The enormous and widely underestimated costs of late-life mental disorders justify major new investments. The personal and societal costs of mental illness and addictive disorders are high, but advances in research and treatment will help save lives, strengthen families, and save taxpayer dollars.

#### THE BENEFITS OF RESEARCH ON PUBLIC HEALTH

The U.S. Surgeon General's Report on Mental Health (1999) and the Administration on Aging Report on Older Adults and Mental Health (2001) underscore the prevalence of mental disorders in older persons and provide evidence that research has led to the development of effective treatments. These reports summarize research findings showing that treatments are effective in relieving symptoms, improving functioning, and enhancing quality of life. Preliminary findings suggest that these interventions reduce the need for expensive and intensive acute and long-term services. However, it is also well demonstrated that there is a pronounced gap between research findings on the most effective treatment interventions and implementation by health care providers. This gap can be as long as 15 to 20 years. These reports stress the need for translational and health services research focused on identifying the most cost-effective interventions, as well as creating effective methods for improving the quality of health care practice in usual care settings. A major priority (neglected to date) is the development of a health services research agenda that examines the effectiveness and costs of proven models of mental health service delivery for older persons.

Special attention also needs to be paid to inadequately or poorly studied, serious late-life mental disorders. Illnesses such as schizophrenia, anxiety disorders, alcohol dependence and personality disorders have been largely ignored by both the research community and the funding agencies, despite the fact that these conditions take a major toll on patients, their care givers, and society at large. Many of AAGP's members are at the forefront of groundbreaking research on Alzheimer's disease, depression, and psychosis among the elderly, and we strongly believe that more research funds must be focused in these areas. Improving the treatment of late-life mental health problems will benefit not only the elderly, but also their children, whose lives are often profoundly affected by their parents' illness.

While the funding increases supported by this Subcommittee in recent years have been essential first steps to a better future, a committed and sustained investment in research is necessary to allow continuous progress on the many research advances made to date.

#### NATIONAL INSTITUTE OF MENTAL HEALTH

In his fiscal year 2006 budget, the President proposed an increase of \$200 million for the National Institutes of Health (NIH), which would bring the entire NIH budget to a level of \$28.8 billion. However, this 0.7 percent increase over the fiscal year 2005 funding level pales in comparison with recent annual double-digit increases. A decline in adequate funding increases could have a devastating impact on the ability of NIH to sustain the ongoing, multi-year research grants that have been initiated in recent years.

For NIMH, the President is proposing \$1.418 billion for scientific and clinical research, a 0.4 percent increase over the agency's fiscal year 2005 appropriation of

\$1.412 billion. It is important to note that from fiscal year 1999 through fiscal year 2005, NIMH received increases that lagged behind the increases received by many of the other NIH institutes. Furthermore, the increase proposed by the Administration for NIMH for fiscal year 2006 is lower than that proposed for most of the other institutes at NIH. As Congress moves forward with deliberations on the fiscal year 2006 budget, AAGP believes that NIMH should receive a percentage increase that, at the very minimum, is equal to the average percentage increase for the other NIH institutes.

Commendable as recent funding increases for NIH and NIMH have been, AAGP would like to call to the Subcommittee's attention the fact that these increases have not always translated into comparable increases in funding that specifically address problems of older adults. Data supplied to AAGP by NIMH indicates that while extramural research grants by NIMH increased 59 percent during the five-year period from fiscal year 1995 through fiscal year 2000 (from \$485,140,000 in fiscal year 1995 to \$771,765,000 in fiscal year 2000), NIMH grants for aging research increased at less than half that rate: only 27.2 percent during the same period (from \$46,989,000 to \$59,771,000). Furthermore, despite the fact that over the past four years, Congress, through Committee report language, has specifically urged NIMH to increase research grant funding devoted to older adults, this has not occurred.

AAGP is pleased that NIMH has recently renewed its emphasis on mental disorders among the elderly, and commends the recent creation of a new Aging Treatment and Prevention Intervention Research Branch at NIMH. AAGP would like the scope of this Branch increased into a comprehensive aging Branch that is responsible for all facets of clinical research, including translational, interventions, and disease-based psychopathology. The Branch should also be given adequate resources to fulfill its primary mission within NIMH.

In addition to supporting research activities at NIMH, AAGP supports increased funding for research related to geriatric mental health at the other institutes of NIH that address issues relevant to mental health and aging, including the National Institute of Aging (NIA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the National Institute on Drug Abuse (NIDA), and the National Institute of Neurological Disorders and Stroke.

#### CENTER FOR MENTAL HEALTH SERVICES

It is also critical that there be adequate funding increases for the mental health initiatives under the jurisdiction of the CMHS within SAMHSA. While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. SAMHSA provides funding to State and local mental health departments, which in turn provide community-based mental health services to Americans of all ages, without regard to the ability to pay. AAGP was pleased that the final budgets for fiscal years 2002, 2003, 2004, and 2005 included \$5 million for evidence-based mental health outreach and treatment to the elderly. AAGP worked with members of this Subcommittee and its House counterpart on this initiative, which is a very important first step in addressing the mental health needs of the nation's senior citizens. Increasing this mental health outreach and treatment program must be a top priority, as it is the only Federally funded services program dedicated specifically to the mental health care of older adults.

Funding for the dissemination and implementation of evidence-based practices in "real world" care settings must also be a top priority for Congress. Despite significant advances in research on the causes and treatment of mental disorders in older persons, there is a major gap between these research advances and clinical practice in usual care settings. The greatest challenge for the future of mental health care for older Americans is to bridge this gap between scientific knowledge and clinical practice in the community, and to translate research into patient care. Adequate funding for this geriatric mental health services initiative is essential to disseminate and implement evidence-based practices in routine clinical settings across the states. Consequently, we would urge that the \$5 million for mental health outreach and treatment for the elderly included in the CMHS budget for fiscal year 2005 be increased to \$20 million for fiscal year 2006.

Of that \$20 million appropriation, AAGP believes that \$10 million should be allocated to a National Evidence-Based Practices Program, which will disseminate and implement evidence-based mental health practices for older persons in usual care settings in the community. This program will be a collaborative effort, actively involving family members, consumers, mental health practitioners, experts, professional organizations, academics, and mental health administrators. With \$10 million dedicated to a program to disseminate and implement evidence-based practice in geriatric mental health, there will be an assured focus on facilitating accurate,

broad-based sustainable implementation of proven effective treatments, with an emphasis on practice change and consumer outcomes. Such a program should include several development phases including identification of a core set of evidence-based practices, development of evidence-based implementation, and practice improvement toolkits and field-testing of evidence-based implementation. This program will provide the foundation for a longer-term national effort that will have a direct effect on the well-being and mental health of older Americans.

The Community Mental Health Services Block Grant Program distributes funds to 59 eligible States and Territories through a formula based upon specified economic and demographic factors. Applications must include an annual plan for providing comprehensive community mental health services to adults with a serious mental illness and children with a serious emotional disturbance. Because the mental health needs of our Nation's elderly population are often not met by existing programs and because the need for such services is dramatically and rapidly increasing, AAGP recommends that SAMHSA require States' plans to include specific provisions for mental health services for older adults. Experience has demonstrated that States do not make adequate provisions for older adults. This population, which has unique needs, has been neglected in the planning process. Steps need to be taken to ensure that adequate mental health services are available to them.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

One of the most valuable resources in our efforts to improve access to and the quality of geriatric mental health services is the Agency for Healthcare Research and Quality (AHRQ). In recent years the Agency has supported important research on mental health topics including studies on children's mental health issues, the impact of mental health parity on consumers' share of mental health costs, improving care for depression in primary care, and cultural issues in the treatment of mental illness in minority populations. This work has led to important contributions to the mental health literature, and the advancement of effective diagnosis and treatment of mental illness. We applaud these efforts and urge the Committee to increase support for the critical work of this Agency.

However, we are concerned that the research agenda of the Agency has not given more attention to geriatric mental health issues. The prevalence of undiagnosed and untreated mental illness among the elderly is alarming. Conditions such as depression, anxiety, dementia, and substance abuse in older adults are often misdiagnosed or not recognized at all by primary and specialty care physicians. There is accumulating evidence that depression can exacerbate the effects of cardiac disease, cancer, strokes, and diabetes. Research has also shown that treatment of mental illness can improve health outcomes for those with chronic diseases. Effective treatments for mental illnesses in the elderly are available, but without access to physicians and other health professionals with the training to identify and treat these conditions, far too many seniors fail to receive needed care.

AAGP believes there is an urgent need to translate findings from aging-related biomedical and behavioral research into geriatric mental health care. By utilizing the resources of the evidence-based practice centers under contract to AHRQ, results from geriatric mental health research can be evaluated and translated into findings that will improve access, foster appropriate practices, and reduce unnecessary and wasteful health care expenditures. We urge the Committee to direct AHRQ to support additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population. We also believe a high priority should be given to the dissemination of scientific findings about what works best, to encourage physicians and other health professionals to adopt "best practices" in geriatric mental health care.

#### CONCLUSION

Based on AAGP's assessment of the current need and future challenges of late life mental disorders, we submit the following fiscal year 2006 funding recommendations:

1. The current rate of funding for aging grants at NIMH and CMHS is inadequate. Funding for NIMH and CMHS aging-related health services grants should be increased to be commensurate with current need—at least three times their current funding levels. In addition, the substantial projected increase in mental disorders in our aging population should be reflected in the budget process in terms of dollar amount of grants and absolute number of new grants.

2. To help the country's elderly access necessary mental health care, previous years' funding of \$5 million for evidence-based mental health outreach and treatment for the elderly within CMHS must be increased to \$20 million.

3. A fair grant review process will be enhanced by committees with specific expertise and dedication to mental health and aging.

4. Adequate infrastructure and funding within both NIMH and CMHS to support the development of initiatives in aging research, to monitor the number and quality of applicants for aging research grants, to promote funding of meritorious projects, and to manage those grant portfolios.

5. The scope of the recently formed Aging Treatment and Prevention Intervention Research Branch at NIMH should be increased to include all relevant clinical research, including translational, interventions, and disease-based psychopathology, and must receive NIMH's full support so it may fulfill its primary mission.

6. AHRQ should undertake additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population, and dissemination of information on best practices.

7. Funding for NIAAA must be increased by at least 20 percent to enable it to undertake more research and collect more data focused on issues such as the link between alcohol use and late-life suicide and the impact of alcohol use across the lifespan.

AAGP strongly believes that the present research infrastructure, professional workforce with appropriate geriatric training, health care financing mechanisms, and mental health delivery systems are grossly inadequate to meet the challenges posed by the expected increase in the number of older Americans with mental disorders. Congress must support funding for research that addresses the diagnosis and treatment of mental illnesses, as well as programs for delivery of geriatric mental health services that increase the quality of life for those with late-life mental illness.

AAGP looks forward to working with the members of this Subcommittee and others in Congress to establish geriatric mental health research and services as a priority at NIMH, CMHS, AHRQ and NIAAA.

---

PREPARED STATEMENT OF THE AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION

The American Autoimmune Related Diseases Association (AARDA) is the only national voluntary health agency advocating for the over 100 autoimmune diseases as a genetically and clinically interrelated family, like cancer. AARDA's aim is to initiate, foster and facilitate collaboration in autoimmune awareness, education, advocacy and research. AARDA initiated, supports and facilitates the National Coalition of Autoimmune Patient Groups (NCAPG), a coalition of 25 voluntary health agencies focusing on individual autoimmune diseases.

The family of autoimmune diseases is under-recognized and as a result poses a major healthcare problem in the United States. These diseases afflict over 22 million Americans, more than twice as many as cancer. Treatment costs exceed \$120 billion per year and are rising rapidly, putting autoimmune disease's financial burden on the same level as heart and stroke disease and cancer. Autoimmune diseases are one of the top ten leading causes of death in females under the age of 65.

Autoimmune diseases are a major cause of chronic disability, further increasing their financial burden on society. Well-known autoimmune diseases include lupus, rheumatoid arthritis, multiple sclerosis, and juvenile (Type 1) diabetes. Lesser-known are scleroderma, Crohn's disease, myasthenia gravis, polymyositis, autoimmune liver diseases, Sjögren's syndrome and autoimmune blood disorders.

There is a huge disparity in autoimmune disease research funding compared to other major disease groups, such as cancer and heart disease. And some autoimmune diseases get a disproportionate amount of research funding compared to the others.

Congress addressed these issues in the Children's Health Act of 2000, which mandated the National Institutes of Health (NIH) Autoimmune Disease Coordinating Committee to develop an integrated Autoimmune Diseases Research Plan to address the entire family of autoimmune diseases and their common underlying cause—the immune system mistakenly attacking healthy body tissue and organs. All NIH institutes, the CDCP, VA, FDA and many patients' organizations provided input to develop and review the Research Plan. It is an excellent plan recommending an integrated cost-effective approach to autoimmune disease research and information dissemination.

Some of the Autoimmune Diseases Research Plan's recommendations have been implemented, but most have not. Much remains to be done, especially in the new and promising research areas identified in the Plan. AARDA strongly supports additional funding for the NIH Autoimmune Disease Coordinating Committee to further

expand implementation of the Autoimmune Diseases Research Plan. This additional funding will allow the Coordinating Committee to pursue promising research in the areas of environmental triggers, biomarkers and underlying disease mechanisms to help identify individuals at risk of developing an autoimmune disease and develop techniques to prevent the disease or minimize its impact.

AARDA respectfully requests Congress to appropriate \$40 million for the NIH Autoimmune Disease Coordinating Committee to expand implementation of the Autoimmune Diseases Research Plan to study environmental triggers of autoimmune disease. This research will pay for itself many times over by helping to reduce the major financial burden the family of autoimmune diseases places on our country.

On behalf of the many millions afflicted with an autoimmune disease and their families, thank you for the opportunity to address this important issue as Congress develops the Labor, HHS fiscal year 2006 budget. For More information, contact Virginia T. Ladd, Director, American Autoimmune Related Diseases Assoc., 22100 Gratiot, Eastpointe, MI., 48021, 586-776-3900 (p) 586-776-3903 (F)

#### PREPARED STATEMENT OF THE AMERICAN BRAIN COALITION

##### WHAT IS THE AMERICAN BRAIN COALITION?

The American Brain Coalition (ABC) is a nonprofit organization that seeks to reduce the burden of brain disorders and advance the understanding of the functions of the brain. ABC, unlike any other organization, brings together all types of organizations representing the 50 million individuals affected by brain disorders. This includes the afflicted patients, the families of those that suffer, the caregivers, and the professionals that research and treat diseases of the brain.

ABCs' goals are to: (1) promote research funding and progress towards cures, (2) help to build a healthcare system that is more responsive to people with both acute and chronic brain disorders, and (3) advance public understanding about the causes, impacts, and consequences of neurologic and psychiatric illness in our society.

The brain is the center of human existence, and the most complex living structure known. As such, ABC members have a broad range of interests. Among others, the coalition includes organizations and individuals that:

- are clinicians who treat neurological diseases
- are scientists who research the brain, including the neurological and psychiatric disorders that affect it
- investigate basic and clinical aspects of epilepsy
- fund research on Rett Syndrome, a debilitating neurological disorder
- are pioneers in educational and vocational training for the mentally retarded
- have family members affected by mental health conditions, such as depression, schizophrenia, and obsessive-compulsive disorder
- are affected by Parkinson's disease and essential tremor

##### CONGRESSIONAL SUPPORT ACCELERATES DISCOVERY

The National Institutes of Health (NIH), the world's premier medical research enterprise, is leading the way in research related to the brain. Thanks to this subcommittee, Congress held to its commitment to double the budget of the NIH in the late 1990s and early 2000s. The primary goal for the added funds was to discover better treatments and cures for human disease. Since then, scientists have amassed a wealth of medical knowledge. Today, researchers have a greater understanding of how the brain and nervous system function due to NIH-funded research. On behalf of the millions of Americans suffering from a disorder of the brain, ABC thanks the Chairman and Ranking Member for their continued support of this life altering research.

Many recent scientific discoveries, including those in neurology and psychiatry, have just begun to show their potential. Some accomplishments that are a direct result of NIH research include:

- The development of drugs that reduce the severity of symptoms for those suffering with multiple sclerosis and Parkinson's disease
- The identification of stroke treatment and prevention methods
- The discovery of a new class of anti-depressants that produce fewer side effects than their predecessors
- The creation of new drugs to help prevent epileptic seizures
- The expansion of treatments for the psychotic symptoms of schizophrenia

Insights into the biology of schizophrenia, post-traumatic stress disorder, and other diseases have led to the development of enhanced diagnostic techniques, bet-

ter prevention methods, and more effective treatments. Simply put: the result of Congressional support for research leads to improved patient care.

#### WHAT COMES NEXT? THE FUTURE OF RESEARCH

ABC supports NIH in its entirety, with a more specific interest in the institutes and centers that focus on diseases and disorders of the brain and nervous system. Because the brain affects all parts of the body, brain research is broad and must be conducted across institutes in order to fully understand the diseases that affect so many Americans.

The NIH Neuroscience Blueprint is a framework to enhance cooperation among 15 NIH institutes and centers that support this research. Over the past 10 years, driven by the science, the NIH neuroscience institutes and centers have increasingly joined forces through initiatives and working groups focused on specific disorders. The Blueprint builds on this foundation, making collaboration an everyday part of how the NIH does business in neuroscience. By pooling resources and expertise, the Blueprint can take advantage of economies of scale, confront challenges too large for any single institute, and develop research tools and infrastructure that will serve the entire neuroscience community.

The Neuroscience Blueprint encourages the collaboration necessary in order to advance basic science and to develop new more effective bedside treatments. The following diseases, along with many others, have the potential to be greatly affected from this research.

1. *Stroke*.—Research has already led to the development of more effective stroke treatments, the identification of new prevention methods, and the creation of improved rehabilitation techniques. Despite much progress in stroke research over the past decade, much remains to be done.

With continued funding, therapies to reverse paralysis of limbs may be possible. A preliminary analysis indicates that the resulting financial benefits from reduced medical care, a quicker return to work, and improved quality of life outweigh the costs of therapy. Future studies seek to refine the technique, called constraint-induced movement therapy to further improve outcomes and lower costs.

2. *Epilepsy*.—Research in the field of Epilepsy has already led to the discovery of genetic mutations that play a role in how seizures begin. Additionally, research has aided in the development of a new generation of antiepileptic drugs and better brain scanning techniques that assist in diagnosis.

With continued funding, additional drug therapies might be developed to control seizures. Currently, up to one-third of patients are resistant to drug therapy. More research must be done in order to improve the quality of life for these people. One promising approach may be to use gene therapy to modify the excitability of hyperactive brain cell circuits. Additionally, increased funding might aid in the development of devices that are implanted into the brain that could forewarn doctors and patients of an impending seizure. These tiny devices could then deliver the drugs directly to the epileptic brain region in doses that could be regulated by the patient or doctor. Much more work is needed before such a system could be widely used.

3. *Bipolar Disorder*.—Past funding from NIH and the Department of Veterans Affairs has helped scientists make great progress in understanding bipolar disorder. Today, we know that bipolar disorder is a biologically based disorder, and not a result of a weak personal character. Using the latest brain imaging techniques, scientists have discovered that the brain function and structure in patients with bipolar disorder differs markedly from that in people without the illness.

Continued funding for research could lead to the development of tests for earlier diagnosis and treatment, as well as drug therapies to prevent or reverse the progressive loss of brain cells that occurs with bipolar disorder. Already, scientists are exploring the possibility for low-dose lithium as a preventative measure against atrophy and loss of cells. Research on lithium may prove advantageous for a variety of diseases, including schizophrenia and Alzheimer's disease.

Only with continued funding will scientists be able to bring hope to the millions of Americans suffering from a brain disorder.

#### BEYOND HELPING PEOPLE: FEDERAL INVESTMENTS IN RESEARCH ARE ECONOMICALLY BENEFICIAL

Not only does research save lives, but it is a good investment for the future of America. We know that illness is expensive. Depressive diseases alone cost U.S. businesses \$83 billion in medical expenditures, suicide-related costs, absences from work, and reduced productivity while at work. The annual cost of Alzheimer's disease in the United States is over \$100 billion, with more than \$30 billion of that amount paid out by Medicare. As the baby boomers age, without effective therapy,

the number of people affected by Alzheimer's will quadruple. This number is only expected to increase.

NIH-funded research could alleviate some of the financial strains that brain disorders place on businesses, government, and families. For example, a one month delay in admitting Alzheimer's patients to nursing homes could save \$1 billion per year. Without additional research, the economic burden placed on U.S. resources will be exacerbated.

In addition to helping control costs, the federal investment in research helps stimulate local economies. NIH dollars are sent to every state in the country, helping to employ thousands of people. According to the Bureau of Labor Statistics, nearly 1 million people in the United States are employed in the biosciences. This number is projected to grow at an annual rate of 13 percent.

#### RECOMMENDATION

As the Subcommittee considers the fiscal year 2006 appropriations for the Department of Health and Human Services, we urge you to support a 6 percent increase in funding for the National Institutes of Health in order to sustain the pace of recent discoveries.

Treatments for diseases and disorders of the brain will only be possible if the NIH, the world's leading medical research enterprise, has a longstanding commitment from Congress.

ABC's request is based on the following information:

- \$1 billion is needed to cover biomedical research inflation, which is projected to be 3.5 percent;
- \$560 million is needed to replace the evaluation set-aside (an amount taken from each institute), which this year amounted to 2.4 percent (it used to be 1 percent); and
- The total number of research project grants (RPGs) is declining by 402 from what it was in fiscal year 2005.

Thank you for the opportunity to provide testimony to this Subcommittee.

#### PREPARED STATEMENT OF THE AMERICAN COLLEGE OF CARDIOLOGY

More than 70 million Americans are living with cardiovascular disease, with more than 900,000 of them dying this year from disease-related complications. In fact, heart disease claims more lives than cancer, diabetes, and chronic respiratory diseases combined. As physicians toil to keep these patients alive, another group of individuals is working just as hard to fight the ravages of heart disease: Medical researchers.

The American College of Cardiology (ACC), a 33,000-member nonprofit professional medical society advocating for quality cardiovascular care, supports increased federal funding of medical research and urgently calls on Congress to continue to invest in future cardiovascular care.

As with any financial outlay, there needs to be a healthy return on investment. The same holds true for medical research, and the ACC believes the data speaks loudly. Between 1982 and 2002, death rates attributed to cardiovascular diseases declined by 37 percent. This remarkable achievement can be attributed to clinically proven treatments and techniques for managing heart disease. These life-saving technology advances and treatments originate with cutting-edge research. Without federally-funded clinical trials, there would not be stents or statins, ICDs or AEDs, and millions more Americans would die prematurely from cardiovascular disease.

Each year, agencies such as the National Institutes of Health (NIH) release groundbreaking studies that fundamentally change the course of medicine. This year was no exception. Initially presented at the ACC's Annual Scientific Session in early March and published March 31, 2005, in *The New England Journal of Medicine*, *The Women's Health Study* has left its mark on the cardiovascular world. This 10-year study of 40,000 healthy women showed that aspirin did not reduce the risk of major cardiovascular events, a stark contrast to the effects of aspirin in men. In addition, researchers concluded that many women, especially those 65 and older, may benefit from taking low-dose aspirin every other day with the primary goal to prevent stroke. The results of this study hold immediate implications for the treatment of women at risk for heart disease, but also point to the broader role of understanding and adjusting for gender in the development of medical regimens.

Compelling cardiovascular research conducted by the NIH and the National Heart, Lung and Blood Institute (NHLBI) is critical to physicians winning the fight against heart disease. The ACC does not believe that President Bush's proposed fiscal year 2006 budget reflects the commitment needed to these critical research insti-



tutions. Under the President's plan, the National Institutes of Health (NIH) would receive a 0.5 percent increase, which is significantly less than the current rate of inflation. As one of 27 institutes falling under the NIH umbrella, the NHLBI stands to receive a pittance of this modest increase. The Centers for Disease Control and Prevention (CDC) fare even worse, facing millions of dollars in actual funding cuts for fiscal year 2006.

In order to continue life-saving cardiovascular research and education, the ACC supports the following fiscal year 2006 appropriations funding levels:

- \$30 billion for the NIH, including \$2.3 billion for heart research and \$341 million for stroke research
- \$3.1 billion for the NHLBI, including \$1.9 billion for heart and stroke-related research
- \$55.6 million for the CDC's Heart Disease and Stroke Prevention Program

These allocations will enable core cardiovascular research that improves clinical outcomes and quality of care. As the medical landscape continues to shift with the introduction of new technology and more complex caseloads, evidence-based research serves as the foundation of clinical guidelines that direct physician practice. The ACC draws on federally-funded research to craft documents that set the standard for cardiovascular care and guide the practice of our members worldwide.

Adequately funding research today will reap dividends tomorrow, upon which the federal government through its Centers for Medicare & Medicaid Services (CMS) will undoubtedly benefit. Even now, CMS is sponsoring pilot projects designed to pay physicians based on evidence-driven performance. Advances in medical protocols derived from federally underwritten research will become the backbone for this push to deliver better, more cost-effective patient care.

By investing in medical research now, Congress can help at-risk patients minimize the impact of cardiovascular disease and improve quality of care for more than 70 million heart patients. The ACC encourages the subcommittee to continue its support of federally-funded cardiovascular research by supplying federal agencies with the resources to continue their life-saving work. Thank you for permitting the ACC to share its views on this important topic.

#### PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

The American Dental Hygienists' Association (ADHA) appreciates this opportunity to submit written testimony regarding fiscal year 2006 appropriations for the Department of Health and Human Services.

ADHA is the largest national organization representing the professional interests of the more than 120,000 dental hygienists across the country. Dental hygienists are preventive oral health professionals who are licensed in each of the fifty states. As prevention specialists, dental hygienists understand that recognizing the connection between oral health and total health can prevent disease, treat problems while they are still manageable, and conserve critical health care dollars. Dental hygienists are committed to improving the nation's oral health, a fundamental part of total health.

Indeed, in order to improve access to oral health care, ADHA is working to establish a new oral health care provider, the "Advanced Dental Hygiene Practitioner." This new provider would deliver preventive, therapeutic and restorative services directly to underserved Americans. Please visit the ADHA web site at [www.adha.org](http://www.adha.org) for more information.

#### U.S. SURGEON GENERAL REPORT ON ORAL HEALTH IN AMERICA AND THE NATIONAL ORAL HEALTH CALL TO ACTION

In May 2000, the U.S. Surgeon General issued *Oral Health in America: A Report of the Surgeon General*. This landmark report confirms what dental hygienists have long known: that oral health is an integral part of total health and that good oral health can be achieved. The Surgeon General's Report on Oral Health challenges all of us—in both the public and private sectors—to address the compelling evidence that not all Americans have achieved the same level of oral health and well-being. The Report describes a "silent epidemic" of oral diseases, which affect our most vulnerable citizens—poor children, the elderly and many members of racial and ethnic minority groups.

ADHA suggests that one step that needs to be taken is to improve access to the preventive oral health care services provided by dental hygienists. This is important because unlike most medical conditions, the three most common oral diseases—dental caries (tooth decay), gingivitis (gum disease) and periodontitis (advanced gum and bone disease)—are proven to be preventable with the provision of regular oral health care. Despite this prevention capability, tooth decay—which is an infectious

transmissible disease—still affects more than half of all children by second grade. Clearly, more must be done to increase children’s access to oral health care services.

While the profession of dental hygiene was founded in 1923 as a school-based profession, today the provision of dental hygiene services is largely tied to the private dental office. Increased utilization of dental hygienists in schools, nursing homes, and other sites—with appropriate referral mechanisms in place to dentists—will improve access to needed preventive oral health services. This increased access to preventive oral health services will likely result in decreased oral health care costs per capita and, more importantly, improvements in oral and total health.

As the General Accounting Office (GAO) confirmed in two recent separate reports to Congress, “dental disease is a chronic problem among many low-income and vulnerable populations” and “poor children have five times more untreated dental caries (cavities) than children in higher-income families.” The GAO further found that the major factor contributing to the low use of dental services among low-income persons who have coverage for dental services is “finding dentists to treat them.” Increased utilization of dental hygiene services—appropriately linked to the services of dentists—is critical to addressing the nation’s crisis in access to oral health care for vulnerable populations. Indeed, ADHA is committed to working with the Congress to improve access to oral health care services, particularly for children eligible for Medicaid and the State Children’s Health Insurance Program (SCHIP). ADHA urges this Subcommittee and all members of Congress to support the Medicaid and SCHIP programs. ADHA strongly supports the Smith-Bingaman amendment in the fiscal year 2006 Senate Budget Resolution that strikes cuts to the Medicaid program and calls for a Medicaid Commission to carefully study and recommend changes to the program.

#### NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

As the Surgeon General’s Report on Oral Health so clearly demonstrates, the nation’s oral health can and must be further improved. The National Institute of Dental and Craniofacial Research (NIDCR) is the nation’s focal point for oral health research and NIDCR’s work has yielded significant advancements in oral health.

Over the past 50 years, our nation’s investment in dental and craniofacial research has yielded tremendous advances in American public health. Some of the often-cited examples include a sharp reduction in the once rampant rate of dental caries and tooth loss, improved care of all aspects of gum (periodontal) diseases, and the effective management of oral pain. In its ongoing quest to improve the nation’s oral health, a fundamental part of overall health and general well-being, NIDCR is, for example, working to realize the potential of salivary diagnostics. As NIDCR Director Lawrence A. Tabak, DDS, PhD explains, “scientists have long recognized that our saliva serves as a mirror’ of the body’s health, in that it contains the full repertoire of proteins, hormones, antibodies, and other molecular analytes that are frequently measured in standard blood tests.”

NIDCR’s work in dental research has not only resulted in better oral health for the nation, it has also helped curb increases in oral health care costs. Americans save nearly \$4 billion annually in dental bills because of advances in dental research and an increased emphasis on preventive oral health care. To enable NIDCR to continue and to build upon its important research mission, ADHA joins with other groups in the oral health community to recommend that NIDCR be funded at \$420 million for fiscal year 2006. ADHA further urges that NIDCR be preserved as an independent institute in any future NIH reorganization.

#### DENTAL HEALTH IMPROVEMENT ACT, A COMPONENT OF THE HEALTH CARE SAFETY NET AMENDMENTS ACT OF 2002

ADHA is pleased to see the increasing recognition among federal policymakers of the importance of oral health to overall health and well-being. A primary illustration of this appreciation for the link between oral health and general health is the Dental Health Improvement Act, which was passed by Congress as part of the Health Care Safety Net Amendments Act of 2002 (Public Law 107–261). This important legislation will assist states in addressing the crisis in access to oral health services. ADHA joins with others in the oral health community to recommend \$10 million to fund the oral health programs and initiatives contained within the Act.

#### CENTERS FOR DISEASE CONTROL ORAL HEALTH PROGRAM

ADHA would also like to lend its support to the Centers for Disease Control and Prevention (CDC) Oral Health Program. ADHA joins with other dental groups in urging a budget of \$18 million for the CDC Oral Health Program. This funding level will enable the Oral Health Program to continue its vital work to control and pre-

vent oral disease, including its important work in the area of community water fluoridation and school-based dental sealant programs. ADHA also requests \$130 million for the CDC prevention block grant. Last year, approximately \$3.5 million in block grant monies flowed to the states for critical oral health projects such as replacement of fluoridation equipment.

#### RYAN WHITE HIV/AIDS DENTAL REIMBURSEMENT PROGRAM

Included in the Ryan White CARE Act is a dental reimbursement program that assists in meeting the oral health needs of people living with HIV/AIDS, most of whose care is not covered under existing federal and state assistance programs. The dental reimbursement program provides participating institutions with partial reimbursement for the cost of providing oral health care services to low income people living with HIV and AIDS. In 1999, oral health care was provided to more than 65,000 patients under the program.

The "Ryan White CARE Act Amendments of 2000" rendered—for the first time—dental hygiene programs eligible for the dental reimbursement program. While there are only 55 dental schools in the United States, there are presently 279 accredited dental hygiene education programs in the United States. In fact, all states have at least one dental hygiene education program.

ADHA joins with the American Dental Education Association in recommending \$19 million for this important program. ADHA further urges this Subcommittee to direct HRSA to work to actively encourage and facilitate the participation of dental hygiene programs in the Ryan White HIV/AIDS reimbursement effort.

#### MATERNAL AND CHILD HEALTH PROGRAM

The Maternal and Child Health Block Grant Program provides vital support and services that improve the health of women and children. It is critical that the oral health component of this program be strengthened. This is important because, for example, research increasingly recognizes the link between severe periodontal disease in pregnant women and pre-term low birth weight babies. ADHA strongly supports the MCH programs and urges full funding for fiscal year 2006.

#### HEALTH PROFESSIONS EDUCATION

ADHA supports the important work of Title VII of the Public Health Service Act, in particular, the Allied Health Project Grants and the Scholarships for Disadvantaged Students Program. Allied health disciplines constitute fully 60 percent of the health care work force. The Scholarships Program seeks to recruit and retain minority and disadvantaged students.

ADHA joins the Association of Schools of Allied Health Professions in recommending \$20 million for Allied Health Project Grants and full funding for the Scholarships for Disadvantaged Students program. With the acknowledged need for cost-effective health care providers, it is time to augment funding for and recognition of these important allied health programs. ADHA further urges full funding for the Centers for Excellence Program, the Faculty Loan Repayment Program and the Health Careers Opportunity Program.

#### NATIONAL HEALTH SERVICE CORPS

ADHA strongly supports the National Health Service Corps (NHSC) and its Scholarship and Loan Forgiveness Programs. Scholarships and loan forgiveness provide vital assistance to students entering the health professions. ADHA urges that the committee again direct the NHSC to increase the participation of dental health providers, dentists and dental hygienists alike. This is important because too few Americans—particularly low-income Americans—regularly access needed oral health services. ADHA supports \$213 million for this important effort.

#### INDIAN HEALTH SERVICE DENTAL PROGRAMS

American Indians and Alaska Natives suffer disproportionately from poor oral health. Indeed, 75 percent of American Indian and Alaska Native children aged 2–5 years old experience untreated dental decay (caries). The prevalence of dental disease only increases with age. A staggering 91 percent of American Indian and Alaska Native children aged 15–19 years old experience tooth decay. In fiscal year 2004, the proportion of American Indian and Alaska Natives with access to dental care was only 24 percent. Presently, there are 109 vacancies in the IHS dental program. Clearly, there is much to be done to improve access to oral health services for Alaska Natives and American Indians. Accordingly, ADHA strongly supports the Community Health Aide Program, including the use of dental health aide therapists.

ADHA joins with the American Academy of Pediatrics and the American Dental Association in recommending \$124 million for IHS dental programs.

#### CONCLUSION

In closing, the American Dental Hygienists' Association appreciates the important contributions this Subcommittee has made in improving the quality and availability of oral health services throughout the country. ADHA is committed to working with this Subcommittee—and all Members of Congress—to improve the nation's oral health which, as *Oral Health in America: A Report of the Surgeon General* so rightly recognizes, is a vital part of overall health and well-being.

Please contact our Washington Counsel, Karen Sealander of McDermott Will & Emery (202/756-8024 or [ksealander@mwe.com](mailto:ksealander@mwe.com)), with questions or for further information. Thank you for this opportunity to submit the views of the American Dental Hygienists' Association.

---

#### PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit testimony on the importance of federal funding for diabetes programs at the Centers for Disease Control and Prevention (CDC) and diabetes research at the National Institutes of Health (NIH).

As the nation's leading nonprofit health organization providing diabetes research, information and advocacy, the American Diabetes Association feels strongly that federal funding for diabetes prevention and research efforts is critical not only for the 18.2 million Americans who currently have diabetes, but also for the more than 40 million who have a condition known as "pre-diabetes."

Diabetes is a serious disease, and is a contributing and underlying cause of many of the diseases on which the federal government spends the most health care dollars. In addition to the \$132 billion in 2002 dollars in direct and indirect costs spent solely on diabetes each year, diabetes is a significant cause of heart disease (which costs our nation \$183.1 billion each year), a significant cause of stroke (\$43.3 billion each year), and the leading cause of kidney disease (\$40.3 billion). Diabetes is also the leading cause of adult-onset blindness and lower limb amputations.

Approximately 42,000 people suffering from diabetes live in each congressional district and the number of people living with diabetes in this country is growing at a shocking rate. Between 1990 and 2001, diabetes prevalence in the United States has increased by more than 60 percent. The number of Americans with diabetes is now growing at a rate of 8 percent per year and is the single most prevalent chronic illness among children. Because the systemic damage diabetes imposes throughout the body, it is no surprise that the life expectancy of a person with the disease averages 10–15 years less than that of the general population.

As the statistics listed above illustrate, we are facing an epidemic of diabetes in this country, which if left unchecked could have significant implications for many future generations. The picture, however, is not without hope. We can stem the tide of this disease, but to do so requires a renewed federal commitment not only to research, but also to prevention.

The Association appreciates the increased attention by Congress to diabetes research at the National Institutes of Health (NIH) in recent years. While there is not yet a cure for diabetes, researchers at NIH are working on a variety of projects that represent hope for the millions of individuals with type 1 and type 2 diabetes. The Association strongly encourages you to provide a 6 percent increase to the NIH to fulfill this promise. Unfortunately, while the death rate due to diabetes has increased by more than 40 percent in recent years, diabetes research funding has not kept pace. Indeed, from 1987–2001, appropriated diabetes funding as a share of the overall NIH budget has dropped by more than 20 percent (from 3.9 percent to 2.9 percent). Over the last 4 years, Congress has begun to address this discrepancy. We respectfully ask you to continue this commitment.

While the NIH continues to work towards finding a cure, we must also adequately fund the diabetes prevention and outreach work being done at the Centers for Disease Control and Prevention. Therefore, we are requesting:

—At least a 10 percent increase over fiscal year 2005 levels for the CDC's Center on Chronic Disease Prevention and Health, including an additional \$10 million increase for the CDC's Division of Diabetes Translation (DDT); and

—Restoration of the Preventive Health & Health Services Block Grant.

The CDC's Division of Diabetes Translation is critical to our national efforts to prevent and manage diabetes because they translate the research that has already been done to real programs at the community level. Currently, for every \$1 that diabetes costs this country, the federal government invests less than \$.01 to help Amer-

icans prevent and manage this deadly disease. This dynamic must be changed. While the Association strongly believes that significant funding is needed to fully fund programs in all 50 states, our request of \$10 million recognizes the current budget realities.

In 2004 DDT provided support for more than 50 state- and territorial-based Diabetes Prevention and Control Programs (DPCPs) to increase outreach and education, and reduce the complications associated with diabetes. However, funding constraints required DDT to provide severely limited support to 24 states, 8 territories, and D.C. This level of funding, referred to as “capacity building,” allows a state to do surveillance, but is not enough for the state to do much—or anything—in the way of intervention.

DDT was able to provide the higher level of support, “basic implementation,” to the other 26 states. At the basic implementation level, states are able to devise and execute community-level programs. With an additional \$10 million over fiscal year 2005 funding levels, an additional 7 states could start to receive the substantial benefits of basic implementation programs.

The basic implementation programs undoubtedly make a major impact on local communities. For example, Daviess County in Kentucky is using their DPCP funding to support a community-based program that has trained more than 500 health professionals through professional education programs, screened and referred more than 1,500 people for diabetes through innovative events designed to reach the neediest individuals, provides test strips and emergency medications to more than 150 individuals annually, and lead comprehensive media and outreach campaigns to educate the public to recognize the risk factors for diabetes. While this example highlights the accomplishments from only one county in one state; it demonstrates the broad approach enabled by the basic implementation programs. Our goal is to make this a reality for the rest of the country, so that communities have the ability to invest in their future by investing in diabetes prevention and education.

Without fully-funded diabetes programs and projects in all parts of the country, it will be exceedingly difficult—if not impossible—to control the escalating costs associated with diabetic complications and to stem the epidemic rise in diabetes rates. State DPCPs, when provided with enough funding, are proven programs that have been extremely successful in helping Americans prevent and manage their diabetes. In the Division of Diabetes Translation Program Review fiscal year 2004, the CDC stated, “The Basic Implementation DPCPs serve as the backbone for our growing primary prevention efforts. These state programs are the key elements to our success in meeting the challenges of controlling and preventing diabetes.” For example, in Minnesota, the DPCP initiated a unified, statewide strategic plan for combating diabetes which resulted in more than 800,000 Minnesotans getting educational messages through television, radio, print, and web coverage. In Utah, innovative messaging such as bus wraps on public transportation are being used to inform hard-to-reach, at-risk populations of the NDEP messages, “You are the Heart of Your Family” and “Control Your Diabetes. For Life.” Americans in every state should have access to such quality programs. Unfortunately, the Division’s fiscal year 2005 budget of just over \$63 million, and the President’s request for near flat-funding in fiscal year 2006, will prevent more counties from implementing programs such as the one described above.

In addition to DPCP, the CDC’s Division of Diabetes Translation also conducts other activities to help people currently living with diabetes. For example, CDC works with NIH to jointly sponsor the National Diabetes Education Program (NDEP), which seeks to improve the treatment and outcomes of people with diabetes, promote early detection, and prevent the onset of diabetes. The CDC is also currently working to develop a National Public Health Vision Loss Prevention Program that will investigate the economic burden and strength the surveillance and research of this all-to-common complication of diabetes. In addition, CDC funds work at the National Diabetes Laboratory to support scientific studies that will improve the lives of people with diabetes. In fiscal year 2004, the Division of Diabetes Translation alone published 46 manuscripts on the care, prevention, and science of diabetes.

The Association is also supportive of restoration of the CDC’s Preventive Health & Health Services Block Grant (PBG). The PBG, which allows states to develop innovative health programs at the community level, received \$132 million in FY05, but is currently slated for no funding for fiscal year 2006. These programs have been very successful. For example, New York State uses theirs to help fund state-wide regional partnerships that provide much needed diabetes prevention and control activities for medically underserved individuals and communities. Currently, about \$2.2 million goes toward diabetes-related programs. While this is a relatively

small amount, it is nonetheless important to the communities it is currently helping.

The Association, and the millions of individuals with diabetes we represent, firmly believes that we could rapidly move toward curing, preventing, and managing this disease by increasing funding for diabetes programs and research both at CDC and NIH. Your leadership is essential to accomplishing this goal. As you are considering fiscal year 2006 funding, we ask you to remember that chronic diseases, including diabetes, account for nearly 70 percent of all health care costs as well as 70 percent of all deaths annually. Unfortunately, less than \$1.25 per person is directed toward public health interventions focused on preventing the debilitating effects associated with chronic diseases, demonstrating that federal investment in chronic disease prevention remains grossly inadequate. We cannot ignore those Americans who are currently living with diabetes and other diseases.

In closing, the American Diabetes Association strongly urges the Subcommittee and Congress to provide a 10 percent increase for the CDC's Center on Chronic Disease Prevention and Health, including a \$10 million increase for the CDC's Division of Diabetes Translation, and to restore the Preventive Health & Health Services Block Grant. Providing this funding would be an important step towards empowering states to fight diabetes at the community level. Additionally, we urge the Subcommittee to increase NIH funding by 6 percent to allow for an increased commitment to diabetes research.

On behalf of the 18.2 million Americans with diabetes—a disease that crosses gender, race, ethnicity and political party; a disease that is among the most costly, debilitating, deadly and prevalent in our nation; and a disease that is exploding throughout our nation—thank you for the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

Agency	Amount
National Institutes of Health .....	30.1
National Heart, Lung, and Blood Institute .....	3,117.4
National Institute of Allergy and Infectious Disease .....	4,667.1
National Institute of Environmental Health Sciences .....	680.0
National Institute of Nursing Research .....	146.2
Fogarty International Center .....	71.0
Centers for Disease Control and Prevention .....	8,500.0
National Institute for Occupational Safety and Health .....	326.0
Office on Smoking and Health .....	130.0
Environmental Health: Asthma Activities .....	70.0
Tuberculosis Control Programs .....	215.0

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

American Lung Association (ALA) is pleased to present our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Lung Association is the oldest voluntary health organization in the United States, with a National Office, constituent, and affiliate associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association today fights lung disease in all its forms, with special emphasis on asthma, tobacco control and environmental health. The Lung Association is funded by contributions from the public, along with gifts and grants from corporations, foundations and government agencies. The American Lung Association achieves its many successes through the work of thousands of committed volunteers and staff.

MAGNITUDE OF LUNG DISEASE

Each year, an estimated 341,500 Americans die of lung disease. Lung disease is America's number three killer, responsible for 1 in every 7 deaths. More than 25 million Americans suffer from a chronic lung disease. This year, lung diseases cost the U.S. economy an estimated \$94.9 billion.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include: chronic obstructive pulmonary disease, lung cancer, tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis and asthma.

Mr. Chairman, while our comments today will focus on selected parts of the Public Health Service; the American Lung Association is firmly committed to appropriate funding for all sectors of our nation's public health infrastructure.

#### COPD

Chronic Obstructive Pulmonary Disease, or COPD, is a growing health problem. Yet it remains relatively unknown to most Americans and much of the research community. COPD is an umbrella term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis. COPD is the fourth leading cause of death in the United States and worldwide.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It has been estimated that 16 million patients have been diagnosed with some form of COPD and as many as 16 million more are undiagnosed. New government data based on a 1998 prevalence survey suggest that 3 million Americans have been diagnosed with emphysema and 9 million are diagnosed with chronic bronchitis. Emphysema affects more men than women, while chronic bronchitis affects more women than men. In 1999, 119,524 people in the United States died of COPD. During the period 1979-1998, the number of deaths from COPD rose almost 126 percent. COPD costs the U.S. economy an estimated \$30.4 billion a year.

Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Research in the genetic susceptibility underlying COPD is making progress. Research is also showing promise for reversing the damage to lung tissue caused by COPD.

Despite these promising research leads, the American Lung Association feels that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world. The American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to COPD research programs.

#### ASTHMA

Asthma is a chronic lung disease in which the bronchial tubes of the lungs become swollen and narrowed, preventing air from getting into or out of the lung. A broad range of environmental triggers that vary from one asthma-sufferer to another causes these obstructive spasms of the bronchi.

Asthma is on the rise. A 1998 survey found that an estimated 26 million Americans (including 8.6 million children under the age of 18) have at some point in their lifetime been told by their doctor that they have asthma. Rates are increasing for all ethnic groups and especially for African American and Hispanic children. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition.

Asthma is expensive. The growth in the prevalence of asthma will have a significant impact on our nation's health expenditures, especially Medicaid. Currently, asthma costs the United States \$12.7 billion annually, including \$8.1 billion in direct medical expenditures. Asthma attacks bring nearly two million people to the emergency room each year. Asthma also kills. In 1998, 5,438 people in the United States died as a result of an asthma attack. That is a 109 percent increase from 1979. A disproportionate share of these deaths occurred in African American families.

#### *Federal Response to Asthma*

The federal response to asthma has three components: research, programs and planning. We are pleased to report that, with support from the subcommittee, we are making progress on all three fronts.

#### *Asthma Research*

As the prevalence of asthma has grown, so has asthma research. Researchers are developing better ways to treat and manage chronic asthma. Research supported by National Heart, Lung and Blood Institute (NHLBI) has shown that using corticosteroids to treat children with mild to moderate asthma is safe and effective. For several years there had been concern that corticosteroids would stunt the growth of children who used them. This five-year study showed that children had

a one-year small reduction in their growth rate. But they had normal growth rates compared with children who did not use corticosteroids for the following four years. Children who used corticosteroids did suffer fewer asthma attacks and made fewer trips to the emergency room.

#### *Genetic Research*

Genetic Research is also providing insights into asthma. Physicians have noticed that while most people respond well to inhaled beta-agonists—a commonly prescribed drug to treat asthma—some patients do not respond or have worse asthma using inhaled beta-agonists. Researchers in the NHLBI supported Asthma Clinical Research Network have discovered that a genetic variation in the beta-adrenergic receptor determines how well asthma patients will respond to inhaled beta-agonists. This discovery will enable physicians to better target the drugs they proscribe to treat asthma.

Researchers supported by NHLBI have developed better animal models to allow expression of selected asthmatic genetic traits. This will allow researchers to develop a greater understanding of how genes and environmental triggers influence asthma's onset, severity and long-term consequences.

#### *Asthma Programs*

Last year, Congress provided approximately \$32.7 million for the Centers for Disease Control and Prevention (CDC) to conduct asthma programs. The American Lung Association recommends that CDC be provided \$70 million in fiscal year 2006 to expand its asthma programs.

### TUBERCULOSIS

Mr. Chairman, tuberculosis has been with us since the dawn of time. It is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis* (TB). TB primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine.

TB is spread through coughs, sneezes, speech and close proximity to someone with active tuberculosis. People with active tuberculosis are most likely to spread TB to others they spend a lot of time with, such as family members or coworkers. It cannot be spread by touch or sharing utensils used by an infected person.

There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2001, there were 15,991 cases of active TB reported in the United States.

The Institute of Medicine (IOM) recently published a report, entitled *Ending Neglect: The Elimination of Tuberculosis in the United States*. The report documents the cycles of attention and progress toward TB elimination, the periods of insufficient funding and the re-emergence of TB. The American Lung Association is pleased to note that, for the time being, TB rates in the United States are declining. From a high in 1992 of 26,673 new cases, we have seen 9 straight years of decline. However, the drop in 2001 was reportedly only 2 percent, indicating a leveling off of the overall decline in cases and a cause for concern within the public health community. This is no time to lower our defenses in funding TB programs.

While declining overall TB rates is good news, the emergence and spread of multi-drug resistant TB poses a significant threat to the public health of our nation. Continued support is needed if the United States is going to continue progress toward the elimination of TB.

The IOM report provides the United States with a road map of recommendations on how to eliminate TB in the United States. The IOM report identifies needed detection, treatment, prevention and research activities. The American Lung Association has endorsed the IOM report and its recommendations. We estimate it will cost \$528 million for the CDC Tuberculosis Elimination Program to implement the report recommendations.

The NIH also has a prominent role to play in the elimination of TB. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances has put the goal of an effective TB vaccine within reach. In addition, the American Lung Association encourages the subcommittee to fully fund the tuberculosis vaccine blueprint development effort at the National Institutes of Allergy and Infectious Disease (NIAID).

#### *Fogarty International Center TB Training Programs*

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international phy-



sicians and researchers. The goal is to develop a cadre of health professionals in the developing world who can begin controlling the global AIDS epidemic.

Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area TB treatment and research. This supplemental program has been highly successful in beginning to create the human infrastructure to treat the nearly two billion people who have TB worldwide.

However, we believe TB training grants should not be offered exclusively to institutions that have received AIDS training grants. The TB grants program should be expanded and open to competition from all institutions. The American Lung Association recommends Congress provide \$71 million for FIC to expand the TB training grant program from a supplemental grant to an open competition grant.

#### RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

Protecting the health of our nation's workforce will require research, training, tracking and new technologies. The American Lung Association recommends that the subcommittee provide \$326 million for the National Institute for Occupational Safety and Health (NIOSH) at the Centers for Disease Control and Prevention (CDC), including \$25 million for the NIOSH National Occupational Research Agenda (NORA). NORA represents a partnership research plan for occupational disease. The NORA agenda was developed with input from labor, business and the health community.

#### CONCLUSION

In conclusion, Mr. Chairman, lung disease is a growing problem in the United States. It is America's number three killer, responsible for 1 in 7 deaths. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of one year. Worldwide, tuberculosis kills three million people each year, more people than any other single infectious agent does. Mr. Chairman, the level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

#### PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The American Psychological Association (APA) is the largest association of psychologists in the world, representing 155,000 members, affiliates and students. APA exists to advance psychology as a science, a profession, and a means of promoting education and human welfare. APA members serve as scientists funded by the National Institutes of Health and Centers for Disease Control and Prevention, as teachers and professors in our nation's high schools, colleges and universities, and as health professionals who treat patients in public and private clinics and programs. APA encourages the committee to strengthen U.S. investment in a continuum of programs on health promotion, disease prevention and care, ranging from basic research to clinical applications that will improve the health and education of all Americans. We appreciate the opportunity to submit testimony for the record.

#### U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

##### *National Institutes of Health*

The Administration's fiscal year 2006 budget proposes an NIH funding increase of 0.5 percent, lower than the biomedical inflation rate. This would not allow NIH to take advantage of many scientific opportunities. The success rate is already falling from one in three grant applications funded, to one in four. APA encourages the Committee to include a six percent funding increase for NIH in this year's legislation.

Funding increases for the NIH Office of Behavioral and Social Sciences Research (OBSSR) have been negligible for the past two years, and the Administration's budget continues the trend (the request is \$26.2 million). The Committee has praised OBSSR for making it easier for NIH institutes to cooperate to fund cross-cutting initiatives. OBSSR has been able to leverage substantive funding initiatives with a small budget. However, its ability to do so is eroding. OBSSR is planning trans-NIH programs to fund behavioral and social research on health disparities in minority populations, and on how gene/environment interactions affect health. It would benefit from a six percent increase. APA supports an appropriation of \$27.66 million for OBSSR.

Critically important behavioral research is being conducted by most NIH institutes. We can list only a few examples here. Epidemiology studies supported by

NIAAA show that alcohol is a drug of choice for youth and that it is associated with a host of consequences in this age group, including death and increased risk of harm and other negative outcomes. Recent data show that 18- to 24-year-olds have the highest prevalence of alcohol dependence of any age group. These and other data make it clear that alcohol has become entrenched in the developmental processes of adolescence, and that the developmental changes of adolescence appear to make this age group particularly vulnerable to alcohol's effects. Research by NIDA and others shows that the human brain does not fully develop until about age 25. Having insight into how the human brain works, and understanding the biological underpinnings of risk taking among young people will help in developing more effective prevention programs. NIAAA and NIDA are to be commended for pursuing research to understand how to extricate alcohol and other addictive drugs from adolescent development and how to change adolescents' behaviors toward addictive substances.

Psychological research supported by the NICHD is providing critical answers to many questions about childhood development, including how children learn to read and how they can overcome learning disabilities. Additional work is needed to improve our understanding of the role of cognition in learning mathematical and scientific concepts. Additional research is also needed to inform the public health community of how best to modify high-risk behaviors in children and families that contribute to the rising incidence of childhood obesity.

As NIMH implements its reorganization, APA is encouraging the institute to maintain its support for a comprehensive research portfolio that includes funding for a broad array of basic behavioral research and continues to support research on the promotion of mental health and the study of psychological, social, and legal factors that influence behavior. Given the increasing burden of mental disorders on children and adolescents, behavioral interventions are especially needed for children and adolescents with eating disorders, attention deficit-hyperactivity disorder, post-traumatic stress disorder and the most common forms of depression. Translational research in the behavioral and social sciences is especially needed to address how basic behavioral processes, such as cognition, emotion, motivation, development and social interaction, inform the diagnosis, treatment and delivery of services for mental disorders.

APA remains concerned that basic behavioral research at NIH—that is, research on the mechanisms that influence and underlie behavior, conducted outside a disease context—is vulnerable to budget pressures and pressures to demonstrate effective interventions. NIH institutes must balance the imperative for translation with the need to continue posing basic questions that will fuel the next generation of interventions. Much basic research is supported at NIH by the National Institute of General Medical Sciences, yet NIGMS funds very little basic behavioral research. APA asks that the committee continue to encourage or direct NIGMS, as it has for the past five years, to fill some of the gaps that now appear in NIH support of basic behavioral research and research training.

#### ADMINISTRATION FOR CHILDREN AND FAMILIES

##### *Prevention of child maltreatment*

Nationwide, an estimated 896,000 children are abused and neglected each year, resulting in an estimated 1,400 child deaths. The negative effects of child maltreatment can persist into adulthood. An increase of \$15 million will enhance prevention activities for child maltreatment by population-based monitoring to capture information about children outside child protective service systems and improve data collection to inform policy, research and public awareness programs. These funds will also advance research to prevent the negative consequences of child maltreatment and to examine risk and protective factors to further the development and implementation of culturally and linguistically appropriate prevention and intervention approaches.

##### *Bullying prevention*

Research indicates that bullying directly affects approximately one in three school children within a school semester. In addition, research confirms that bullying among children poses serious risks for victims and perpetrators and may seriously undermine the climate of schools. APA urges the adoption of research-based comprehensive bullying prevention programs and adequate federal funding to support the implementation of effective, comprehensive bullying prevention programs.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION BUREAU OF HEALTH PROFESSIONS

*Graduate Psychology Education (GPE) Program*

Funding in the amount of \$6 million for fiscal year 2006 is requested to continue the Graduate Psychology Education (GPE) Program, which was established in fiscal year 2002. The GPE Program, administered by the Bureau of Health Professions, is the only federal program dedicated solely to psychology education and training.

Funded in fiscal year 2003 at \$4.5 million and flat-funded for fiscal year 2004 and fiscal year 2005, the funds are now obligated to 27 grants on a three year cycle. As a result there will be no new competition this year. Without a modest increase of \$1.5 million there will not be a new competition in fiscal year 2006. The \$6 million request for fiscal year 2006 will enable hundreds of interested universities and training sites (e.g., veterans hospitals, children's hospitals, academic science centers and public health facilities) to apply for a GPE grant to increase the number of psychologists practicing in underserved rural and urban communities.

The GPE Program provides grants to APA accredited doctoral, internship and post-doctoral programs in support of interdisciplinary training of psychology students for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill persons, and victims of abuse and trauma), especially in rural and urban communities. Furthermore, the GPE Program addresses the need for mental health services that was well documented in the New Freedom Commission on Mental Health Report (2003): about 1 in 5 American adults (44 million people) experience a mental disorder in a given year and 28 percent of adults meet the full criteria for a mental or addictive disorder.

## SUBSTANCE ABUSE, MENTAL HEALTH SERVICES ADMINISTRATION CENTER FOR MENTAL HEALTH SERVICES

*Mental and Behavioral Health Services on Campus Program*

Funding in the amount of \$5 million for fiscal year 2006 is requested for the newly established Mental and Behavioral Health Services on Campus Program, which is part of the Garrett-Lee-Smith Memorial Act that provides support for youth suicide early intervention and prevention programs, technical assistance centers for suicide prevention, and mental and behavioral services on campuses. The program also helps identify the best means, strategies and solutions for addressing the mental and behavioral health needs of our college aged youth.

The Mental and Behavioral Health Services on Campus program received \$1.5 million from fiscal year 2005 funds. The requested increased funding for \$5 million in fiscal year 2006 will help ensure that SAMSHA administrators will be able to implement the program in a way that best addresses the needs that exist on college campuses. Academic failure on our college campuses, which is often associated with mental or behavioral problems, not only results in personal loss, but loss in federal investment (student financial assistance), as well. In the most severe cases, unaddressed psychological problems can lead to depression and even suicide—a loss that can never be measured.

*Minority AIDS Initiative*

The estimated number of AIDS cases from 1999 to 2003 has increased for racial and ethnic minorities, including African Americans, Latino/as, Asian Pacific/Islanders and American Indians/Alaska Natives. Many persons with HIV/AIDS have mental and/or substance abuse disorders. While treatment can enhance overall health and well-being, racial and ethnic minorities have less access to, and lower utilization of, mental health and substance abuse services. Accordingly, APA recommends an additional \$5 million, for a total of \$15 million, for the Minority AIDS Initiative to provide culturally competent and accessible mental health and substance abuse services to persons of color living with HIV/AIDS.

## CENTER FOR SUBSTANCE ABUSE PREVENTION

*Rapid HIV Testing*

Each year, 25 to 30 percent of HIV-infected people who come to public clinics for HIV testing do not return a week later to receive their test results. With the rapid HIV test, results are available in about 20 minutes. Greater availability of this test can increase overall HIV testing and reduce the number of people—an estimated 225,000 Americans—who are unaware of their HIV infection. APA strongly supports the Rapid HIV Testing Initiative to train mental health and substance abuse service providers on rapid HIV testing and prevention counseling and urges an additional \$4.8 million, for a total of \$9.6 million, for fiscal year 2006. Mental health treatment

services for individuals testing positive should also be provided as a critical component of rapid HIV testing.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) NATIONAL CENTER FOR INJURY PREVENTION AND CONTROL

*Suicide prevention*

An increase of \$5 million over the fiscal year 2005 appropriation for suicide prevention activities will allow CDC to support the evaluation of suicide prevention planning, programs, and communication efforts to change knowledge and attitudes and to reduce suicidal behavior. These evaluation efforts will support communities to identify promising and effective suicide prevention strategies that follow the public health model and build community resilience.

*National Violent Death Reporting System (NVDRS)*

An increase of \$10 million over the fiscal year 2005 appropriation for the NVDRS will allow approximately 20 additional states to be funded to gather and share state-level data about violent deaths. This state-based system collects data from medical examiners, coroners, police, crime labs, and death certificates to understand the circumstances surrounding violent deaths. The information can be used to develop, inform, and evaluate violence prevention programs.

NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH (NIOSH)

APA recommends an overall increase of \$40 million over the fiscal year 2005 appropriation for NIOSH. As the only federal agency for occupational safety and health research and prevention, NIOSH provides national and international leadership to prevent work-related illness, injury, and death by gathering information, conducting scientific research, and translating the knowledge gained into products and services.

U.S. DEPARTMENT OF EDUCATION

*Institute for Education Sciences*

Support for research is particularly critical at the Institute of Education Sciences as it seeks to translate scientifically based research findings into classroom practice. To support the highest quality cognitive, developmental, and educational science, we would encourage IES to hold a field-initiated studies competition in the next fiscal year to encourage innovative research driven by scientific opportunities.

APA appreciates the opportunity to present appropriations recommendations for the written record, and encourages members of the Committee to contact our Public Policy Office at (202) 336-6062 with questions or concerns about this statement.

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL SOCIETY

SUMMARY OF RECOMMENDATIONS

- As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$30 billion for NIH in fiscal year 2006.
- APS requests Committee support for increased behavioral and social science research and training at NIH in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.
- Committee support is requested for specific behavioral science activities at a number of individual institutes. This statement provides examples to illustrate the exciting and important behavioral and social science work being supported at NIH.

Mr. Chairman, Members of the Committee: The American Psychological Society is a nonprofit organization dedicated to the promotion, protection, and advancement of the interests of scientifically oriented psychology in research, application, teaching, and the improvement of human welfare. Our 16,000 members are scientists and educators at the Nation's universities and colleges.

On behalf of our members, I would like to thank you for your leadership in the bipartisan effort to double NIH budget. As a result, NIH has experienced a period of unparalleled growth in the past 5 years, and the progress achieved as a result of research funded by NIH will lead us into a new era of discovery and innovation. Unfortunately, that progress is threatened by the Administration's request for fiscal

year 2006, which at only .7 percent (or \$196 million) over fiscal year 2005 will not even cover the costs of inflation, never mind sustain and advance the nation's investment in NIH. As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$30 billion for NIH in fiscal year 2006, an increase of 6 percent over fiscal year 2005 funding levels. This increase would help provide a stable base of funding for the Nation's public health research enterprise and allow NIH to continue its important scientific pursuits.

Within the NIH budget, APS is particularly focused upon the behavioral and social sciences research activities of NIH.

#### THE IMPORTANCE OF BEHAVIORAL RESEARCH IN ADDRESSING THE NATION'S HEALTH

In any realistic picture of our Nation's health, a core finding is that behavior is central to many, maybe to most of our Nation's leading health concerns: heart disease; stroke; lung disease and certain cancers; obesity; AIDS, suicide; teen pregnancy, drug abuse and addiction, depression and other mental illnesses; neurological disorders; alcoholism; violence; injuries and accidents—all have large behavioral components. Further, nearly 40 percent of premature deaths in the United States can be attributed to smoking, physical inactivity, poor diet, or alcohol misuse according to the Centers for Disease Control and Prevention.

None of the conditions or diseases described above can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating and preventing them. For example, before you address how to change attitudes and behaviors around AIDS, you need to know how attitudes develop and change in the first place. Or, before you can change decisions about any risky behavior, you need to know how judgments and decisions are made on a range of topics. Similarly, before you address memory decline in the elderly, you need to know the basics of learning and memory and how that changes with age. And before you address the complexity of the interactions among genetics, the brain, and schizophrenia, you need to know the basics of cognition, emotion, culture, behavioral aspects of neuroscience, and behavioral genetics.

APS members include thousands of scientists who, with NIH support, conduct basic, applied, and clinical research related to physical and mental health at our Nation's leading universities and colleges. Virtually every institute at NIH supports some amount of psychological science. Examples include: The connections between the brain and behavior; research into how children grow and develop; management of debilitating chronic conditions such as diabetes and arthritis as well as mental disorders; and the behavioral aspects of smoking and drug and alcohol abuse, so that science may find ways for people to escape addiction.

NIH Director Dr. Elias Zerhouni, has expressed strong support for behavioral science at NIH, and sees this research as critical to our Nation's health. "We are aware of the challenge in social and behavioral science. It's going to be front and center," he has stated. He went on to add, "The bill for the nation will be unbearable in health and social costs without recognition of the role of behavior." However, to date, behavioral research has not received the recognition or support needed to reverse the effects of behavior-based health problems in this Nation.

APS asks that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, by encouraging NIH to advance a model of health that includes behavior in deciding its scientific priorities, and by encouraging the establishment of a stable infrastructure to support basic behavioral science research at NIH.

#### BASIC BEHAVIORAL SCIENCE RESEARCH NEEDS A STABLE INFRASTRUCTURE

Twenty-four of the 27 institutes at NIH fund behavioral science research, and seven institutes commit over \$100 million to this enterprise. Six institutes commit over 20 percent of their resources to behavioral science research. However, most of these institutes do not fund research into the fundamental behavioral processes that underlie the diseases and conditions that constitute some of the most vexing health problems facing us today. Traditionally, such basic behavioral research has been supported by the National Institute of Mental Health (NIMH). NIMH, for any number of historical reasons, has been the home for far more basic behavioral science than any other institute. Many basic behavioral and social questions were being supported by NIMH, even if their answers also could be applied to other institutes. Recently, NIMH has begun to aggressively reduce its support for many areas of the most basic behavioral research, saying that, like many other Institutes, it too is disease specific and must focus its energy on battling mental illness through

translational and clinical research. This means that previously funded areas now are not being supported.

NIMH is to be commended for promoting the transfer of knowledge into application for mental illness. But this is happening at the expense of critical basic behavioral research. Without progress in our understanding of fundamental behavioral processes, there will not be a sufficient body of knowledge to translate into application. Until other institutes begin to support larger amounts of basic behavioral science research connected to their respective missions, it is essential that NIMH's programs of research in behavioral phenomena such as cognition, emotion, psychopathology, perception, development, and others continue to flourish. APS asks the Committee to encourage NIMH's continued efforts to strengthen the ties between basic and clinical behavioral research, and to encourage NIMH's basic behavioral science portfolio in order to ensure continued progress in our understanding of the causes, treatment and prevention of mental illness and the promotion of mental health.

#### NIGMS SHOULD SUPPORT BASIC BEHAVIORAL SCIENCE RESEARCH AND TRAINING

Answering basic social and behavioral science questions is central to the overall NIH mission. The recent change at NIMH regarding basic behavioral research illustrates the problem of depending too much on non-structural support at any one agency for fundamental behavioral and social science research. Basic behavioral and social science needs a dependable structure of its own.

The most appropriate location is the National Institute of General Medical Sciences (NIGMS), also known as NIH's "basic research institute". NIGMS already has a mandate to support basic behavioral research and training, but that mandate has not been fulfilled in part because NIMH already was serving that function.

Since fiscal year 1999, this Committee has repeatedly issued report language urging NIGMS to fund basic behavioral research and training, saying, for example: "The Committee is concerned that NIGMS does not support behavioral science research training. As the only Institute mandated to support research not targeted to specific diseases or disorders, there is a range of basic behavioral research and training that NIGMS could be supporting. The Committee urges NIGMS, in consultation with the Office of Behavioral and Social Sciences, to develop a plan for pursuing the most promising research topics in this area." [Senate fiscal year 2000 Appropriations Report 106-166, Senate fiscal year 2001 Appropriations Report 107-293, Senate fiscal year 2002 Appropriations Report 107-84, Senate fiscal year 2003 Appropriations Report 107-216, Senate fiscal year 2004 Appropriations Report 108-82]

Two years ago, Senators Specter, Inouye, and Harkin, engaged in a colloquy on the Senate floor expressing the Committee's strong support for basic behavioral research and training, and expressing their concern that NIH had not responded to this matter after many years of report language. Since then, NIH commissioned a task force to study the matter and report back to the Director's Advisory Committee. The panel formally recommended the establishment of a secure and stable home for basic behavioral science research and training at an NIH institute, and, in particular, suggested that an institute such as NIGMS should be that home, as this Committee has recommended for years.

NIGMS is on record saying except for a few fields of inquiry, behavioral studies largely fall outside of its research mission, and are instead deemed to be within the missions of other institutes at the National Institutes of Health. And APS believes this line of thinking may still hold true within NIGMS. However, NIGMS' statutory mandate encompasses "general or basic medical sciences and related natural or behavioral sciences [emphasis added] which have significance for two or more other national research institutes" (TITLE 42, CHAPTER 6A, SUBCHAPTER III, Part C, subpart 11, Sec. 285k).

Basic behavioral research in the cognitive, psychological and social processes underlying substance abuse and addiction (significance for NIDA, NIAAA, NCI and NHLBI), obesity (significance for NIDDK, NHLBI, and NICHD) and the connections between the brain and behavior (significance for NIMH, NINDS, and NHGRI) just to name a few, all are within the NIGMS mission. Given the statutory mandate, the recommendations of a recent Director's advisory council's task force, the strong Congressional interest, the scientific imperative, and most important, the health needs of the Nation, APS asks the Committee to direct NIGMS to develop a plan for establishing a basic behavioral science research and training program at NIGMS.

## NIH NEEDS A COMPREHENSIVE BEHAVIORAL SCIENCE RESEARCH TRAINING STRATEGY

The outcomes of science are unpredictable. Yet there is one aspect of science where the time and money invested is guaranteed to pay off: the training of our future scientists. We know that if we provide support now for a young investigator, we will have a well-trained, highly-qualified scientist as a result. This is a serious issue in behavioral science at NIH, where the demand for behavioral science investigators at NCI, NIMH, and other institutes outpaces the current supply of behavioral science researchers. In order to meet the future needs of research in health and behavior, NIH must have a comprehensive training strategy in place today, one that focuses on training young investigators in the core disciplines of behavioral and social science research as well as in multidisciplinary perspectives.

APS is hopeful that NIH will take a closer look at forthcoming recommendations from a congressionally mandated National Academy of Sciences (NAS) study of research personnel needs with regard to the National Research Service Awards (NRSA). It is anticipated that this study will be transmitted to Congress and NIH in the near future. When NAS conducted this study in 2000, NIH selectively implemented NAS's recommendations and ignored important findings with regard to the need for increased training, if at all. This Committee has taken note of the behavioral science recommendations from this study in the past, and has supported increasing NRSA awards as a mechanism to increase behavioral science research training. APS asks the Committee to developments closely.

More generally, APS asks the Committee to support the development of a comprehensive training strategy for behavioral and social science research at NIH. This strategy should include all training mechanisms, and should be balanced between interdisciplinary research and traditional core disciplines in the behavioral sciences.

## BEHAVIORAL SCIENCE AT KEY INSTITUTES

In the remainder of my testimony, I would like to highlight examples of the cutting edge behavioral science research being supported by individual institutes.

*National Institute of Mental Health (NIMH)*

NIMH is funding behavioral research ranging from neural information processing to social psychology decision-making. Ultimately, this investment will help researchers understand and improve the way people think, plan, and make choices about their future as it relates to everything from chronic mental illness to AIDS. For example, one NIMH study is aimed at identifying how people understand the near future versus the distant future with the hopes of relating study findings to HIV prevention. By investigating how temporal distance from future events influences judgments and decisions regarding those events, researchers hope to identify the advantages and disadvantages of decision-making at different points in time.

An NIMH-funded project is examining the operation of attention at two coarsely defined stages of processing: visual perception and visual working memory. By comparing "memory-intensive" tasks in which working memory is overloaded but the perceptual demands are minimal with "perception-intensive" tasks in which memory is not overloaded but the perceptual demands are great, researchers expect to see attention operate at different stages in these tasks. By developing methods to isolate and assess perceptual-level and working memory-level property mechanisms, researchers will be able to more easily identify attentional mechanisms compromised in a given disorder. This program of research will have important long-term implications for psychological/psychiatric disorders in which attention is compromised, such as attention deficit disorder, many anxiety disorders, even schizophrenia.

Similarly, the NIMH project titled "Executive Processes-Behavioral and Neuroimaging Study" will help scientists better understand the brain mechanisms responsible for so-called "executive" brain functions, such as the ability to stay focused, to multi-task, and to respond with action. Studying these executive processes, which play a central role in cognition, could influence how we look at behavioral and psychological functioning, from the changes that occur over the life span to early diagnosis and treatment of dementia and other conditions involving reduced cognitive capacities.

*National Institute on Drug Abuse (NIDA)*

By supporting a comprehensive research portfolio that stretches across basic neuroscience, behavior, and genetics, the National Institute on Drug Abuse (NIDA) is leading the Nation to a better understanding and treatment of drug abuse. APS applauds NIDA for strengthening its efforts to study adolescent brain development to examine the influence drug exposure has on behavioral, psychological, and physiological development. New research supported by NIDA reveals that drug addiction

is a “developmental disease” that often starts during the early developmental stages in adolescence, an age at which 3 million 12–17 year olds reported using illicit drugs last year. If we can better understand the effects structural brain changes have on functions like thinking, decision-making, sensation and perception we will be able to better develop targeted and more likely effective prevention strategies from the brain development perspective. APS asks this Committee to support this and other critical behavioral science research at NIDA, and to increase NIDA’s budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

*National Institute on Alcohol Abuse and Alcoholism (NIAAA)*

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) works to examine the biological, chemical and behavioral factors associated with alcohol abuse and consumption, the third highest cause of preventable death in the United States according to the Centers for Disease Control and Prevention. Over time, NIAAA has broadened its behavioral science portfolio to understand the underlying psychological and cognitive processes that lead people to drink, and the impact of chronic alcohol abuse on those processes. Today, the institute is stepping up its efforts via its Improving Effectiveness of Treatment initiative to move beyond what we understand about today’s behavior therapies and to further understand the mechanisms that determine how and why alcohol-related behavior changes. And since these changes are influenced by neurobiological, psychological and social factors, this new and exciting research includes multiple levels of research to ensure an integrated understanding to improve behavior strategies. APS asks this Committee to support NIAAA’s behavioral science research efforts, and to increase NIAAA’s budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from alcohol abuse and alcohol dependence.

*National Cancer Institute (NCI)*

The National Cancer Institute (NCI) is an agency that continues to make enormous advances in the behavioral sciences to achieve effective cancer prevention and control. Since its Behavioral Research Program was launched in 1997, NCI has funded comprehensive behavioral science research programs ranging from basic behavioral science to research on the development, testing and dissemination of disease prevention and health promotion interventions in areas such as tobacco use, diet, and even sun protection. APS applauds NCI’s foresight to conduct transdisciplinary research within the program’s five branches of Tobacco Control, Cancer Communications, Health Disparities, Energy Balance, and Cancer Survivorship because it set forward a new path for science—and APS believes disciplines are only made stronger when complimented by others. Take for example the agency’s Centers for Transdisciplinary Research on Energetics and Cancer within the Energy Balance branch. This initiative brings together NCI’s investment in diet, weight and physical activity research priorities by bringing together scientists from multiple disciplines to carry out projects ranging from the biology and genetics of energy balance to behavioral, sociocultural and environmental influences on nutrition, physical activity, weight, energy balance and energy transferred to or expended in life processes. In addition to training established scientists, this investment fosters collaboration among transdisciplinary teams. APS asks Congress to support NCI’s behavioral science research and training initiatives and to encourage other institutes to use these programs as models.

*National Institute on Aging (NIA)*

APS is particularly pleased with NIA’s dedication to behavioral research through the Behavioral and Social Research (BSR) Program—and its 3 branches of individual behavior, population and social processes and research resources and development—that supports basic social and behavioral research and research training by studying the dynamic interplay between individuals’ aging; their changing biomedical, social, and physical environments; and multilevel interactions among psychological, physiological, social, and cultural levels. Agency-conducted research like that of the Behavioral and Imaging Approaches to Implicit Memory in Aging study will ultimately make a major contribution to our understanding of age-related changes in memory. As researchers carefully integrate behavioral and neuroimaging studies to broaden and deepen current understanding of age-related changes in implicit memory, they are evaluating decision accuracy in both young and elderly subjects to assess the neural substrates supporting encoding and retrieval of implicit memory. APS asks the Committee to support NIA’s behavioral science research efforts and to increase NIA’s budget in proportion to the overall increase at NIH in order to continue its high quality research to improve the health and wellbeing of older Americans.



*Office of Behavioral and Social Sciences Research (OBSSR)*

I'm pleased to report that psychological scientist David Abrams, from Brown University, has been appointed as the Director of the Office of Behavioral and Social Sciences Research at NIH. We ask the Committee to join us in welcoming Dr. Abrams to this position, and to support OBSSR in its efforts to achieve a strengthened behavioral science research enterprise at NIH.

It's not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those reviewed in this statement, many other institutes play a key role in NIH behavioral science research enterprise. These include the National Heart, Lung, and Blood Institute, the National Institute of Neurological Disorders and Stroke, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Nursing Research, and the National Institute for Human Genome Research. Behavioral science is a central part of the mission of these institutes, and their behavioral science programs deserve the Committee's strongest possible support.

---

 PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

Chairman Specter and members of the Subcommittee, the American Society of Hematology (ASH) thanks you for the opportunity to submit written testimony on the fiscal year 2006 Departments of Labor, Health and Human Services, and Education Appropriations Bill. In addition, ASH sincerely thanks the Subcommittee for its support of biomedical research.

The Society represents nearly 14,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; non-malignant conditions including anemia, thrombosis, and bleeding disorders; and congenital disorders such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, gene therapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

Hematologists treat a diverse group of patients. For example, anemia is a condition that has enormous consequences in the quality-of-life and functioning of the elderly; sickle cell disease is an inherited blood disorder that primarily affects African Americans. The hematological cancers—leukemia, lymphoma, and myeloma—strike men and women of all ages; in 2005, nearly 115,000 Americans will be diagnosed with and more than 53,000 will die from these cancers.

The study of blood and its disorders involves a number of NIH Institutes, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA). The Society supports the leadership of these Institutes and commends them for their vision and responsible research portfolio management.

The Society's requests this year focus on translating basic scientific findings into improved treatments for patients with serious blood diseases. New comprehensive approaches to clinical research funding will advance our understanding of how to treat these and other diseases, enable patients to participate in high quality clinical protocols, and attract and train much-needed clinicians and clinical researchers to the field of hematology.

## FISCAL YEAR 2006 FUNDING REQUESTS

*NIH Funding*

ASH fully supports the Ad Hoc Group for Medical Research Funding recommendation of \$30 billion for NIH in fiscal year 2006. This 6 percent increase represents an important step in maintaining NIH's commitment to medical research funding so that the progress made during the doubling years is not eroded. Research programs are not spigots that you can turn on and off without compromising their effectiveness. Innovative scientific teams working in sophisticated labs cannot be sustained without some stability in medical research funding from year to year. It is critical that the US maintain its commitment to medical research.

For fiscal year 2006, the Bush Administration proposed \$28.845 billion, a \$196 million or 0.7 percent increase over last year. This is the third consecutive year that the President's Budget request for NIH has not kept pace with medical inflation. Only continued, sustained investment in life-saving medical science today will provide cures and therapies for tomorrow. A proposed NIH budget along the lines of

President Bush's recommendation is effectively a cut in funding; it doesn't keep up with the cost of medical inflation.

Moreover, NIH budgets in the range proposed by the Bush Administration will force NIH to drop paylines substantially below the 33rd percentile—where they are generally considered unhealthy for the biomedical research enterprise. Estimated paylines for most NIH Institutes in fiscal year 2006 are less than the 18th percentile. Low paylines create an atmosphere of hopelessness for even established investigators and little incentive for young researchers to take the chance that their grant would receive funding. More funding at NIH would provide the Institutes the opportunity to raise their paylines and fund more qualified and innovative research.

In addition, there needs to be a highly-trained scientific workforce for NIH to meet its research objectives. Training the next generation of biomedical researchers has traditionally been the responsibility of NIH. Under the President's fiscal year 2006 Budget proposal, NIH will support almost 400 fewer full time training positions than last year. Without funding for the next generation of physician scientists, the biomedical research enterprise will not be prepared for future efforts.

The Society is proud that NIH-sponsored research in hematology has led to important discoveries and generated new treatments and pharmaceutical products with broad applicability to human diseases. We have all benefited from past investments in NIH research. Recent advances include the incredibly effective hematologic drug Gleevec—a breakthrough in treating chronic myelogenous leukemia—that is one of the first drugs of its kind to be approved that targets specific molecules in cancer cells, leaving healthy cells unharmed. Moreover, ASH has always emphasized the synergy that is vital to successful scientific work. Basic research on the blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer and AIDS. As a result of this cross-fertilization, the Society remains firmly committed to broad-based support for biomedical research and to the existing peer-review process as the best way to identify and prioritize scientific grants.

In fiscal year 2006, ASH also urges the Subcommittee to recognize the following areas of hematology research that have shown impressive progress and offer the potential of future advances:

*Coordination of the Issues Common to the Hemoglobinopathies*

Sickle cell anemia and thalassemia are inherited blood disorders caused by mutations in the genes for the hemoglobin molecule—the protein in red blood cells that carries oxygen to all parts of the body—and affect the normal functioning of hemoglobin in our blood. These conditions cause many problems including moderate to severe anemia, chronic pain, iron overload with its associated diabetes, liver and heart failure, enlarged spleen, bone weakness, pulmonary hypertension, and stroke. Although these disorders share many common issues, their research programs at NHLBI are organized into two parallel structures that could possibly benefit from the expertise of researchers focused on the other disorder. ASH believes there is an opportunity to determine the science and management issues common to the hemoglobinopathies and identify areas of scientific collaboration and promising new research directions in sickle cell anemia and thalassemia.

*Expansion of Research Activities in the Underlying Causes of Thrombosis at NHLBI and NIA*

Venous and arterial thrombosis (blood clots) are serious conditions that can lead to heart attacks, strokes, limb loss, and respiratory dysfunction. Vascular biology research provides the foundation for understanding the underlying causes of atherosclerosis, angiogenesis, inflammation, and thrombosis. Greater understanding of vascular biology will lead to more knowledge about the prevention of thrombosis, which has implications into the further research of heart disease, stroke, recurrent fetal loss, complications associated with sickle cell anemia and diabetes, as well as the interruption of the blood supply to tumors and cancers.

Recent research disclosed that deep vein thrombosis affects up to 2 million Americans annually. Overall, thrombosis has sharply increased rates in the elderly and causes significant mortality and morbidity. With an expanding elderly population, thrombosis could become an even more serious health care problem. Although age is a known and important risk factor for thrombosis, there are other major research questions that need to be investigated in order to improve its diagnosis and treatment, such as the underlying causes of thrombosis. ASH believes that new research initiatives in the underlying causes of thrombosis will be helpful for improving the diagnosis and treatment of this potentially fatal complication of many diseases.

*Strengthening of Support for Clinical and Translational Blood Cancer Research*

In 2005, nearly 115,000 Americans will be diagnosed with a hematologic malignancy, such as leukemia, lymphoma, and multiple myeloma. Moreover, more than 53,000 Americans will die from these cancers, compared to 40,870 for breast cancer, 30,350 for prostate cancer, and 56,290 for colon and rectum cancer. The blood cancers strike individuals of all ages, races, and each gender, and serve as valuable prototypes for the development of therapies for all types of malignant disorders. The Society hopes to work with NCI to strengthen its support for translational and clinical blood cancer research and use all available mechanisms to support blood cancer research by improving treatments and rapidly moving research advances from the laboratory bench to the patient's bedside.

*Expansion of Research Opportunities in Erythroid Differentiation, Oxidant Injury, and Metabolomics*

High quality hematology research in iron metabolism, gene regulation, and stem cell plasticity is currently being funded by NIDDK. ASH hopes to work with the Institute to continue advancing research in these areas and set new priorities in cutting edge hematology topics, such as erythroid differentiation, oxidant injury, and metabolomics.

*Funding for the Sickle Cell Treatment Act (Public Law 108-357)*

Sickle Cell Disease (SCD) is an inherited blood disorder that is a major health problem in the United States. More than 2.5 million Americans, mostly African-Americans, have the sickle cell trait. SCD occurs in approximately 1 in 300 African-American newborns each year. The average life span for a patient with this devastating disease is 45 years. While we continue to make progress with treatments, patients suffer debilitating pain and dangerous problems such as blood clots and strokes.

As part of fiscal year 2005 Appropriations legislation, Congress provided \$200,000 for the Health Resources and Services Administration to set up a demonstration program for sickle cell disease health centers and establish the National Coordinating Center to collect sickle cell disease-related data as authorized in the Sickle Cell Treatment Act (Public Law 108-357).

For fiscal year 2006, ASH requests \$10 million to continue to build this program by creating 40 Health Centers across the United States that would provide education, treatment (i.e., genetic counseling and testing), and continuity of care for individuals with sickle cell disease. In addition, this support would train health professionals at the 40 centers as well as establish a National Coordinating Center to collect, monitor and distribute information on best practices for the prevention and treatment of sickle cell disease. This recommendation has bipartisan, bicameral support as well as the backing of the Congressional Black Caucus and many other health, children's, church, union and African-American groups.

ASH believes that the centers created through the Sickle Cell Treatment Act will improve the lives of SCD patients through disease management programs to help them live longer, healthier lives while funding research to find a comprehensive cure and providing community education about this disease and its treatment options.

CONGRESSIONAL OVERSIGHT OF THE NIH PUBLIC ACCESS POLICY

The Society remains concerned about the impact of the NIH Public Access Policy on the agency's budget, researchers, and not-for-profit journals. ASH requests that the Subcommittee continue to be engaged in the oversight of the policy's implementation. Moreover, the Society urges the Subcommittee to call for an analysis of the financial impact of the policy on the NIH budget and individual research grants.

CONCLUSION

This is an exciting time to be engaged in biomedical research and the Society is proud that ASH members are participating in so many innovative studies. ASH praises the NIH leadership for the excellent stewardship of the hematology research portfolio at NCI, NHLBI, NIDDK, and NIA. The opportunities in hematology research are immense, particularly in translational research. Partnerships and cooperative ventures involving multiple academic centers are necessary for clinical research projects to succeed and need special attention from NIH. When properly conceived and implemented, ASH believes these studies will lead to improved therapies for patients with debilitating and deadly blood disorders. The Society sincerely

hopes that the Subcommittee will continue its longstanding support of biomedical research and will find the means to fund NIH at \$30 billion in fiscal year 2006.

In addition, ASH requests that the Subcommittee provide \$10 million for the Sickle Cell Treatment Act (Public Law 108-357) in fiscal year 2006. This support will create a network of centers across the United States for the education, treatment, and continuity of care for individuals with sickle cell disease, a major health care problem.

Thank you again for the opportunity to submit testimony. Please contact Jeff Coughlin, ASH Government Affairs Manager, at (202) 776-0544 or [jcoughlin@hematology.org](mailto:jcoughlin@hematology.org) if you have any questions or need further information on hematology research, fiscal year 2006 NIH funding, and support for the Sickle Cell Treatment Act.

---

#### PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), representing 43,000 members in the microbiological sciences, is pleased to provide a statement on the fiscal year 2006 funding for the Centers for Disease Control and Prevention (CDC). Although the fiscal year 2006 budget request includes important funding for influenza vaccine, childhood immunizations, global disease detection, and the Strategic National Stockpile, the ASM is concerned about the proposed budget reduction of \$491 million for CDC at a time when new health challenges, including a possible influenza pandemic, threaten public health. The 2003 Institute of Medicine (IOM) report, *Microbial Threats to Health*, warns that the magnitude and urgency of microbial threats demand renewed concern and commitment. The IOM report emphasizes the importance of strong CDC programs including greater global capacity for responding to infectious disease outbreaks, better case reporting by health care providers and laboratories, and expanded efforts related to antimicrobial resistance.

With people at risk from a broad range of health threats, our public health system will not be able to respond adequately without appropriate resources for public health programs. The ASM, therefore, recommends an increase of 8 percent in the fiscal year 2006 budget for the CDC. CDC's importance to safeguarding public health, both nationally and globally, is now unprecedented, but the level of funding for CDC is not keeping pace with its growing responsibilities to address new health threats. Infectious disease public health needs have been and will continue to increase and CDC's funding must remain strong to address them.

#### CDC INFECTIOUS DISEASE PROGRAMS

The CDC recently reorganized programs to better adapt to changing health threats. The Infectious Diseases Coordinating Center oversees three major programs, the National Immunization Program, the National Center for Infectious Diseases, and the National Center for HIV/AIDS, Sexually Transmitted Diseases and Tuberculosis Prevention. The President's budget includes \$1.7 billion related to domestic prevention and control of infectious diseases through these programs.

#### INFLUENZA

The National Center for Infectious Diseases is responsible for measuring progress in global influenza surveillance and detection to prepare for a pandemic influenza outbreak. Funding for pandemic influenza preparedness is appropriated through the Department of Health and Human Service's (DHHS) Public Health and Social Services Emergency Fund (PHSSEF). The budget proposes \$120 million for the expansion of year-round vaccine production capacity, a priority in the DHHS's draft *Pandemic Influenza Response and Preparedness Plan*. A significant investment will be required to enhance vaccine capacity to address the threat of pandemic influenza by developing a newer generation of influenza vaccine that can be quickly produced and deployed to strengthen the public health infrastructure on state and local levels, and to ensure that needed vaccines, antivirals and antibiotics are readily available.

#### HIV/AIDS

Under the CDC reorganization, programs focused on HIV/AIDS, sexually transmitted diseases (STDs), and tuberculosis are managed through the National Center for HIV, STD, and TB Prevention (NCHSTP). The budget proposes \$956 million, \$658 million of which is focused on prevention of these infectious diseases. Despite CDC efforts over the past two decades, the number of new HIV infection cases each year continues to remain high and the number of Americans living with HIV/AIDS is increasing. In fiscal year 2003, CDC launched a different U.S. initiative, based

on new rapid testing techniques for immediate patient results, designed to better prevent infections through earlier notification and to help identify the estimated 180,000 to 280,000 people not aware of their HIV-positive status.

#### GLOBAL HEALTH

The agency's recent reorganization also coordinated programs under the Office of Global Health (OGH) to track and prevent the international spread of diseases like measles, polio, and HIV/AIDS. The overarching goals are to recognize outbreaks faster, wherever in the world they occur, and to better control and prevent further outbreaks. Global disease detection mandates steady expansion of surveillance systems worldwide, as trade and travel allow rapid spread of previously unknown or unanticipated pathogens. Clinical and public health laboratory capacity must be strengthened together with epidemiologic and communications capabilities. The World Health Organization goal of eradicating polio by 2005 has suffered some setbacks recently, with wild poliovirus spreading in some African countries during 2003 and 2004. But last year, cases of the disease declined by nearly 50 percent in India, Pakistan, and Afghanistan. Since the WHO global initiative began in 1988, CDC and others have invested more than \$3 billion in the polio campaign. An estimated 250,000 lives have been saved and 5 million cases of childhood paralysis prevented. The CDC also partners with other federal agencies in the Global AIDS Program and in the President's Emergency Plan for AIDS Relief. In fiscal year 2004, nearly 2 million HIV laboratory tests and 275,000 tuberculosis infection laboratory tests were conducted under auspices of the Global AIDS Program. In addition, antiretroviral drug therapy was provided for nearly 19,000 AIDS patients in nine countries. By the end of 2003, the active spread of measles had been stopped in the Western Hemisphere. That year the CDC and its partners vaccinated more than 115 million children worldwide. Unfortunately measles persists as one of the world's leading child killers with an estimated 30 million cases and 700,000 deaths each year.

#### ANTIMICROBIAL RESISTANCE

Overuse of antimicrobials seriously increases the prevalence of pathogens resistant to commonly prescribed drugs. Antimicrobial resistance is considered one of the pressing issues faced by the CDC and other public health institutions. The 2003 Annual Report of the Antimicrobial Resistance Interagency Task Force reported that the number of cases of invasive pneumococcal disease in children in seven geographic areas declined by 75 percent in 2002 due to widespread use of pneumococcal vaccine, thereby reducing the use of antimicrobials which may become resistant. In fiscal year 2004, the CDC inaugurated a national media campaign about antibiotic resistance, to educate both patients and health care providers about the serious ramifications of overprescribing antibiotics. Also in fiscal year 2004, extramural grants were awarded for applied research in the estimate of economic costs for antimicrobial resistant human pathogens of public health importance. The purpose of the grant program is to obtain information that might impact and improve the current methods of preventing the emergence and spread of antimicrobial resistance. ASM supports sufficient budgetary increases in such prevention programs. The return on investment creates enormous health and economic benefits to the American public.

#### IMMUNIZATIONS

The CDC's immunization program would receive \$2.1 billion under the proposed fiscal year 2006 budget, to support the two primary goals of the program: at least 90 percent of all 2-year-olds to receive the recommended vaccines, and assurances of an adequate annual influenza vaccine supply. Investments in immunization programs are proven cost-savers. For example, every dollar spent on measles-mumps-rubella vaccine saves an estimated \$23 in health-care costs. Fiscal year 2006 funds would flow through the Vaccines for Children program and the Section 317 program, the former to provide vaccinations to children otherwise underserved in the health care system, the latter to subsidize state immunization efforts. As part of the overall CDC immunization focus, \$197 million is requested for influenza-related activities, representing a nine-fold increase over fiscal year 2001 appropriations. Funds would further expand the pediatric vaccine stockpile initiated last year, purchase additional doses of influenza vaccines for the general public, and encourage greater vaccine production for next winter's flu season. The fiscal year 2006 emphasis on immunization activities is a prudent use of federal funds needed to protect the public.

## SURVEILLANCE

DNA technology provides some of the notable cutting-edge science upon which CDC testing and surveillance programs are built and operated. The PulseNet system, which tracks foodborne illness outbreaks, is one particularly extensive use of such technology. These illnesses affect more than 76 million Americans each year; periodic outbreaks often are widely publicized in the national media. One example is the 2004 outbreak of salmonellosis among more than 500 people across five states, which CDC epidemiologists tied to contaminated restaurant tomatoes. Another is a multi-state incident of hepatitis A infecting more than 1,000 people after they ingested imported green onions. Similar surveillance systems now exist in Europe, Pacific Rim countries, and Latin America. The CDC's Tuberculosis Genotyping Program, initiated in fiscal year 2004, also fingerprints the genetic profiles of pathogens, enabling case investigators to assess very quickly how and where the bacterium is spreading. It already has described outbreaks in several states, permitting rapid deployment of preventive measures.

## BIOTERRORISM PREPAREDNESS

Defenses against possible bioterrorist attacks are a collaborative initiative among federal, state, and local agencies and authorities. The CDC is largely responsible for sufficient supplies of countermeasures such as vaccines and portable treatment units. The Administration proposes an increase of \$56 million for bioterrorism preparedness activities at the CDC, for a total of \$1.6 billion in fiscal year 2006. Six hundred million is proposed for further enhancing the Strategic National Stockpile (SNS). Specifically, the Medical Contingency Station project will be enhanced and increased funding will also help to pay for BioShield acquisitions and the purchase of additional anthrax antibiotics for the SNS. The CDC maintains the capacity to transport SNS materials and personnel to any location within the United States within 12 hours. During fiscal year 2004, the CDC nearly tripled the amount of medical countermeasures against anthrax, now capable of treating 30 million people.

Since 2001, the CDC has recognized the importance of anti-bioterrorism capabilities at the state and local levels, where attacks are most likely to occur. About \$4.5 billion has been invested in CDC programs to assure state and local preparedness. The agency's Laboratory Response Network (LRN) now includes 134 reference labs in all states, up from 91 in 2001, nearly all capable of detecting agents of anthrax, tularemia and smallpox. Five veterinary diagnostic laboratories are now part of the system, recognizing the importance of animal-to-human transmission of disease pathogens. More than 8,800 laboratory personnel have been trained for bioterrorism emergencies under CDC auspices. During fiscal year 2004, CDC invested about \$846 million to improve the ability of 62 state, local, and territorial health departments to respond to terrorism, infectious disease outbreaks, and other public health crises. The CDC funded the Cities Readiness Initiative, to boost delivery of medicines and other supplies during large-scale emergencies. The current proposed budget for fiscal year 2006 however, decreases support for state and local capacity. A report released this March by New York University concludes that bioterrorism-related training and equipping of local response personnel like paramedics have been seriously neglected, an example of yet unmet needs.

## BUILDINGS AND FACILITIES

Since 2001, the CDC has initiated or completed construction of more than 2.7 million square feet of laboratory and administrative space, replacing badly deteriorating buildings that were unsafe and inadequate. This year will mark the completion in Atlanta of a new Infectious Disease Laboratory, the Scientific Communications Center, the headquarters building with an Emergency Operations Center to coordinate quick responses, and the Environmental Toxicology Laboratory. The fiscal year 2006 request includes \$22.5 million to complete a replacement Vector Borne Infectious Diseases lab in Fort Collins, Colorado and an additional \$7.5 million to fund miscellaneous repairs and improvements. CDC's master plan for its buildings and facilities includes additional building renovations that are currently on hold, with hope to be funded in the near future. ASM applauds expenditures in recent years to replace the former CDC facilities in such poor condition and supports the completion of the master plan when funds can be allocated.

The ASM appreciates the opportunity to provide written testimony and would be pleased to assist the Subcommittee as it considers its appropriation for the CDC for fiscal year 2006.

## PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), the largest single life science society with over 43,000 members, is pleased to submit a statement on the fiscal year 2006 appropriation for the National Institutes of Health (NIH). The ASM appreciates the strong support that the Congress has provided for NIH supported biomedical research. Congress's investment in NIH has paid tremendous dividends in terms of human health improvements. We can expect progress against disease to continue because of recent scientific advances and new opportunities for applications of research knowledge gained from basic research discoveries. The challenge of infectious diseases, cancer, diabetes and other chronic diseases will continue to increase, thus, strong support for NIH is needed.

The ASM recommends a 6 percent increase in the budget for NIH in fiscal year 2006 and believes this increase would improve the pace of scientific investigation and the translation of science into new and better approaches to prevent, diagnose and treat diseases. A funding increase of this magnitude would allow NIH to take fuller advantage of innovative tools and technologies and the many extraordinary research achievements that have been made during the recent past. It would help to respond to urgent disease threats and realize more of the important medical treatment and public health goals that loom on the near horizon.

The ASM considers a 6 percent increase justified for NIH if it is to continue current programs and deal with new and pressing needs, including the threat from pandemic influenza, other emerging infectious diseases such as the recent and unexpected outbreak of SARS, the AIDS pandemic, a myriad of infectious and chronic diseases that continue to take a human toll worldwide and biodefense initiatives.

Since fiscal year 2003, the NIH budget has flattened, and at less than 1 percent, the proposed fiscal year 2006 budget increase will result in difficult funding decisions for research programs. Because the budget request for NIH falls below the current biomedical rate of inflation, which is about 3.5 percent, biomedical research will face a slowdown in the pace of scientific progress. This static state in funding comes at a rare time with unprecedented opportunities for major advances in human health and also at the very time that our nation's competitors are significantly increasing their investments in research. Their investments are based on the demonstrated positive impact of biotechnology and biomedical research on economic development. The European Union has set a goal of becoming the most competitive knowledge based economy in the world by 2010. Without increased investment in federally funded research in the United States, we stand to diminish the growth of U.S. technology.

## BASIC RESEARCH AND TRAINING

The ASM emphasizes the importance of providing increased support for basic research and the training and participation of young investigators in biomedical fields. Basic research and human ingenuity provide the underpinning of new knowledge that is necessary for successful medical breakthroughs. Basic research drives scientific creativity and productivity, making increased funding for investigator initiated research project grants a particularly critical issue when making funding decisions. Under the proposed fiscal year 2006 budget for NIH, the total number of research project grants (RPGs) supported falls below that of fiscal year 2005 by over 400 and no inflationary increases are provided for direct, recurring costs in non-competing RPGs. The ASM recommends increased funding for NIH to ensure a continuum of high quality research project grants and scientist training programs to keep biomedical research in the future as vigorous as it is today.

Specifically, ASM draws attention to the fact that scientific knowledge of microbes and their role in life and in the environment is key to new discoveries that will benefit human health. For example, the study of microbes resulted in the discovery that DNA is the genetic material of life and was responsible for the molecular revolution that has transformed biology. Research into basic life processes of bacteria is a critical underpinning of cellular studies that contribute to progress in the life sciences. Research on bacteria is urgent because more bacteria are becoming resistant to antibiotics, raising the specter of untreatable diseases. NIH should increase support for basic microbiology research and training and review research portfolios of the National Institute of General Medical Sciences (NIGMS), which provides support for fundamental research, and coordinate with other agencies such as the National Science Foundation (NSF) and the Department of Energy (DOE) to ensure that scientific opportunities in important areas of basic bacteriology physiology and genetics research are receiving adequate attention. The ASM recommends that NIH take steps such as workshops, requests for proposals and training grants to increase the infrastructure in this important area of science.

## INFECTIOUS DISEASES

Over the past 10 years, new and emerging microbial threats have continued to challenge the research community as well as the public health infrastructure. Despite scientific and medical advances, infectious diseases persist as the third leading cause of death in the United States and the second leading cause of death worldwide. A recent report from the Institute of Medicine on microbial threats to public health concluded that a comprehensive infectious disease research agenda is essential for successful anti-disease campaigns. The basic and applied research supported by the National Institute of Allergy and Infectious Diseases (NIAID) is essential to responding to infectious disease public health challenges. Unfortunately, the budget for the NIAID would increase by only 1.3 percent in the request for fiscal year 2006, far less than the amount needed to maintain or accelerate NIAID supported work to combat a myriad of infectious diseases.

Influenza is a familiar infectious disease threat with the proven potential for decimating pandemics. Influenza develops in about 20 percent of U.S. citizens each year and an estimated 36,000 die annually from complications of influenza in the United States, with 250,000 to 500,000 deaths worldwide. In the United States influenza and pneumonia remain the leading infectious cause of mortality and are ranked seventh among all causes of death. Influenza viruses steadily mutate and new strains periodically move from animal hosts to humans. World attention is drawn to outbreaks of avian influenza in Southeast Asia with about 55 infected persons and 42 deaths since January 2004. The current strain of H5N1 influenza could acquire characteristics that permit transmission among humans which could lead to a worldwide influenza pandemic. The 1918 influenza pandemic killed at least 20 million people and pandemic avian influenza could kill millions of people. The NIH Influenza Genomics Project conducts rapid sequencing of the complete genomes of thousands of avian and human influenza viruses and newly emerging ones and will study the molecular basis of how new strains of influenza virus emerge and characteristics that contribute to virulence. Research is being done to develop a live attenuated vaccine candidate against each of 15 isolated hemagglutinin proteins that may speed the development of a vaccine against a potential pandemic strain. Using reverse genetics technology, a genetically engineered vaccine candidate against H5N1 was developed in weeks. This technology was also used to identify a genetic mutation in a H5N1 viral gene that makes the virus more lethal.

In late 2002, Severe Acute Respiratory Syndrome (SARS) became the first severe newly emergent infectious disease of the 21st century, but was rapidly characterized and contained. Because of air travel by its earliest victims, SARS reached five countries within 24 hours and more than 30 countries on 6 continents within 6 months of the initial diagnosed case. Nearly 8,000 persons became ill and international travel and trade were greatly affected. The global cost of SARS has been estimated at about \$80 billion. NIAID funded research in collaboration with the Centers for Disease Control and Prevention (CDC) demonstrated that SARS is a viral disease and a new coronavirus was identified quickly as the causative agent. By May of 2003, an international collaboration of researchers had decoded the genetic sequence of the virus to develop a candidate vaccine that in November 2004 entered early phase tests in humans. Less than 2 years separated the discovery that SARS is a new infectious disease and the beginning of vaccine testing in humans, a process that traditionally can take decades. Results came quickly because of research and public health cooperation, NIAID resources and new molecular biology techniques. Research and technology developed during past disease outbreaks facilitate NIAID responses to unique or sporadic challenges like SARS, West Nile virus, Ebola virus, and bovine spongiform encephalopathy.

Research yields major insights into the pathogenic mechanisms of established diseases such as HIV/AIDS, tuberculosis and malaria. An estimated 40 million people worldwide are living with HIV/AIDS. NIAID research has made possible critical discoveries about the basic biology of HIV and the immune response to HIV infection which has led to the development of therapies that suppress the growth of the virus. Approximately 20 antiretroviral medications that target HIV have been developed and approved by the Food and Drug Administration. More scientific research is needed on the virus to identify additional targets for therapeutic interventions and vaccines. Despite the fact that tuberculosis (TB) is one of the oldest infectious diseases known, the global incidence rate is still increasing. More than one third of the world is latently infected with TB. Every day there are 5,000 deaths due to TB. A big part of the problem is the increasing number of patients with the deadly combination of TB and HIV. The only available medicines to treat and diagnose TB are from another era. Rapid development of new tools is greatly needed to address the growing problems of multi-drug resistant TB. Malaria is one of the major killers of



humans in the world with an estimated 300 million acute illnesses each year and more than 1 million deaths. Both tuberculosis and malaria pathogens are increasingly resistant to commonly used antimicrobial drugs. Genomic and postgenomic techniques are being applied to identify key molecular pathways that could be exploited to develop TB interventions and vaccines. The complete genomic sequence of the malaria vector and parasite were completed in 2002, providing powerful tools to further characterize the genes and proteins involved in the life cycle of the malaria parasite. NIAID supported programs in basic and applied areas are contributing to knowledge that is needed to design new vaccines, therapeutics and diagnostics against these formidable infectious diseases that exact a terrible social, economic and human toll globally.

The NIAID research portfolio is challenged as never before to address new and emerging infectious diseases and those that have affected humans for thousands of years but are still a public health threat. NIAID supports important research on the hepatitis viruses which cause liver inflammation and tissue damage and can cause chronic infections. There are more than 25 identified sexually transmitted infections (STIs) that affect more than 15 million people in the United States. STIs can lead to infertility, complications in pregnancy, cervical cancer, low birth weight, congenital/perinatal infections and other chronic conditions and are of critical global and national health priority because of their impact on women and infants. NIAID basic and clinical research studies on mechanisms of pathogenesis of STIs and prevention strategies for the control of these infections are essential. Bacterial and viral infections of the gastrointestinal tract often lead to diarrheal disease and to chronic conditions such as ulcers and stomach cancer. In the United States, diarrhea is the second most common infectious illness and diarrheal diseases account for 15 to 34 percent of deaths in some countries. Infection with *Helicobacter pylori* is a major risk factor for developing peptic ulcer disease, stomach cancer and primary gastric B cell lymphoma. NIAID supports research to understand, prevent and treat enteric diseases through a variety of initiatives. NIAID also sponsors research on West Nile Virus, which first emerged in 1999 in New York City, other insect-borne diseases such as Lyme Disease and fungal diseases that can cause severe systemic infections.

#### BIODEFENSE RESEARCH

The NIH is responsible for the implementation of the strategic plan for biodefense research. The NIH biodefense budget, proposed at \$1.7 billion for fiscal year 2006, is part of the budget for NIAID, the lead agency at NIH for infectious diseases and immunology research. Research is the backbone of the NIAID biodefense efforts and includes genomics and studies of pathogenesis and host defense, microbial physiology and animal disease models. Sustained funding by the Administration and Congress over the past few years is making possible significant progress evidenced by over 60 NIAID biodefense initiatives now in place.

Following the September 11, 2001 terrorist attack in the United States and terrorist events using biological agents, awareness about the potential of bioterrorism and the vulnerability of people to a bioterrorism event prompted the U.S. Government to pursue a range of programs and capabilities to prepare for future emergencies (Homeland Security Presidential Directive 10). Among these was increased funding for research and development of medical countermeasures within the Department of Health and Human Services to enable the country to mount a successful medical and public health response to a biological attack on the civilian population should such a terrible event occur. In 2002 the ASM testified before Congress that pathogenic microbes pose a threat to national security whether they occur naturally or are released in a bioterrorism attack. Biodefense research is part of the continuum of biomedical research aimed at protecting the nation and the world against infectious diseases. The ASM supports having federal biomedical and infectious disease research efforts related to civilian human health prioritized and conducted by and at the direction of the DHHS and NIH.

In early 2002, the NIAID convened a panel of experts, the Blue Ribbon Panel on Bioterrorism and Its Implications for Biomedical Research, to provide guidance on the future biodefense research agenda, research resources, facilities and scientific personnel. The NIAID developed research priorities and goals for potential agents of bioterrorism with particular emphasis on the "Category A" agents considered by the CDC and NIH as the worst currently recognized potential bioterror threats. The NIAID developed the NIAID Strategic Plan for Biodefense Research, The NIAID Biodefense Research Agenda for CDC Category A Agents, and the NIAID Biodefense Research Agenda for Category B and C Priority Pathogens. Approximately 60 NIAID initiatives were funded in fiscal years 2002–2004, including funding for a

network of 8 nationwide multidisciplinary Regional Centers of Excellence (RCE) for Biodefense and Emerging Infectious Diseases Research, 2 National Biocontainment Laboratories (NBLs), and 9 Regional Biocontainment Laboratories (RBLs) to provide secure space for the expanded civilian biodefense research program. The genomes of the biological agents listed as posing the most severe threats have been sequenced; new animal models have been developed to test promising drugs and repositories have been established to catalog reagents and specimens. NIAID is sponsoring basic research to understand structure, biology and mechanisms by which potential bioweapons cause disease, studies to elucidate how the human immune system responds to dangerous pathogens and technology to translate basic research into medical countermeasures to detect, prevent and treat diseases caused by potential biological weapons.

Advances in biodefense research are outlined in the NIAID Biodefense Research Agenda for CDC Category A Agents Progress Report and the NIAID Biodefense Research Agenda for Category B and C Priority Pathogens Progress Report. NIAID supported biodefense research is conducted through collaborative efforts with academic institutions and public/private partnerships and scientific communications are open, facilitating scientific and medical progress against infectious diseases. NIAID anticipates that the large investment mandated by the government in civilian biodefense research will advance scientific knowledge that will have positive spin offs for other diseases.

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

Agency	Amount
National Institutes of Health .....	30,000.0
National Heart, Lung and Blood Institute .....	3,117.0
National Institute of Allergy and Infectious Disease .....	4,667.0
National Institute of Environmental Health Sciences .....	680.0
Fogarty International Center .....	71.5
National Institute of Nursing Research .....	146.0
Centers for Disease Control and Prevention .....	8,500.0
National Institute for Occupational Safety and Health .....	326.0
Environmental Health: Asthma Activities .....	70.0
Tuberculosis Control Programs .....	215.0

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society that focuses on respiratory and critical care medicine. For 100 years, the ATS has continued to play a leadership role in scientific and clinical expertise in diagnosis, treatment, cure and prevention of respiratory diseases. With approximately 13,500 members who help prevent and fight respiratory disease around the globe, through research, education, patient care and advocacy, the Society's long-range goal is to decrease morbidity and mortality from respiratory disorders and life-threatening acute illnesses.

LUNG DISEASE IN AMERICA

Lung disease in America is a serious problem. Each year, an estimated 342,000 Americans die of lung disease. Lung disease is responsible for one in every seven deaths, making it America's number three cause of death. More than 35 million Americans suffer from a chronic lung disease. In 2005, lung diseases cost the U.S. economy an estimated \$139.6 billion in direct and indirect costs, a total of 5.9 percent of the U.S. economy.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include chronic obstructive pulmonary disease, lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma and severe acute respiratory syndrome (SARS).

The ATS is pleased that the Subcommittee provided increases in the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) budget last fiscal year. However, we are extremely concerned with the president's fiscal year 2006 budget that proposes a mere 0.5 percent increase for NIH and significant cuts for CDC. We ask that this Subcommittee recommend a 6 percent increase for NIH and an 8.1 percent increase for the CDC. In order to stem the devastating effects of lung disease, research funding must continue to grow to sustain the medical breakthroughs made in recent years. There are three lung diseases that illustrate the need for further investment in research and public health programs: Chronic Obstructive Pulmonary Disease, pediatric lung disease, specifically asthma and tuberculosis.

#### COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide. Yet, COPD remains relatively unknown to most Americans. COPD is the term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis and is a growing health problem.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It is estimated that 11.2 million patients have COPD while an additional 13 million Americans are unaware that they have this life threatening disease.

According to the National Heart, Lung and Blood Institute (NHLBI), COPD cost the U.S. economy an estimated \$37.2 billion in 2004. Unfortunately, NHLBI spends about \$44,000 a year on COPD research. We recommend the Subcommittee encourage NHLBI to devote additional resources to finding improved treatments and a cure for COPD.

Medical treatments exist to relieve symptoms and slow the progression of the disease. Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Despite these leads, the ATS feels that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world. Clearly more needs to be done to make Americans aware of COPD, its causes and symptoms. We were pleased to participate in an NHLBI-sponsored workshop to formulate strategies toward implementing a National COPD Education and Prevention Program. As this effort continues, we encourage the NHLBI to maintain its partnership with the patient and physician community in the next stages in the development of the National COPD Education and Prevention Program.

While additional resources are needed at NIH to conduct COPD research, CDC has a role to play as well. The ATS encourages the CDC to add COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the National Health Information Survey (NHIS) and the Behavioral Risk Factor Surveillance Survey (BRFSS). By collecting information on the prevalence of COPD, researchers and public health professionals will be better able to understand and control the disease.

#### PEDIATRIC LUNG DISEASE

Lung disease affects people of all ages. The ATS is pleased to report that infant death rates for various lung diseases have declined for the past ten years. However, of the seven leading causes of infant mortality, four are lung diseases or have a lung disease component. In 2002, lung diseases accounted for 21 percent of all deaths under one year of age. It is also widely believed that many of the precursors of adult respiratory disease start in childhood. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

The pediatric origins of chronic lung disease extend back to early childhood factors. For example, many children with respiratory illness are growing into adults with COPD. In addition, it is estimated that close to 20.3 million people suffer from asthma, including an estimated 6.1 million children. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. Asthma is the third leading cause of hospitalization among children under the age of 15 and is the leading cause of chronic illness among children.

The ATS feels that the NIH and the CDC must play a leadership role in the ways to assist those with asthma. National statistical estimates show that asthma is a growing problem in the United States. However, we do not have accurate data that provide regional and local information on the prevalence of asthma. To develop a

targeted public health strategy to respond intelligently to asthma, we need locality-specific data. CDC should take the lead in collecting and analyzing this data.

Last year, Congress provided approximately \$32 million for the CDC to conduct asthma programs. We recommend that CDC be provided \$70 million in fiscal year 2006 to expand programs and establish grants to community organizations for screening, treatment, education and prevention of childhood asthma.

#### TUBERCULOSIS

Tuberculosis (TB) is a global public health crisis that remains a concern for the United States. Tuberculosis is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis*. Tuberculosis primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine. The statistics for TB are alarming. Globally, one-third of the world's population is infected with the TB germ, 8–10 million active cases develop each year and 2–3 million people die of tuberculosis annually. It is estimated that 10–15 million Americans have latent tuberculosis. Tuberculosis is the leading cause of death for people with HIV/AIDS.

While we are pleased that CDC has reported 12 straight years of decline in United States TB rates, we remain concerned that TB rates in African Americans remain high and the TB rates in foreign-born Americans is growing. In addition, there has also been an increase in the number of TB cases among people with HIV/AIDS, prisoners, the homeless and certain immigrant communities.

Upon review of this information, many have concluded that a cycle of neglect has begun, reminiscent of a previous resurgence in the early 1980's. The ATS, in collaboration with the National Coalition for Elimination of Tuberculosis, recommends an increase of \$105 million for TB control in fiscal year 2006 to allow the CDC undertake an unprecedented initiative, Intensified Support and Activities to Accelerate Control (ISAAC), to enhance, maximize and target resources to sustain the momentum of the past decade and accelerate the control and elimination of tuberculosis. ISAAC targets tuberculosis in African Americans, tuberculosis along the United States-Mexico border, allows for universal genotyping of all culture positive TB cases, and expands clinical trials for new tools for the diagnosis and treatment of tuberculosis.

In the efforts to eliminate tuberculosis, it is important to note that in 2004 foreign-born residents accounted for nearly 54 percent of U.S. tuberculosis cases. The CDC is working to enhance screening of immigrants and refugees overseas, test recent arrivals from countries that have high TB rates, and cooperate with authorities to control tuberculosis along the United States-Mexico border.

The NIH also has a prominent role to play in the elimination of tuberculosis. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances have put the goal of an effective TB vaccine within reach. The National Institute of Allergy and Infectious Disease has developed a Blueprint for Tuberculosis Vaccine Development. We encourage the Subcommittee to fully fund the TB vaccine blueprint. We also encourage the NIH to continue efforts to develop drugs to combat multi-drug resistant tuberculosis a serious emerging public health threat.

It is clear that efforts to eliminate tuberculosis must continue. From recent TB outbreaks in Fort Wayne, IN and Chesapeake, VA to the hundreds of people being tested for tuberculosis in Houston, TX and Santa Barbara, CA, tuberculosis is still a problem in the United States today.

#### PHYSICIAN WORKFORCE SUPPLY

As the number of people diagnosed with lung diseases rises, we need to ask, who will be treating lung disease patients in the future? The ATS is concerned about the supply of physicians in the United States. A recent study published in the *Journal of the American Medical Association* predicts that there will be an acute shortage of physicians trained to treat patients with critical care illness and lung disease starting in 2007.<sup>1</sup> While the study focuses on supply of pulmonary/critical care physicians, what is driving the shortage is the predicated increase in demand for physician services caused by the aging of the U.S. population.

We are pleased that the Bureau of Workforce Analysis at Health Resources and Services Administration (HRSA) has taken an interest in this issue and will soon be releasing a study on pulmonary/critical care physician supply in the United

<sup>1</sup>D. Angus, et al. Current and Project Workforce Requirements for Care of the Critically Ill and Patients with Pulmonary Disease: Can We Meet the Requirements of an Aging Population? *JAMA* 2000; 284:2762–2770.

States. We believe the HRSA study will confirm an existing shortage of pulmonary and critical care physicians. Should the HRSA study confirm a shortage of physicians, Congress will then need to take action to address the shortage before it reaches a crisis. Potential steps Congress could take include: increasing existing caps on training positions for pulmonary/critical care, expanding the J-1 visa waiver program, increasing class sizes in medical schools, and expanding loan forgiveness and accelerated deductions of interests on loans for students enrolled in critical care training programs.

#### LUNG-DISEASE OPPORTUNITIES AND ADVANCES

Pulmonary researchers have made significant advances in lung disease research. The following are identified areas of lung disease research that the NHBLI has said it will be exploring in the next year:

- HIV-Related Pulmonary Complications. As mentioned earlier, the rate of persons with HIV who are also contracting TB are steadily growing. We applaud the NHLBI for its research on the roles of co-infections, immune factors and genetic predisposition in the pathogenesis of HIV-related pulmonary disease.
- COPD and lung cancer research. Nearly a quarter of a million Americans die each year of either COPD or lung cancer. NHLBI hopes to address the gap in knowledge that a common pathogenetic mechanism may be involved as a risk factor for COPD and lung cancer. The research will focus on a search for the similarities of the cellular and molecular mechanisms that lead to COPD and lung cancer. This new research could have important implications for the prevention and management of both diseases.
- Sleep Apnea or Sleep Disordered Breathing (SDB). SDB is a medical condition associated with upper airway obstruction and cessation of breathing that leads to repeated episodes of asphyxia during the night. SDB is very prevalent in the U.S. population with conservative estimates set at 2 percent to 3 percent of all children, 5 percent of middle age adults, and in excess of 15 percent of the aged population. The major health-related implications and morbid consequences of SDB include the neurocognitive and cardiovascular morbidities, depression, hypertension, increased frequency of myocardial infarction and stroke, and increased frequency of motor vehicle accidents due to the increased sleepiness induced by the disruption of sleep in SDB patients. Both the frequency of SDB and its consequences are anticipated to increase in the next decades due to the aging of the overall U.S. population and the ongoing epidemic of obesity that afflicts our country. The ATS supports the need for more research into the causes, diagnosis and treatment of SDB.

In conclusion, lung disease is a growing problem in the United States. It is this country's third leading cause of death, responsible for one in seven deaths. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of one year. Worldwide, tuberculosis kills 3 million people each year, more people than any other single infectious agent. The level of support this Subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers.

---

#### PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COALITION

The CDC Coalition is a nonpartisan association of more than 100 groups committed to strengthening our nation's prevention programs. Our mission is to assure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, researchers, educators, and citizens served by CDC programs. We are grateful for the opportunity to present our views to the Subcommittee.

It is time to support CDC as an agency—not just the individual programs that it funds. In the best professional judgment of the CDC Coalition—given the challenges and burdens of chronic disease, terrorism and disaster preparedness, new and re-emerging infectious diseases and our many unmet public health needs and missed prevention opportunities—the agency will require funding of \$8.65 billion to support its mission for fiscal year 2006.

The CDC Coalition is pleased with the support the Subcommittee has given to CDC programs over the years, including your recognition of the need to fund chronic disease prevention, infectious disease preparedness, and environmental health pro-

grams. By translating research findings into effective intervention efforts in the field, the agency has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. From anthrax to West Nile to smallpox to SARS, the Centers for Disease Control and Prevention is the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

In fiscal year 2002, Congress appropriated \$7.7 billion for CDC. In fiscal years 2003, 2004 and 2005, Congress appropriated \$7.1 billion, \$7.2 billion, and \$8.0 billion, respectively. Now the President's proposed budget for the agency in fiscal year 2006 is \$7.5 billion—a \$500 million cut from last year's funding, and \$200 million below the fiscal year 2002 funding level. We are moving in the wrong direction. Public health is being asked to do more, not less. As far as we can tell, in light of the current workload placed on the public health service—in addition to the threat of emerging diseases such as the avian flu—it simply does not make any sense to cut the budget for CDC at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability.

Until we are committed to a strong public health system, every crisis will force trade offs. For instance, the Administration's recent reprogramming request to make up for the vaccine shortage with money originally appropriated by Congress for chronic disease prevention programs (COPP and the Preventive Health and Health Services Block Grant) and bioterror preparedness funds is the most recent concrete example of attention to one disease coming at the expense of another.

CDC serves as the lead agency for bioterrorism preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. In the best professional judgment of CDC Coalition members, given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities, the agency will require at least level funding to adequately fulfill its mission for fiscal year 2006.

We are concerned that the President's budget proposes cutting the state and local capacity grants for terrorism by almost \$130 million, and eliminating the anthrax preparedness program. We encourage the Subcommittee to restore these cuts to ensure that our local communities can be prepared in the event of an act of terrorism.

Heart disease remains the nation's number one killer. In 2002, 696,947 people died of heart disease (51 percent of them women), accounting for 29 percent of all U.S. deaths. Stroke is the third leading cause of death after heart disease and cancer and a leading cause of serious, long-term disability. In 2002, stroke killed 162,672 people (62 percent of them women), accounting for about 1 of every 15 deaths. In 1998, the U.S. Congress provided funding for CDC to initiate a national, state-based heart disease and stroke prevention program with funding for eight states. Currently, 32 states and the District of Columbia are funded, 21 as capacity building programs and 12 as basic implementation programs. The CDC Coalition recommends \$55.6 million for the Heart Disease and Stroke Prevention Program.

The CDC carries out crucial work to reduce the incidence, morbidity and mortality of cancer through prevention, early detection, treatment, rehabilitation, and palliation. Cancer is the second leading cause of death in the United States. In 2004, about 1.4 million new cases of cancer will be diagnosed, and more than 563,700 Americans—about 1,500 people a day—will die of the disease. The financial cost of cancer is also significant. According to the National Institutes of Health, in 2003, the overall cost for cancer in the United States was \$189.5 billion: \$64.2 billion for direct medical expenses, \$16.3 billion for lost worker productivity due to illness, and \$109 billion for lost worker productivity due to premature death. Among the ways they are fighting cancer, the CDC funds programs to detect colorectal, ovarian, prostate, skin, breast and cervical cancers, as well as maintain a cancer registry to track cancer incidence. The CDC coalition recommends \$385 million for the Cancer Prevention and Control activities of the CDC.

Nearly 16 million Americans have diabetes, including over 5 million who don't know it. During 1980–2002, the number of people with diabetes in the United States more than doubled, from 5.8 million to 13.3 million. Although more than 18 million Americans have diabetes, 5.2 million cases are undiagnosed. Each year, 12,000–24,000 people with diabetes become blind, more than 42,800 develop kidney failure,

and about 82,000 have leg, foot, or toe amputations. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers. Without additional funds, most states will not be able to create programs based on these new data. States also will continue to need CDC funding for diabetes control programs that seek to reduce the complications associated with diabetes. The CDC Coalition recommends \$150 million for CDC's diabetes prevention efforts.

Over the last 25 years, obesity rates have doubled among United States adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The CDC funds programs to encourage the consumption of fruits and vegetables, to get sufficient exercise, and to develop other habits of healthy nutrition and activity. The CDC Coalition recommends \$70 million for CDC's Division of Nutrition and Physical Activity.

Arthritis and chronic joint symptoms affect nearly 70 million Americans, or about one of every three adults, making it one of the most prevalent diseases in the United States. As the population ages, this number will increase dramatically. The CDC Coalition recommends \$25 million for the arthritis programs of the CDC.

More than 400,000 people die prematurely every year due to tobacco use. The CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit with ways to do so. The CDC Coalition recommends \$145 million for the CDC's tobacco control programs.

Each day 4,400 young people try their first cigarette. At the same time, daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 percent in 2001. Almost 80 percent of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30 percent of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and about 3 million become infected with a sexually transmitted disease. School health programs are one of the most efficient means of correcting these problems, shaping our nation's future health, education, and social well-being. CDC's Adolescent and School Health program supports coordinated school health programs that reduce disease risk factors. In 2003, CDC supported 22 state-coordinated school health programs. The CDC Coalition recommends \$82.4 million for school health programs.

The President's budget proposes the elimination of the Childhood Obesity Prevention Program (COPP), also referred to as the VERB or CDC Youth Media campaign. The success of the COPP program shows that over 30 percent of the target audience, children ages 9 to 10 years old, increased their physical activity as a direct result of the VERB media campaign. This type of success warrants continued funding to empower our children to respond to the growing concerns of the obesity epidemic and improve the health of this nation. We encourage the Subcommittee to restore the cuts and fund the COPP program at \$70 million.

Public health programs delivered at the local level should be flexible to respond to local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from Prevention Block Grant programs is strong, yet so many requests go unfunded. However, the President's budget proposes the elimination of the Preventive Health and Health Services Block Grant. As states use their Prevention Block Grant dollars to address high priority needs such as emerging and chronic diseases, child safety seat programs, suicide prevention, smoke detector distribution and fire safety programs, adult immunization, oral health, work-site wellness, infectious disease outbreaks, food safety, emergency medical services, safe drinking water, and surveillance needs—we can scarcely understand why the Prevention Block Grant should be eliminated. In fact, the Prevention Block Grant has been flat funded since fiscal year 2000. We encourage the Subcommittee to restore the cuts and fund the Prevention Block Grant at \$132 million.

Much of CDC's work in chronic disease prevention and health promotion, and in other programs areas, is guided by its prevention research activities. Prevention research considers the factors associated with illness, disability, and injury, such as lifestyles or exposure to environmental toxins, and the best ways to address these factors and thereby promote health. By answering these questions, prevention research links biomedical research, which focuses on human physiology and disease treatment, to policies and public health interventions that promote wellness and reduce the need for treatment.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. These activities are critically impor-

tant, as CDC estimates that between 800,000 and 900,000 Americans currently are living with HIV. Also, the number of people living with AIDS is increasing, as effective new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is our best defense against the AIDS epidemic that has already killed over 400,000 U.S. citizens and is devastating the populations of nations around the globe, and CDC's HIV prevention efforts must be expanded.

Elimination of tuberculosis and sexually transmitted diseases (STDs), especially syphilis, is now within our grasp. These welcome opportunities, if adequately funded now, will save millions in annual health care costs in the future. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. State and local STD control programs depend heavily on CDC funding for their operational support.

CDC conducts the National Health and Nutrition Examination Survey (NHANES), the only national source of objective health data to provide accurate estimates of diagnosed and undiagnosed medical conditions in the population. NHANES is a unique collaboration between CDC, the National Institutes of Health (NIH), and others to obtain data for biomedical research, public health, tracking of health indicators, and policy development. Through physical examinations, clinical and laboratory tests, and interviews, NHANES assesses the health status of adults and children in the United States. Mobile exam centers travel throughout the country to collect data on chronic conditions, nutritional status, medical risk factors (e.g., high cholesterol level, obesity, high blood pressure), dental health, vision, illicit drug use, blood lead levels, food safety, and other factors that are not possible to assess by use of interviews alone. Findings from this survey are essential for determining rates of major diseases and health conditions and developing public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's REACH 2010 Demonstration Program, Racial and Ethnic Approaches to Community Health (REACH), helps states address these serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. The CDC Coalition recommends \$50 million for the REACH program.

The CDC Coalition is requesting a \$5 million increase, for an appropriation of \$46 million for Steps to a HealthierUS (STEPS) program. Additional resources will allow for the creation of programs in more states. Furthermore, while the President's budget request includes \$1.5 million to support the YMCA Pioneering Healthier Communities initiative, \$3 million is needed to fully fund and continue to expand this important effort. This would enable the funding 20 NEW Pioneering Healthier Community projects with one-time start up grants; provide funding for a conference in 2005 to train these community leadership teams, and establish an office within the Centers for Disease Control and Prevention that would assist YMCAs, non-profits and local/state health departments in initiating, evaluating and sustaining healthy community change efforts.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save health care costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination. Significant racial and ethnic disparities in vaccination levels persist among the elderly. Childhood immunization programs at CDC also need a funding boost, to ensure sufficient purchase and delivery of the recently-approved varicella and pneumococcal vaccines. In addition, developing functional immunization registries in all states will be less costly in the long run than maintaining the incomplete systems currently in place.

Injury at work remains a leading cause of death and disability among U.S. workers. During the period from 1980 through 1995, at least 93,338 workers in the United States died as a result of injuries suffered on the job, for an average of about 16 deaths per day. The Bureau of Labor Statistics (Department of Labor) has identified 5,915 workplace deaths from acute traumatic injury in 2000. BLS also estimates that 5.7 million injuries to workers occurred in 1997 alone; while NIOSH estimates that about 3.6 million occupational injuries were serious enough to be treated in hospital emergency rooms in 1998. The injury prevention and workforce protection initiatives of NIOSH need continued support.

Of the 4 million babies born each year in the United States, 3 percent are born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20 percent of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. An es-



estimated 54 million people in the United States currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. Direct and indirect costs associated with disability exceed \$300 billion.

Created by the Children's Health Act of 2000 (Public Law 106-310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities. We encourage the Subcommittee to provide at least \$135 million in fiscal year 2006 funding for the NCBDDD. This would be a modest increase of \$10 million and would further surveillance, research and prevention activities related to birth defects and developmental disabilities and improve the lives of those living with disabilities.

We also encourage the Subcommittee to provide \$10 million for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. As with the public health workforce, the environmental health workforce is declining. Furthermore, the agencies that carry out these services are fragmented and their resources are stretched. These services are the backbone of public health and are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, *E. coli* and lead in drinking water.

We appreciate the Subcommittee's hard work in advocating for CDC programs in a climate of competing priorities. We encourage you to consider our request for \$8.65 billion for CDC in fiscal year 2006. Members of the CDC Coalition are grateful for this opportunity to present our views to the Subcommittee.

---

#### PREPARED STATEMENT OF THE CHARCOT-MARIE-TOOTH ASSOCIATION (CMTA)

I want to thank the Subcommittee for this opportunity to share information about Charcot-Marie-Tooth (CMT) disorder and to express support for expanded CMT research funded by the National Institutes of Health (NIH).

#### BACKGROUND ON CMT

CMT is the most common inherited neurological disorder, affecting approximately 125,000 Americans. The disease affects people across their lifespan and is found world wide in all races and ethnic groups. Unlike muscular dystrophy, which strikes the muscles, CMT adversely affects the nerves that control the muscles. Individuals afflicted with CMT slowly lose normal use of their feet and legs and hands and arms as nerves to the extremities degenerate. The muscles in the extremities weaken due to the loss of stimulation by the affected nerves, and there is often a loss of sensory nerve function.

Even though there are different types of CMT, CMT is largely inherited in an autosomal pattern, meaning when one parent has the disease (either the father or the mother), there is a 50 percent chance it will be passed onto each child. The degree of severity can vary greatly from patient to patient, even within the same family. A child may or may not be more severely disabled than his or her parent. In most cases, CMT does not affect life expectancy; however, in certain forms the disease is more severe: debilitating children so that they require wheelchairs and even resulting in premature death. There are currently no effective treatments—although physical therapy, occupational therapy, and moderate physical activity are beneficial.

#### STATUS OF CMT RESEARCH

CMT was described over 100 years ago; yet, it has only been in the last 10 years that rapid advances in our understanding of CMT have occurred. We now know there are at least 30 different genetic causes of CMT, and the genetic location of many more types are known. Identification of the known CMT genes has led to the development of diagnostic tests, enabling many people to receive a firm diagnosis and evaluate risk to other family members. Despite identifying more genes associated with CMT, we are just beginning to understand how the genes, when abnormal, cause CMT.

To elucidate the complexities surrounding CMT, the CMTA funded the CMT North American Database, which is housed at Indiana University. Simply put, the database is a standardized collection of data about a large number of people with all types of CMT that includes detailed information about a person's medical, genetic, and family histories. Having a central repository of standardized information of CMT patients will accelerate the pace of CMT research, by providing detailed in-

formation about large numbers of uniformly evaluated patients to qualified researchers. Information contained in the database should provide a more accurate picture of the range of disability caused by the various types and sub-types of CMT. The database will also be a rich resource to tap when drugs or other CMT treatments become available for testing.

In addition to the database, for several years, CMTA has funded a quality research program including the sponsorship of many fellowships and national and international meetings. Ongoing studies are investigating the molecular basis of various forms of CMT, the molecular biology of molecules known to cause CMT, relationships between CMT and other neurodegenerative diseases such as ALS, and the development of rational clinical therapies to potentially treat CMT. The National Institutes of Health (NIH), in particular, the National Institute of Neurological Disorders and Stroke (NINDS), has co-funded several of these activities.

#### CMT RESEARCH AND THE NATIONAL INSTITUTES OF HEALTH

Despite providing modest support for a handful of successfully competed applications, NIH has not launched a coordinated effort to stimulate more CMT research opportunities nor invested sufficient resources. In fact, according to the NINDS, from fiscal year 2002 to fiscal year 2005, funding for CMT research at NINDS declined in real terms, even as total NIH dollars and funding of neuropathy research increased.

We are pleased the report that the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education requested on CMT research at NIH last year has contributed to the understanding of relevant trans-NIH activities. Moreover, we are encouraged by NIH's announcement that it is beginning to plan a workshop on peripheral neuropathies, but believe that such a workshop should focus intensively on CMT so that it will result in outcomes which will be directly relevant to CMT research and could lead to a relevant program announcement or request for applications on CMT, specifically.

We are confident the Subcommittee's continued interest in CMT research will help the NIH and CMT field work together to identify potential future research opportunities that could be incorporated into existing trans-NIH initiatives, such as the Blueprint for Neurosciences, or developed from the upcoming scientific workshop into a request for applications or program announcement.

Unlike many other areas of research, CMT did not experience a largess of funding during the NIH doubling period. In spite of this fact, in recent years, researchers made substantial progress towards understanding CMT. Yet, additional advances in the field will be hampered without additional resources from the NIH. This support would not only benefit CMT. Data from CMT research has the potential to translate into direct benefits for research into other neurodegenerative disorders, such as ALS and MS, which devastate hundreds of thousands of Americans. Therefore, by increasing its support for CMT, NIH will also be facilitating research into other neurodegenerative diseases.

#### FISCAL YEAR 2006 REQUEST

CMTA believes the Administration's request for the NIH in fiscal year 2006 is inadequate. Providing NIH with less than a one percent increase, as proposed, would fund the agency well below the rate of biomedical research inflation index (3.5 percent) and limit the agency's ability to invest in emerging areas of sciences, such as CMT, that are in dire need of an infusion of federal support. We urge the Subcommittee to increase funding for the NIH in fiscal year 2006. Moreover, we urge the Subcommittee to continue to express an interest in CMT and work with NIH to ensure that any workshop on peripheral neuropathies is intensively focused on CMT so that it will result in outcomes which will be directly relevant to CMT research and could lead to a relevant program announcement or request for applications on CMT, specifically. We encourage and strongly support any such program announcement or request for applications on CMT.

Once again, I thank the Subcommittee for expressing its interest in CMT and for this opportunity to testify.

---

#### PREPARED STATEMENT OF THE COALITION FOR AMERICAN TRAUMA CARE

The Coalition for American Trauma Care is pleased to provide you with its recommendations for fiscal year 2006 appropriations for public health programs that support trauma care, trauma care research, and injury prevention.

The Coalition for American Trauma Care is a nonprofit association of national health and professional organizations that seeks to improve care for the seriously injured patient through improved delivery of trauma care services, research and rehabilitation activities. The Coalition also supports efforts to prevent injury from occurring.

Injury is one of the most important public health problems facing the United States today. It is the leading cause of death for Americans from age 1 through age 44. More than 145,000 people die each year from injury, 88,000 from unintentional injury such as car crashes, fires, and falls, and 56,000 from violence-related causes. Over 85 children and young adults die from injuries in the United States every day translating into 30,000 deaths annually. Injury is also the most frequent cause of disability. Millions of Americans are non-fatally injured each year leaving many temporarily disabled and some permanently disabled with severe head, spinal cord, and extremity injuries. Because injury so often strikes the young, injury is also the leading cause of years of lost work productivity and, at an estimated \$224 billion in lifetime costs each year, trauma is our nation's most costly disease.

Attention to injury was never more important in the wake of the September 11, 2001 attacks. Particularly concerning is our failure, as a nation, to fully implement organized systems of trauma care in every state and region which numerous studies have demonstrated are essential to saving the lives of those who are severely injured. The Health Resources and Services Administration's (HRSA) completed analysis of a 2002 survey of the states that shows only eight states had comprehensive trauma systems, 12 states did not have even rudimentary elements of a trauma system and the remaining states are were in various stages of incomplete development. And yet a new Harris Poll, commissioned in November, 2004 to learn about the American public's views of and support for trauma systems found that:

- Almost everyone recognizes the importance of having a trauma system in their state.
- Large majorities feel that having a trauma system in place is as important as, or more important than, having State police or HAZMAT teams.
- About two in three Americans would be extremely or very concerned if they learned that the trauma system in their state did not meet recognized standards.
- Americans are willing to spend their own money to have trauma centers and trauma systems in place in their states.
- Generally, Americans have high expectations of their states' trauma centers and systems when it comes to handling natural disasters or terrorist attacks.

*Trauma Care Systems.*—The Coalition is opposed to the elimination of this program in the President's fiscal year 2006 budget request and urges you to provide \$12 million in fiscal year 2006 for HRSA's Trauma-EMS systems program. This is the amount provided in Senate authorizing legislation (S. 265) adopted unanimously by the Senate HELP Committee on February 9. The Trauma-EMS program was funded at \$3.0 million in fiscal year 2001, and \$3.5 million for fiscal year 2002–2005. Fully 80 percent of the appropriated dollars, as authorized, is provided for state grants to further trauma system development. States receive 100 percent federal funding in the first grant year and must provide a 2:1 state to federal match in Year 2, and a 3:1 match in Year 3. States may do this through in-kind assets. Thus, this seriously under-funded program provides both critical federal leadership and leverages scarce state resources.

The program has been making steady progress toward the goal of extending and strengthening organized systems of trauma care across the nation. In receiving grants from fiscal year 2002–2004 states had to assure:

1. A lead agency for the state trauma system.
2. Identification of a state-level trauma system manager.
3. A multidisciplinary statewide trauma stakeholder group.
4. Completion of the 2002 National Assessment (with fiscal year 2001 funding).
5. A statewide trauma system plan.

After these components were in place (or for those states with advanced trauma systems), the program funded additional state-specific trauma system projects.

A follow-up assessment of state progress in trauma system development is being planned for fiscal year 2005.

*National Center for Injury Prevention and Control.*—The Coalition supports \$168 million in funding in fiscal year 2006 for the National Center for Injury Prevention and Control which is currently funded at \$138 million. While the Coalition remains a strong supporter of the National Center for Injury Prevention and Control, members would like to see more balance in support for unintentional injuries. Significant increases in the NCIPC in recent years have largely been earmarked for violence prevention—an important focus for NCIPC after disturbing incidents in public

schools around the country. However, unintentional injury remains the leading killer of children and young adults and NCIPC's efforts to translate what works into communities should receive increased funding. These efforts help prevent, for example, the 20,000 head injuries that occur every year by encouraging the use of bicycle helmets, and reduce burn-related injuries through smoke detector implementation programs. The Coalition is also disappointed that as the funding base for the National Center for Injury Control and Prevention has grown, the relative amount of funding for acute care research and demonstration has diminished.

*Traumatic Brain Injury (TBI).*—Traumatic brain injury is a leading cause of trauma-related disability. Brain injury is a silent epidemic that compounds every year, but about which still little is known. The Coalition is opposed to the proposed elimination of this important program in the President's fiscal year 2006 budget request and urges you to provide a total of \$30 million for the Traumatic Brain Injury (TBI) Act, reauthorized as part of the Children's Health Act of 2000 (Public Law 106-310), as follows: \$8.715 million for CDC for surveillance—the legislation directs the CDC to build upon its work with state registries to collect information to help improve service delivery to people who have sustained a TBI and to expand monitoring of the incidence and prevalence of TBI to include all age groups and individuals in institutional settings. In 2003, the CDC launched the first phase of the National Information Center for TBI (NCITBI)—a “one call” national information center that provides persons with brain injury and their circles of support toll-free information on State-specific resources and linkage to services. The CDC has also been directed to monitor the incidence, outcomes and services needs of people who sustain injuries, including TBI, during mass casualty events. The Coalition also supports \$15.193 million for the HRSA TBI State Grant Program—this Program was established to improve access to health and other services for individuals with TBI and their families by awarding competitive grants to States and Territories; and \$6 million for HRSA Protection and Advocacy Services for persons with TBI. In addition, the Coalition requests that you include report language to ensure that the National Institutes on Neurological Disorders and Stroke (NINDS) within NIH increases core funding to \$2 million for each of its six Centers and that NINDS dedicate \$1.0 million for funding a new coordinating and administrative network for the six Centers. We also request that NINDS dedicate funding to establish a new category of training grants to incentivize individuals to pursue careers in TBI bench science research. NINDS currently funds six bench science research centers at \$1.0 million each. These six Centers represent groups of renowned basic and clinical physician-scientists working collaboratively on translational research programs who have developed the clinically-relevant laboratory models that will serve as the foundation for future research—it is imperative that we invest in the infrastructure that is now in place.

*Children's EMS.*—The Coalition is opposed to the proposed elimination of this program in the President's fiscal year 2006 budget request and urges you to provide \$20 million in fiscal year 2006, which maintains the fiscal year 2005 funding level. While children currently account for up to 30 percent of all emergency department visits and 10 percent of ambulance runs annually, many facilities lack the specialized equipment needed to care for children. Moreover, many emergency personnel do not have the necessary education or training to provide optimal care to children. In order to assist local communities in providing the best emergency care to children the Children's EMS program needs to continue and continue at the fiscal year 2005 funding level.

*Preventive Health/Health Services Block Grant (PHHS).*—The Coalition is opposed to the proposed elimination of this program in the President's fiscal year 2006 budget supports an fiscal year 2006 funding level of \$132 million, which maintains the same funding level as provided in fiscal year 2005. The Coalition rejects the President's request to eliminate this program because it is duplicative of other activities within the CDC. The PHHS Block Grant provides flexible funding to states to allow them to address specific health problems identified under the Healthy People 2010 assessment process. The funding allows states to take innovative approaches to address significant health issues and complements, not duplicates, some of CDC's other program activities. In addition, the PHHS Block Grant is the largest single source of federal funding for support basic state Emergency Medical Services' (EMS) infrastructure—the first line of defense against death and disability resulting from severe injury.

The Coalition for American Trauma Care is disappointed by the President's fiscal year 2006 budget which proposes elimination of all funding for four programs specifically designed to build infrastructure to ensure that trauma and emergency medical services are available and appropriate to need: HRSA's Trauma-EMS systems program; HRSA's Traumatic Brain Injury program; HRSA's Children's EMS pro-

gram and CDC's Preventive Health and Health Services Block Grant. If these cuts were enacted, the results would be devastating for emergency care in the United States for everyone and particularly for children and those who have suffered head injury. The burden of injury in America has been well documented by numerous IOM reports and injury facts speak for themselves: injury is the leading cause of death and disability for children and adults up to age 44. While much more can and needs to be done to prevent injury from occurring at all, we will never be able to eliminate it entirely. Cutting these programs will not lessen the injury burden in America; on the contrary, it will significantly increase the burden of death, disability and direct and indirect health care costs. We need to increase our investment in these program areas, not reduce our commitment.

The Coalition greatly appreciates the support the Subcommittee has provided to trauma related programs in the past and looks forward to working with the Subcommittee in the coming weeks and months.

---

PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding is pleased to provide the Subcommittee with testimony recommending fiscal year 2006 funding levels for the agencies and programs of the U.S. Public Health Service. Since 1970, the Coalition's member organizations, representing 40 million health care professionals, researchers, lay volunteers, patients and families, have been advocating for sufficient resources for PHS agencies and programs to meet the changing health challenges confronting the American people. The Coalition for Health Funding is the nation's oldest, most broadly based alliance focused on the breadth of discretionary health spending. One of the important principles that unites the Coalition's members is that the health needs of the nation's population must be addressed by strong, sustained support for a continuum of activities that includes biomedical, behavioral and health services research; community-based disease prevention and health promotion; health care services for vulnerable and medically underserved populations; ensuring a safe and effective food and drug supply; and education of a health professions workforce in adequate numbers to address the breadth of need.

The Coalition for Health Funding believes the Bush Administration, and Congress, are missing an important opportunity to improve the health of all Americans by not making a stronger investment in the agencies and programs of the U.S. Public Health Service. Federal spending for public health is low compared to other health spending, amounting to three percent of total health care spending according to the Centers for Medicare and Medicaid, and yet an investment in public health has the potential to slow unsustainable growth in mandatory costs, reduce lost productivity at work, school and home, and strengthen every citizen's contribution for a healthy, economically strong America. Mounting evidence-based studies ([www.thecommunityguide.org](http://www.thecommunityguide.org); [www.aspe.hhs.gov/health/prevention/prevention.pdf](http://www.aspe.hhs.gov/health/prevention/prevention.pdf); [www.modelprograms.samhsa.gov](http://www.modelprograms.samhsa.gov)) demonstrating the effectiveness of prevention, early intervention, access to basic health care services and associated cost-savings support investing in public health programs and activities. Instead, over the past two fiscal years we have seen an erosion of resources, beginning with the budget phase, with flat-funding, or cuts in funding, effected for many programs during the Committee phase of the appropriations process followed by across-the-board cuts in the omnibus bills for all health programs. The President's fiscal year 2006 budget request takes these reductions considerably further by proposing to cut funding for the seven major public health agencies by \$1.1 billion below fiscal year 2005 levels, a cut of 2.2 percent as the accompanying table shows.

The Coalition for Health Funding urges the Subcommittee on Labor, Health and Human Services and Education to reject the President's proposal to reduce the nation's investment in public health and instead join 425 health organizations that, in letter dated February 1, 2005, urged the President and Congress to make an investment in public health of \$3.5 billion over fiscal year 2005 levels. As that letter states:

"The health of all Americans is at risk from an unprecedented range of threats, including: chronic diseases and disabilities, infectious and food borne illnesses, biological and chemical terrorism, mental disorders and substance abuse, catastrophic injuries, and a shortage of healthcare providers and trained public health workers. Our nation's public health system will not be able to respond adequately to these threats without additional resources for the continuum of medical research, prevention, treatment and training programs. We urge you to increase discretionary funding for public health through the Function 550 budget allocation in fiscal year 2006

by \$3.5 billion. This investment is critical to improving the health, safety and security of our nation.”

The following is a partial list of the Coalition’s fiscal year 2006 recommendations for specific U.S. Public Health Service agencies. The Coalition developed these recommendations working with eight other health coalitions with a more targeted focus on one agency, or major activities within a particular agency. The table that follows provides the Coalition’s recommendations for all the major public health agencies.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

The Coalition supports \$30.1 billion in fiscal year 2006 for the National Institutes of Health, a 6 percent increase over the fiscal year 2005 funding level, to provide sufficient resources to sustain the momentum of the recently completed campaign to double the nation’s investment in the promising research supported and conducted by the NIH. The President’s request to provide \$28.6 billion, or a .5 percent increase over fiscal year 2005, is inadequate to fully reap the research opportunities that the doubling campaign have made available. NIH is engaging the next generation of biomedical research to integrate and aggregate basic research, computational capabilities, and clinical evidence into new cures. Transforming America’s health for the 21st century will require a longstanding commitment from our country and its leaders. The pace and intensity of this transformation is critical. Health improvements will only be possible if the medical research enterprise runs smoothly. Recent discoveries NIH supported research has made possible include: lifestyle intervention can reduce the onset of Type II diabetes as occurred in 58 percent of those at risk in a recent trial; islet cell transplantation has reduced the need for insulin for 250 individuals with juvenile diabetes; low-cost diuretics are as effective as newer, costlier drugs in lowering high blood pressure that affects one in four Americans, potentially saving money and enhancing compliance; newer antidepressant medications are more targeted to specific brain function resulting in fewer side effects and enhanced compliance; great advances in understanding the genetic factors in Alzheimer’s Disease holds promise for treatment for the growing number of Americans afflicted with this devastating disease; new vaccines have been developed against Haemophilus influenzae type b, pneumococcal disease, Hepatitis A and B and a new Ebola vaccine is currently in trial.

Scientific discoveries are the result of a series of incremental steps that pave the way for future breakthroughs. This process needs sustained support. A funding increase of only .5 percent will delay important initiatives leading to earlier, more targeted diagnoses; more targeted, effective treatment options; and more comprehensive, cost-effective prevention strategies.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The Coalition for Health Funding recommends an overall funding level of \$8.65 billion for CDC in fiscal year 2006. This amount is \$616 million more than the fiscal year 2005 funding level and \$1.1 billion more the President’s request for fiscal year 2006. The Coalition believes this is the amount needed to enable CDC to carry out its vital mission of disease prevention and health promotion.

The Coalition opposes the President’s request to cut \$130 million from State and Local Preparedness grants and shift the funds to the Strategic National Stockpile (SNS) to purchase vaccines and terrorism countermeasures and fund a new \$50 million Mass Casualty Initiative. Any SNS purchases and new federal terrorism initiatives, if deemed warranted, should be funded from new resources and not at the expense of State and Local Preparedness. State and Local health departments are in the third year of expanded funding for terrorism preparedness. The effect of a 14 percent cut will seriously jeopardize momentum in addressing critical capacity needs. Funding should be restored, at least, to fiscal year 2005 levels and the commitment to rebuilding the nation’s neglected public health infrastructure resumed and sustained.

The Coalition also opposes the proposed elimination of funding for the Preventive Health and Health Services Block Grant. This funding provides the only source of flexible funding to state health departments to help them meet Healthy People 2010 goals. The funding is often used in innovative ways which complement, not duplicate, other disease-specific categorical programs. It is also the only source of funding for many states to monitor well-contamination in poor rural areas. And it helps states cope with unexpected challenges such as emerging infectious diseases like West Nile Virus and the health consequences of disasters. Taken together, the proposed cut in the State and Local Bioterrorism grant program coupled with the elimination of the Preventive Block Grant seriously undermines funding for building State and Local public health capacity, a major Congressional goal expressed in leg-

isolation the year before (Public Law 106–505) and the year after (Public Law 107–188) the attacks of September 11, 2001.

The Coalition is displeased that most of the rest of the programs and activities conducted by the CDC are proposed for flat funding in the President's budget. This is especially egregious for chronic disease programs at a time when the nation faces an epidemic of obesity and the ensuing increase in diabetes, heart disease, kidney disease, cancer, arthritis and other costly diseases. There should be a major national investment in finding ways to address this problem. The VERB program, eliminated in the President's budget, provides a model for reaching young adolescents; it should be replicated.

Similarly, there is insufficient funding provided for infectious disease programs, most of which are flat-funded. The United States is still only partially prepared for diseases such as West Nile virus and pandemic flu, and has not committed funds to combat antimicrobial resistance commensurate with the scope and severity this problem presents in the United States. There are 40,000 new HIV infections each year which means the United States burden of HIV/AIDS is growing, not stagnant. The President's budget request does include increases for the National Immunization Program (+\$50 million), but the Coalition supports an increase of \$282 million in order to meet the national goal of vaccinating 90 percent of children and adults.

Finally, the Coalition is, overall, deeply disappointed that the President's budget request cuts funding for the CDC, the nation's leading disease prevention/health promotion agency, by more than 6 percent, instead of investing in this agency's potential for saving health care costs.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The Coalition for Health Funding recommends an overall funding level of \$7.5 billion for HRSA in fiscal year 2006. This amount is \$691 million, or 10 percent, more than the fiscal year 2005 funding level, and is \$1.5 billion more than the President's request. This is the amount that the Coalition believes is needed to provide adequate resources for the important programs that HRSA administers that address access to needed medical and health care services for medically underserved populations.

The Coalition is pleased that the President has requested a significant 17 percent increase for Community Health Centers (CHC) for a total of \$2.038 billion. These centers provide basic health care services for those who are medically underserved in both rural and inner city communities across the nation. With the number of uninsured rising, CHCs are more important than ever.

There are many other areas in the HRSA budget that the President proposes to cut deeply that the Coalition opposes. Chief among these is the elimination of the Title VII Health Professions Education programs. These programs are beginning to document formally what their supporters have long known: that they have a solid track record in recruiting and training the kind of health professionals that practice in, and stay in, medically underserved areas. Graduates of these programs are 3–10 times more likely to practice in underserved areas and are 2–5 times more likely to be minorities. The Title VII programs also have a solid track record in training needed health professionals in short supply including pharmacists, allied health professionals, dentists, a range of public health practitioners, psychologists, and physician assistants. These shortages will become worse as increasing numbers of the nation's healthcare workforce begin to retire and the babyboom generation requires increased care as it ages.

The Coalition also opposes the elimination of five other programs: Community Access Program, an innovative program of coordinated service delivery to the uninsured that does not duplicate other available programs; the Trauma-EMS program which fosters statewide trauma system development to provide appropriate emergency response for seriously injured individuals—an important terrorism readiness component; the Children's EMS program which builds appropriate emergency response capacity for children; the Traumatic Brain Injury program which helps brain-injured individuals become successful community participants; the universal newborn screening program which ensures that all states screen infants for a core set of screening tests for genetic, metabolic, hormonal, or functional conditions many of which can be treated if detected and disability averted. The Coalition also opposes the \$115 million cut to a number of rural programs, and the \$101 million cut to the Children's Hospitals Graduate Medical Education program.

Also disturbing is the proposed level funding for many other programs. This includes the Nursing Education programs despite considerable documentation of the nursing shortage crisis. It also includes the Ryan White CARE Act programs at a time when the United States is experiencing 40,000 new HIV infections per year.

The President's request for Ryan White programs, when compared to fiscal year 2005 levels, provides level funding for all titles except for the AIDS Drug Assistance Program which receives a \$10 million increase—not enough to eliminate waiting lists for the life-saving drugs. The Maternal and Child Health Block Grant is a critical safety net program for poor women and special needs children. Flat-funding actually cuts services at a time when there is an upsurge in the number of families needing TANF assistance. Family Planning services, which support 4,600 clinics across the United States that provide comprehensive services including screening for cancer, HIV, and other diseases as well as contraception and teen pregnancy prevention, are another critical safety net service that needs increased resources.

Overall, the President proposes to cut existing HRSA programs by \$838 million, or over 12 percent, at a time when the numbers of uninsured individuals and families is rising and they are turning to federally funded programs for assistance and care.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

The Coalition for Health Funding recommends an overall funding level of \$3.5 billion for SAMHSA in fiscal year 2006. This amount is \$262 million, or 8 percent, more than the fiscal year 2005 funding level, and \$316 million more than the President's budget request, which includes a 54 million cut for SAMHSA programs.

The Coalition is pleased that, for the third year, the President requests an increase for substance abuse treatment, although substantially less at \$25 million than the last two years. However, once again, the increase comes at the expense of prevention which is slated for a \$15 million cut. Substance abuse is a significant and very costly national problem involving an estimated 21.6 million Americans—over 9 percent of the population—and needs investment in both treatment and prevention. SAMHSA has developed a set of evidence-based model prevention programs that community-based organizations need help in implementing. On the treatment side, of the 1 million Americans who express a need for substance abuse treatment in a regularly conducted household survey, 273,000 (26 percent) report they made an effort to obtain treatment, but were unable to do so. Clearly, a stronger investment—which the President has championed—needs to be made to provide treatment when it is sought.

The Coalition is very disappointed that the President's budget cuts mental health program funding at SAMHSA by \$64 million. There is no additional investment made in response to the findings and recommendations of the President's New Freedom Commission on Mental Health, the first such commission in over 25 years. The Commission advised the President that youth with mental and emotional problems face enormous access barriers and that an alarming 80 percent of youth in juvenile detention facilities have mental disorders. Yet the President's budget cuts the Jail Diversion program in half and the successful Youth Violence Prevention program by \$27 million. These cuts should not be accepted in the aftermath of the Red Lake school massacre in Minnesota.

The Coalition sincerely appreciates this opportunity to provide its fiscal year 2006 funding recommendations to the Subcommittee for the agencies and programs of the U.S. Public Health Service. The Coalition's recommendations for all of the public health agencies are provided in the accompanying table. The Coalition, and its member organizations, look forward to working with the Subcommittee in the weeks ahead to improve the health of all Americans.

#### COALITION FOR HEALTH FUNDING 2006 RECOMMENDATIONS

[Dollars in millions]

Agency	Fiscal year 2005	President's request fiscal year 2006	President's dollar request fiscal year 2006—fiscal year 2005	Percent President's request fiscal year 2006—fiscal year 2005	CHF recommendation fiscal year 2006	Dollar difference CHF recommendation fiscal year 2006—fiscal year 2005	Percent difference CHF recommendation fiscal year 2006—fiscal year 2005
NIH <sup>1</sup> .....	\$28,444	\$28,590	+\$146	+0.5	\$30,150	+\$1,706	+6.0
CDC <sup>2</sup> .....	8,034	7,543	-491	-6.1	8,650	+616	+7.7
HRSA <sup>1</sup> .....	6,809	5,972	-837	-12.3	7,500	+691	+10.0
SAMHSA <sup>1</sup> .....	3,269	3,215	-54	-1.6	3,531	+262	+8.0
AHRQ .....	319	319	.....	.....	443	+124	+38.0
FDA <sup>1</sup> .....	1,450	1,500	+50	+3.4	1,566	+116	+8.0
IHS <sup>1</sup> .....	2,985	3,048	+63	+2.1	3,218	+232	+7.8



COALITION FOR HEALTH FUNDING 2006 RECOMMENDATIONS—Continued

[Dollars in millions]

Agency	Fiscal year 2005	President's request fiscal year 2006	President's dollar request fiscal year 2006—fiscal year 2005	Percent President's request fiscal year 2006—fiscal year 2005	CHF recommendation fiscal year 2006	Dollar difference CHF recommendation fiscal year 2006—fiscal year 2005	Percent difference CHF recommendation fiscal year 2006—fiscal year 2005
Totals .....	51,310	50,187	- 1,123	- 2.2	55,058	+ 3,747	+ 6.8

<sup>1</sup> Reflects Total Budget Authority.

<sup>2</sup> Reflects Total Program Level.

PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

(1) A 6 percent increase for the National Institute of Diabetes, and Digestive and Kidney Diseases, and the National Institute of Allergy and Infectious Diseases and a corresponding increase for Inflammatory Bowel Disease Research at both institutes.

(2) \$1.5 Million for the National Inflammatory Bowel Disease Epidemiological Program at the Centers for Disease Control and Prevention.

(3) \$25 million for CDC's National Colorectal Cancer Screening Awareness Program.

INTRODUCTION

Mr. Chairman, thank you very much for the opportunity to present the views of the Crohn's and Colitis Foundation of America (CCFA). I am Rodger DeRose, President and Chief Executive Officer of CCFA and I am honored to represent the people of this country who suffer from Crohn's disease and ulcerative colitis.

Crohn's disease and ulcerative colitis are chronic disorders of the gastrointestinal tract which represent a leading cause of morbidity from digestive illness. Because they behave similarly, these disorders are collectively known as inflammatory bowel disease (IBD). IBD can cause severe diarrhea, abdominal pain, fever, and rectal bleeding. Moreover, IBD related complications can include; arthritis, osteoporosis, anemia, liver disease, and colon cancer. Crohn's disease and ulcerative colitis are not fatal, but they can be devastating. We do not know their cause, and there is no medical cure.

CCFA is a non-profit, voluntary organization dedicated to finding a cure for Crohn's disease and ulcerative colitis. Throughout its 38-year history, CCFA has sponsored basic and clinical research of the highest quality. The Foundation also offers a wide range of educational programs for patients and healthcare professionals, and provides support services to assist people in coping with these chronic intestinal diseases.

We are extremely grateful Mr. Chairman, for your support of IBD related programs in the fiscal year 2005 Labor-HHS bill. Your leadership is making a tremendous difference in the lives of the patients and families that we serve.

RECOMMENDATIONS FOR FISCAL YEAR 2005

(1) *National Institutes of Health*

CCFA has developed highly successful research partnerships with the NIH. We are particularly proud of our longstanding collaborations with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) which sponsors the majority of IBD research at NIH, and the National Institute of Allergy and Infectious Diseases (NIAID).

In 2001, a team of investigators from NIDDK, CCFA, and the private industry announced that they had identified the first gene for Crohn's disease. This historic breakthrough opens up exciting new pathways of research focused on the development of improved therapies for Crohn's disease patients. The research which led to the discovery of the gene would not have been possible without the strong support that Congress has provided to the NIDDK in recent years.

Some of the most promising IBD research supported by the NIH has focused on translating findings from studies conducted on animal models to humans with IBD. These animal models have enabled researchers to form the current hypothesis that

Crohn's disease and ulcerative colitis are caused by a malfunctioning immune system, wherein components of the patient's immune system overreact to normal intestinal bacteria. We know that people are susceptible to this malfunction because of their genetic makeup but further research is necessary to determine which bacteria are responsible, how these bacteria interact with the intestine's immune system, and which immune system components are involved.

Mr. Chairman, IBD patients and their families are pinning their hopes for a better life on medical advancements made through NIH sponsored research. For this reason, CCFA recommends a 6 percent increase for NIDDK, NIAID, and NIH overall in fiscal year 2006. Moreover, CCFA encourages the subcommittee to increase IBD research funding within NIDDK and NIAID at the same rate as NIH overall.

*(2) Centers for Disease Control and Prevention*

*IBD Epidemiology Program*

Mr. Chairman, CCFA estimates that "up to one million" people in the United States suffer from IBD. Unfortunately, we do not have an exact number; due to the complicated nature of those diseases, patients may remain undiagnosed or misdiagnosed for several years.

One of CCFA's main public policy objectives has been the establishment of a nationwide IBD epidemiological program in partnership with the Centers for Disease Control and Prevention.

We are extremely grateful for your leadership in providing \$750,000 within CDC's National Center for Chronic Disease Prevention and Health Promotion for this much needed project in the fiscal year 2005 Labor-HHS bill. This program, which was initially funded through private support provided to CDC from our Foundation, will further our understanding of both the prevalence of IBD in the United States, and the demographic characteristics of this unique patient population.

The cultivation of patient demographic information is critically important to our biomedical research efforts given that environmental factors are believed to play a major role in the development and progression of IBD. If we are able to generate an accurate analysis of the geographic makeup of the IBD patient population, it will provide us with invaluable clues about the potential causes of IBD.

CDC, in partnership with our scientific experts, are making significant progress on the epidemiology study. Phase one of the study has been completed and is being prepared for publication this summer. Plans are currently underway to expand the study to other key areas of investigation. For fiscal year 2006, CCFA respectfully requests an appropriation of \$1.5 million for the continuation of the epidemiology study within the National Center for Chronic Disease Prevention and Health Promotion.

*Colorectal Cancer Prevention*

Finally Mr. Chairman, in addition to coping with either Crohn's disease or ulcerative colitis, many IBD patients are at high risk for developing colorectal cancer. As you may know, colorectal cancer is the third most commonly diagnosed cancer for both men and women in the United States and the second leading cause of cancer-related deaths. Because people who have suffered from IBD for more than 8 years are susceptible to this disease, CCFA has a long history of actively promoting the benefits of colorectal cancer screening.

Although colorectal cancer is almost entirely curable when detected early, studies have shown a tremendous need to: (1) inform the public about the availability and advisability of screening and (2) educate healthcare providers about screening guidelines. CDC's National Colorectal Cancer Roundtable is actively working to address these challenges by partnering with organizations like CCFA to implement a national public awareness campaign emphasizing the importance of screening and early detection. Moreover, CDC's "Screen for Life" awareness campaign is actively promoting the importance of colorectal cancer screening via television, radio and print media. CCFA encourages the subcommittee to provide CDC with \$25 million in fiscal year 2006 to support its colorectal cancer prevention activities.

Once again, Mr. Chairman, thank you for the opportunity to present the views of Crohn's and Colitis Foundation of America. We look forward to continuing to work with you on these important issues.

---

PREPARED STATEMENT OF THE DEVELOPMENTAL DISABILITIES RESEARCH CENTERS  
ASSOCIATION

Mr. Chairman, on behalf of the Developmental Disabilities Research Centers Association (DDRCA), I thank you for this opportunity to share with you and your

Committee, some of the exciting achievements that are happening in the world of developmental disabilities and mental retardation research. I am Steven F. Warren, Director of the Kansas Mental Retardation and Developmental Disabilities Research Center at the University of Kansas and Chair of the Developmental Disabilities Research Centers Association. First, let me tell you a little about our Association.

The DDRCA is a national resource that grew out of Congress' mandate in 1963 to establish "centers of excellence" in mental retardation and developmental disabilities research. With funding from the National Institute of Child Health and Human Development, our 20 member Centers represent the nation's first sustained and integrated effort to prevent and treat disabilities through biomedical and behavioral research. Today, we are the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. We believe that our Centers, and the network they form, substantially foster communication, innovation, and excellence in research. We work collaboratively on a number of research projects, and together with the Society for Developmental Pediatrics, produce the quarterly publication, "Mental Retardation and Developmental Disabilities Research Reviews." Each edition highlights the exciting new research on a developmental disability.

Our research Centers are located within premier research intensive universities and often are affiliated with major medical centers which provide academic, scientific and often clinical expertise as well as institutional support. Collectively, our work represents a multidisciplinary, vigorous, and innovative research program directed at understanding, treating and eventually substantially reducing the incidence of developmental disabilities including mental retardation. Additionally, our investigators are engaged in a very important mission—training the next generation of scientific investigators and clinicians in this area of great importance to America's children and families.

Although a significant portion of the research portfolios at the Centers consists of fundamental studies that are directed at understanding the biological and behavioral processes in animal models and human subjects, each Center directs considerable attention toward seeking solutions to practical issues and problems. Our connection to the University Centers for Excellence in Developmental Disabilities (UCEDDs) is critical in relating our research to practice. The scope of the research conducted at the Centers encompasses every known major dimension of mental retardation.

Over the last three decades there has been a huge payoff in the federal investment in the Developmental Disabilities Research Centers. Many disorders that cause intellectual disabilities can be prevented or treated to improve developmental outcomes. The Centers' scientific achievements have helped improve quality of life for individuals and families affected by disabilities. Among the most exciting aspects of this research is the work that is getting close to understanding the fundamental biological mechanisms that contribute to many of these disabilities with development of interventional strategies. I am pleased to share some examples with you.

*Brain Imaging Technologies.*—We are all familiar now with magnetic resonance imaging or MRI technology. Many of us have experienced this technology as it has been used increasingly over the past 12 years as a way for physicians to see increasingly higher resolution images of the brain as well as to measure local brain activity and metabolism. Functional magnetic resonance imaging (fMRI) provides a way to examine brain processing during complex behavior such as thinking and reading. Signal abnormalities associated with several diseases and syndromes that dramatically affect behavior and cognition have been characterized, including fragile X syndrome, Rett syndrome, Turner syndrome, Tourette syndrome and neurofibromatosis.

At the Kennedy Krieger Institute (KKI), the Mental Retardation Developmental Disability Research Center at Johns Hopkins University in Baltimore, MD., they have utilized functional brain imaging to establish a link between the lowering of vocabulary in children with neurofibromatosis (NF-1) and enlargement of the cerebrum. More detailed imaging techniques called spectroscopy imaging was then used to locate the specific regions of the brain that linked with the loss of vocabulary and cognitive functioning. A similar type of cerebral enlargement was discovered in autistic children by investigators at the University of North Carolina Mental Retardation Research Center. Understanding the processes of increased rates of brain growth will help lead researchers to finding preventive measures to stop the results of loss of IQ or vocabulary in these children.

*Brain Growth and Development.*—We are aware that the brain develops complex circuitry both under the guidance of internal genetic cues and in response to the brain's interaction with the outside world through activity and experiences ranging from simple sensation to complex behavioral interaction between the child and others. Developmental problems result when genetic errors occur either through the expression of an inherited copy of a deleterious gene, through chromosomal abnormali-

ties or when environmental factors may modify the expression pattern of genes. In addition, the developing brain is particularly sensitive to exposure to environmental toxins such as alcohol or lead. These insights into brain development provide a foundation for prevention through biomedical and behavioral intervention. During the initial formation of the brain in the fetus and in early postnatal life of the child, new nerve cells are forming and each one must extend fine processes that migrate through the brain to their correct targets and then they must establish the right connections (synapses) and assemble those synapses into the functional networks of communication sites whereby each cell in our brain talks to the next and communicates with the outside world. Many developmental disorders such as neonatal seizures that occur due to the mislocation of the brain's nerve cells to abnormal sites (heterotopia) or due to the failure of synapses to form their proper structural arrangements through a refinement process such as fragile X syndrome, result from the failure of synaptic connections to properly form in the developing brain. In order to understand a brain that has developed abnormally, leading to mental retardation or other developmental disabilities, it is necessary to understand the normal processes that guide this development.

At the Civitan International Research Center and Mental Retardation Research Center at the University of Alabama at Birmingham, investigators have discovered a new particle that forms in nerve cells during their earliest stages of development that brings together all of the necessary molecules to allow formation of a newborn synapse. At the University of North Carolina Mental Retardation research Center, investigators have determined the chemical pathways for regulating the migration of newborn neurons' in the developing brain. Several groups of investigators have determined how the fragile X gene product protein plays a role in the normal refinement of synapses in the normal developing brain and the consequences of interference with this protein's production in humans with fragile X syndrome and animal models. The functional consequences of this abnormal development include abnormally strong responses to sensory stimuli as determined by investigators from the University of Colorado Mental Retardation/Developmental Disabilities Research Center. This work is providing the scaffolding for designing strategies for specifically targeting early molecular events in the formation of the brain that may go awry in order to prevent or correct disorders of synaptic development.

*Language and Communication.*—Language and communication are key aspects in a human's ability to function in society. Researchers now know that the first 48 months of life is an optimal period in brain development for language acquisition and therefore is a period when intervention can have the greatest impact on a child's overall communication ability. With this in mind, researchers are asking the question, "Are there linkages between language impairments and various developmental disabilities or syndromes?"

The Kansas Mental Retardation Developmental Disability Research Center asked a more specific question. "Do some children with Specific Language Impairment (SLI) and children with some forms of autism share a genetic relationship?" Research conducted in Kansas suggests that this may be the case. Children with SLI often show a particular grammar deficit, an inability to accurately mark tense in the sentences they produce. Research reveals that this deficit may even be inherited. Collaboration with researchers at the Shriver Center Mental Retardation Research Center in Massachusetts shows that children with autism were also found to exhibit this tense-marking deficit. On the other hand, collaboration with researchers at the University of Louisville in Kentucky demonstrated that children with William's syndrome do not show this deficit. Researchers at the University of Texas Health Sciences Center in Houston have found that in dyslexic children, remedial training is helpful and that this training results in changes in patterns of brain activation similar to those seen in proficient readers. This work will ultimately lead to better identification and effective interventions to limit the disability caused by these disorders.

*Early Identification and Intervention.*—Researchers are learning that early intervention as well as early identification of a problem can lead to dramatically different life outcomes for a child and his/her family. At the Civitan International Research Center at the University of Alabama at Birmingham MRRC, investigators have begun using a dramatic new training regimen in children with cerebral palsy. This therapy termed pediatric constraint induced intensive therapy (PCIIT) involves limiting the child's use of the most affected limb with intensive training of the other limb over several weeks. Similar to its beneficial effect in adults who have experienced stroke, this therapy results in improved use of the trained limb. Investigators will evaluate whether this therapy in children results in similar massive functional reorganization of the brain as occurs in adult stroke patients. The Mental Retardation Research Center at the University of Washington in Seattle, has devoted a

great deal of its research to early intervention studies. Behavioral scientists there have enhanced the ability to recognize autism in the first two years of life. The new neuropsychological and brain-imaging findings in autism indicate that the severity observed reflects different underlying neurobiological bases that can be readily identified; these findings may now help focus early intervention programs. Other investigators in this field have identified and characterized the unique peer interaction deficits experienced by a vast majority of young children with developmental disabilities. Researchers who study early intervention developed a methodology to evaluate parent/child interactions using feeding and teaching scales, a methodology that has been extremely useful in identifying problem areas for children who are at risk. Researchers at the Waisman Mental Retardation Research Center at the University of Wisconsin in Madison, Wisconsin, have developed a method using gene sequencing technology to determine if children suffer from a rare but progressive disorder in children that has profound effects on cognitive development, Alexander's disease. By comparing their results with gene analysis to those obtained with more conventional clinical and fMRI analysis, these investigators have determined that a more definitive early diagnosis can be made with modern genetic tests. This work is contributing to our ability to identify and treat developmental disorders earlier and more effectively.

*Genetics.*—About 40 to 60 percent of known causes of moderate to severe mental retardation have genetic origins. Researchers are working on DNA probes designed to identify specific genes, to distinguish abnormal genes, and to identify genes responsible for specific disabilities such as Duchenne muscular dystrophy. Investigators have succeeded in mapping genes responsible for disabilities caused by enzyme defects, storage diseases, and other inborn errors of metabolism. Researchers have identified genes located on chromosome 21 known to be associated with Down syndrome and Alzheimer's disease. Researchers at the Baylor College of Medicine Mental Retardation Research Center in Houston, TX have discovered an X chromosome-linked gene that is associated with a large percentage of patients with Rett syndrome a neurodevelopmental disorder that primarily affects infant girls (the leading cause of mental retardation in girls) causing loss of speech, purposeful hand movements, seizures, ataxia and apraxia, episodes of apnea (breath holding) and sometimes death. Utilizing a mouse model, investigators at Baylor are investigating which genes are silenced in Rett and the underlying biological consequences of this process on neural development and synaptic function. Mutations in the same gene that causes Rett syndrome can also lead to other developmental disorders including autism and mild mental retardation as well as bipolar disorders and schizophrenia. Researchers at the University of Kansas Institute for Child Development have determined that children with Prader-Willi syndrome (the most common known form of genetically caused obesity) who have a life threatening eating disorder also display obsessive compulsive disorder (OCD). Both of these disorders may be caused by a gene defect on chromosome 15 causing lack of inhibition of brain centers involved with OCD and other brain centers that regulate growth hormone. This work is giving investigators a rich source of animal models to precisely identify the mechanisms whereby genetic defects cause developmental disorders and is providing the potential therapeutic targets for correcting the consequences of these disorders in humans.

While we have come a long way over the last 30 years, we still have far to go. With knowledge generated by the DDRCs, we will be able to:

- Use brain imaging and genetic methods to better understand the causes of specific disabilities and design strategies for treatment.
- Develop new therapies to prevent or reverse some of the symptoms of specific disabilities.
- Better understand the process of brain cell development and enrichment through studying the interplay of the brain's own chemistry with a child's experiences.
- Prevent many types of developmental disabilities by treating maternal infections and viruses transmitted to their infants.
- Capitalize on the brain's natural "plasticity" to optimize brain development in children born with developmental disabilities through early intervention or by extending the period of brain development.
- Design learning environments so all children have improved academic outcomes, including those with learning and intellectual disabilities.
- Determine which child with a disability will respond best to which speech or communication learning approach.
- Develop culturally competent psychological and medical assessment and treatment procedures for children born into minority families.

- Prevent and treat atypical behavior among children and adults with disabilities who are especially prone to such difficulties, such as children with autism, fragile X syndrome, or Rett's syndrome.
  - Assist families in preparing their adult sons and daughters with disabilities for successful lives of their own and prepare older people with developmental disabilities for coping with the normal process of aging.
- To address our concerns, we respectfully ask the Committee to increase NIH funding to \$30.067 billion for fiscal year 2006. Additionally, we ask that you increase funding for NICHD to the level of \$1.34 billion for fiscal year 2006.

Again, I thank you Mr. Chairman for taking time to learn about the DDRC network and the scope of work being conducted at these Centers across the nation. Together we believe that we are making strong headway in finding solutions to the many diseases and disabilities, which affect the children and adults of our society. With your continued support, and that of the Subcommittee, we can make great strides into the future.

---

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Provide increased funding for the National Institutes of Health (NIH) at 6 percent for fiscal year 2006. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases by 6 percent.
- Continue focus on digestive disease research and education at NIH, including the areas of Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Colorectal Cancer, Endoscopic Research, Pancreatic Cancer, Celiac Disease, and Hemochromatosis.
- \$30 million for the Centers for Disease Control and Prevention's (CDC) Hepatitis Prevention and Control activities.
- \$25 million for the Center for Disease Control and Prevention's (CDC) Colorectal Cancer Screening and Prevention Program.

Chairman Specter, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 27 professional societies and patient organizations concerned with the many diseases of the digestive tract. The Coalition has as its goal a desire to improve the health and the quality of life of the millions of Americans suffering from both acute and chronic digestive diseases.

The DDNC promotes a strong federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, Celiac Disease, and Hemochromatosis.

Mr. Chairman, the social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The DDNC would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). With respect to the coming fiscal year the DDNC is recommending an increase of 6 percent (\$1.7 billion) to \$30.1 billion for the National Institutes of Health (NIH) and all of its Institutes.

Specifically the DDNC recommends:

- \$5.1 billion for the National Cancer Institute (NCI).
- \$1.9 million for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).
- \$4.66 billion for the National Institute of Allergy and Infectious Diseases (NIAID).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies.

With the completed and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

## INFLAMMATORY BOWEL DISEASE

In the United States today about 1 million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. Crohn's disease and ulcerative colitis are not usually fatal but can be devastating. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. In 1998, the FDA approved the first drug ever specifically to fight Crohn's disease, a remarkable milestone. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium will continue its work in IBD research. Given the recent advancements in treatment for these diseases and the increased risk that IBD patients have for developing colorectal cancer, the DDNC strongly believes that generating improved epidemiological information on the IBD population is essential if we are to provide patients with the best possible care. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to initiate a nationwide IBD surveillance and epidemiological program in fiscal year 2006.

## HEPATITIS C: A LOOMING THREAT TO HEALTH

It is estimated that there are over 4 million Americans who have been infected with Hepatitis C of which over 2.7 million remain chronically infected. About 10,000 die each year and the Centers for Disease Control and Prevention (CDC) estimates that the death rate will more than triple by 2010 unless there is additional research, education, and more effective treatments and public health interventions. Hepatitis C infection is the largest single cause for liver transplantation and one of the principal causes of liver cancer and cirrhosis. There is currently no vaccine for hepatitis C, and treatment has limited success, making the infection among the most costly diseases in terms of health care costs, lost wages, and reduced productivity. Patients who are older at the time of infection, those who continually ingest alcohol, and those co-infected with HIV demonstrate accelerated progression to more advanced liver disease.

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of state health departments, particularly to enhance resources available to the hepatitis C state coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health, education, communication and training materials about prevention, diagnosis and medical management for hepatitis A, B, and C.

The DDNC supports \$30 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

## COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally. Although colorectal cancer is preventable and curable when polyps are detected early, a General Accounting Office report issued in March 2000 documented that less than 10 percent of Medicare beneficiaries have been screened for colorectal cancer. This report revealed a tremendous need to inform the public about the availability of screening and educate health care providers about colorectal cancer screening guidelines. In 2003, the New York City Department of Health has recommended colonoscopy for everyone over age 50 to prevent colorectal cancer.

The DDNC recommends a funding level of \$25 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports en-

hanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

#### PANCREATIC CANCER

In 2002, an estimated 28,300 people in the United States were found to have pancreatic cancer and approximately 28,200 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 2 out of 10 patients will live 1 year after the cancer is found and only a very few will survive after 5 years. Although we do not know exactly what causes pancreatic cancer, several risk factors linked to the disease have been identified:

- (1) Age: Most people are over 60 years old when the cancer is found;
- (2) Sex: Men have pancreatic cancer more often than women
- (3) Race: African Americans are more likely to develop pancreatic cancer than are white or Asian Americans
- (4) Smoking
- (5) Diet: Increased red meats and fats
- (6) Diabetes

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

#### IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable and fickle disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

The unpredictable bowel symptoms may make it next to impossible to leave your home. It is difficult to ease the pain than may repeatedly occur periodically throughout the day. A patient can become reluctant to eat for fear that just eating a meal will trigger symptoms all over again. IBS has a broad and significant impact on a person's quality of life. It strikes individuals from all walks of life and results in a significant toll of human suffering and disability.

While there is much we don't understand about the causes and treatment of IBS, we do know that IBS is a chronic complex of systems affecting as many as 1 in 5 adults. In addition:

- (1) It is reported more by women than men
- (2) It is the most common gastrointestinal diagnosis among gastroenterology practices in the United States
- (3) It is a leading cause of worker absenteeism in the United States
- (4) It costs the U.S. Health Care System an estimated \$8 billion annually.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders.

#### CELIAC DISEASE

Celiac Disease is a life-long condition in which the body develops an allergy to gluten, a protein found in wheat, barley, and rye, which can result in damage to the small intestine. Celiac disease affects as many as two million Americans. Onset of the disease can occur at any age. The common symptoms of Celiac Disease include fatigue, anemia, chronic diarrhea or constipation, weight loss, and bone pain. The only treatment for celiac disease is strict adherence to a gluten-free diet. Undiagnosed and untreated celiac disease can lead to other disorders such as



osteoporosis, infertility, neurological conditions, and in rare cases cancer. Persons with Celiac Disease often have other associated autoimmune disorders as well.

#### DIGESTIVE DISEASE COMMISSION

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the United States, identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases. The Commission's subsequent report in 1979 laid the groundwork for significant progress in the area of digestive disease research.

After almost 25 years, however, the burden of digestive diseases among the U.S. population remains substantial. The DDNC, therefore, calls upon Congress to establish a contemporary Digestive Diseases Commission to address the numerous digestive disorders that remain in today's diverse population.

The Commission should be comprised of the nation's leading non-governmental scientists, physicians, and health professionals, including practicing clinical gastroenterologists and researchers studying in the field of digestive diseases. Congress should charge the Commission with the following:

(1) Conducting a comprehensive study of the present state of knowledge of the incidence, duration, and morbidity of, and mortality rates resulting from, digestive diseases and of the social and economic impact of such diseases;

(2) Evaluating the public and private facilities and resources (including trained personnel and research activities) for the diagnosis, prevention, and treatment of, and research in, such diseases; and

(3) Identifying programs (including biological, behavioral, nutritional, environmental, and social programs) in which, and the means by which, improvement in the management of digestive diseases can be accomplished.

The Commission also should develop and recommend a long-range plan for the use and organization of national resources to effectively deal with digestive diseases, related nutritional disorders and basic biological processes and mechanisms in nutrition which are related to digestive diseases. Finally, the Commission should recommend for each of the Institutes of the NIH whose activities are to be affected by the long-range plan estimates of the expenditures needed to carry out each Institute's part of the overall program.

#### CONCLUSION

The DDNC understand the challenging budgetary constraints and times we live in that is subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health.

Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

#### DIGESTIVE DISEASE NATIONAL COALITION

The Digestive Disease National Coalition was founded 25 years ago. Since its inception, the goals of the coalition have remained the same: to work cooperatively to improve access to and the quality of digestive disease health care in order to promote the best possible medical outcome and quality of life for current and future patients with digestive diseases.

#### PREPARED STATEMENT OF THE DORIS DAY ANIMAL LEAGUE

The Doris Day Animal League represents 350,000 members and supporters nationwide who support a strong commitment by the federal government to research, development, standardization, validation and acceptance of non-animal and other alternative test methods. We are also submitting our testimony on behalf of People for the Ethical Treatment of Animals and the Animal Welfare Institute and their 800,000 members and supporters. Thank you for the opportunity to present testimony relevant to the fiscal year 2006 budget request for the National Institute of Environmental Health Sciences for the Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for the Interagency Coordinating Committee for the Validation of Alternative Test Methods (ICCVAM) activities for fiscal year 2006.

In 2000, the passage of the ICCVAM Authorization Act into Public Law 106-545, created a new paradigm for the field of toxicology. It requires federal regulatory agencies to ensure that new and revised animal and alternative test methods be scientifically validated prior to recommending or requiring use by industry. An internationally agreed upon definition of validation is supported by the 15 federal regulatory and research agencies that compose the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM), including the EPA. The definition is: "the process by which the reliability and relevance of a procedure are established for a specific use."

#### FUNCTION OF THE ICCVAM

The ICCVAM performs an invaluable function for regulatory agencies, industry, public health and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the federal regulatory agencies that regulated the particular endpoint the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test methods as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulator burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test methods. In addition, from the perspective of animal protection advocates, ICCVAM can serve to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce or replace animals, should be expeditiously integrated into federal toxicological regulations, requirements and recommendations.

#### HISTORY OF ICCVAM

The ICCVAM is currently composed of representatives from the relevant federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for NIEHS to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97-3981, "Validation and Regulatory Acceptance of Toxicological Test Methods." This report, and subsequent revisions, has become the sound science guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' NICEATM. Representatives from federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, several methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. In addition, the ICCVAM is working to streamline assessment of methods from the European Union (EU) that have already been validated for use within the EU. The open public comment process, input by interested stakeholders and the continued commitment by the federal agencies has led to ICCVAM's success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

#### REQUEST FOR APPROPRIATIONS

On December 19, 2000, the "ICCVAM Authorization Act" which makes the entity a permanent standing committee, was signed into Public Law No. 106-545. For several years, the NIEHS has provided between \$1 and \$2.6 million per fiscal year to the NICEATM for ICCVAM's activities. In order to ensure that federal regulatory agencies and their stakeholders benefit from the work of the ICCVAM, it is important to fund it at an appropriate level. I respectfully urge the Subcommittee to support increasing appropriations from within NIEHS' existing budget request for NICEATM for ICCVAM's activities to \$3.6 million for fiscal year 2006. This appro-

priation request includes all FTEs, funding for independent peer review assessment of test methods and meetings of the ICCVAM and other activities as deemed appropriate by the Director of the NIEHS.

REQUEST FOR COMMITTEE REPORT LANGUAGE

The NIEHS should support the NICEATM/ICCVAM in creating a five-year roadmap for assertively setting goals to prioritize ending the use of antiquated animal tests for specific endpoints. While the stream of methods forwarded to the ICCVAM for assessment has remained relatively steady, it is imperative that the ICCVAM take a more proactive role in isolating areas where new methods development is on the verge of replacing animal tests. These areas should form a collective call by the federal agencies that compose ICCVAM to fund any necessary additional research, development, validation and validation assessment that is required to eliminate the animal methods. We also strongly urge the NICEATM/ICCVAM to closely coordinate research, development and validation efforts with its European counterpart, the European Centre for the Validation of Alternative Methods (ECVAM) to ensure the best use of available funds and sound science. This coordination should also reflect a willingness by the federal agencies comprising ICCVAM to more readily accept validated test methods proposed by the ECVAM to ensure industry has a uniform approach to worldwide chemical regulation.

We also respectfully request the Subcommittee consider the following report language for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations bill:

“In order for the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) to carry out its responsibilities under the ICCVAM Authorization Act of 2000, the Committee strongly urges the National Institute of Environmental Health Sciences (NIEHS) to strengthen the resources provided to ICCVAM for methods validation reviews in fiscal year 2006. ICCVAM and NIEHS activities must include up-front validation study design, execution and review to ensure that new and revised test methods, non-animal test methods, and alternative test methods (such as QSARs, mechanistic screens, high throughput assays, and toxicogenomics) are deemed scientifically valid before they are recommended or adopted for use by federal agencies or used in implementing the National Toxicology Program’s (NTP) Road Map and Vision for NTP’s toxicology program in the 21st century.”

Thank you for the opportunity to submit this request on behalf of our more than 1.1 million members and supporters.

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

Provide increased funding for the National Institute of Health at 6 percent for fiscal year 2006. Increase funding for the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Deafness and other Communication Disorders (NIDCD), and the National Eye Institute (NEI) by 6 percent.

FISCAL YEAR 2006 RECOMMENDATIONS FOR NIH

- NIH: \$30.1 billion
- NINDS: \$1.63 billion
- NEI: \$709 million
- NIDCD: \$417.6 million

Continue to accelerate funding for intramural and extramural dystonia research at NINDS.

Provide funding for NINDS to conduct an epidemiological study and to increase public and professional awareness of dystonia.

Continue to expand NIDCD’s intramural and extramural research on dysphonia. Continue to expand NEI’s intramural and extramural research on dystonia.

Chairman Specter, thank you for the opportunity to submit testimony to the Subcommittee on behalf of the Dystonia Medical Research Foundation (DMRF). Dystonia has affected the lives of many Americans and we are thankful to be able to provide for you our recommendations for fiscal year 2006 federal funding with regards to dystonia research.

Dystonia is a neurological disorder characterized by powerful and painful involuntary muscle spasms that causes the body to twist, repetitive jerking movements, and sustained postural deformities. There are several different variations of dystonia, in-

cluding: focal dystonias which affect specific parts of the body, such as the arms, legs, neck, jaw, eyes, vocal cords; and generalized dystonia, affecting many parts of the body at the same time. Some forms of dystonia are genetic and others are caused by injury or illness. Dystonia does not affect a person's consciousness or intellect, but is a chronic and progressive movement disorder for which, at this time, there is no known cure. The Foundation estimates that some form of dystonia affects about 300,000 people in North America.

Even though there is no known cure for dystonia, there are treatments to lessen the severity of the symptoms of the disease such as oral medications, botulinum toxin injections, and in some cases surgery. Having increased access to these medical therapies is becoming an increasing larger issue for the community as a whole.

In the past few decades, dystonia researchers have made several exciting scientific advancements and have been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures, directly benefiting those affected. Genetics, in particular, is opening up a new understanding into the cause and pathophysiology of the disorder. Thus far, 13 dystonia related genes or gene loci have been identified. In 1997, the DYT1 gene for childhood early onset dystonia was identified, and we now have a genetic test available to confirm diagnosis of this particular type of dystonia. Most recently, in 2002, the gene for myoclonus dystonia was identified. However the community is still without a diagnostic test and misdiagnosis still occurs too frequently.

Deep brain stimulation is a surgical procedure that was originally developed to treat Parkinson's disease but is now being applied to severe cases of dystonia. Deep brain stimulation has drastically improved the lives of dozens of dystonia patients during the past few years. Individuals who were previously bedridden by muscle spasms and pain are able to walk without assistance, to speak clearly, to dress themselves, to get a driver's license, to date, to travel, and to live the life of an able-bodied person. Deep brain stimulation is currently used primarily to treat severe cases of generalized dystonia but its promising role in treating focal dystonias is being explored. Surgical interventions are a crucial and active area of dystonia research.

#### RESEARCH, AWARENESS, AND SUPPORT

Now is an exciting time to be involved in dystonia research and awareness. Researchers are becoming more interested in movement disorders and dystonia at the National Institutes of Health (NIH), and research is yielding promising clues for better understanding and management of this disorder.

One way the Dystonia Medical Research Foundation has advocated for more research on dystonia, is by funding "seed" grants to researchers. Thus far, the Dystonia Foundation has funded over 370 grants, and 5 fellowships, totaling more than \$18 million. Due to our advocacy there are a growing number of talented researchers dedicated to understanding the biochemistry of dystonia, genetic causes, new therapeutics and the necessity of an epidemiology study.

Another primary goal of the Dystonia Foundation is education of both lay and medical audiences. The Foundation conducts regular medical workshops and patient symposiums to present, discuss, and disseminate comprehensive medical and research data on dystonia. In January 2001, NINDS co-sponsored a genetics and animal models meeting, designed to involve not only prominent researchers but inviting junior investigators to participate in the discussions. Additionally, in October 1996, the NIH was one of our co-sponsors for an international medical symposium, which featured 60 papers on dystonia and 125 representatives from 24 countries. The Young Investigators Award Program and the Residency Program are in place to entice emerging medical professionals into the field of dystonia research and cultivate future dystonia experts.

Since 1995, over 3,000 educational medical videos have been distributed to hospitals, medical and nursing schools, and at medical conventions. In addition to medical and coping publications, we have a children's video to educate families and increase public awareness of this devastating disorder in younger populations. Media awareness is conducted throughout the year, and especially during Dystonia Awareness Week, observed nationwide from October 14 through 20. Local volunteers have been successful in securing news stories on dystonia in local venues as well as national media shows such as Good Morning America, The Oprah Winfrey Show, and Maury Povich. Through his friendship with the mother of a dystonia patient, screen star Kirk Cameron has taken an interest in promoting dystonia awareness, and the Dystonia Foundation is in the process of investigating the possibility of a public service announcement and several appearances at fundraising events.

The Dystonia Foundation has over 200 chapters, support groups, and area contacts across North America. In addition, there are 15 international chairpersons whose mission is to promote awareness, children's advocacy, development, extension, Internet resources, leadership, medical education, and symposiums. Furthermore, patient symposiums are held internationally and regionally to provide the latest medical and coping information to dystonia patients and others interested in the disorder.

#### DYSTONIA AND THE NATIONAL INSTITUTES OF HEALTH

The Dystonia Medical Research Foundation recommends an increase to \$30.1 billion or 6 percent for NIH overall, and a 6 percent increase for NINDS, and NIDCD. We at DMRF request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We also urge the Subcommittee to recommend that NINDS provide the necessary funding for additional extramural research and a large-scale dystonia epidemiological study. There is also an imperative need for NINDS to increase its efforts to educate the public and medical community about dystonia through co-sponsorship of workshops and seminars. We also encourage the Subcommittee to support NIDCD in its efforts to revamp its strategic planning process by implementing a Strategic Planning Group which will help NIDCD as they: consider applications for high program priority; develop program announcements and requests for applications; and develop new research areas in the Intramural Research Program.

The National Institute of Neurological Disorders and Stroke (NINDS) awarded seven grants in fiscal year 2004 for dystonia research in response to the Program Announcement, "Studies into the Causes and Mechanisms of Dystonia" (August 2002). In addition, the National Institute on Deafness and Other Communication Disorders (NIDCD) funded an eighth study on brainstem systems and their role in spasmodic dysphonia.

DMRF also supports the many intramural researchers studying dystonia. Research includes: exploring improved clinical rating scales for dystonia, elevations of sensory motor training, utilizing botox as a possible treatment for focal hand dystonia, characterization of abnormalities in sensory regions of the brain, treatments for spasmodic dysphonia, anatomy imaging of the affect of dystonia on brain activity, and exploring the link between laryngitis and spasmodic dysphonia. The public awareness impact of pianist Leon Fleisher's treatment through the NIH intramural research program has had a tremendously positive impact.

NINDS continues to work with dystonia research and voluntary disease groups in the community. In January 2004, NINDS sponsored a workshop at Emory University on the Pathology of Dystonia, and in October 2004, NINDS participated in a workshop to develop a strategic plan for a series of studies on the epidemiology of dystonia. NINDS also provided funding in September 2004 to a researcher affiliated with the Dystonia Medical Research Foundation (DMRF) to provide partial support for a multi-year series of workshops focused on evolving areas of research that are critical for the development of therapeutics.

Dystonia is the third most common movement disorder after Parkinson's Disease and tremor, and affects many times more people than better known disorders such as Huntington's Disease, muscular dystrophy and ALS or Lou Gehrig's Disease. We ask that NINDS fund dystonia-specific extramural research at the same level that it supports research for other neurological movement disorders.

#### CONCLUSION

The ultimate goal of the Dystonia Foundation is a cure for dystonia. Until that goal is realized, we are hungry for knowledge about the nature of dystonia and for more effective treatments with fewer side effects. We have amassed many exceptional and diligent researchers; who are committed to our goal, and our top priority is funding their very important research. But the Foundation cannot do it alone. We need federal support through NIH, NINDS, NIDCD and NEI to continue to fund quality scientific research and eliminate this debilitating disease.

Combine the thwarting of scientific progress with the decreased access to therapies and all the progress of the last few years could be wiped away. We ask that you aggressively support medical research, specifically for movement disorders and brain research. By doing so, you are doing a tremendous service for my family and myself and to the hundreds of thousands of people and families affected by dystonia.

Thank you very much.

## THE DYSTONIA MEDICAL RESEARCH FOUNDATION

The Dystonia Medical Research Foundation was founded 25 years ago and has been a membership-driven organization since 1993. Since its inception, the goals of the Foundation have remained the same: to advance research for more effective treatments of dystonia and ultimately a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

PREPARED STATEMENT OF THE FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY SOCIETY, INCORPORATED (FSH SOCIETY, INC.)

Mr. Chairman, it is a pleasure to submit this testimony to you today.

My name is Daniel Paul Perez, of Lexington, Massachusetts, and I am testifying as President & CEO, of the FacioScapuloHumeral Muscular Dystrophy Society (FSH Society, Inc.) and as an individual who has lived with facioscapulohumeral muscular dystrophy (FSHD) for nearly 43 years. FSHD is the third most prevalent form of muscle disease. It affects 1/20,000 people. For men, women, and children the major consequence of inheriting FSHD is a lifelong progressive and severe loss of all skeletal muscles. Most people are familiar with Duchenne muscular dystrophy (DMD) that affects boys. What they are not aware of is, that in any given moment, there are probably more individuals with FSHD alive than with Duchenne MD (14,800 vs. 11,000). Recently, the NIH identified significant gaps in FSHD and a preponderance of DMD research grants and reported that it only has five (5) active projects on facioscapulohumeral muscular dystrophy in its entire NIH wide portfolio.

We have given testimony before the U.S. Congress every year since 1994. We have submitted 26 written testimonies and 5 oral testimonies to the U.S. Senate and U.S. House Appropriations Subcommittees on Labor, Health, Human Services and Education and Related Agencies. We have had considerable report language written in the appropriations budget from the committees directed to the National Institutes of Health (NIH) with regard to improving the portfolio at the NIH in FSHD in nearly every year that we have come before you. In April 2000, prior to the passage of the "Muscular Dystrophy CARE Act 2001" law, we testified that Congressional directive on FSHD has been and is repeatedly ignored by the NIH. Since 2001, we have been working closely with the NIH on the MD CARE ACT 2001 law mandated research plan. Prior to all of the activity around the MD CARE Act 2001, we noted then that the NIH is seriously out of compliance with the previous four years of Congressional Directives. Incredibly, today in the calendar year 2005 heading into the fiscal year 2006 the NIH still is out of compliance and has an anemic portfolio on FSHD. Going back in time, in 2000 we reported the NIH had not responded to the past and prior years of Report Language.

The Report Language for 2000 has been responded to in an untimely manner and mainly ignored. The 2000 Report Language is as follows: "The Committee is concerned that NIH has not responded to a previous request to develop a plan for enhancing NIH research into Facioscapulohumeral (FSH) disease. The Committee urges NIH to promptly convene a research planning conference and to establish a comprehensive portfolio into the causes, prevention, and treatment of FSH disease through all available mechanisms, as appropriate. The Director is requested to be prepared to testify on the status of this initiative at the fiscal year 2001 appropriations hearing." (House Report 3037, p. 81 for NINDS, p. 97 for NIAMS.) The status of fiscal year 2000 Report Language is as follows: FSHD extramural research is almost non-existent. Intramural research on FSHD is non-existent at NIH.

The Report Language for 1999 has been ignored and the status of the Report language for fiscal year 1999 is not done. The 1999 Report Language is as follows: "The Committee encourages the Institute to continue and expand research efforts focused on aiding in the diagnosis and treatment of FSHD." (House Report, NINDS Section, p. 103), and, "The Committee was pleased with the Institute's response to last year's request which encouraged NIH to stimulate research in the area of facioscapulohumeral disease (FSHD). However, the Committee notes that NIAMS has not responded in developing a plan for enhancing FSHD research, and has not addressed the question of whether an intramural program in this area would be beneficial. Therefore, the Committee urges NIH to conduct a research planning conference in the near future in order to explore scientific opportunities in FSHD research, both intramurally and extramurally." (House Report, NIAMS Section, p. 120-121.) The status of 1999 Report Language is as follows: FSHD extramural research is almost non-existent. Intramural research on FSHD is non-existent at NIH.

The Report Language for 1998 has been ignored and the status of Report language for fiscal year 1998 is not done. The 1998 Report Language is as follows: "The Committee has heard compelling testimony about facioscapulohumeral (FSH) dis-

ease, which causes progressive and severe loss of skeletal muscle. FSHD research includes aspects such as molecular genetics, neurological function and muscular dystrophy involving multiple NIH Institutes. The Committee encourages NIH to take steps to stimulate research in this area and requests NIH to develop a plan for enhancing NIH research into FSH disease (FSHD), including an assessment of whether an intramural research program in this area would be beneficial." (House Report, p. 101.) In 2005, the status of 1998 Report Language is as follows: FSHD extramural research is almost non-existent. Intramural research on FSHD is non-existent at NIH.

We have worked hard to be sure that our constituency understands and supports the doubling of the NIH budget and have been very successful in helping to grow the NIH budget from \$10.326 billion to \$28.649 billion. In the same period, we saw FSHD funding increase by about \$1.3 million. This year we will spare you the heartache of our personal story and the pain and suffering our disease brings in its train. This year we simply would like you to ask the NIH "Where did the money that Congress appropriated and further directed through appropriations report language go?"

We formerly request a congressional investigation, hearing or some other Congressional action regarding the absolute failure of the NIH to increase funding in facioscapulohumeral muscular dystrophy (FSHD). We have been testifying and generating report language and laws for a dozen years and have done the yeoman's share in building the base for FSHD. Despite the specific directions from the Congress in report language as shown above and with a public law and a federal advisory committee on muscular dystrophy, the NIH has failed to follow through on improving FSHD research. Despite our active involvement with the NIH, the NIH has made the grant review process very secretive, has turned down opportunities to shed light on the grant decision making process and still has not responded to congressional letters and inquiries on the lack of facioscapulohumeral muscular dystrophy (FSHD) research in the NIH portfolio.

I would like to illustrate what we have done at the FSH Society, Inc. to improve the funding and portfolio of muscular dystrophy (MD) and FSHD. The FSH Society (Society) has represented the FSHD community of researchers and clinicians by the following activities on the Hill, in the districts, and at the NIH. The FSH Society was the first on the Hill and at the NIH and before Parent Project Duchenne Muscular Dystrophy (PPDMD) and MDAUSA for many years since 1993. The Society has given nearly three dozen Congressional testimonies, in writing and in person, before the committee to support the doubling of the NIH budget and to encourage spending on muscular dystrophy. The Society has succeeded in achieving nearly a dozen sections of report language in appropriations reports. I have served on numerous NIH research and planning task forces. The Society has had countless hundreds of meetings with the Directors, Staff and program officers of the NIH NINDS, NIAMS, NICHD, NHGRI, ORD and the OD. I served on the five year long range planning meeting for the NIH NIAMS July 1999. I rewrote the MD CARE Act 2001 bills to include all muscular dystrophies, ages and genders, and to establish the Muscular Dystrophy Coordinating Committee (MDCC) federal advisory committee with public members, and to establish five national centers for MD not at the exclusion of the basic research, and much more. The Society has contributed to supporting two NIH funded FSHD research planning conferences (1997, 2000). I work closely and collaboratively with NIH program directors. I serve on the MDCC at the request of Secretary Tommy G. Thompson and Dr. Elias Zerhouni. I helped write the MDCC NIH research plan submitted to Congress in summer 2004. I continually encourage FSHD researchers to submit NIH grant applications for R01, R21, R03, P01, U54, K, T, F training and mentoring awards and Director's Pioneer Awards. The Society has given testimony before the Institute of Medicine (IOM) on improving the Center for Scientific Review (CSR) grant review process for FSHD. The FSH Society itself has funded \$1.1 million in \$30,000 a year fellowships to more than 2 dozen researchers in 5 years, leading to nearly 7 dozen publications in top tier journals. The FSH Society helps the NIH FSHD patient registry and existing Wellstone Cooperative Research Center's as a volunteer health agency.

As a grant agency, the FSH Society has world renowned and leading clinicians and researchers peer reviewing applications, funding research, reviewing progress reports and preliminary data and ideas. We know and have comprehension on the quality of applicants and projects and data being submitted to you in the NIH grant applications for FSHD research. I have first hand knowledge of the research as well as our Nobel quality advisors. I can tell you that researchers of Wellstone, Nobel, and Howard Hughes stature working on FSHD have had applications on FSHD rejected by the NIH. However, their applications on other types of muscular dystrophy have been funded by the very same agency.

Mr. Chairman, as you know, the National Institute of Child Health and Human Development (NICHD), the National Institute of Arthritis and Musculoskeletal Disorders (NIAMS), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Human Genome Research Institute (NHGRI) are four of the National Institutes of Health (NIH) institutes called upon by the Muscular Dystrophy Community Assistance Research and Education Act of 2001 (MD CARE Act 2001) to develop a research plan for muscular dystrophy (MD) research and education conducted through the National Institutes of Health. Certainly, other NIH institutes will be called into action where appropriate such as NHLBI, NEI, NIA, NIMH, NCRR, FIC, and OD.

We rewrote the MD CARE Act 2001 bill from the Muscular Dystrophy Children's Assistance Research and Education Act 2001, covering only the childhood form of Duchenne MD (DMD), to the Muscular Dystrophy Community Assistance Research and Education Act 2001 covering all forms of MD. We rewrote the bill to include all forms of muscular dystrophy affecting men, women, and girls in addition to boys because it was the right thing to do. Oddly, in 2004 Duchenne MD received a commanding portion of the muscular dystrophy funding and seven of the other muscular dystrophy types have little or no funding from the NIH.

An analysis was presented at the December 2004 MD CARE Act mandated Muscular Dystrophy Coordinating Committee (MDCC) meeting of the 164 grants in the NIH portfolio for future planning purposes related to the five sections of the muscular dystrophy research plan. Subsequent to the meeting, I requested the details of the 164 grants used for the December 1, 2004 discussion from Dr. John Porter (DHHS NIH NINDS), the Executive Secretary of the MDCC. It has been communicated that this compilation was done for planning purposes. From discussions with Dr. Porter we understand that this view of grants differs from the muscular dystrophy portfolios as presented by the budget and NIH OCPL offices regarding the various institutes along coding parameters. The 164 grants were assembled with a degree of scientific subjectivity and based on professional expertise and judgment. The December 2004 MDCC meeting yielded an analysis of a subjective grouping of the NIH wide 164 muscular dystrophy grants. Eight were reported related to FSHD. At that time, the NIH identified that 8 out of 164 grants are on FSHD! Only eight out of 164 grants are for research on FSHD the third most prevalent dystrophy that affects men, women and children!

The details of the data of the 164 grants as presented at the December 1, 2004 MDCC for the grants with funding start dates in 2004 shows 35 grants funded for the 2004 year to that date. The count by dystrophy for calendar year 2004 is: 18 for Duchenne muscular dystrophy (DMD), 2 for Limb Girdle muscular dystrophy (LGMD), 1 for Myotonic muscular dystrophy (DM), 1 for facioscapulohumeral muscular dystrophy (FSHD), 7 for stem cell research, and 6 for other research. To reiterate by dystrophy the total grants awarded in 2004 were: 18 for DMD, 2 for LGMD, 1 for DM, and 1 for FSHD! The most recent year of funding data shows that the non-Duchenne muscular dystrophy group is not doing well in terms of numbers of grants and funding. We request a hearing that focuses on this issue with immediacy and attention to ameliorating this unequal growth. Oddly, there is an order of magnitude difference between Duchenne muscular dystrophy (DMD) and the entire complement of all other dystrophies.

What has happened in facioscapulohumeral muscular dystrophy (FSHD) research in the five years since the MD CARE Act was signed and what has happened since the thirteen years since we first started asking NIH to invest and build the facioscapulohumeral muscular dystrophy portfolio? NIH has rejected nearly four dozen grant applications on facioscapulohumeral muscular dystrophy of R03, R21, R01, P01, U54, NIH Director Pioneer Award Nominations mechanisms and more. The funding track record speaks for itself. To date in fiscal year 2005 the NIH has rejected every FSHD application it has received. It is difficult to attract investigators to FSHD when there is no money made available for them and it becomes a downward spiral to attract new and promising investigators.

Incredibly, the NIH NIAMS, NINDS, NICHD, NHGRI FSHD funding is still non-existent. Since 2001, the overall NIH wide muscular dystrophy budget has increased from \$21.0M to \$42.2M in fiscal year 2006 estimated and enacted. Since 2001, the FSHD budget has increased from \$500,000 to \$1.6M in fiscal year 2006 estimated.



NATIONAL INSTITUTES OF HEALTH (NIH) MUSCULAR DYSTROPHY AND FSHD APPROPRIATIONS HISTORY <sup>1</sup>

[In millions of dollars]

Fiscal year	Total NIH dollars on MD	NIAMS dollars on MD	NINDS dollars on MD	NICHD dollars on MD	NHGRI dollars on MD	NIH wide dollars on FSHD
2000 .....	12.6	4.8	4.9	1.2	.....	0.4
2001 .....	21.0	9.2	8.2	0.5	0.3	0.5
2002 .....	27.6	11.1	9.8	0.6	2.3	1.3
2003 .....	39.1	15.5	13.2	4.5	2.1	1.5
2004 .....	38.7	15.0	14.8	3.8	0.3	2.2
2005ES .....	41.0	16.3	13.7	4.8	2.2	1.6
2005EN .....	42.2	15.2	16.6	5.0	0.3	1.6
2006ES .....	42.2	15.2	16.7	5.0	0.3	1.6

<sup>1</sup> Source: NIH/OD Budget Office & NIH OCPL.

NIH NIAMS. The NIAMS is ostensibly the lead institute at the NIH on muscular dystrophy. After all of our efforts the NIH National Institute of Arthritis and Musculoskeletal Disorders (NIAMS) now has only one research contract that it is co-funding with NIH NINDS for FSHD for \$186,233 per year? Not one single research grant for FSHD, the third most prevalent dystrophy! The total muscular dystrophy portfolio ending December 15, 2005 was 58 projects, including Wellstone Cooperative Research Centers (CRC) components for a total of \$14,992,725.

NIH NINDS. The NINDS is the second largest NIH contributor towards muscular dystrophy research funding. The NIH National Institute of Neurological Disorders and Stroke (NINDS) now has three research grants, one research contract, and one-quarter of a Wellstone CRC for FSHD for a total of \$1,386,620 in fiscal year 2004. The total muscular dystrophy fiscal year 2004 portfolio reported February 1, 2005 was 39 projects, including Wellstone CRC components for a total of \$14,756,290.

NIH NICHD. The NICHD is third largest NIH contributor towards muscular dystrophy research funding. The NIH National Institute of Child Health and Human Development (NICHD) does not have a single research grant or project directly focused on covering FSHD, which is the third most prevalent dystrophy that affects both boys and girls. The total muscular dystrophy fiscal year 2004 portfolio reported December 1, 2004 was 15 projects, including Wellstone CRC components for a total of \$3,837,633.

NIH NHGRI. The NHGRI is historically the fourth largest NIH contributor towards muscular dystrophy research funding. The NIH National Human Genome Research Institute (NHGRI) does not have a single research grant or project directly focused on covering FSHD. The total muscular dystrophy fiscal year 2004 portfolio reported on December 1, 2004 was 1 project (Z01-HG000215-02), including Wellstone CRC components for a total of \$281,396. The project is Hereditary Inclusion Body Myopathy (HIBM) and HIBM is not a type of muscular dystrophy.

Astonishingly, the total NIH wide spending on muscular dystrophy decreased from \$39.1 million (fiscal year 2003) to \$38.7 million (fiscal year 2004). Something is wrong with this trend given the Appropriations Subcommittee's interest in this area and the efforts of the patient and research communities to shore up and improve muscular dystrophy research.

NATIONAL INSTITUTES OF HEALTH (NIH) APPROPRIATIONS HISTORY <sup>1</sup>

[Dollars in millions]

Fiscal year	NIH overall dollars	MD research dollars	MD percent of NIH	FSH research dollars	FSHD percent of MD	FSHD percent of NIH
2000 .....	\$17,821	\$12.6	0.071	\$0.4	3.18	0.0022
2001 .....	20,458	21.0	0.103	0.5	2.38	0.0024
2002 .....	23,296	27.6	0.118	1.3	4.71	0.0056
2003 .....	27,067	39.1	0.144	1.5	3.83	0.0055
2004 .....	27,887	38.7	0.139	2.2	5.67	0.0079
2005E .....	28,495	41.0	0.144	1.6	3.90	0.0056
2006E .....	28,640	42.2	0.147	1.6	3.79	0.0056

<sup>1</sup> Source: NIH/OD Budget Office & NIH OCPL.

The NIH NIAMS, NINDS, NICHD, NHGRI the four lead institutes on muscular dystrophy reported a combined total of 113 projects on muscular dystrophy totaling \$33,869,044 in fiscal year 2004. Of that total amount facioscapulohumeral muscular dystrophy (FSHD) received \$1,572,853 for three grants, one contract and one-quarter of a Wellstone CRC.

Looking at the three existing Wellstone Cooperative Research Centers (CRCs) the NIH NICHD is spending \$1,631,994, the NIH NIAMS is spending \$1,224,971, and the NIH NINDS is spending \$1,462,151. Only one-quarter of the Wellstone CRC funded by the NIH NINDS specifically works on FSHD. One more Wellstone center is currently in the process of being funded and none of the work at the fourth Wellstone pertains to FSHD. Of \$4,319,116 funded to the first three Wellstone CRCs, only \$365,538 is directly titled for FSHD. Only 8.46 percent of the total Wellstone expenditure is being spent on the third most prevalent form of muscular dystrophy that affects both men and women.

Mr. Chairman, we are troubled by the NIH grant review process used for the Wellstone Center applications as NIH uses a review process that deviates from its rigorous adherence to stating that it funds projects of the highest scientific merit. The Wellstone applications are reviewed for scientific merit and then the entire score is adjusted upward or downward based on a “gestalt” or an impression. The NIH NIAMS extramural program director writes that as an “example, one or more of the research projects may have very high scientific merit but lack relevance or contribute little to the Center [Wellstone] as a whole; conversely, research projects with relatively lower scientific merit may provide necessary strengths to the other components of the Center, and make a major contribution to the Center as a whole.” This changing of the rules has not worked in the favor of FSHD research and in fact quite the opposite in round two of the Wellstone evaluations. We ask the committee to hold a hearing to more closely examine if scientific quality is abrogated by a more subjective review standard.

Mr. Chairman, we are asking you to inquire about the abysmal performance record in FSHD funding and FSHD oriented Wellstone CRCs by the NIH. Last, at the end of the day, we all recognize that simply not enough grants are being submitted by the extramural research community to the NIH. Note that the NIH has done nothing to date to specifically encourage or targeted to draw in FSHD research applications in five or six years. For most of fiscal year 2004, there was no active program announcement on the street in muscular dystrophy from the NIH giving researchers no obvious avenues or handles to submit basic research grants. Of course, researchers are not restricted from submitting applications and can always submit grants in the absence of a call for proposal but most look for a program announcement or call for applications as a signal of NIH interest. The NIH is certainly not receiving enough grants applications for FSHD, but it also manages to reject almost every one of the scarce few being submitted by the top FSHD researchers in the world. It can be said that the volunteer health agencies and extramural community of researchers have done everything in their power to grow the area of research and to promote new researchers and research projects. We have been very successful as shown above and need the NIH to capitalize on our success and investments. The NIH has recognized that there is a systemic problem and has even self-identified a significant gap as relates to FSHD, but it has not stated what and if anything it intends to do to ameliorate the unequal growth and opportunity for muscular dystrophies other than Duchenne muscular dystrophy.

At the December 2004 MD CARE Act mandated Muscular Dystrophy Coordinating Committee (MDCC) the staff and Director’s of the NIH admitted there was a problem in the gap with FSHD research. The follow-up has been deferred to programmatic staff and the implementation details of the pending muscular dystrophy research plan. The NIH did not say exactly when it would follow-up on funding new research in FSHD. The NIH has a history in FSHD of committing to address this issue and never following through. The two prior NIH sponsored research planning conferences on FSHD are an example. Only a minor fraction of the 2000 NIH planning conference research plan developed by the NIH has been implemented. At this point, we are unsure if the lack of FSHD research in the NIH portfolio is a problem of miscommunication or perhaps a more deliberate and calculated on the part of the NIH.

We also ask that Congress request an explanation from the program staff and Directors of the NIH NIAMS, NHGRI, OD and NICHD for the inability to do better in the area of FSHD despite repeated Congressional requests. We implore Congress to request the NIH to specifically build the research portfolio on FSHD through all available means, including re-issuing specific calls for research on FSHD at an accelerated rate, to make up for historical and present neglect.

Mr. Chairman, we trust your judgment on the matter before us. We believe the Committee should explore why muscular dystrophy in general and FSHD in particular has been left behind in the great rise in research support at the NIH. Frankly, we are extremely frustrated that amid a huge increase in funding and strong unambiguous expressions of Congressional support, the NIH commitment in facioscapulohumeral muscular dystrophy (FSHD) is so feeble. Mr. Chairman thanks to your extraordinary efforts, consideration and work in this area I have hope that we will find solutions and that hope keeps me going.

Mr. Chairman, again, thank you for providing this opportunity to testify before your Subcommittee.

---

PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR  
EXPERIMENTAL BIOLOGY

INTRODUCTION TO FASEB

The Federation of American Societies for Experimental Biology (FASEB) is a coalition of 22 scientific societies who together represent more than 66,000 biomedical research scientists. The mission of FASEB is to enhance the ability of biomedical and life scientists to improve, through their research, the health, well-being and productivity of all people.

FASEB'S RECOMMENDATION FOR NIH FUNDING IN FISCAL YEAR 2006

As your committee begins deliberations on appropriations for agencies under its jurisdiction, FASEB would like to offer its views on funding for the National Institutes of Health (NIH). FASEB recommends that the National Institutes of Health receive \$30.07 billion in fiscal year 2006, an increase of 6 percent over the level for the previous fiscal year. This level of funding is consistent with our analysis of what is needed to prevent the curtailment of vital research programs.

NIH'S MISSION

The National Institutes of Health (NIH) is the single most important source of funding that drives advances in basic biomedical research and clinical medicine. Over the past 50 years, NIH research has transformed the practice of medicine and made significant improvements in the long-term health of our citizens. Even greater benefits are possible in the next two decades, if we are positioned to capitalize on the many profound advances in fundamental science.

Modern medical research is poised to revolutionize the prevention, diagnosis and treatment of disease. These opportunities coincide with urgent public health needs. The baby boom generation is graying; without more effective strategies against chronic diseases, such as osteoporosis, Parkinson's and Alzheimer's diseases, and heart disease, the health care needs of this generation will place enormous economic and social burdens on their children and our Nation. In addition, new and emerging infectious diseases are a constant threat to our society; without novel and improved methods for predicting, detecting, controlling and preventing emerging and re-emerging diseases, our nation will be ill prepared to respond to the major public health challenges of the twenty-first century. To meet all of these challenges with improvements in patient care depends on continuous scientific discovery that will usher in a new age in the practice of medicine.

NOVEL MEDICAL PRACTICE MADE POSSIBLE BY NIH-FUNDED RESEARCH

The pace of advancement continues to accelerate such that there are new treatments that substantially increase the quality and length of life for a large number of Americans. Most of these successes were only made possible because of basic research and committed clinical development. Below, we have highlighted some major advances in prevention and treatment of heart disease, infectious diseases, cancer, vaccines, obesity and diabetes, and women's diseases. We point out how basic research is benefiting Americans and increasing their longevity and quality of life. At the same time, we indicate some of the many areas of medicine that provide opportunities for important advances in the future.

*Cardiovascular Disease.*—Without doubt, one of the most important advances in human health for an aging population has been the investigation and treatment of cardiovascular disease (CVD). Basic research identified the limiting step in cholesterol biosynthesis, and this led directly to the development of statins. These wonder drugs lower levels of blood lipids, and they are remarkably effective in the reduction of coronary events and death from coronary heart disease. Without the basic re-

search, drug development for the treatment of hypercholesterol would have languished for years.

Although important progress has been made, there is need to understand the causes of CVD, and find new means of prevention. Studies published within the past 2 years affirm that CVD is strongly affected by inflammation, and that the most reliable early predictors of disease are blood proteins that reflect chronic inflammation such as C-reactive protein. Further research into the prevention of dangerous inflammatory responses promises to substantially reduce the major cause of death in Americans.

*Infectious Diseases.*—Like HIV/AIDS, Ebola and West Nile virus, SARS reminds us that emerging and reemerging infectious diseases are constant threats to national and international public health. In 2003, SARS rapidly moved across the globe, becoming a worldwide health emergency that resulted in quarantines, travel warnings, and mounting economic damage. The ability of NIH to marshal its resources to rapidly initiate development of diagnostics, therapeutics and vaccines against SARS has positioned us well in our quest for tools to detect, treat and prevent SARS.

*Cancer.*—Using monoclonal antibodies (mAb), scientists have also identified the cell surface receptors that characterize many different cells of the body. These same mAb can be chemically engineered for use as biologic drugs in the treatment of many different diseases. The mAb reagent that targets a lymphocyte receptor has become a proven therapy for non-Hodgkin's B cell lymphoma; many patients remain disease-free for several years after having failed chemotherapy. Based on more recent clinical trials, this same drug may also be effective in the treatment of several forms of autoimmune disease including rheumatoid arthritis. Many other engineered mAb are being tested in clinical trials for use as biologic drugs, and again, more research is needed to identify new disease targets.

The latest genetic technologies are also beginning to deliver important tools for the treatment of cancer. Recently, NIH-supported research has been used to develop technologies where virtually the entire genome can be studied on a small chip (DNA microarray). A recent example of the promise of this technology comes from the study of chronic lymphocytic leukemia (CLL). CLL patients fall into two categories: those whose tumors progress slowly and those with highly malignant tumors that require aggressive therapy. Microarray analyses identified the expression of a single gene that discriminates these tumor types with a high degree of accuracy. This has now led to a simple blood test to determine tumor prognosis and guide therapy. Microarray analyses will be used in the future to analyze each individual cancer as a way of guiding highly individualized therapies, and this will in turn result in a new generation of highly effective treatments.

*Vaccines.*—Vaccine research and development proceeds at a rapid pace using new tools from a variety of fields. Hemophilus influenza type b is one of the leading causes of invasive bacterial infection in young children worldwide. The development of a vaccine for this disease has dramatically decreased the incidence of pediatric meningitis from approximately 20,000 to 200 cases per year in the United States. The cost for treating this disease and its complications was \$500 million annually, whereas the cost of vaccination is presently no more than fifty cents per patient. The development of this successful vaccine evolved naturally out of NIH-supported research in basic immunology and many additional breakthroughs are anticipated. For example, similar vaccines are being tested to prevent pneumococcal and meningococcal infections that often result in pneumonia or meningitis.

New sequencing techniques made possible from the Human Genome Project allow the rapid decoding of genomes of bioterrorism threats as well as rapidly mutating pathogens. Immunologists have created a malaria vaccine that was made possible by genome sequencing of the malaria parasite and its mosquito host, and recent results in children show that this vaccine can convey a 50 percent decline in infections. The genome sequence of each pathogen facilitates the identification of virulence factors, which in turn, constitute the best targets for vaccination. For example, the creation of a SARS DNA microarray chip, available from NIAID, will aid in the rapid development of vaccines against this recently identified pathogen. The complementary nature of basic and clinical research is no where more apparent than in the advantage that vaccine research takes of chemical structures determined by x-ray crystallography. The recent discovery of the 3-D structure of the anthrax bacterium will speed development of novel antitoxins to protect our populace against bioterrorism. Thus, work on the horizon promises vaccines that will confer resistance to previously uncontrollable infectious agents.

*Obesity and Diabetes.*—The obesity epidemic continues to rise. The projected health care requirements arising from complications associated with excessive weight will substantially expand the costs of Medicare and private health insurance

in an aging population. In response to this crisis, NIH has increased funding in obesity research and this has led to an explosion of new information concerning the regulation of metabolism and the causes of pathogenesis. For example, the 2004 Lasker Prize was shared by two American NIH-funded researchers and a Frenchman for their work on nuclear receptors, and in part for the role these receptors play in insulin resistance and metabolism of fat cells. This work holds great promise for therapeutic intervention since nuclear receptors are easily targeted by modified versions of steroid hormones. Remarkably, some of the most incisive work has come from basic studies using model organisms, such as worms and flies, where genetic screens have identified the essential metabolic pathways.

Over the period of the NIH budget doubling, researchers have discovered previously unknown hormones such as Resistin and Gherlin. Resistin is a fat-cell derived hormone that, in excess, causes problems with carbohydrate metabolism, and this in turn can result in diabetes. Gherlin, along with Leptin, has been found to be important in the modulation of appetite. In another area of metabolic research, we now understand the molecular basis for trans fatty acid and saturated fatty acid effects on LDL cholesterol, and this has important implications both in weight control and in cardiovascular disease.

Health care costs more than twice as much for diabetes patients as for all other individuals. Eliminating or reducing the health problems caused by diabetes could significantly improve the quality of life for people with diabetes and their families while at the same time potentially reducing national expenditures for health care services and increasing productivity in the U.S. economy. These costs will increase dramatically if the epidemic is allowed to worsen. Indeed, it was recently predicted by the Centers for Disease Control that one out of three children born in the United States in the year 2000 will develop diabetes in his or her lifetime.

Obesity affected 44 million Americans as of 2001, an increase of 74 percent from 1991. Obesity is a major risk factor for diabetes and is also associated with cardiovascular disease and cancer. The total cost attributable to obesity amounted to \$99.2 billion in 1995. Approximately \$51.7 billion of those dollars were direct medical costs. The number of restricted-activity days, bed-days, and work-lost days increased substantially between 1988 and 1994, while the number of physician visits attributed to obesity increased 88 percent during the same period.<sup>1</sup> The health-related economic cost of obesity to U.S. business is substantial, representing approximately 5 percent of total medical care costs.<sup>2</sup>

*Women's Health.*—Recent work has demonstrated that estrogen and related compounds reduce brain damage from stroke in experimental animals. With these new findings it is extremely important that support for existing and new research to resolve the controversy of safety and risks of hormone replacement therapy be continued and increased. Such a resolution will have a wide impact on women's health concerns such as osteoporosis, stroke, Alzheimer's disease and memory loss.

#### COMPETITIVE PEER REVIEW

Part of the success of American science derives directly from the system for awarding research grants. The majority of NIH funding comes in response to investigator-initiated research proposals that are evaluated by a committee of experts in each scientific field. Elaborate care is taken to ensure that conflicts of interest are minimized and each research proposal is evaluated on its merit. Over many years this competitive system has promoted the highest quality research, and it is a shining example of a program based on "reward for excellence." No scientist can afford to rest on his or her previous accomplishments. As opposed to the entitlement system of funding found in some other countries, the American system rewards productivity, innovation, and impact. While FASEB welcomes new ideas to make the system function even more efficiently, we support the basic concept of peer review as practiced by NIH.

#### THE IMPORTANCE OF CONTINUING THE MOMENTUM

There has never been greater opportunity for advancing biomedical science and generating more effective practices for clinical medicine. Within our reach are dramatic new breakthroughs that can lessen the economic and human costs of disease.

In response to the massive amounts of new information being generated in every field of biomedical science, the NIH has recently developed a framework of priorities that NIH as a whole must address in order to optimize its entire research portfolio.

<sup>1</sup>Obesity Research 1998; 6 (2): 97–106.

<sup>2</sup>American Journal of Health Promotion 1998; 13 (2): 120–127.

The NIH Roadmap<sup>3</sup> identifies the most compelling opportunities in three main areas and will (1) promote a quantitative understanding of the many interconnected networks of molecules that comprise our cells and tissues, their interactions, and their regulation; (2) explore new organizational models for team science; and (3) foster large-scale epidemiological studies and clinical trials to enhance the state of medical treatment and move new therapies into practice. Specialized core facilities and consortia are being promoted to bring together scientists from different disciplines as a way of accelerating discovery. FASEB supports the goals and vision of this initiative, although we maintain that most novel discovery and innovative research will continue to originate from individual investigators. In order to maintain our rate of discovery and build the infrastructure outlined in the Roadmap, NIH requires adequate support for agency-initiated and investigator-initiated projects.

The momentum generated from doubling the NIH budget has energized biomedical science at every level. We see new young investigators making some of the most important discoveries. Training initiatives have encouraged talented students to choose a career in academic medicine. These highly talented and motivated individuals spend 10 years or more after college in graduate school and postdoctoral appointments. In 2003, only 16.6 percent of new investigators obtained funding within their first 3 years of applying for these critical grants, thereby making it very difficult for these young scientists to establish their new innovative research programs.

It is impossible to predict which cures and therapies might be lost if funds for medical research are curtailed, but it is certain that inconsistent NIH funding sends a chilling message to young scientists in training and those just entering the research field. Scientific competition will always be intense, but exceptionally talented young scientists must be assured that sufficient research funding will be available or they will be forced to pursue alternative careers.

#### RECOMMENDATION

FASEB understands that the fiscal year 2006 budget for discretionary spending is projected to be constrained in light of the large deficit, the expenditures for defense and homeland security and the growth in entitlement obligations. However, FASEB strongly believes that the scientific opportunities for progress in medical research have never been greater. Therefore, FASEB recommends that the National Institutes of Health receive \$30.07 billion in fiscal year 2006, an increase of 6 percent over the level for the previous fiscal year.

---

#### PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS)

The Friends of the National Institute of Environmental Health Sciences (NIEHS) group appreciates the opportunity to comment on the fiscal year 2006 appropriation for the institute. The Friends of NIEHS is a coalition committed to expanding the National Institutes of Health's (NIH) environmental health research portfolio through increased appropriations for NIEHS. Comprised of over 50 patient, healthcare provider, children's health, and industry groups, the Friends of NIEHS represents an enormously broad constituency dedicated to improving the nation's knowledge about our health and our environment.

Over the last several years Congress has shown a strong commitment to health research sponsored by NIH. This financial commitment has allowed the nation to dedicate resources to emerging scientific opportunities that will lead to beneficial health outcomes for Americans. We thank Congress for fulfilling its commitment to double the NIH overall budget. However, we remain concerned about how we will fund these opportunities in the upcoming years.

This dilemma is particularly true for the NIEHS. This institute plays a critical role in what we know about the relationship between our environmental exposures and disease onset. Through the research sponsored by this Institute, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases and ailments have confirmed environmental triggers. Specifically, NIEHS has played an important role in discovering the mechanisms by which DES (diethylstilbestrol) causes damage, through its historical and ongoing work on DES in the animal model. Continuing research of these mechanisms is vital to help determine future health events related to DES, such as the possibility of third generation effects in the grandchildren of women who took DES during pregnancy. Our expanded knowledge, as a result, al-

---

<sup>3</sup><http://nihroadmap.nih.gov/>.

lows both policy makers and the general public to make important decisions about how to reduce toxin exposure and reduce the risk of disease and other negative health outcomes.

As the nation continues to steel itself from terrorist threats, the Friends of NIEHS applauds Congress's commitment to bolstering research funding in the area of infectious disease as a part of national anti-bioterrorism effort. The coalition, however, feels that an effort that only targets bioterrorism falls short of truly protecting the nation as it leaves the public vulnerable to chemical terrorism. Funding is critical for future initiatives such as research concerning the possible health effects of exposure to low levels of hazardous chemicals and the use of an Environmental Medical Unit (EMU), as previously supported by Congress and underway in Japan, to examine populations affected by toxicant-induced intolerances to determine the biomarkers and mechanisms by which to identify individual susceptibility so as to avoid placing such individuals in hazardous situations.

In an effort to continue the expansion of this knowledge base, the Friends of NIEHS supports a \$35 million increase in funding for NIEHS over fiscal year 2005 levels, bringing the total appropriation for fiscal year 2006 to \$680 million. This additional funding will allow the Institute to continue current projects and pursue promising research in the areas of individual susceptibilities (due to gender, age, racial/ethnic backgrounds, etc.), environmental disease triggers and technologies (such as toxicogenomics and mouse genomics).

While there are many competing interests that must be considered in the fiscal year 2006 budget, a top priority for Americans is medical research that explores the relationship between disease and the environment. The members of the Friends of NIEHS respectfully request a total of \$680 million for fiscal year 2006 for the National Institute of Environmental Health Sciences. Thank you for this opportunity to discuss the importance of these programs as the Congress configures the Labor-HHS fiscal year 2006 budget.

The Friends of NIEHS respectfully requests Congress to appropriate a total of \$680 million for fiscal year 2006.

---

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG  
ABUSE COALITION

Mr. Chairman and Members of the Subcommittee: The Friends of the National Institute on Drug Abuse (FoN) a burgeoning coalition of over 50 organizations, is pleased to provide testimony to support the extraordinary work of the NIDA. Although a new coalition, it is comprised of organizations representing scientists, health professionals, and advocates for preventing and treating substance use disorders as well as understanding the causes and public health consequences of addiction. Pursuant to clause 2(g)4 of House Rule XI, the Coalition does not receive any federal funds.

Drug abuse and addiction represent a major health crisis in America, and create an economic burden of over \$484 billion per year. One way we can and should continue to address this problem is through scientific research. Because of the critical importance of drug abuse research for the health and economy of our nation, we write to you today to request your support for a 6 percent increase for NIDA in the Fiscal 2006 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. That would bring total funding for NIDA in Fiscal 2006 to \$1,067,040,300. Recognizing that so many health research issues are inter-related, we also support a 6 percent increase for the National Institutes of Health overall, which would bring its total to \$30 billion for Fiscal 2006.

NIDA is the world's largest supporter of research on the health aspects of drug abuse and addiction. The Institute supports a comprehensive research portfolio that has led to our current understanding of addiction as a preventable developmental disorder and a chronic relapsing disease associated with long-lasting changes in the brain and the body that can affect all aspects of a person's life. NIDA's research portfolio is broad and deep, and spans the continuum of basic neuroscience, behavior and genetics research through applied health services research and epidemiology. This work deserves continuing, strong support from the Congress. Some examples include:

New research supported by NIDA and others reveals that drug addiction is a "developmental disease." That is, it often starts during the early developmental stages in adolescence and sometimes as early as childhood. This is a time when the brain undergoes major changes in both structure and function. We now know that the brain continues to develop throughout childhood and into early adulthood. Exposure to drugs of abuse at an early age may increase a child's vulnerability to the effects

of drugs and may impact brain development. As a result, NIDA has increased its emphasis on adolescent brain development to better understand how developmental processes and outcomes are affected by drug exposure, the environment and genetics. Recent advances in genetic research have enabled researchers to start to investigate which genes make a person more vulnerable, which genes protect a person against addiction, and how genes and environment interact. As part of the prevention portfolio NIDA is also involving pediatricians and other primary care providers to develop tools, skills and knowledge to be able to screen and treat patients as early as possible, including patients with mental disorders who may be at a high risk to develop addiction. We know that if we do not intervene early, drug problems can last a lifetime, making prevention a high research priority.

Treatment research is another priority area for NIDA. Significant effort is underway to develop, test, and ensure the delivery of evidence-based interventions to all practitioners and patients across the country. Building on advances from the Institute's basic neuroscience and behavioral research program NIDA has introduced a number of effective medications and behavioral treatments. The Institute also continues to look for more innovative, efficacious, and cost-effective ways to treat patients for a variety of addictions, including addiction to nicotine. NIDA is also using the National Drug Abuse Treatment Clinical Trials Network (CTN) to help respond to emerging public health needs like prescription drug abuse and the increases in patients who are seeking treatment for both substance abuse and mental disorders.

Another priority area for NIDA is curtailing the spread of HIV/AIDS. Because illicit drug use can impact decision-making and increase the likelihood that an individual will engage in risk-taking behaviors, treatment for drug abuse is, itself, HIV prevention. Drug abuse treatment can reduce activities related to drug use that increase the risk of getting or transmitting HIV. NIDA is especially interested in reducing HIV/AIDS rates in racial and ethnic minority populations, which are disproportionately affected by this disease.

Recognizing substance abuse as a disorder that can affect the course of other diseases, including HIV/AIDS, mental illness, trauma, cancer, cardiovascular disease and even obesity is critical to improving the health of our citizens. NIDA has launched several efforts to reach out to numerous professions within the healthcare community to address these issues.

#### ADDITIONAL SUCCESS STORIES, CHALLENGES AND OPPORTUNITIES

*Adolescent Brain Development—How Understanding the Brain Can Impact Prevention Efforts.*—NIDA maintains a vigorous developmental research portfolio focused on adolescent populations. NIDA working collaboratively with other NIH Institutes has shown that the human brain does not fully develop until about age 25. This adds to the rationale for referring to addiction as a “developmental disease;” it often starts during the early developmental stages in adolescence and sometimes as early as childhood, a time when we know the brain is still developing. Having insight into how the human brain works, and understanding the biological underpinnings of risk taking among young people will help in developing more effective prevention programs. FoN believes NIDA should continue its emphasis on studying adolescent brain development to better understand how developmental processes and outcomes are affected by drug exposure, the environment and genetics.

*Medications Development.*—NIDA has demonstrated leadership in the field of medications development by partnering with private industry to develop anti-addiction medications resulting in a new medication, buprenorphine, for opiate addiction. FoN recommends that NIDA continue its work with the private sector to develop much needed anti-addiction medications, for cocaine, methamphetamine, and marijuana dependence.

*Co-Occurring Disorders.*—NIDA recognizes substance abuse rarely occurs in isolation. And to adequately address co-occurring substance abuse and mental health problems, NIDA has developed robust collaborations with other agencies (such as NIAAA, NIMH and SAMHSA) to stimulate new research to develop effective strategies and to ensure the timely adoption and implementation of evidence-based practices for the prevention and treatment of co-occurring disorders. Through these initiatives, NIDA is supporting research to determine the most effective models of clinically appropriate treatment and how to bring them to communities with limited resources. FoN recognizes the imperative for continued funding of essential research into the nature of and improved treatment for these complex disorders and endorses these efforts.

*Drug Abuse and HIV/AIDS.*—One of the most significant causes of HIV virus acquisition and transmission involves drug taking practices and related risk factors



in different populations (e.g. criminal justice, pregnant women, minorities, and youth). Drug abuse prevention and treatment interventions have been shown to be effective in reducing HIV risk. Therefore, FoN trusts that NIDA will continue its support of research that is focused on the development and testing of drug-abuse related interventions designed to reduce the spread of HIV/AIDS in these populations.

*Emerging Drug Problems.*—NIDA recognizes that drug use patterns are constantly changing and expends considerable effort to monitor drug use trends and to rapidly inform the public of emerging drug problems. FoN believes NIDA should continue supporting research that provides reliable data on emerging drug trends, particularly among youth and in major cities across the country and will continue its leadership role in alerting communities to new trends and creating awareness about these drugs.

*Reducing Prescription Drug Abuse.*—NIDA research has documented recent increases in the numbers of adults and young people who are using prescription drugs for non-medical purposes. Reducing prescription drug abuse, particularly among our Nation's youth will continue to be a priority for NIDA. FoN endorses NIDA's programmatic research designed to further the development of medications that are less likely to have abuse/addiction liability, and to develop prevention and treatment interventions for adolescents and adults who are abusing prescription drugs.

*Reducing Methamphetamine Abuse.*—NIDA continues to recognize the epidemic abuse of methamphetamine across the United States. Methamphetamine abuse not only affects the users, but also the communities in which they live, especially due to the dangers associated with its production. FoN believes NIDA should continue to support research to address the medical consequences of methamphetamine abuse. Topics of particular concern include: understanding the effects of prenatal exposure to methamphetamine and developing pharmacotherapies and behavioral therapies to treat methamphetamine addiction.

*Reducing Inhalant Abuse.*—For the second year in a row, NIDA's Monitoring the Future Survey (MTF) has shown an increase in the use of inhalants by 8th graders. Inhalants pose a particularly significant problem since they are readily accessible, legal, and inexpensive. They also tend to be abused by younger teens and can be highly toxic and even lethal. FoN applauds NIDA's inhalant research portfolio and believes NIDA should continue its support of research on prevention and treatment of inhalant abuse, and to enhance public awareness on this issue as it did recently with the release of a Community Drug Alert Bulletin: Inhalants, as well as its new dedicated web site, [www.inhalants.drugabuse.gov](http://www.inhalants.drugabuse.gov).

*General Medical Consequences of Drug Abuse.*—NIDA recognizes that addiction is a disorder that affects the course of other diseases such as cancer, cardiovascular and infectious diseases. Therefore, FoN believes that NIDA should continue to support research on the medical consequences associated with drug abuse and addiction.

*Long-Term Consequences of Marijuana Use.*—NIDA research shows that marijuana can be detrimental to educational attainment, work performance, and cognitive function. However, more information is needed in order to assess the full impact of long-term marijuana use. Therefore, FoN recommends that NIDA continue to support efforts to assess the long-term consequences of marijuana use on cognitive abilities, achievement, and mental and physical health, as well as work with the private sector to develop medications focusing on marijuana addiction.

*Translating Research Into Practice.*—NIDA has been a leader working with State substance abuse authorities to reduce the current 15- to 20-year lag between the discovery of an effective treatment intervention and its availability at the community level. In particular, NIDA worked with SAMHSA on a recent RFA designed to strengthen State agencies' capacity to support and engage in research that will foster statewide adoption of meritorious science-based policies and practices. FoN believes that NIDA should continue collaborative work with States to ensure that research findings are relevant and adaptable by State Substance Abuse systems. NIDA is also to be congratulated for its broad and varied information dissemination programs as part of an effort to ensure drug abuse research is used in everyday practice. The Institute is focused on stimulating and supporting innovative research to determine the components necessary for adopting, adapting, delivering, and maintaining effective research-supported policies, programs, and practices. As evidence-based strategies are developed, FoN urges NIDA to support research to determine how these practices can be best implemented at the community level.

*Primary Care Settings and Youth.*—NIDA recognizes that primary care settings, such as offices of pediatricians and general practitioners, are potential key points of access to prevent and treat problem drug use among young people; yet primary care and drug abuse services are commonly delivered through separate systems.

FoN encourages NIDA to continue to support health services research on effective ways to educate primary care providers about drug abuse; develop brief behavioral interventions for preventing and treating drug use and related health problems, particularly among adolescents; and develop methods to integrate drug abuse screening, assessment, prevention and treatment into primary health care settings.

*Utilizing Knowledge of Genetics and New Technological Advances to Curtail Addiction.*—NIDA recognizes that not everyone who takes drugs becomes addicted and that this is an important phenomenon worthy of further exploration. Research has shown that genetics plays a critical role in addiction, and that the interplay between genetics and environment is crucial. The science of genetics is at a crucial phase—technological advances are providing the tools to make significant breakthroughs in disease research. For example, FoN believes NIDA should take advantage of new high-resolution genetic technologies which may help to develop new tailored treatments for smoking.

*Combating Nicotine Addiction.*—NIDA understands that the use of tobacco products remains one of the Nation's deadliest addictions and FoN supports NIDA's continuing efforts to address this major public health problem through its comprehensive research portfolio.

*Reducing Health Disparities.*—NIDA research demonstrates that the consequences of drug abuse disproportionately impacts minorities, especially African American populations. FoN was pleased to learn that NIDA formed a Subgroup of its Advisory Council to address this important topic and applauds NIDA for working to strategically reduce the disproportionate burden of HIV/AIDS among the African American population. FoN believes that researchers should be encouraged to conduct more studies in this population and to target their studies in geographic areas where HIV/AIDS is high and or growing among African Americans, including in criminal justice settings.

*The Clinical Trials Network—Using Infrastructure to Improve Health.*—NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN), which was established in 1999 and has grown to include over 17 research centers or nodes spread across the country. The CTN provides an infrastructure to test the effectiveness of new and improved interventions in real-life community settings with diverse populations, enabling an expansion of treatment options for providers and patients. FoN suggests NIDA continue to develop ways to use the CTN as a vehicle to address emerging public health needs.

*Neuroscience Blueprint and Training.*—NIDA is one of the 15 Institutes and Centers involved in the NIH Blueprint activities and FoN recommends that NIDA continue to demonstrate leadership to foster additional training in cross-cutting scientific issues.

*Neuroimaging and the Developing Brain.*—NIDA has also demonstrated leadership in the development and application of neuroimaging technologies to gain a greater understanding of the circuitry of the human brain underlying drug addiction. FoN encourages NIDA to utilize neuroimaging technology to improve its understanding of how the brain of children and adolescents develop.

*Behavioral Science.*—NIDA has long demonstrated a strong commitment to supporting behavioral science research. FoN encourages NIDA to continue to determine the interplay of behavioral, biological, and social factors that affect development and the onset of diseases like drug addiction to understand common pathways that may underlie other compulsive behaviors such as gambling and eating disorders.

*Drug Treatment in Criminal Justice Settings.*—NIDA is very concerned about the well-known connections between drug use and crime. Research continues to demonstrate that providing treatment to individuals involved in the criminal justice system decreases future drug use and criminal behavior, while improving social functioning. Blending the functions of criminal justice supervision and drug abuse treatment and support services create an opportunity to have an optimal impact on behavior by addressing public health concerns while maintaining public safety. FoN strongly supports NIDA's efforts in this area, particularly the Criminal Justice Drug Abuse Treatment Studies (CJ-DATS), a multi-site set of research studies designed to improve outcomes for offenders with substance use disorders by improving the integration of drug abuse treatment with other public health and public safety systems.

#### CONCLUSION

It is true that many challenges remain. However, only the resources available for carrying out its vital mission limit the potential contributions of NIDA-funded research to the lives of countless individuals. This is why the Friends of NIDA ask you to provide an appropriation of \$1,067,040,300 billion to the Institute so that our

nation and the world will continue to benefit from NIDA's commitment to improving health and scientific advancement.

We understand that the fiscal year 2006 budget cycle will involve setting priorities and accepting compromise. However, in the current climate, we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserve to be prioritized accordingly. We look forward to working with you to make this a reality.

Thank you, Mr. Chairman, and the Subcommittee, for your support for the National Institute on Drug Abuse.

---

#### PREPARED STATEMENT OF THE HEART RHYTHM SOCIETY

The Heart Rhythm Society (HRS) thanks you and the Subcommittee on Labor, Health and Human Services and Education for your past and continued support of the National Institute of Health, and specifically the National Heart, Lung and Blood Institute (NHLBI). The Heart Rhythm Society is the international leader in science, education and advocacy for cardiac arrhythmia professionals and patients, and the primary information resource on heart rhythm disorders. Its mission is to improve the care of patients by promoting research, education and optimal health care policies and standards. Founded in 1979 to address the scarcity of information about the diagnosis and treatment of cardiac arrhythmias, the Heart Rhythm Society is the preeminent professional group representing more than 3,700 specialists in cardiac pacing and electrophysiology in 64 countries.

The Heart Rhythm Society recommends the Subcommittee continue its commitment to supporting biomedical research in the United States and recommends Congress provide NIH with a 6 percent increase for fiscal year 2006. This translates into an appropriation of \$30 billion for NIH, with \$3.1 billion designated to the National Heart, Lung, and Blood Institute (NHLBI). This increase will enable the NIH and NHLBI to sustain the level of research that leads to research breakthroughs and improved health outcomes.

In particular, the Heart Rhythm Society recommends Congress support research into abnormal rhythms of the heart, known as cardiac arrhythmias. HRS appreciates the actions of Congress to double the budget of the NIH in recent years. The doubling of the NIH budget has served to promote a series of innovations that have improved treatments and cures for a variety of medical problems facing our nation.

#### RESEARCH ACCOMPLISHMENTS

In our field for example, this research has provided critically important insights into the genetic basis of sudden death syndrome, which takes the lives of infants, children and young adults born with inherited defects in the ion channels or contractile proteins of the heart. SIDS (Sudden Infant Death Syndrome) remains the leading cause of death for infants one month to one year of age, continuing to claim the lives of approximately 2,500 babies each year.<sup>1</sup> Our research has led to the recognition that sudden infant death syndrome is due, in part, to abnormal rhythms of the heart. This research is offering these babies a chance at a normal life span.

Major advances have also been realized in our ability to treat atrial fibrillation and to prevent the complications of stroke. Atrial fibrillation is found in about 2.2 million Americans and is an independent risk factor for stroke, increasing the risk about 5-fold. About 15–20 percent of strokes occur in people with atrial fibrillation. Stroke is a leading cause of serious, long-term disability in the United States and people who have strokes caused by AF have been reported as 2–3 times more likely to be bedridden compared to those who have strokes from other causes. Each year about 700,000 people experience a new or recurrent stroke and in 2002 stroke accounted for more than 1 of every 15 deaths in the United States.<sup>2</sup>

Ablation therapy has provided a cure for individuals whose rapid heart rates had previously incapacitated them, giving them a new lease on life. Important advances have been made in identifying patients with heart failure and those who had suffered a heart attack and are at risk for sudden death. The development and implantation of sophisticated internal cardioverter defibrillators (ICD) in such patients has saved the lives of hundreds of thousands and provided peace of mind for families

<sup>1</sup>First Candle/SIDS Alliance, Facts on SIDS, 2005 <http://www.sidsalliance.org/FC-PDF4/Expectant%20Parents/facts%20on%20sids.pdf>.

<sup>2</sup>American Stroke Association and American Heart Association, Heart Disease and Stroke Statistics—2005 Update, 2005 <http://www.americanheart.org/downloadable/heart/1105390918119HDSStats2005Update.pdf>.

everywhere, including that of Vice-President Cheney. A new generation of pacemakers and ICDs is restoring the beat of the heart as we grow older, permitting us to lead more normal lives. Many of these advances are due to the research sponsored by the NHLBI.

#### BUDGET JUSTIFICATION

These impressive strides notwithstanding, cardiac arrhythmias continue to plague our society and take the lives of loved ones at all ages, nearly one every minute of every day. Sudden Cardiac Arrest is a leading cause of death in the United States, claiming an estimated 325,000 lives every year, or one life every two minutes.<sup>3</sup> The burden of morbidity and mortality due to cardiac arrhythmias is predicted to grow dramatically as the baby boomers age. Atrial fibrillation strikes 3–5 percent of people over the age of 65,<sup>4</sup> presenting a skyrocketing economic burden to our society in the form of healthcare treatment and delivery. As previously mentioned one in seven of all strokes are due to atrial fibrillation. It is estimated in 2005 that the direct and indirect cost of stroke will be \$56.8 billion.<sup>5</sup> Cardiac diseases of all forms increase with advancing age, ultimately leading to the development of arrhythmias.

The above progress we have witnessed in recent years is gradually eroding as the resources available to the academic scientific and medical community are diminished. The budgets appropriated by Congress to the NIH in the past two years averaged 2.8 percent and were far below the level of scientific inflation. These vacillations in funding cycles threaten the continuity of the research and the momentum that has been gained over the years.

It is for this reason that we are asking for your support to increase NIH appropriations by 6 percent for a fiscal year 2006 budget of \$30 billion for NIH and \$3.1 billion for NHLBI. The Heart Rhythm Society recommends Congress specifically acknowledge the need for cardiac arrhythmia research to prevent sudden cardiac arrest and other life threatening conditions such as sudden infant death syndrome, definitive therapeutic approaches for atrial fibrillation and the prevention of stroke, and other genetic arrhythmia conditions.

Thank you very much for your consideration of our request. If you have any questions or need additional information, please contact Amy Melnick, Vice-President, Health Policy at the Heart Rhythm Society (amelnick@hrsonline.org or 202-464-3434). Thank you again for the opportunity to submit testimony.

#### PREPARED STATEMENT OF THE HEMOPHILIA FEDERATION OF AMERICA

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Continued support for the completion of Ricky Ray Hemophilia Relief Fund “half-cases”.
- An additional \$10 million for Hemophilia Treatment Centers through the Maternal Child Health Bureau at the Health Resources and Services Administration.
- Continued support for the Centers for Disease Control and Prevention’s hemophilia grant program, including expansion of the program to additional patient-based organizations within the hemophilia community.
- A 6 percent increase overall for the National Institutes of Health, including a 6 percent increase for the National Heart, Lung, and Blood Institute, and the National Institute for Allergy and Infectious Diseases.

##### INTRODUCTION

The Hemophilia Federation of America (HFA) is a national voluntary health organization that both assists and advocates for the blood clotting disorders community. The Federation was founded in 1994 and exists for the purpose of serving its constituents as an advocate for blood safety, best practices treatment for hemophilia, issues involving health insurance, and enhancing the quality of life for those who suffer with hemophilia and other blood clotting disorders. Our mission is to serve the needs of all families with coagulation disorders and mitigate the complications of treatment. Our vision at the Hemophilia Federation of America is that the blood

<sup>3</sup>Heart Rhythm Foundation, The Facts on Sudden Cardiac Arrest, 2004 [http://www.heartrhythmfoundation.org/its\\_about\\_time/pdf/provider\\_fact\\_sheet.pdf](http://www.heartrhythmfoundation.org/its_about_time/pdf/provider_fact_sheet.pdf).

<sup>4</sup>Heart Rhythm Society, Atrial Fibrillation & Flutter, 2005 [http://www.hrspatients.org/patients/heart\\_disorders/atrial\\_fibrillation/default.asp](http://www.hrspatients.org/patients/heart_disorders/atrial_fibrillation/default.asp).

<sup>5</sup>American Stroke Association, Impact of Stroke, 2005 <http://www.strokeassociation.org/presenter.jhtml?identifier=1033>.

clotting disorders community has removed all barriers to both choice of treatment and quality of life.

The Hemophilia Federation of America provides a multitude of programs and services to the bleeding disorder community. These programs include the Emergency Room Triage Program, which educates emergency room physicians and support staff to the sensitivities of patients with hemophilia need in an ER medical setting. The Moms on a Mission and Dads in Action programs work to intimately educate parents of those with hemophilia to be active in the care of their child and understand the care that the disorder needs to lead a healthy, productive life. The Helping Hands Project assists struggling families of hemophilia patients with resources to meet their medical and living expenses, because of the high costs of hemophilia treatment. HFA is proud of the services our organization provides to the hemophilia community and encourages the community to take advantage of them.

#### RICKY RAY HEMOPHILIA RELIEF FUND

Mr. Chairman, we are extremely grateful for your leadership last year in supporting efforts to finalize pending "half-cases" within the Ricky Ray Hemophilia Relief Fund.

The closing of the Ricky Ray fund in November of 2003 marked the completion of the 5-year period that the federal government designated to provide compassionate payments to those in the hemophilia community who were infected with HIV/AIDS due to contaminated anti-hemophilia factor concentrates in the 1980s.

In the closing days of the Fund, the program administrator contacted HFA to ask for our assistance in the completion of many unfinished cases. He brought to our attention 43 cases where the entitled family only received half of the compassionate payment, due to a parent's absence from a patient's life. The Ricky Ray Fund administrator asked the Federation to assist him in the adjudication of those cases that qualified for additional support. HFA would like to thank the subcommittee for its assistance in working with the community to provide the remaining payments and encourage you to continue this support until this process is completed.

#### HEMOPHILIA TREATMENT CENTERS/HEALTH RESOURCES AND SERVICES ADMINISTRATION

In 1974, Congress created a network of Hemophilia Treatment Centers (HTCs) throughout the United States. This treatment centers remain essential to ensuring that comprehensive and specialized care is available for persons with bleeding disorders. There are currently over 130 HTCs in the United States. These centers abide by federal guidelines for the delivery of comprehensive hemophilia services as developed by the Maternal Child Health Bureau and the Centers for Disease Control and Prevention.

Hemophilia Treatment Centers provide family centered, state of the art medical and psychosocial services, as well as education and research to persons with inherited bleeding disorders. The bleeding disorder community utilizes many services through the Hemophilia Treatment Centers. These services include diagnostic evaluations for hemophilia, von Willebrand disease and other bleeding disorders. They also include annual comprehensive evaluations, clinical trials on new blood clotting therapies, coordination with the individual's primary care physician, emergency consultations, hematological management for surgeries, dental procedures and child-birth. Hemophilia Treatment Centers educate patients and family members on infusion training, encourage collaboration with HTC clinicians throughout the United States, participate in CDC research, and collaboration with the hemophilia voluntary health community.

For fiscal year 2006 HFA encourages the subcommittee to increase funding for HTC's at the Maternal and Child Health Bureau by \$10 million.

#### HEMOPHILIA GRANT PROGRAM AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, HFA strongly supports the expansion of the Centers for Disease Control and Prevention's hemophilia grant program. This important initiative provides support for education and awareness activities regarding hemophilia, as well as disease management, blood safety, and surveillance projects.

Given the important contributions that all voluntary organizations in the hemophilia community make to patients and families, we are recommending that steps be taken to ensure that additional organizations can participate in the hemophilia program on an annual basis. Based on the current structure of the grant program, only one organization is able to receive funds to support patients. In order to maximize the effectiveness of this important initiative, we believe that additional organizations should be empowered to participate in the CDC program on an annual basis.

We encourage the subcommittee to support our efforts in this area in fiscal year 2006 bill.

NATIONAL INSTITUTES OF HEALTH

HFA applauds the National Heart, Lung and Blood Institute and the National Institute of Allergy and Infectious Diseases for their support of hemophilia research. In addition, we are grateful to the subcommittee for recognizing the growing problem of women and bleeding disorders, which if left untreated, can lead to such dangerous medical conditions as anemia, unnecessary hysterectomies, and complications during menstruation.

Patients and families in the hemophilia community are placing their hopes for a better quality of life on treatment advances made through biomedical research. For fiscal year 2006, we encourage the subcommittee to provide a 6 percent increase overall for NIH, and a 6 percent increase for NHBLI and NIAID.

Mr. Chairman, thank you for the opportunity to present the views of the Hemophilia Federation of America. If you have any questions, please do not hesitate to contact HFA's Washington Representative, Dale Dirks at (202) 544-7499.

PREPARED STATEMENT OF THE HEPATITIS FOUNDATION INTERNATIONAL

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

—Continue the great strides in research and prevention at the National Institutes of Health (NIH) by providing a 6 percent budget increase for fiscal year 2006. Increase funding for the National Institute for Allergy and Infectious Diseases (NIAID), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA) by 6 percent.

—\$41 million in fiscal year 2006 for a hepatitis B vaccination program for high risk adults at CDC as recommended by the National Hepatitis C Prevention Strategy.

—\$40 million in fiscal year 2006 for CDC's Prevention Research Centers.

—Continued support of the National Viral Hepatitis Roundtable.

Mr. Chairman and members of the subcommittee thank you for your continued leadership in promoting better research, prevention, and control of diseases affecting the health of our nation. I am Thelma King Thiel, Chairman and Chief Executive Officer of the Hepatitis Foundation International (HFI), representing members of 425 patient support groups across the nation, the majority of whom suffer from chronic viral hepatitis.

Currently, five types of viral hepatitis have been identified, ranging from type A to type E. All of these viruses cause acute, or short-term, viral hepatitis. Hepatitis B, C, and D viruses can also cause chronic hepatitis, in which the infection is prolonged, sometimes lifelong. While treatment options are available for all types of hepatitis, individuals with chronic viral hepatitis (types B, C, and D) represent the majority of liver failure and transplant patients. Treatment options and immunizations are available for most types of hepatitis (see below). However, all types of viral hepatitis are preventable.

HEPATITIS A

The hepatitis A virus (HAV) is contracted through fecal/oral contact (i.e. fecal contamination of food, or diaper changing tables if not cleaned properly), and sexual contact. In addition, eating raw or partially cooked shellfish contaminated with HAV can spread the virus. Children with HAV usually have no symptoms; however, adults may become quite ill suddenly experiencing jaundice, fatigue, nausea, vomiting, abdominal pain, dark urine/light stool, and fever. There is no treatment for HAV; however, recovery occurs over a 3 to 6 month period. About 1 in 1,000 with HAV suffer from a sudden and severe infection that may require a liver transplant. Luckily, a highly effective vaccine can prevent HAV. This vaccination is recommended for individuals who have chronic liver disease (i.e. HCV or HBV) or clotting factor disorders, in addition to those who travel or work in developing countries.

HEPATITIS B

Hepatitis B (HBV) claims an estimated 5,000 lives every year in the United States, even though we have therapies to both prevent and treat this disease. This disease is spread through contact with the blood and body fluids of an infected indi-

vidual. Unfortunately, due to both a lack in funding to vaccinate adults at high risk of being infected and the absence of an integrated preventive education strategy, transmission of hepatitis B continues to be problematic. Additionally, there are significant disparities in the occurrence of chronic HBV-infections. Asian Americans represent four percent of the population; however, they account for over half of the 1.3 million chronic hepatitis B cases in the United States. Current treatments have limited success in treating the chronically infected and there is no treatment available for those who are considered "HBV carriers". Preventive education and vaccination are the best defense against hepatitis B.

#### HEPATITIS C

Infection rates for hepatitis C (HCV) are at epidemic proportions. Unfortunately, as many are not aware of their infection until several years after infection, we are dealing with an "epidemic of discovery". This creates a vicious cycle, as individuals who are infected continue to spread the disease, unknowingly. Hepatitis C is also spread through contact with an infected individual's blood. The CDC estimates that there are over 4 million Americans who have been infected with hepatitis C, of which over 2.7 million remain chronically infected, with 8,000–10,000 deaths each year. Additionally, the death rate is expected to triple by 2010 unless additional steps are taken to improve outreach and education on the prevention of hepatitis C, new research is undertaken, and case-finding is enhanced and more effective treatments are developed. As there is no vaccine for HCV, prevention education and treatment of those who are infected serve as the most effective approach in halting the spread of this disease.

#### PREVENTION IS THE KEY

Only a major investment in immunization and preventive education will bring these diseases under control. All newborns, young children, young adults, and especially those who participate in high-risk behaviors must be a priority for immunization, outreach initiatives and preventive education. We recommend that the following activities be undertaken to prevent the further spread of all types of hepatitis:

- Provide effective preventive education in our elementary and secondary schools helping children avoid the ravages of health problems resulting from viral hepatitis infection.
- Training educators, health care professionals, and substance abuse counselors in effective communication and counseling techniques.
- Public awareness campaigns to alert individuals to assess their own risk behaviors, motivate them to seek medical advice, encourage immunization against hepatitis A and B, and to stop the consumption of any alcohol if they have participated in risky behaviors that may have exposed them to hepatitis C.
- Expansion of screening, referral services, medical management, counseling, and prevention education for individuals who have HIV/AIDS, many of whom may be co-infected with hepatitis.

HFI recommends an increase of \$41 million in fiscal year 2006 for further implementation of CDC's Hepatitis C Prevention Strategy. This increase will support and expand the development of state-based prevention programs by increasing the number of state health departments with CDC funded hepatitis coordinators. The Strategy will use the most cost-effective way to implement demonstration projects evaluating how to integrate hepatitis C and hepatitis B prevention efforts into existing public health programs. Additionally, HFI recommends that \$10 million be used to train and maintain hepatitis coordinators in every state.

CDC's Prevention Research Centers, an extramural research program, plays a critical role in reducing the human and economic costs of disease. Currently, CDC funds 26 prevention research centers at schools of public health and schools of medicine across the country. HFI encourages the Subcommittee to increase core funding for these prevention centers, as it has been decreasing since this program was first funded in 1986. We recommend the Subcommittee provide \$40 million for the Prevention Research Centers program in fiscal year 2005.

#### INVESTMENTS IN RESEARCH

Investment in the National Institutes of Health (NIH) has led to an explosion of knowledge that has advanced understanding of the biological basis of disease and development of strategies for disease prevention, diagnosis, treatment, and cures. Countless medical advances have directly benefited the lives of all Americans. NIH-supported scientists remain our best hope for sustaining momentum in pursuit of scientific opportunities and new health challenges. For example, research into why

some HCV infected individuals resolve their infection spontaneously may prove to be life saving information for others currently infected. Other areas that need to be addressed are:

- Reasons why African Americans do not respond to antiviral agents in the treatment of chronic hepatitis C.
- Pediatric liver diseases, including viral hepatitis.
- The outcomes and treatment of renal dialysis patients who are infected with HCV.
- Co-infections of HIV/HCV and HIV/HBV positive patients.
- Hemophilia patients who are co-infected with HIV/HCV and HIV/HBV.
- The development of effective treatment programs to prevent recurrence of HCV infection following liver transplantation.
- The development of effective vaccines to prevent HCV infection.

The Hepatitis Foundation International supports a 6 percent increase for NIH in fiscal year 2006. HFI also recommends a comparable increase of 6 percent in hepatitis research funding at the National Institute of Diabetes and Digestive and Kidney Diseases and the National Institute of Allergy and Infectious Diseases.

#### NATIONAL VIRAL HEPATITIS ROUNDTABLE

Victims of hepatitis suffer emotionally as well as physically. They experience discrimination in employment, strained personal relationships and severe depression when treatments fail to control their illness as well as during their treatment. Traditionally, however, there has not been an organized effort to periodically convene all stakeholder organizations that play a role in hepatitis prevention, education, treatment and patient advocacy. Successfully addressing viral hepatitis will require a comprehensive and strategic approach developed by all key stakeholders.

In order to fill this void, HFI and CDC co-founded the “National Viral Hepatitis Roundtable”. HFI believes that a National Viral Hepatitis Roundtable will enhance and assist CDC’s viral hepatitis mission for the prevention, control, and elimination of hepatitis virus infections in the United States, as well as the international public health community. It will provide an infrastructure for the sharing of information and education of all stakeholders.

The “National Viral Hepatitis Roundtable” is a coalition of public, private, and voluntary organizations dedicated to reducing the incidence of infection, morbidity, and mortality from viral hepatitis in the United States through research, strategic planning, coordination, advocacy, and leadership.

HFI is dedicated to the eradication of viral hepatitis, which affects over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle. Thank you for providing this opportunity to present our testimony.

#### THE HEPATITIS FOUNDATION INTERNATIONAL

The Hepatitis Foundation International (HFI) is dedicated to the eradication of viral hepatitis, a disease affecting over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle.

Our mission has four distinct parts:

- Teach the public and hepatitis patients how to prevent, diagnose, and treat viral hepatitis.
- Prevent viral hepatitis by promoting liver wellness and healthful lifestyles.
- Serve as advocates for hepatitis patients and the related medical community worldwide.
- Support research into prevention, treatment, and cures for viral hepatitis.

#### PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Provide a 6 percent increase for fiscal year 2006 to the National Institutes of Health (NIH) budget. Within NIH, provide proportional increases of 6 percent to the various institutes and centers, specifically, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
- Continue to accelerate funding for extramural clinical and basic functional gastrointestinal research at NIDDK.
- Continue to urge NIDDK to develop a strategic plan setting research goals on IBS and functional bowel diseases and disorders.



- Urge NIDDK to develop a standardization of scales to measure incontinence severity and quality of life and to develop strategies for primary prevention of fecal incontinence associated with childbirth.
- Provide funding to NIDDK and the National Cancer Institute (NCI) for more research on the causes of esophageal cancer.

Chairman Specter and members of the Subcommittee, thank you for the opportunity to present this written statement regarding the importance of functional gastrointestinal and motility research.

IFFGD has been serving the digestive disease community for fourteen years. We work to broaden the understanding about functional gastrointestinal and motility disorders in adults and children.

IFFGD speaks about and raises awareness on disorders and diseases that many people are uncomfortable and embarrassed to talk about. The prevalence of fecal incontinence and irritable bowel syndrome, as well as a host of other gastrointestinal disorders affecting both adults and children, is underestimated in the United States. These conditions are truly hidden in our society. Not only are they misunderstood, but the burden of illness and human toll has not been fully recognized.

Given that we have been diligently working for the past thirteen years, it is an exciting time to work for IFFGD, not only are we serving more and more people, but we are beginning to be able to privately fund research. Our first research awards were made on April 6, 2003.

Since its establishment, the IFFGD has been dedicated to increasing awareness of functional gastrointestinal disorders and motility disorders, among the public, health professionals, and researchers. In November of 2002, we hosted a conference on fecal and urinary incontinence, the proceedings of which were published in *Gastroenterology*, the Official Journal of the American Gastroenterological Association. During the first week of April 2003 we also hosted the Fifth International Symposium on Functional Gastrointestinal Disorders, which was a great success in bringing scientists from across the world together to discuss the current science and opportunities on irritable bowel syndrome and other functional gastrointestinal and motility disorders. The IFFGD has become known for our professional symposia. We consistently bring together a unique group of international multidisciplinary investigators to communicate new knowledge in the field of gastroenterology. In 1 week, we will be holding the Sixth International Symposium on Functional Gastrointestinal Disorders.

The majority of the diseases and disorders we address have no cure. We have yet to understand the pathophysiology of the underlying conditions. Patients face a life of learning to manage chronic illness that is accompanied by pain and an unrelenting myriad of gastrointestinal symptoms. The costs associated with these diseases are enormous, conservative estimates range between \$25–\$30 billion annually. The human toll is not only on the individual but also on the family. Economic costs spill over into the workplace. In essence these diseases reflect lost potential for the individual and society. The IFFGD is a resource and provides hope for hundreds of thousands of people as they try to regain as normal a life as possible.

#### FECAL INCONTINENCE

At least 6.5 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and in the elderly of both sexes. Often it is a symptom associated with various neurological diseases and many cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with multiple sclerosis, diabetes, colon cancer, uterine cancer, and a host of other diseases.

Damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction can cause fecal incontinence. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most try to hide the problem as long as possible, so they withdraw from friends and family. The social isolation is unfortunate but may be reduced because treatment can improve bowel control and make incontinence easier to manage.

In November 2002, the International Foundation for Functional Gastrointestinal Disorders (IFFGD) sponsored a consensus conference—"Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities." Among other outcomes, the conference resulted in six key research recommendations:

1. More comprehensive identification of quality of life issues associated with fecal incontinence and improved assessment and communication of treatment outcomes related to quality of life.
2. Standardization of scales to measure incontinence severity and quality of life.
3. Assessment of the utility of diagnostic tests for affecting management strategies and treatment outcomes.
4. Development of new drug compounds offering new treatment approaches to fecal incontinence.
5. Development and testing of strategies for primary prevention of fecal incontinence associated with childbirth.
6. Further understanding of the process of stigmatization as it applies to the experience of individuals with fecal incontinence.

#### IRRITABLE BOWEL SYNDROME (IBS)

Irritable Bowel Syndrome affects approximately 30 million Americans. This chronic disease is characterized by a group of symptoms, which can include abdominal pain or discomfort associated with a change in bowel pattern, such as loose or more frequent bowel movements, diarrhea, and/or constipation. Although the cause of IBS is unknown, we do know that this disease needs a multidisciplinary approach in research and treatment.

Similar to fecal incontinence and depending on severity, IBS can be emotionally and physically debilitating. Because of persistent bowel irregularity, individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home.

In the House and Senate fiscal year 2003, 2004, and 2005 Labor, Health and Human Services, and Education Appropriations bills, Congress recommended that the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) develop an IBS strategic plan. The development of a strategic plan on IBS would greatly increase the institute's progress toward the needed research on this functional gastrointestinal disorder.

#### GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Gastroesophageal reflux disease, or GERD, is a very common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. But sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. Periodic heartburn is a symptom that many people experience. There are several treatment options available for individuals suffering from GERD.

Gastroesophageal reflux (GER) affects as many as one third of all full term infants born in America each year. GER results from an immature upper gastrointestinal motor development. The prevalence of GER is increased in premature infants. Many infants require medical therapy in order for their symptoms to be controlled. Up to 25 percent of older children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction. In this population, the natural history of GER is similar to that of adult patients, in whom GER tends to be persistent and may require long-term treatment.

#### ESOPHAGEAL CANCER

Approximately 13,000 new cases of esophageal cancer are diagnosed every year in this country. Although the causes of this cancer are unknown, it is thought that this cancer may be more prevalent in individuals who develop Barrett's esophagus. Diagnosis usually occurs when the disease is in an advanced stage, early screening tools are currently unavailable.

#### CHILDHOOD DEFECATION DISORDERS AND DISEASES

*Chronic Intestinal Pseudo-Obstruction (CIP).*—About 200 new cases of CIP are diagnosed in American Children each year. Often life threatening, the future for children severely affected with CIP is brightened by the evolving promise of cure with intestinal or multi-organ transplantation.

*Hirschsprung's disease.*—A serious childhood and sometimes life-threatening condition that can cause constipation, occurs only once in every 5,000 American children born each year. Approximately 20 percent of children with HD will continue

to have complications following surgery. These complications include infection and/or fecal incontinence.

*Functional constipation.*—Millions of children (1 in every 10) each year will be diagnosed with functional constipation. In fact, it is the chief complaint of 3 percent of pediatric outpatient visits and 10–25 percent of pediatric gastroenterology visits.

FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS AND THE NATIONAL  
INSTITUTES OF HEALTH

The International Foundation for Functional Gastrointestinal Disorders recommends an increase of 6 percent or 1.7 billion for NIH overall, and a 6 percent increase for NIDDK. However, we request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We urge the subcommittee to provide the necessary funding for the expansion of the NIDDK's research program on functional gastrointestinal (FGI) and motility disorders, this increased funding will allow for the growth of new research, a prevalence study and a strategic plan on IBS, and increased public and professional awareness of FGI and motility disorders.

A primary tenant of IFFGD's mission is to ensure that clinical advancements concerning GI disorders result in improvements in the quality of life of those affected. By working together, this goal will be realized and the suffering and pain millions of people face daily will end.

Thank you.

*The International Foundation for Functional Gastrointestinal Disorders*

The International Foundation for Functional Gastrointestinal Disorders is a non-profit education and research organization founded in 1991. IFFGD addresses the issues surrounding life with gastrointestinal (GI) functional and motility disorders and increases the awareness about these disorders among the general public, researchers, and the clinical care community.

PREPARED STATEMENT OF THE LYMPHOMA RESEARCH FOUNDATION

I am Melanie Smith, Director of Public Policy and Advocacy for the Lymphoma Research Foundation (LRF). LRF appreciates the opportunity to submit this statement to the record of the Labor, Health and Human Services and Education Appropriations Subcommittee. The LRF is the nation's largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and healthcare professionals with critical information on the disease. Our ultimate goal is to find a cure for all forms of lymphoma. To that end, we fund some of the world's leading lymphoma researchers at outstanding academic institutions. These researchers are engaged in research aimed at understanding the basic mechanisms of lymphoma and improving the current treatments for the disease. LRF also aims to equip those who are diagnosed with lymphoma with up-to-date information about treatment options. The organization sponsors educational conferences at which the leaders in lymphoma research and treatment address patients and families regarding cutting edge research and the most recent developments in therapies.

BACKGROUND ON LYMPHOMA

Lymphoma is a major health problem. It is the most common form of blood cancer and the third most common form of childhood cancer. In 2005, approximately 56,390 cases of non-Hodgkin's lymphoma (NHL) will be diagnosed in this country, and more than 19,000 Americans will die from NHL. Also this year, 7,350 cases of Hodgkin's lymphoma will be diagnosed, and more than 1,400 Americans will die from the disease. Nearly 500,000 Americans are living with lymphoma.

In recent years, there have been exciting reports regarding the improvements in treatments for a number of forms of cancer, as well as reports that the incidence of cancer overall is declining. Regrettably, NHL stands in contrast to the general trends in cancer incidence, and the treatment options for NHL remain inadequate. Since the early 1970s, incidence rates for NHL have nearly doubled, although incidence rates have stabilized the last few years. And the 5-year survival rate for NHL stands at 59 percent. These are not satisfactory numbers, and they serve as measures of the work we still have to do.

## RESEARCH ON LYMPHOMA

We have learned a great deal about the genetic, molecular, and cellular basis of cancer. We do not know the cause of most lymphomas, but there is increasing information to suggest a link between environmental factors and infections and the development of many lymphomas. The environmental factors may include chemicals, toxins, drugs, infectious agents, such as hepatitis C and Epstein Barr virus, and the gastric pathogen *Helicobacter pylori*. There is strong evidence that in some individuals, immune dysfunction is a critical factor in the development of lymphoma.

Our knowledge of cancer has improved significantly in the last decade, in large part due to the strong commitment of Congress to the National Institutes of Health (NIH) and its willingness to boost NIH funding. These funds have supported strong basic and clinical researchers who are focused on unlocking the secrets to cancer. There is a need to sustain that commitment to NIH, in order to equip scientists engaged in basic research and facilitate the translation of basic research findings into new treatments. This is certainly true in the case of lymphoma. There is a need to clarify the interactions among the environmental, viral, and immunogenetic factors that contribute to development of lymphoma and to ensure the development of new treatments based on our enhanced understanding of lymphoma.

Over the last decade several new lymphoma treatments have been developed, expanding the options for those who are diagnosed with the disease. Lymphoma patients and researchers have clearly benefited from the nation's significant investment in research, and Congress deserves the appreciation of the community of lymphoma patients and researchers. Among the lymphoma treatments approved in the last decade are a monoclonal antibody and two different radioimmunotherapies. While we applaud the new treatments of the last decade, they are not magic bullets. For many, lymphoma remains a fatal disease.

New therapies that capitalize on different research approaches are currently under investigation. These include therapeutic vaccines, immunotherapies, proteasome inhibitors, and examination of the microenvironment of lymphomas. Other work is focused on refining the chemotherapy regimens and developing treatment regimens with lower toxicities. All of this work deserves the support of private and public research funders.

## ROLE OF NIH IN LYMPHOMA RESEARCH

Although LRF plays a critical and creative role in funding lymphoma research, NIH is, and will remain, the key player in this field. NIH is the pivotal player not only because of the magnitude of its financial commitment to lymphoma research, but also because of the role it can play in bringing together all of the partners in the research community—NIH intramural researchers, academic researchers, private foundations, industry, and the Food and Drug Administration (FDA).

NIH is also in the best position to encourage, facilitate, and fund the translation of basic research findings into new treatments. It is absolutely critical that we not lose the research momentum that has been the result, in significant part, because of the doubling of the NIH budget between fiscal year 1999 and fiscal year 2003. We recognize that funding for NIH will not be increased as rapidly in the near future as it was from fiscal year 1999 to fiscal year 2003, but we urge Congress to protect the investment in NIH research and to realize that a rapid deceleration in research funding threatens the past investment.

LRF recommends that Congress urge NIH to direct special attention to translational and clinical research. LRF proposes that NIH strengthen its lymphoma research program by several actions:

- The National Cancer Institute (NCI) should boost its support for translational and clinical lymphoma research. NCI should evaluate its current investment in clinical research and expand or initiate programs to strengthen the clinical research effort.
- NCI should also increase its support for correlative studies of tumor biology and treatment response, as well as its investment in research on the late and long-term effects of current lymphoma treatments.
- NCI should strengthen its research effort focused on understanding the complex interaction among environmental, viral and immunogenetic factors that are involved in the initiation and promotion of lymphoma.
- Although NCI has historically been the lead institute in funding lymphoma research, other institutes—the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Aging (NIA), and the National Institute of Environmental Health Sciences (NIEHS)—should also evaluate and improve their lymphoma research programs. A lymphoma-focused program to investigate environmental/viral links is warranted.

A strong partnership among voluntary health agencies like LRF, academic researchers, industry, and NIH will be optimal for advancing lymphoma research and improving the outlook for those who are diagnosed with the disease. New strategies are necessary for the rapid translation of basic research findings into new treatments. These strategies may include systems for funding collaborative research projects that engage researchers in multiple institutions and multiple disciplines, including academic researchers and industry. Private foundations are looking at creative means to ensure that their research dollars are optimized, and we encourage NIH to employ the same creative and flexible approaches.

ROLE OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION IN BLOOD CANCER EDUCATION

LRF is actively engaged in providing patients and their families and caregivers complete and up-to-date information about lymphoma, lymphoma research, and lymphoma treatment options. Because of our strong history in this area, we were gratified when Congress authorized and funded a program at the Centers for Disease Control and Prevention (CDC) for public and patient education on blood cancers. LRF was one of nine organizations that received grants, funded by fiscal year 2004 appropriations, for public and patient education regarding the blood cancers. The benefits of our federally funded program, Lymphoma Awareness for Multicultural Populations (LAMP), which includes outreach to underserved communities, are already being realized.

Congress was also generous in providing funding for this program in fiscal year 2005, an action that will allow the organizations to continue their programs and conduct full evaluations of their strategies for outreach and education. We urge Congress to provide a third year of funding, because the programs are being operated on a 3-year cycle. Their full potential will be realized only if they run for the full 3-year anticipated cycle.

LRF believes that strong partnerships will be a key feature of efforts to improve lymphoma treatments and provide lymphoma patients current information about their disease and treatment options. We encourage NCI to fund collaborative research ventures, and we urge CDC to continue its support of those private organizations that have years of experience in patient education. Those who receive a diagnosis of lymphoma face difficult choices, and we must work together to improve their options and their lives.

---

PREPARED STATEMENT OF MENDED HEARTS, INC.

I am Robert H. Gelenter, a volunteer for the Mended Hearts, Inc., a national heart disease patient support group with more than 289 chapters across the United States and in Canada. We visit patients in approximately 460 hospitals throughout the United States. I have been appointed by the group to assist in this lobbying effort—a volunteer position.

More than 29 years ago, I was diagnosed with a rare heart disease. After having severe chest pains and trouble breathing for more than two years, I was diagnosed with hypertrophic cardiomyopathy (HCM), a disease in which the heart enlarges. The heart muscle eventually thickens so much that it can't pump blood effectively. The heart muscle does not grow in the normal parallel patterns. Rather it grows in a haphazard manner. It affects men and women of all ages. When you read of a young athlete who has dropped dead on an athletic field the odds are very good that he or she had HCM. HCM is one of the leading causes of sudden cardiac death. There is no cure for this disease.

Medication may work and there is a surgical procedure that may alleviate the pain. If that doesn't work a patient may need a heart transplant, yet spare organs are scarce. The doctor who made my diagnosis was trained at the National Heart, Lung, and Blood Institute of the National Institutes of Health.

Initially, I received several medications, which allowed me to engage in most activities. But, some activities, such as walking up hills, caused severe shortness of breath and severe chest pains. But, generally I could function normally. However, after about 11 years, the discomfort was increasing, and it became apparent that I was in serious trouble. I could not walk 60 feet without having to stop to catch my breath. Sometimes the pain was so great that I would almost double over in the middle of the street. My wife told me that my face would become gray. The perspiration would pour off my body. If I was lucky I could find a chair to sit on. The quality of my life had deteriorated so drastically that I knew I needed some treatment.

In 1988, I went to Georgetown University Medical Center for an angiogram—the gold standard for diagnosing heart problems. The cardiologist who performed the

angiogram told me that he had bad news and worse news. The bad news was that I had a 95 percent blockage in my left anterior descending heart artery—the so-called “widow makers spot.” The worse news was that I had a major chance of having a severe heart attack with a less than a 5 percent chance of surviving that heart attack because of the hypertrophic cardiomyopathy. At this point, my wife was quietly crying and I was perspiring profusely. Since Georgetown University Medical Center did not have the expertise to operate on me, they called the NIH to see if they would accept me as a patient. I was sent home pending notice from the NIH.

The NIH accepted me. After entering the National Heart, Lung, and Blood Institute on February 6, I was operated on February 11, 1988. No matter how trite the expression—that was the first day of the rest of my life. The surgery, considered drastic and rare as it is, is still the gold standard throughout the world for the treatment of hypertrophic cardiomyopathy. The Morrow Procedure, in honor of the innovator, was developed and improved at the NIH.

Although this surgery is no longer performed at the National Heart, Lung, and Blood Institute, there is another experimental ongoing protocol in which the same effect is being attempted by using alcohol to deaden the excessive heart tissue.

I am on medication for the rest of my life. My condition is progressive. Ten years ago, I was fitted with a pacemaker to insure that my heart beats at the correct rate. I am 100 percent dependent on this pacemaker. Without the pacemaker, there are times when my normal heart beat is so slow that I would die.

I am eternally grateful to the physicians funded by the National Heart, Lung, and Blood Institute, particularly to Dr. MacIntosh and his staff, for the gift of life. Because of this marvelous research supported by the NHLBI, I have lived 17 years pain free. I have seen two children graduate from college and three grandchildren born, I have shared these years with a wonderful wife. I have been able to work at my profession—attorney at law.

I have had the gift of life restored to me. To express my gratitude for that gift, I visit patients recovering from heart episodes at two hospitals, Washington Hospital Center and Washington Adventist Hospital.

If this tale of woe is not enough about 2½ years ago, I suddenly began to have mini strokes. I experienced four episodes within 7 months. The last episode was just a year ago. Medication now seems to have the incidents under control.

I respectfully ask for the fiscal year 2006 appropriation in the following amounts:

—NIH \$30 billion, including \$2.3 billion for heart research and \$341 million for stroke;

—NHLBI \$3.1, including \$1.9 billion for heart and stroke-related research; and

—NINDS \$1.6 billion, including \$183 million for stroke research.

My experience is proof that the research supported by the National Heart, Lung, and Blood Institute and the National Institute for Neurological Disorders and Stroke benefits not just the patients at the NIH Clinical Center, but throughout the United States. The benefits go worldwide as well.

Heart attack, stroke and other cardiovascular diseases remain the No. 1 killer and major cause of disability of men and women in the United States. Nearly 40 percent of people who die in the United States die from cardiovascular diseases. Last year, nearly 930,000 Americans died from cardiovascular diseases, including more than 150,000 under the age of 65.

Thank you for your support of National Heart, Lung, and Blood Institute’s heart research and the National Institute for Neurological Disorders and Stroke’s stroke research.

---

#### PREPARED STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The 3 million volunteers and 1,400 staff members of the March of Dimes appreciate the opportunity to submit the Foundation’s federal funding recommendations for fiscal year 2006. The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to prevent polio. Today, the Foundation works to improve the health of mothers, infants, and children by preventing birth defects and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 52 chapters in every state, the District of Columbia and Puerto Rico.

The volunteers and staff of the March of Dimes are deeply concerned that the funding recommendations and levels in the President’s Budget and congressional Budget Resolutions will not be sufficient to support biomedical research and services needed to improve the health of children and families. For instance, the infant mortality rate increased in 2002 for the first time since 1958. Increases in deaths due

to premature birth, birth defects, and maternal complications during pregnancy account for most of the increase. In our judgment, the funding increases recommended below are fully justified and would have an immediate positive impact on this disturbing trend and thereby lead to an overall improvement in the health of the nation's children.

#### NATIONAL INSTITUTES OF HEALTH

The March of Dimes joins the larger research community in recommending a 6 percent increase in funding for the National Institutes of Health (NIH), bringing total federal support to just over \$30 billion. The Administration's fiscal year 2006 budget proposal is insufficient to keep up with inflation and certainly will not sustain the necessary investment in medical research.

##### *National Institute for Child Health and Human Development*

The mission of the National Institute for Child Health and Human Development (NICHD) is closely aligned with that of the March of Dimes. According to the National Center for Health Statistics (NCHS), in 2002, more than 480,000 babies were born prematurely in the United States—1 in 8 births. Premature birth accounts for nearly 24 percent of deaths in the first month of life. Those babies that survive are more likely than full-term infants to face serious multiple health problems including cerebral palsy, mental retardation, chronic lung disease, and vision and hearing loss. Preterm labor can happen to any pregnant woman and the causes of nearly half of all preterm births are unknown.

The NICHD has made a major commitment to understanding and preventing premature birth but additional funding is desperately needed. The March of Dimes recommends a 10 percent increase for NICHD in fiscal year 2006 and an increase of at least \$100 million over the next five years to boost prematurity-related research. This increase should be devoted to a comprehensive biomedical research program to study preterm delivery etiology, prevention, and treatment regimens.

Last year, the NCHS reported the first increase in the U.S. infant mortality rate since 1958 and 61 percent of this increase was due to an increase in the birth of premature and low birth weight babies. An analysis of Agency for Healthcare Research and Quality data conducted by the March of Dimes Perinatal Data Center estimated that the total national hospital bill for premature babies was \$15.5 billion in 2002. The financial burden of prematurity is expected to continue to worsen until prevention of preterm births is better understood and clinical interventions are developed.

The NICHD began a major new initiative involving genomic and proteomic research into the causes of premature birth in an effort to accelerate knowledge in the mechanisms responsible for premature birth. The RFA soliciting proposals for the establishment of a collaborative network for premature birth research was issued in June 2004. The NICHD received an excellent response to this RFA and had anticipated the start of this initiative in early 2005. The March of Dimes is very disturbed that the start of this crucial initiative has now been delayed because of insufficient funding.

Unfortunately, even a 10 percent increase in funding would not be enough to enable NICHD to begin implementing the National Children's Study (NCS) of environmental and genetic influences on child health and development. The goal of the NCS is to pinpoint causes and find prevention and treatment strategies for many of today's childhood diseases and disorders. The planning of the study is largely complete and the study is ready to be piloted. On November 16, 2004, the Request for Proposals for the first NCS study sites and the data-coordinating center were published. But beyond the pilot sites, the future of this important study is uncertain without additional funding. The cost of this study is dwarfed by the \$269 billion annual cost of treating the diseases and conditions it is designed to address, including preterm birth, according to NICHD estimates. If study findings were to result in only a 1 percent reduction in those costs, the expense of the entire study could be recovered in a single year. The March of Dimes believes it would be shortsighted to put off this study.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

##### *Division of Reproductive Health*

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health, but does not have the resources it requires to study the growing problem of preterm birth. Therefore, the March of Dimes recommends a \$20 million increase in fiscal year 2006 to expand research related to preterm birth. Worsening rates of

preterm birth require an expanded, comprehensive prevention research agenda to identify the causes, risk factors, and to find clinical interventions that are effective in preventing preterm labor. In particular, two specific programs should receive additional funding: (1) the Pregnancy Risk Assessment Monitoring System and (2) epidemiological research.

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a state-specific, population based surveillance system designed to identify and monitor maternal behaviors and experiences before, during, and after pregnancy. Currently, CDC supports cooperative agreements with 29 states and New York City through which PRAMS monitors approximately 62 percent of all U.S. births. Data collected through PRAMS is used by researchers and policy makers to increase understanding of adverse pregnancy outcomes, to develop maternal and child health programs, and to incorporate the most up to date research findings into standards of practice. The March of Dimes recommends an increase of \$5 million to expand PRAMS so that CDC can develop better national estimates on behavioral as well as demographic risk factors for preterm birth.

Epidemiological research conducted at CDC is vital to reducing the incidence of preterm birth. The March of Dimes recommends an increase of \$15 million to expand research on the prevention of preterm delivery for women at risk, focusing especially on factors contributing to higher rates of preterm delivery among African-American women. Increasing CDC's activities related to identifying the causes of preterm birth would improve early detection of women at risk for preterm labor and lead to new interventions for those at greatest risk.

#### *National Center on Birth Defects and Developmental Disabilities*

Created by the Children's Health Act of 2000 (Public Law 106-310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities. The March of Dimes recommends at least \$135 million in fiscal year 2006 funding for the NCBDDD.

Of particular interest to the March of Dimes is the NCBDDD's comprehensive birth defects program that includes surveillance, research and prevention activities. Of the four million babies born each year in the United States, 3 percent are born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20 percent of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. In fact, birth defects contribute substantially to the nation's health care costs. According to CDC, the medical treatments and supportive services for the 17 most common birth defects exceed \$8 billion annually. A modest increase of \$6 million in funding for surveillance, research and prevention activities is a vital step to making progress in reducing the incidence of birth defects.

NCBDDD provides funding to states to develop, implement, and/or expand community-based birth defects surveillance systems, programs to prevent birth defects, and activities to improve access to health services for children with birth defects. Surveillance is vitally important for the early detection of new birth defects, for discovering the causes of birth defects and for evaluating the effectiveness of prevention programs. Due to lack of funds, CDC will only fund 15 states in fiscal year 2005, down from 28 states in fiscal year 2004. Additional resources are needed to fund all states seeking CDC assistance and increase assistance to states already receiving funds.

The National Birth Defects Prevention Study is the largest case-control study of birth defects ever conducted. This CDC-funded study is being carried out by 9 regional Centers for Birth Defects Research and Prevention located in Arkansas, California, Georgia, Iowa, Massachusetts, New York, North Carolina, Texas, and Utah. These centers obtain data and identify cases for inclusion in the study and conduct epidemiological research on birth defects. With adequate funding, this study has the potential to dramatically increase understanding of the causes of birth defects and is already providing information for improvement of programs to prevent birth defects. The causes of nearly 70 percent of birth defects are still unknown.

The centers study possible genetic and environmental causes, the use of certain medications during pregnancy, maternal diet, and vitamin use. This study provides the nation a continuing source of information on potential causes of birth defects. For example, in response to a scientific study showing a possible association between the drug loratadine, also sold under the brand name Claritin®, and the occurrence of the birth defect hypospadias the National Birth Defects Prevention Study



conducted a review that showed no association. This information is useful to physicians as well as women who take loratadine and become pregnant.

The NCBDDD also is conducting a national public and health professions education campaign designed to increase the number of women taking folic acid. CDC estimates that up to 70 percent of neural tube defects (NTDs), serious birth defects of the brain and spinal cord including anencephaly and spina bifida, could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily, beginning before pregnancy. Since fortification of U.S. enriched grain products with folic acid, the rate of NTDs in the United States has decreased by 26 percent. It is critical that CDC increase its campaign efforts to educate every woman of childbearing age and their providers about the importance of folic acid to further reduce the rates. Therefore, the March of Dimes recommends an appropriation of at least \$4 million in fiscal year 2006 for the Folic Acid Education Campaign.

#### ADDITIONAL CDC PROGRAMS

##### *National Immunization Program*

If we are to meet the Healthy People 2010 goals of vaccinating 90 percent of children and adults, CDC, states and localities will need sufficient resources to ensure that those in need of immunizations receive them. Annually, 4 million children should be immunized against 12 preventable diseases before the age of two. Yet, nearly 25 percent of two-year-olds have not received all of the recommended vaccine doses. CDC's National Immunization Program provides grants to 64 state, local, and territorial public health agencies to reduce the incidence of disability and death resulting from vaccine preventable diseases. To move the nation closer to the goal of vaccinating at least 90 percent of children and adults, the March of Dimes urges the Subcommittee to continue its longstanding policy of ensuring that federal vaccine programs are adequately funded. For fiscal year 2006, the March of Dimes recommends an overall increase of \$232 million in order to ensure that the National Immunization Program has the resources it needs to account for vaccine price increases, introduction of new vaccines, and to facilitate implementation of recommendations developed by the Institute of Medicine.

##### *Polio Eradication*

April 12, 2005 marks the 50th anniversary of the declaration that the poliovirus vaccine developed by Dr. Jonas Salk was safe and effective. The March of Dimes, formerly known as the National Foundation for Infantile Paralysis, funded Dr. Salk's groundbreaking work on the polio vaccine. Although eradication of polio in the United States resulted in a shift in the Foundation's focus to a new set of challenges pertaining to children's health, the March of Dimes continues to support completing the task of polio eradication worldwide. Global polio eradication will save lives and reduce unnecessary health-related costs. The March of Dimes supports a funding level of \$106.4 million for CDC's fiscal year 2006 global polio eradication activities. With polio epidemics now confined to only 6 countries (Nigeria, India, Pakistan, Niger, Egypt and Afghanistan), it is important that the U.S. government maintain its commitment to completion of the worldwide eradication initiative.

##### *National Center for Health Statistics*

The Foundation also supports the vital work of the National Center for Health Statistics (NCHS), which provides data essential for research and programmatic initiatives. For example, the National Vital Statistics System is a major source of information on the utilization of prenatal care and on adverse birth outcomes such as preterm births, low birthweight, and infant mortality. Increased funding would allow CDC to modernize this system using web-based technology that facilitates rapid compilation of accurate and comprehensive data obtained from health professionals and facilities. This information is needed to track trends in birth outcomes and to support birth defects registries. Data from NCHS' surveys are also important to identify emerging trends and optimal uses of existing program resources. Additional resources would also enable CDC to continue the National Survey of Family Growth, which provides essential information on factors affecting birth outcomes.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

##### *Newborn Screening*

Newborn screening is a vital public health activity used to identify genetic, metabolic, hormonal and/or functional conditions in newborns that left untreated can cause disability, mental retardation, and even death. Although nearly all babies born in the United States are screened for some genetic birth defects, the number and quality of these tests varies from state to state. The March of Dimes rec-

ommends that every baby born in the United States receive, at a minimum, screening for a core set of 29 metabolic disorders including hearing deficiencies.

In fiscal year 2005, the Congress provided funding for implementation of Title XXVI of the Children's Health Act of 2000. This program is designed to strengthen state newborn screening programs; to improve states' ability to develop, evaluate, and acquire innovative testing technologies; and to establish and improve programs to provide screening, counseling, testing and special services for newborns and children at risk for heritable disorders. Unfortunately, funding for Title XXVI activities was obtained by diverting a portion of the SPRANS section of the Maternal and Child Health Block Grant which the Administration proposes to level fund in fiscal year 2006. The March of Dimes recommends that Title XXVI of the Children's Health Act be funded at a level of \$25 million in new money to support HRSA's work with states to improve newborn screening programs across the nation.

*Maternal and Child Health Block Grant*

Federal funding for Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant, has failed to keep pace with increased demand for services. Although the Block Grant provides funds for a growing number of community-based programs such as home visiting, respite care for children with special health care needs and "wrap around" services for pregnant women and children enrolled in Medicaid and SCHIP, the funding level for the Grant has not increased since fiscal year 2002. In order for maternal and child health programs to continue to shoulder responsibility for additional services, it must be adequately funded. The March of Dimes recommends fully funding Title V at the authorized level of \$850 million.

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's staff and volunteers look forward to working with Members of the Subcommittee to improve the health of mothers, infants and children.

MARCH OF DIMES FISCAL YEAR 2006 FEDERAL FUNDING PRIORITIES

[In millions of dollars]

Program	Fiscal year 2005 funding	March of Dimes fiscal year 2006 recommendation
National Institutes of Health (Total) .....	28,444.0	30,150.0
National Institute of Child Health & Human Development .....	1,270.0	1,397.0
National Human Genome Research Institute .....	489.0	518.0
National Center on Minority Health and Disparities .....	196.0	208.0
Centers for Disease Control and Prevention (Total) .....	8,034.0	8,650.0
Center on Birth Defects and Developmental Disabilities .....	125.0	135.0
Birth Defects Research & Surveillance .....	14.0	20.0
Folic Acid Education Campaign .....	2.0	4.0
Immunization .....	479.0	711.0
Polio Eradication .....	106.4	106.4
Safe Motherhood/Infant Health (NCCDPHP) .....	45.0	65.0
Pregnancy Risk Assessment Monitoring System .....	7.3	12.3
Prevention Research (Preterm Birth) .....	1.5	16.5
National Center for Health Statistics .....	109.0	118.0
Health Resources and Services Administration (Total) .....	6,809.0	7,500.0
Maternal and Child Health Block Grant .....	730.0	850.0
Newborn Screening .....	2.0	25.0
Newborn Hearing Screening .....	10.0	10.0
Consolidated (Community) Health Centers .....	1,734.0	2,038.0
Healthy Start .....	102.0	102.0
Agency for Healthcare Research and Quality .....	319.0	440.0

PREPARED STATEMENT OF THE NATIONAL COALITION FOR HEART AND STROKE RESEARCH

My name is Jack Owen Wood. I solicit your support for more aggressive federal funding for research into prevention and treatment of the sister diseases, stroke and heart disease. Strokes and heart attacks are occurring at an alarming rate.

I am representing the National Coalition for Heart and Stroke Research. The coalition consists of 18 national organizations representing more than 5 million volun-

teers and members united in support for increased funding for heart and stroke research. Members of the Coalition include:

American Academy of Neurology; American Academy of Physical Medicine and Rehabilitation; American Association of Neurological Surgeons; American College of Cardiology American College of Chest Physicians; American Heart Association; American Neurological Association; American Stroke Association; American Vascular Association Foundation; Association of Black Cardiologists; Children's Cardiomyopathy Foundation, Inc.; Citizens for Public Action on Blood Pressure and Cholesterol, Inc.; Congress of Neurological Surgeons; Heart Rhythm Society; Mended Hearts, Inc.; National Stroke Association; Society of Interventional Radiology; and Society for Vascular Surgery.

I will deal primarily with one man's personal experience with stroke and its functional and financial costs—my own. I have only the use of my right arm.

I was born in 1937, raised in Vicksburg, Mississippi, earned an engineering degree at Mississippi State University and currently reside in Port Orchard, Washington. I worked for the Boeing Company in Seattle, am a former Director of the Washington State Energy Office, served as Director of Cost and Revenue Analysis and as the Forecasting Manager for a major Northwest Area Natural Gas Utility until May 1, 1995.

On May 1, 1995, at the age of 57, I was stricken and severely disabled by my stroke. Two years later I experienced a triple bypass heart operation. You might say I've "been there and done that" for both major cardiovascular diseases. So you see, I am an expert.

Years ago I was offered an exciting and rewarding volunteer opportunity. I was asked to lead the "Jack Wood Stroke Victor Tour" for the American Heart Association.

The Jack Wood Stroke Victor Tour was a 5-state lobbying tour. Through it I tried to meet personally with every Northwest Congressional representative on his or her home turf (in Alaska, Idaho, Montana, Oregon and Washington). In each meeting I was joined by local people, stroke survivors and their families and medical professionals. I told my story and asked them to join the Congressional Heart and Stroke Coalition and to support increased federal funding for heart and stroke research.

I am proud to say I traveled to 18 communities and met personally with 28 members of our delegation or their staff.

One of the most powerful memories for me was the frequency in which Members of Congress or staff members related their personal experience with stroke. One member I spoke to lost both parents to stroke. I suspect many of you have stories too.

I realize your interest is greater than the physical impact of my stroke. Your concern must include the financial impact, not only to me, but also on our country from increased health care costs and lost productivity and its many implications.

I have confronted the difficult and painful task of calculating that cost to me. Besides being a man whose stroke took his ability to pick up and play with his grandchildren and his livelihood, I remain a statistician at heart. I could not resist calculating and telling that part of my story. But please remember my story is not dissimilar to that of many of the 5.4 million stroke survivors in the United States. Many of whom were stricken in their prime earning years. Who in a matter of moments, seemingly without warning, are transformed from a contributor and provider to a receiver and patient.

Allow me to highlight three figures that I feel sum up my data and should be important to you. I estimate that my stroke at age 57:

- Reduced my earnings before retirement age 65 by more than \$600,000.
- Subsequently, the cost to the federal government in lost income and other taxes, early Medicare payments and Social Security disability payments is more than \$320,000.
- My HMO spent approximately \$150,000 to respond to and treat my stroke.
- One man, over \$1 million.

About 700,000 Americans will suffer a stroke this year costing this nation an estimated \$57 billion in medical expenses and lost productivity.

Earlier I described a stroke as occurring seemingly without warning. All too often as in my case, people either don't know or ignore the signs of a stroke, even one in progress. When my stroke hit I denied it. It took me two days after my stroke to acknowledge it and seek help. Because of research into new treatments, we now have tPA, a clot-busting drug, which if administered within 3 hours of the onset of stroke symptoms, can dramatically reduce the damage of clot-based strokes. Had I recognized and acknowledged my stroke, gone to a hospital with a neurologist on staff and had there been tPA, the impact of my stroke most certainly would have been lessened.

What is even more painful to me is that my impending stroke could have been detected. Unfortunately, we need to create easier and less expensive diagnostic techniques so that effective diagnostics can be given routinely as part of regular health exams. And they must be covered through insurance.

I am not asking for your sympathy. Instead, please think of me as two of the ghosts in the famous Dickens' story. Please don't misunderstand, I am not casting you as Scrooge. See me as both the ghosts of things past and things yet to be. I too am here to tell you, the future, which I represent, needs not be. It is largely up to you.

I hope my story and estimate of the cost of my stroke convinces you that taking on stroke and heart disease through increased research, leading to better prevention, diagnosis and treatment is fiscally responsible. The human and financial costs are astronomical.

Thank you for your past support of research.

---

#### PREPARED STATEMENT OF THE NATIONAL HEMOPHILIA FOUNDATION

Thank you for the opportunity for the National Hemophilia Foundation (NHF) to submit testimony to the Chairman and Members of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. NHF is a national voluntary health organization dedicated to improving the health and welfare of people affected by bleeding and clotting disorders, including hemophilia, women's bleeding disorders, and thrombophilia.

#### BACKGROUND

Bleeding and clotting disorders are caused by genetic defects in the body's blood coagulation system, usually a missing protein that prevents or slows down blood clotting, or sometimes causes excessive clotting. There are several types of bleeding disorders. The most recognized bleeding disorder is hemophilia, a predominantly male disorder affecting approximately 20,000 individuals in the United States. The most common bleeding disorder is von Willebrand disease, which affects between one to two percent of the U.S. population. Thrombophilia, a blood clotting disorder effecting 2 million people each year, puts both men and women at risk of developing dangerous blood clotting in veins and arteries. These clots can obstruct the blood flow through the vessels causing pain and swelling of the tissue in the area and can lead to permanent tissue damage as well as death.

#### PREVENTION AND TREATMENT

##### *Centers for Disease Control and Prevention*

The national network of hemophilia treatment centers (HTCs) created by Congress in 1974 remains essential to ensuring that comprehensive and specialized care is available for persons with bleeding and clotting disorders. The HTC role has expanded dramatically over the last three decades, evolving with the needs of the hemophilia and bleeding disorders community to provide coordinated care, blood safety surveillance, prevention, and improved disease management. This expansion also has included outreach and treatment for women with bleeding disorders and persons with thrombophilia.

These programs, carried out by the Hereditary Blood Disorders Program in the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC), have demonstrated significant reductions in mortality and morbidity. More than 75 percent of the hemophilia community participates in one of the 140 centers that comprise the HTC network and more than 10,000 women receive care at a HTC. Despite this dramatic growth in support and services, HTC funding has not increased in the last 10 years. Support for an increase has been identified in Congress, and Congressman Tom Price (R-GA) and many of his colleagues have sponsored a letter of support encouraging the Committee to allocate an additional \$7 million for HTC funding. NHF urges the Committee's strong support for this additional funding to ensure HTCs can carry out needed education, prevention, blood safety, surveillance, and outreach programs with the bleeding and clotting disorders community.

##### *Health Resources and Services Administration*

HTCs also receive needed funding as a special project of regional and national significance within the Maternal and Child Health Bureau (MCHB) Block Grant set-aside. MCHB funds are utilized by HTCs to cover the non-reimbursable costs of providing on-going nursing, prevention, dental, and rehabilitative services and support.

MCHB funding for HTC has remained steady for the past 20 years, resulting in eroded resources over time. MCHB funds for the HTC disease management network are essential to meeting the needs of the bleeding and clotting disorders community. NHF urges the Committee to maintain funding support for the HTCs through MCHB.

#### HEMOPHILIA RESEARCH

##### *Bleeding and Clotting Disorders Research*

NHF is appreciative of the Committee's continued commitment to research. The strengthened research funding provided by the Committee to the National Institutes of Health has brought about rapid advances in science. Within NIH, the National Heart, Lung, and Blood Institute (NHLBI) has taken the lead on advancing research on bleeding and clotting disorders and the complications of these disorders. NHF is particularly appreciative of NHLBI's collaborative research program with the Foundation to support research on improved and novel therapies for treating these disorders and, like the Institute, has been overwhelmed by the scientific community's positive response to this approach. NHF encourages the Committee to increase its funding support for NHLBI such that valuable initiatives like the collaborative research program can be sustained.

##### *Hepatitis C Virus*

HCV continues to severely impact the hemophilia and bleeding disorders community. As a result of their dependence on blood-based products, the hemophilia and bleeding disorders community has been severely affected by HIV and hepatitis. More than 80 percent of people with hemophilia born before 1992 have the Hepatitis C Virus (HCV). Today, nearly half of all persons with hemophilia have HCV. NHF has been grateful for the support of the Committee in encouraging continued partnerships between NHF and the National Institute of Allergy and Infectious Disease (NIAID) to address the importance of developing and advancing research initiatives for addressing HCV within the bleeding disorders community. NHF requests that NIAID continue to work with the Foundation's medical and scientific leadership and develop a report by March 31, 2006 on HCV research strategies that are being pursued within the bleeding disorders community.

Over the last 20 years, the National Cancer Institute (NCI) has collected samples from patients with hemophilia infected with HIV and HCV through the Multi-Center Hemophilia Cohort Study. This cohort offers a rich database for improving the understanding of HCV and has served as the basis of significant peer reviewed findings. NHF understands that NCI has decided to no longer fund further research studies of the cohort. NHF requests the Committee's support in urging NCI to ensure the samples obtained through this cohort are preserved and accessible for future research. NHF also requests a report on possible future research opportunities provided by the cohort samples.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has played a significant role in advancing and coordinating NIH's HCV research activities. With the high incidence of HCV within the bleeding disorders community, it is critical to further investigate and understand treatment options and advancements. NHF urges the Committee's support for NHF to work with NIDDK in developing and advancing research initiatives to address HCV within the bleeding disorders community.

#### RECOMMENDATIONS

We are grateful for the Committee's support of bleeding and clotting disorders research, prevention, treatment, and outreach initiatives. For fiscal year 2006, we urge the Committee to:

- Strengthen funding support for hemophilia and bleeding and clotting disorders prevention and treatment programs by providing an additional \$7 million for the HTC network through CDC's Hereditary Blood Disorders Program.
- Provide continued support for the HTC network through MCHB.
- Maintain support at NHLBI for research on improved and novel therapies for bleeding and clotting disorders.
- Provide support for continued collaboration between NHF and NIAID in developing and advancing research initiatives for addressing HCV within the bleeding disorders community.
- Preserve NCI samples obtained through the Multi-Center Hemophilia Cohort Study and ensure their accessibility for future research initiatives.
- Provide support for NIDDK to work with NHF in addressing HCV within the bleeding disorders community.

Thank you for the opportunity to provide this statement to the Committee.

---

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and distinguished members of the Subcommittee, we appreciate the opportunity to submit written testimony on behalf of the National Multiple Sclerosis Society. The Society was founded in 1946. Since its inception, the Society's highest priority has been to support research aimed at finding the cause of MS, better treatments, and a cure. In 2005, the National MS Society will spend over \$35 million on MS research supporting over 350 MS investigations. By the end of 2005, the Society cumulatively will have expended some \$460 million since awarding its first three grants in 1947. This represents the largest privately funded program of basic, clinical, and applied research and training related to MS in the world.

The federal government must continue its vital role in furthering the scientific understanding of MS. To this end, the Society supports the following:

- That the National Institutes of Health (NIH), in partnership with the Society, invest additional funds to identify and characterize MS susceptibility genes and bring additional research focus to the primary progressive form of MS.
- That NIH, in collaboration with the Society, other MS organizations, and other federal research agencies, undertake a study of the incidence, demographics and environmental factors that may contribute to disease onset.
- The National Institute on Disability and Rehabilitation Research (NIDRR) in the Department of Education fund one additional Medical Rehabilitation Research and Training Center for MS and take steps to stimulate individual research projects.
- That Congress increase fiscal year 2006 NIH funding by 6 percent.

Multiple sclerosis is a chronic, unpredictable and often disabling disease of the central nervous system. Symptoms range from numbness in the limbs, to loss of vision, memory deficits, and in some instances partial or total paralysis. The progress, severity and specific symptoms of MS in any one person can vary and cannot yet be predicted, but advances in research and treatment are giving hope to those affected by the disease.

The federal investment in the National Institutes of Health (NIH) and the National Institute on Disability and Rehabilitation Research (NIDRR) plays a major role in MS research. At the NIH, there are two institutes that conduct or fund the majority of MS research: the National Institute of Neurological Disorders and Stroke (NINDS) which funds 75 percent, and the National Institute of Allergy and Infectious Diseases (NIAID) which funds about 20 percent. The National Center for Medical Rehabilitation Research (NCMRR—a unit of the National Institute of Child Health and Human Development) also funds a small amount of MS research specifically targeting rehabilitation issues. In addition to the NIH, the NIDRR through the Department of Education invests in MS research.

For fiscal year 2005 and fiscal year 2006, it is estimated that NIH expenditures on MS research will be approximately \$102 and 103 million, respectively. For fiscal year 2005 and fiscal year 2006 NIDRR expenditures on MS research will be approximately \$1.5 million per year out of a total budget of \$140 million per year. While this demonstrates one measure of the federal investment in MS research, this amount pales in comparison with the annual direct and indirect disease cost—approximately \$23 billion for all people with MS in the United States.<sup>1</sup>

The National MS Society has had a long and productive relationship with the NIH, particularly with NINDS. Our founder Sylvia Lawry helped spearhead the legislation that established NINDS in 1950. The Society has been pleased to work with the NINDS on many areas of mutual interest and we hope to strengthen our partnership with NINDS and expand our relationships with other federal funders of MS research in the coming year.

The Society supports the NIH Neuroscience Blueprint, announced last Fall, that reinforces intra-collaboration and information-sharing among 14 NIH Institutes that conduct or support research on the brain and nervous system. The Blueprint should accelerate the translation of basic neuroscience discoveries into better ways to treat and prevent nervous system disease.

---

<sup>1</sup>Based on a 1994 Duke University study, indexed for 2004 by the National MS Society, the average annual cost of MS is estimated at \$57,500 per person due to lost wages, increased medical care and other expenses. Nationwide, there are an estimated 400,000 people with MS.

## INVESTING IN RESEARCH PRIORITIES RELEVANT TO MS

The National MS Society will continue to pursue research opportunities with NIH and NIDRR in priority areas that are key to furthering the understanding of MS. We continue to monitor NIH's progress in expanding its commitment to MS research as suggested by Congress.

In 2004, as part of our NIH advocacy efforts, the Society had the following congressional "report language" added by the House and Senate Appropriations Conference Committee as an instruction to NIH in the fiscal year 2004 omnibus appropriations package:

"The conferees urge NINDS to increase its overall investment in multiple sclerosis (MS) research. Special emphasis on imaging, biological markers and clinical trials for new therapeutics should be areas of high priority. The conferees are pleased to note the development of a joint symposium on MS genetics sponsored by NINDS and the National MS Society, and encourage the Institute to take a more active role at the NIH in furthering MS genetics research by developing collaborative strategies with the National Human Genome Research Institute and other relevant NIH institutes. The conferees request that NIH report back to Congress no later than September 30, 2004 with progress in its efforts to expand its commitment to multiple sclerosis. The conferees also are pleased to note a major success in past years in the creation of a joint collaborative research program in "gender and immunity" between the National Institute on Allergy and Infectious Diseases (NIAID) and a major voluntary association for the disease, in which NINDS participates. The conferees encourage NINDS to seek similar collaborative activities related to MS."

The Society was pleased to receive a copy of the report. While the Society is gratified by the many intramural and extramural activities and progress described in the report, we are disappointed to note that it did not address steps that NINDS would take to expand its commitment MS research as requested by the committee. We urge NINDS to increase its commitment to MS by:

- Partnering with the Society to invest additional resources to help solve the genetic basis of MS.
- Working with the Society to bring additional research focus to the primary progressive form of MS (PPMS).

Family studies of people with MS and their relatives, have shown that the risk for MS depends on relatedness to the affected individual, that is, a sibling has a higher risk of developing MS than a cousin. In no other disease have recurrence risks been so comprehensively catalogued in groups of biological and social relatives. A strategy is needed to penetrate the genetics of MS. Although the NIH and the National MS Society have invested independently substantial funds in MS genetics over the past decade, this is an area that calls for additional collaboration. The past few years have seen real progress in the development of laboratory and analytical approaches to the study of genetic disorders. The Society encourages the NIH to move forward with the Society as a true partner in identifying those DNA regions that can be prioritized for encoding MS susceptibility genes. The identification and characterization of the MS genes will help to define the basic etiology of the disease, to help predict the course of the disease, and to influence therapeutics.

Advances in immunology have provided clinicians with powerful tools to better understand the underlying causes of MS, leading to new therapeutic advances. Although there are FDA-approved treatments for relapsing MS, there are no approved treatments for progressive MS. The primary progressive form of MS (PPMS) is characterized from the onset by the absence of acute attacks and instead involves a gradual clinical decline. Approximately 10 percent of individuals are diagnosed with PPMS from the onset. Clinically this form of the disease is associated with a lack of response to any form of immunotherapy. This leads to the concept that PPMS may in fact be a very different disease as compared to relapsing remitting MS. The Society identifies the study of progressive MS as an area that merits greater attention by the research community in order to increase our understanding of PPMS and to have effective therapies for this progressive form of the disease. In the upcoming year, the Society encourages NIH to help the Society address this underserved area of MS research.

In addition to efforts at the NIH, the Society is pleased to note that for more than 20 years, NIDRR has funded a Medical Rehabilitation Research and Training Center (MRRTC) for MS. However, the institute's overall investment in MS research remains limited, \$1.5 million in fiscal year 2005. The NIDRR portfolio includes only two current projects related to MS, the aforementioned MRRTC and a Rehabilitation Research and Training Center on Health and Wellness in Long Term Disability that is only partially focused on MS. In contrast, spinal cord injury, with a preva-

lence less than that of MS, has 39. Since the advent of FDA-approved MS disease-modifying treatments in 1993, persons with MS have had access to therapeutics which can slow the progression of disability. However, in order to maintain maximum levels of independence, persons with MS need rehabilitation to address residual deficits. Unfortunately, due to the limited support for MS rehabilitation research, we know relatively little about the efficacy of rehabilitative interventions in MS. We therefore urge the NIDRR to increase its support for MS rehabilitation research through the funding of at least one additional MRRTC along with initiatives to stimulate individual research projects.

#### THE IMPORTANCE OF COLLABORATION

The National MS Society cannot overemphasize the importance of collaboration. We are pleased to see that the Roadmap Initiative—a 3-year plan addressing key research issues throughout NIH—continues to develop. The National MS Society encourages NIH to continue its efforts to increase collaboration across institutes and to pursue collaborative opportunities with other organizations. As we see it, there is no other choice.

An area in critical need of attention concerns data related to the incidence, prevalence, and distribution of MS. The last national study of incidence and prevalence of MS in the United States took place more than 30 years ago. Since that time the population of the United States has changed dramatically in size, composition, and distribution. Moreover, numerous questions have arisen concerning possible ethnic, geographic, and local variations in the distribution of MS. Knowledge concerning these distributions and possible causal factors may provide important information concerning the nature of MS and its triggers. Moreover, rational policy formulation for MS health care requires up-to-date information concerning numbers and characteristics of persons with MS down to the state level. Addressing these information needs is beyond the resources of the Society. We therefore urge the NIH, the CDC/ATSDR to work with the Society and perhaps other MS organizations such as the Consortium of MS centers, to begin the task of understanding how many Americans have MS, where they reside, and what environmental factors may have contributed to disease onset.

To date, the Society has been successful with NIH on jointly funding a major initiative on gender and immune function. In 2001, the Society entered into a \$20 million collaborative project with NIAID and other NIH institutes to investigate gender effects on the immune function, including autoimmunity. This is important because most autoimmune diseases (including MS) are far more prevalent in women than men. The Society is co-funding six projects and will contribute up to \$4 million to this project. We would like to engage in other collaborative projects, especially with NINDS.

The Society also was pleased that in 2004 NINDS and NMSS co-sponsored a scientific workshop on biomarkers in MS. As outcomes from this workshop, the Society is looking to work closely with NINDS projects, such as the development of collaborative and international efforts to identify biomarkers for MS. Such efforts would significantly advance our efforts to effectively diagnose and treat MS.

The Society was also pleased that in 2004 NINDS and NMSS co-sponsored a scientific workshop on design of clinical trials in MS. The tremendous increase in potential therapies for MS has created new challenges in the design and execution of new MS therapies. The Society was pleased that an outcome of this workshop was an effort to draft a white paper for the Food and Drug Administration on the topic of use of magnetic resonance imaging (MRI) as a surrogate measure in MS clinical trials. Acceptance of MRI as a valid surrogate measure by the FDA would represent a significant step forward in testing the potential MS therapies and bringing them to approval in a more expeditious manner.

The Society is also currently collaborating with the National Center for Medical Rehabilitation Research (NCMRR—a unit of the National Institute of Child Health and Human Development) on an international workshop to foster rehabilitation research in MS. This workshop will address the critical need to expand the quality and quantity of MS rehabilitation research. It is hoped that from this workshop may emerge opportunities for collaborative support of research initiatives to advance scientific knowledge concerning MS rehabilitation.

#### OVERALL NIH FUNDING INCREASE FOR FISCAL YEAR 2006

The Society is concerned that NIH may face a third year of overall low funding increases. Furthermore, in fiscal year 2004 and fiscal year 2005, only bioterrorism research received a healthy increase, with much smaller increases allocated for disease research. We fear the same may occur in fiscal year 2006. This is particularly



disappointing after the fiscal year 1999–2003 funding campaign that doubled the NIH budget in the 5-year period.

—We urge Congress to appropriate a 6 percent fiscal year 2005 funding increase for NIH.

—While there is a need to increase our country's investment in bioterrorism research, we ask Congress to balance the fiscal year 2006 NIH appropriation to allow growth across all NIH institutes and all areas of disease research.

We thank the Subcommittee for this opportunity to comment and applaud your commitment to advancing the health and well-being of all Americans through investment in biomedical research.

---

PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2006

1. A 6 percent increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

2. Continue to expand the NIDDK Nephrotic Syndrome (NS)/Focal Segmental Glomerulosclerosis (FSGS) research portfolio by aggressively supporting grant proposals in this area and encouraging the National Center for Minority Health and Health Disparities (NCMHD) to initiate studies into the incidence/cause of NS/FSGS in the African-American population.

3. The NephCure Foundation encourages we encourage follow up to the scientific workshop that took place in January, 2005, sponsored by NIDDK, in effort to initiate grant proposals focused on achieving the goals developed by the workshop. The workshop examined observations and opportunities for improved diagnosis and therapeutic interventions for Glomerular disease and Focal Segmental Glomerulosclerosis (FSGS).

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the NephCure Foundation (NCF), a non-profit organization driven by a blue-ribbon panel of respected medical experts and a dedicated band of patients and families working for a common goal—to save kidneys and lives.

I am Ed Hearn, former Major League catcher for the 1986 World Series Champion New York Mets and the Kansas City Royals. My career as a professional athlete came to an abrupt end in 1991, due to a shoulder injury. Upon recuperation, I intended to return to my team. While I was out due to my injury, I began to experience symptoms that indicated kidney malfunction, and within six months, I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS), a debilitating and degenerative kidney disease. Today, after three kidney transplants, the aid of a breathing machine at night, a \$3,000 IV once a month, and \$40,000 of medication to pay for up to 50 pills that I must swallow each day, I live to tell my story and to speak for those suffering from FSGS. My hope is that we can find the means to prevent this life-threatening disease from affecting our youth and from jeopardizing the normalcy of their lives as it has mine and many others. I remain hopeful that a cure for FSGS will be uncovered, but until then, our focus must be on prevention.

TREATMENT TRIALS BEGINNING, BUT NO CURE IN SIGHT

Mr. Chairman, FSGS is one of a cluster of glomerular diseases that attack the one million tiny filtering units contained in each human kidney. These filters are called nephrons and these diseases attack the portion of the nephron called the glomerulus, scarring and often destroying the irreplaceable filters. Scientists do not know why glomerular injury occurs and they are not sure how to stop its inevitable destruction of the kidney.

When I was a teenager, doctors found protein in my urine and told me that some day I might have kidney trouble. I pushed it out of my mind, thinking that some day meant when I was an old man down the road. Some day came faster than anyone expected. I believe that because I was a highly conditioned athlete, and catchers are more conditioned than most athletes, my body initially masked the symptoms of FSGS. Consequently, I retained the façade of physical health, and I do not know when FSGS initially began to internally attack my body.

My first kidney transplant lasted more than seven years until the FSGS returned, as it often does. I received a second kidney from my aunt in 2000, but my body rejected it almost immediately, and I received a third kidney transplant in May of 2002. My story is not unique; there are thousands of other people in this country who have had their lives disrupted due to the sudden onset of FSGS. Although kidney transplants have been very successful for thousands of FSGS patients, there are many patients of whom the body rejects the transplanted kidney or the FSGS comes

back and attacks the transplanted kidney, leaving the patient with no functioning kidneys. He or she must then rely on daily dialysis as a means of survival.

FSGS patients are often on several medications, which cause medical complications and unbearable side effects. FSGS patients, upon diagnosis, often take a downward plunge at a rapid rate, and it is extremely difficult to make a comeback. In the last four years, I have undergone two kidney transplants, two years of dialysis, and a six week course of daily radiation treatment for rapidly spreading cancer that was primarily the result of the high doses of immunosuppressant drugs I am taking for FSGS. In the last three months alone, I have had over 65 medical appointments. As you can see, it is nearly impossible for an FSGS patient to live a normal life.

We are extremely thankful that an NIDDK-funded clinical trial began last year to study the efficacy of the current treatments for FSGS, and that ancillary studies are underway to examine tissue samples of injured glomerulus. However, these clinical trials hold no particular hope for patients who suffer from FSGS.

There are thousands of young people who are in a race against time, hoping for a treatment that will save their lives. The NephCure Foundation today raises its voice to speak for them all, asking you to take specific actions that will aid our quest to find the cause and the cure of NS/FSGS.

First and foremost, we support a 10 percent increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

#### TOO LITTLE DATA ABOUT A GROWING PROBLEM

When glomerular disease strikes, the resulting Nephrotic Syndrome causes loss of protein in the urine and symptoms such as edema, a swelling that often appears first in the face. For example, many physicians mistake children's puffy eyelids as an allergy symptom. Stories of similar misdiagnoses are common at our Foundation. With experts projecting a substantial increase in Nephrotic Syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

The NephCure Foundation has numerous education programs underway, including patient education seminars; the most recent of which took place in March 2004. The next patient education seminar will take place in Washington, DC in May 2005. News of our most recent activities can be found on our web site at [www.nephcure.org](http://www.nephcure.org). However, our efforts alone are not enough.

NIDDK launched a major federal outreach program early in 2002—the National Kidney Disease Education Program—we seek your support in urging NIDDK to assure that glomerular disease receives high visibility in this important program.

#### GLOMERULAR DISEASE STRIKES MINORITY POPULATIONS

Nephrologists tell us that glomerular diseases such as FSGS affect a disproportionate number of African-Americans and, according to NIDDK, “the worst prognosis is observed in African-American children.” NephCure officials have described this situation in a meeting with Dr. John Ruffin, director of the National Center for Minority Health and Health Disparities (NCMHD).

As the NCMHD becomes fully operational and plans programs, our Foundation will continue to work with the Center to encourage the creation of programs to study the high incidence of glomerular disease within the African-American population.

We ask the Committee to join with us in expanding the NS/FSGS research portfolio by requesting that the National Center for Minority Health and Health Disparities seize the opportunity to establish research into the phenomenon of glomerular disease within the African American community.

#### MORE BASIC SCIENCE IS NEEDED

The current FSGS clinical trials which follow an estimated 400 patients over a three year period, are limited, according to the RFA, to examining the “impact of immunomodulatory therapy on proteinuria.” While the trials may lead to safer or more efficient care for children with FSGS, no one is suggesting that they will bring us closer to finding the cause and cure. Science has yet to prove that FSGS is an immune-mediated disease.

Scientists tell us that much more needs to be done in the area of basic science, beginning with collection of tissue and fluid samples from a large number of patients on which years of important scientific research can be founded. NephCure is collaborating with the NIH in a major way to work for such progress.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has agreed to match, dollar-for-dollar, funds raised by NephCure that will allow re-

searchers to obtain DNA samples from hundreds of FSGS patients in upcoming clinical trials. The NIDDK will match up to \$300,000 raised by NephCure for a combined total of \$600,000. These trials are an ancillary study in conjunction with the first-ever national medication trials of FSGS treatment that may possibly lead to better understanding of the more common Nephrotic Syndrome, which can be a precursor to FSGS.

We encourage follow up to the Scientific Workshop that took place in January, 2005, sponsored by NIDDK, in effort to initiate grant proposals focused on achieving the goals developed by the workshop. The workshop examined observations and opportunities for improved diagnosis and therapeutic interventions for glomerular disease and Focal Segmental Glomerulosclerosis (FSGS). This goal is consistent with the NIH Roadmap to Research initiative developed by NIH Director, Dr. Elias Zerhouni.

The workshop united basic science and clinical investigators, FSGS patients, physician researchers, nephrologists from around the world and anyone with an interest in treatment for glomerular diseases to share and collaborate upon advances, challenges and research potential of these debilitating diseases. We must use the conference as a stepping stone and build upon the information collectively gathered to determine the resources needed to carry out these opportunities and challenges. The workshop/conference gave hope to the thousands of young people whose kidneys and lives are threatened by this terrible disease, and it gave honor to their heroic stories.

We anticipate the potential for a Program Announcement and the potential for a Special Emphasis Program Announcement resulting from the conference or some other traditional mechanism to generate grant proposals. These mechanisms to encourage investigator initiated grant proposals should help to continue to expand the NS/FSGS portfolio at NIH.

Mr. Chairman, as you know, patient support and advocacy groups such as the NephCure Foundation work closely with medical research organizations. They share a mutual understanding that unless major research efforts are undertaken, advances and improvements in the health of patients will not occur. Every year, the NephCure Foundation participates in advocating increased funding for the NIH and NIDDK. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.

---

#### PREPARED STATEMENT OF THE NATIONAL PROSTATE CANCER COALITION

Mr. Chairman and members of the Committee, thank you for the opportunity to share my remarks. The National Prostate Cancer Coalition (NPCC) was founded in 1996 to combat a long overlooked killer of men. I came to NPCC in 2001, having just recently been impacted by the disease myself. In 2000, my grandfather was diagnosed with prostate cancer. Having served his country so valiantly in World War II, he was now facing a new battle. Luckily, because of early detection through the prostate specific antigen (PSA) test and the digital rectal exam (DRE), the disease was caught early and, following a radical prostatectomy, he is now cancer free. But there are many men who are not so lucky. That's why you must adequately fund prostate cancer research for veterans like my grandfather, families like mine, and men all over America.

Under the leadership of this committee we have seen prostate cancer research funding increase by nearly \$300 million since in the last 6 years. While we have come a long way, there is still much work to be done. For the second year since the founding of NPCC, prostate cancer deaths will continue to increase in 2005. More than 30,000 lives will be lost to the disease. Occurrences of prostate cancer are increasing as well, to over 230,000 men this year. While cases continue to grow, more men are catching the disease in its early stages, when the disease is most treatable, by early detection through screening.

NPCC would like to offer its gratitude on behalf of the 2 million American men with prostate cancer for the support this committee has offered in the past. The recent doubling of the National Institutes of Health's (NIH) budget has helped prostate cancer research funding to expand to record levels, but we must ensure this funding is used appropriately. To that end, your committee was instrumental in requiring NIH and the National Cancer Institute (NCI) to submit a professional judgment budget for fiscal year 2003–fiscal year 2008 to outline the agencies' plans for prostate cancer research. You have also been influential in requesting a fiscal budget for that document, which was Congress received passed the April 2004 deadline.

The budget requested lacked connectivity to the previous plan and made no references to goals or priorities. While no one disputes the historic importance of doubling, we ask you to encourage NIH and NCI to coordinate with each agency to put forward a comprehensive and cohesive plan that brings us closer to eradicating cancer. Additionally, we respectfully request your oversight to ensure this funding is producing results for prostate cancer.

Huge sums of taxpayers' money have been allocated to NIH over the years and it is now time to examine what this windfall has produced. Therefore, we request that you to ensure that NIH to submits the yearly update on its prostate cancer research portfolio that reflects its progress according to the fiscal year 2003–fiscal year 2008 professional judgment budget that was requested in fiscal year 2005.

We are entering an exciting time in biomedical research. The recent Food and Drug Administration's approval of Avastin has opened a new door for cancer research. Avastin targets cancerous cells by blocking their blood supply, an idea that had been previously dismissed by the medical community as "absurd". The drug not only signals a turning point in changing cancer into a manageable, chronic disease but also demonstrates the value of seeking out novel and innovative research. We must encourage this kind of research at NIH, including assessing the value of stem cell research which has shown promise in research for neurological diseases, diabetes, and cancer.

Developing a new approach to research is a priority for NPCC. The Prostate Cancer Research Funders Conference, first convened in 2001 and then revitalized last fall, seeks to formulate a collaborative, public-private approach to seek out new ways of attacking the problem of prostate cancer. Originally co-convened by NPCC and NCI, participants now also include the Department of Defense, the Veterans Health Administration, the Centers for Disease Control and Prevention, the Food and Drug Administration, Canadian and British government agencies, private foundations/organizations and representatives from industry. Members of the Conference have come together to form a partnership that allows them to focus on key objectives and to address commonly recognized barriers in research. This could propel research forward significantly. As the Conference continues, we ask that the Committee make its functionality part of its oversight commitments to prostate cancer research. Currently, federal agencies participate voluntarily, but they can opt in or out based on the tenure of executive leadership and its time-limited decisions. For the conference to be successful federal agencies engaged in the prostate cancer research should, in our opinion, be required to participate, and we ask for your leadership to make that happen.

Recognizing the importance of cutting edge research initiatives and collaborative research efforts, NIH director Elias Zerhouni, M.D. recently unveiled the NIH Roadmap. The Roadmap's strategy mirrors that of the Funders Conference, specifically by seeking out new approaches and ideas and stimulating cross-institutional and cross-center research for all NIH driven biomedical research. Believing, we think correctly, that the synergies in the Roadmap can achieve outcomes that are greater than those any one Institute or Center can achieve, we support its efforts to advance key biomedical research initiatives at an exponential rate. NPCC applauds the Roadmap and pledges its support to take biomedical research in new directions.

As NIH and NCI look to redefine and increase the efficiencies of their research programs, Congress must equip them with the resources they need to implement new initiatives. Unprecedented increases in NIH and NCI's funding over the last 6 years have created opportunities never before available. We must take advantage of these achievements, to not do so will not only harm cancer patients everywhere but is, quite simply, poor business sense.

NPCC was heartened when the President stated 2 years ago that "in order to win the war against cancer, we must fund the war against cancer," but we are very concerned by recent reports suggesting the Administration's budget for fiscal year 2006 will propose a cut in the overall budget of the National Institutes of Health and other critical programs. Such a cut would be a major reversal in our nation's commitment to the fight against cancer.

Societies for Experimental Biology (FASEB) have stated if increases are held to 2 percent–3 percent the grant funding rate at NIH will drop below 30 percent and approximately 500 fewer grants would be funded. To allow NIH and NCI to adequately continue to fund promising grants and research first realized during the budget doubling, Congress must appropriate at least (\$30.1 billion) in funding for these agencies in fiscal year 2006. That may seem like a large number, but in reality, it is only a small fraction of the estimated \$189 billion that cancer alone costs this nation yearly.

Increasing NIH's budget by 8.5 percent would also allow NCI to dedicate more than \$400 million to prostate cancer research in fiscal year 2005. Last year, NCI

received only a 3.3 percent increase in funding over the previous year's level. Yet, with previously committed grant awards and outlays to the NIH Roadmap, NCI is "effectively operating with a budget that is \$2.7 million less than last year's operating budget (NCI Cancer Bulletin 2/3/04)." The President's fiscal year 2006 budget allocates over \$4.8 billion to NCI, is much less than the fiscal year 2005 increase. This level will mean even tougher choices in awarding grants at NCI. We believe that Congress should fully fund the NCI Director's Bypass Budget at \$6.2 billion, which would rapidly accelerate the nations' fight against all cancers.

As you know, education and early detection through screening are the catalyst to beating prostate cancer. Right now, the PSA blood test and DRE physical exam are the best measures for detecting prostate cancer early. We ask the Committee to allocate at least \$20 million to the Center for Disease Control and Prevention's (CDC) prostate cancer awareness program. We also encourage the Committee to work with CDC to address our concern that the agency places insufficient value on these screening tools.

Thank you again for the leadership you have shown in advancing biomedical and, more specifically, prostate cancer research. Under your leadership, the nation's war on cancer has reached heights never before realized. We look forward to continuing to work with you and the members of the Committee until a cure is found.

---

PREPARED STATEMENT OF THE NATIONAL SLEEP FOUNDATION

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Provide a 6 percent increase for fiscal year 2006 to the National Institutes of Health (NIH) and a proportional increase of 6 percent to the individual institutes and centers, specifically, the National Heart, Lung, and Blood Institute (NHLBI).
- Urge the National Center on Sleep Disorders Research (NCSDR) to partner with other federal agencies, such as the Centers for Disease Control and Prevention (CDC), and voluntary health organizations, such as the National Sleep Foundation (NSF), to develop a collaborative sleep education and public awareness initiative.
- Urge the United States Surgeon General to issue a Surgeon General's Report on Sleep and Sleep Disorders.

Mr. Chairman and members of the Subcommittee, thank you for allowing me to present testimony on behalf of the National Sleep Foundation or NSF. I am Dr. James Walsh, Chairman of the Board of Directors of the National Sleep Foundation, Executive Director of the Sleep Medicine and Research Center affiliated with St. John's Mercy and St. Luke's Hospitals, and Clinical Professor of Psychiatry at St. Louis University. The National Sleep Foundation is an independent, non-profit organization whose mission is to enhance public awareness about the need for sufficient restorative sleep, to increase the detection and treatment of sleep disorders, to foster sleep-related programs and policy for the betterment of public health, and to promote sleep research. We work with thousands of sleep medicine and other health care professionals, researchers, patients, drowsy driving victims throughout the country, and collaborate with many government and private organizations with the goal of preventing health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders, or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. At least 40 million Americans suffer from sleep disorders; yet more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent have ever initiated such a discussion. Millions of individuals struggle to stay alert at school, on the job, and on the road. The latest estimates from the National Highway Transportation Safety Administration and the Federal Motor Carriers Safety Administration implicate fatigue and sleepiness in 1.1 million crashes annually. A recent study in Sweden showed that sleep disturbances are the second greatest risk factor for fatal accidents at work. Sleep apnea, a sleep-related breathing disorder which affects at least 5 percent of adult Americans, is closely related to some of America's most pressing health problems, such as obesity, hypertension, heart failure, and diabetes. Chronic insomnia, experienced by 10 percent of our population is a strong risk factor for depression and other widespread mental health conditions. Sleep disorders, sleep deprivation, and excessive daytime sleepiness add approximately \$15 billion to our national health care bill each year. The National Center on Sleep Disorders Research estimates that by the year 2050, sleep problems will affect as many as 100 million Americans.

Sleep science has clearly demonstrated the importance of sleep to health and well being, yet research studies continue to show that millions of Americans are at risk for the serious health, safety consequences of sleep disorders and inadequate sleep. Moreover their quality of life suffers and the personal and national economic impact is staggering. NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. We must elevate sleep to the top of the national health agenda. We need your help to make this happen.

Our biggest challenge is bridging the gap between the outstanding scientific advances we have seen in recent years and the level of knowledge about sleep held by health care practitioners, educators, employers, and the general public. This gap in knowledge is being discussed as I present this testimony today, by hundreds of concerned professionals. Yesterday and today, the National Center on Sleep Disorders Research, the National Heart, Lung, and Blood Institute, and the Trans-NIH Sleep Research Coordinating Committee are sponsoring a translational conference entitled "Frontiers of Knowledge in Sleep and Sleep Disorders: Opportunities for Improving Health and Quality of Life." This two-day program has assembled health care providers, public health and education experts, policy makers, patient advocacy organizations, sleep medicine specialists, and other stakeholders. It is intended to address how information about sleep and sleep disorders can translate into improvements in public health and safety using cost-effective, comprehensive, and broadly-applied strategies for education, societal change, and improved sleep-related health care.

This conference is an important step in translating research into practice and into a broad-based public health message. The development of a sleep education and public awareness initiative would serve as a key legacy for the sleep translational conference and provide a forum for dissemination of the outcomes of the sleep translational conference. The National Sleep Foundation has been leading the way on public education regarding sleep and sleep disorders since it was founded in 1990. NSF and others have done a lot, but so much more needs to be done in order to educate the public and actually change behavior. Because resources are limited and the challenges great, we think creative and new partnerships need to be created to address the issues that are before us.

In the fiscal year 2005 appropriations bill, Congress recommended that The National Center on Sleep Disorders Research partner with other federal agencies, such as the Centers for Disease Control and Prevention, and voluntary health organizations, such as NSF, to develop an ongoing, inclusive mechanism for public and professional awareness on sleep, sleep disorders, and the consequences of fatigue. Such a collaboration between federal agencies and voluntary health organizations will create an opportunity for dramatically improving public health and safety as well as the quality of life for millions, if not all, Americans. Beginning steps have been taken to establish this collaboration, but continued support from the National Center on Sleep Disorders Research and the Centers for Disease Control and Prevention is critical.

Last year, at a National Institutes of Health sleep conference, the U.S. Surgeon General reported on the profound impact that chronic sleep loss and untreated sleep disorders have on all Americans. He emphasized that dissemination of the existing body of medical knowledge and implementation of expanded clinical practice guidelines regarding sleep and sleep disorders are critically important.

Conferences and workshops held by the Surgeon General involve educating the public, advocating for effective disease prevention and health promotion programs and activities, and providing a highly recognized symbol of national commitment to protecting and improving the public's health.

We believe that it is time that the federal government helps promote sleep as a public health concern through the development of a Surgeon General's report on sleep and sleep disorders in order to call attention to the importance of sleep and develop strategies to protect and advance the health and safety of the nation.

Thank you again for the opportunity to present testimony to this Subcommittee.

---

PREPARED STATEMENT OF THE NTM INFO & RESEARCH, INC.

SPECIFIC RECOMMENDATIONS

NTMIR requests an allocation in the budget to enable NIH, (NIAID & NHLBI) to advance diagnostics and treatments for patients suffering from pulmonary Non-tuberculous Mycobacteria (NTM) disease.

NTMIR requests funds to facilitate and increase multi-centered trials to advance the effectiveness of treatments and to develop new treatments.

NTMIR recommends that CDC/NCHS engage in surveillance to better understand the incidence of NTM disease and assess the level of awareness within the medical community.

NTMIR supports the American Lung Association's request for an increase of \$77 million in funding to combat TB so that we avoid the risk of a rise in incidence that complacency can yield.

NTMIR supports the request of the Ad Hoc Group for Medical Research Funding for a \$30 billion appropriation for NIH in fiscal 2006.

#### WHAT IS PULMONARY NONTUBERCULOUS MYCOBACTERIAL DISEASE (NTM)?

NTM is an infectious disease considered to be of environmental origin as these bacteria are ubiquitous in the water and soil that surround us. Although NTM is diagnosed by the same basic test used to diagnose traditional tuberculosis (TB), it is significantly more difficult to treat. NTM progressively diminishes lung capacity, with all the attendant negative consequences in life.

Unfortunately, even though TB has a significantly high profile, NTM does not because education and awareness have been lacking. Furthermore, there is growing evidence that NTM is many times more prevalent than TB in the United States. For example, the State of Florida Infectious Disease Laboratory reports receiving over twice as many specimens that are NTM positive for every one that is positive for TB. Even more startling, the Agency for Health Care Administration for Florida hospital patient discharges shows almost 9 times the number of patients with the primary diagnosis of NTM versus those with TB.

Doctors in leading treating facilities are reporting that even though NTM is not reportable, they are seeing more NTM patients than TB patients. A current report from Toronto, Ontario indicates that the prevalence may be six times higher than the older data we have in the United States.

NTM is not limited to one strain and has certain strains that are inherently resistant to drug therapy, and in all cases multiple drugs are required on a lengthy to permanent basis. A significant number of patients require short to long term intravenous medication and this is a particular hardship for the elderly because Medicare does not cover in-home therapy. Medicare recipients must be hospitalized one to three times a week driving treatment costs significantly higher than in alternate settings.

#### NTM INFO & RESEARCH (NTMIR)

NTMIR was founded through a partnership of concerned patients and interested physicians who see increasing numbers of people affected by this devastating disease. NTMIR was created to expand professional awareness, diagnosis and treatment, facilitate research and provide patient support. Our mission is a public/private partnership to advance the science and the outcomes for countless patients with NTM disease.

NTMIR has already demonstrated a track record of success since it commenced its activities just two years ago. These include, successful implementation of the NTMInfo.com website and online support group, patient education throughout the country through the replication of an NTM information pamphlet, initiating professional education and Grand Round lectures to increase professional education both for specialists and family physicians, establishment of a partnership of cooperation with public health in the State of Florida and with the American Lung Association of Florida. Our most recent effort resulted in agreement between a major pharmaceutical company, the FDA and a division of HRSA to provide an urgently needed drug for patients who could not otherwise obtain it, some of whom might have died without it.

We anticipate that these efforts will serve as models in other states and at the federal level.

#### FERN R. LEITMAN, PATIENT & DIRECTOR, NTM INFO & RESEARCH, INC.

Fern Leitman is a patient who has severe pulmonary NTM disease that has required ongoing medical therapy since 1996. Nonetheless, in addition to serving as vice president of Philip Leitman, Inc. where she is responsible for asset and acquisition evaluation, she is co-founder of the NTM website and NTM Info & Research, Inc.

Since becoming ill, Fern has dedicated many hours each week to communicating with patients from around the United States to help them understand how they help themselves to battle NTM disease by being an active participant in their own

treatment and care. In spite of living with devastating and chronic illness, Fern Leitman is committed to helping others to live a full life by enhancing the role that NTM Info & Research can play in bringing patients, physicians, and government organizations to a partnership that will raise awareness and actively pursue treatment options to improve the quality of life of those suffering with NTM.

STATEMENT OF FERN LEITMAN

Thank you for the opportunity to submit a statement on behalf of NTM Info & Research and all the patients suffering with pulmonary NTM disease. NTM is an infectious disease that challenges treating physicians. Lung transplantation is usually not an option because immune suppressants complicate treatment.

Before NTM struck and caused me to be very ill, I was extremely driven, highly competitive and very independent. I spent much of my life in sales and was the first woman to sell cars in Florida. I was a partner in a New York based garment manufacturing business and I survived that without a scratch. I enjoy being extremely active but life with nontuberculous mycobacterial disease (NTM) is really tough and debilitating.

This disease has taken away my drive and endurance, one activity at a time. It is insidious, frightening, and misunderstood. Many patients have told us that they can no longer function because they are so short of breath. Others can no longer work and many are hospitalized repeatedly.

The symptoms and the tests to diagnose NTM are much like those for TB. Unfortunately, it is much harder to treat. I am witness to the fact that after almost nine years of drug therapy I am still not well and have been told I will likely require lifelong drug therapy including IV medicines.

Not enough is done because most doctors don't look for this disease. When NTM infected my lungs, I coughed continuously and was fatigued. I had a low-grade fever for years but never looked ill; I had repeated bouts of pneumonia, coughed up blood, and it took 10 years for a diagnosis. We hear the same story from other patients. Unfortunately, it was too late to repair the damage because the middle portion of my left lung was destroyed and there were areas where the tissue had been destroyed throughout both lungs. Many others are suffering with NTM and most don't even know it yet because, sadly, they haven't been diagnosed. Please help them.

PHILIP LEITMAN, PRESIDENT, NTM INFO & RESEARCH, INC.

Philip Leitman co-founded NTM Info & Research when his wife Fern became ill with severe pulmonary NTM disease. Fern and Philip began meeting and hearing from numerous patients who were struggling with NTM and had a lack of understanding about it. His personal commitment has drawn the support of numerous physicians, the media, as well as government and government organizations at various levels. Efforts that began by developing the website, (NTMInfo.com) are now an established not-for-profit seeking to enhance knowledge about NTM through collaborative efforts with leading institutions, government, and patients, as well as increased education to provide broader awareness and understanding of the need for timely diagnosis and effective multi-faceted treatments.

Mr. Leitman has an extensive background in business and international business. He currently is a Regional Vice-Chair of the Council of National Trustees of National Jewish Medical and Research Center, President and co-founder of NTM Info & Research, Inc., Board member of the American Lung Association of Florida, member of the Florida TB Control Coalition, and a former Board member of Senior Care and JVS Rehabilitation Sheltered Workshop.

Philip Leitman is also President and CEO of Philip Leitman, Inc. He is active as a real estate developer in South Florida. He and his wife Fern live in Pinecrest, Florida, and their children and grandchildren live nearby.

STATEMENT OF PHILIP LEITMAN

Fern's doctors say she sets a standard for wanting to survive, wanting to live, and wanting to function highly. I am proud to follow her lead. This is why!

In September 1996, shortly after lung surgery, Fern's health deteriorated to the point where her doctors suggested that we call our children. Fern was rushed to a procedure room to put a bronchoscope into her lungs to see what was happening. At that moment, Fern told me to go back and talk to her roommate at the hospital because that woman had the same illness and was about to have lung surgery. Fern said, "Please tell her that she is not as sick and this won't happen to her." The other woman looked very much like Fern. NTM can affect any one of us but for some unknown reason, it affects more women than men.



What Fern is going through is simply not unique! There are support groups in New York, California, Texas, Florida, and soon in Boston. The NTMInfo.com website has now exceeded one million hits. A number of leading hospitals and a branch of the CDC are linked.

Fern's normal morning routine starts with pulmonary therapy to clear her airways. Then there is a sinus wash. With breakfast, Fern takes five different oral drugs and IV medicines. In addition, there are inhaled medicines. The total time from awakening to being able to leave the house is usually four (4) hours.

While tuberculosis is often known to appear in inner cities and immigrant populations, NTM knows no such boundaries. However, current epidemiologic data is not available. The latest data that we have from the Centers for Disease Control was collected in the 1980's and we urgently need newer data. Current data from the University of Toronto suggests that the prevalence may be six times higher than our older information. We have no reason to believe that Toronto is any different than Chicago or any other major U.S. city.

---

#### PREPARED STATEMENT OF THE OVARIAN CANCER NATIONAL ALLIANCE

On behalf of the Ovarian Cancer National Alliance (the Alliance), I thank the Subcommittee for this opportunity to submit comments for the record regarding the Alliance's fiscal year 2006 funding recommendations that we believe are necessary to help reduce and prevent suffering from ovarian cancer. For 8 years, the Alliance has worked to increase awareness of ovarian cancer and advocated increased federal resources to support research on identifying more effective ovarian cancer diagnostics and treatments. While I recently joined the Alliance as executive director, my journey with ovarian cancer began with my own diagnosis 3 years ago.

As an umbrella organization with 46 state and local groups, the Alliance unites the efforts of more than 500,000 grassroots activists, women's health advocates, and health care professionals to bring national attention to ovarian cancer. As part of this effort, the Alliance advocates sustained federal investment in the Centers for Disease Control and Prevention's (CDC) Ovarian Cancer Control Initiative. The Alliance respectfully requests that Congress provide \$9 million for the program in fiscal year 2006.

#### OVARIAN CANCER'S DEADLY STATISTICS

According to the American Cancer Society, in 2005, more than 22,000 American women will be diagnosed with ovarian cancer, and approximately 16,000 will lose their lives to this terrible disease. Ovarian cancer is the fourth leading cause of cancer death in women. Currently, more than half of the women diagnosed with ovarian cancer will die within 5 years. Among African American women, only 48 percent survive 5 years or more. When detected early, the 5-year survival rate increases to more than 90 percent, but when detected in the late stages, the 5-year survival rate drops to 28 percent.

Today, it is both striking and disheartening to see that despite progress made in the scientific, medical and advocacy communities, ovarian cancer mortality rates have not significantly improved during the past decade, and a valid and reliable screening test—a critical tool for improving early diagnosis and survival rates—still does not yet exist for ovarian cancer. Behind the sobering statistics are the lost lives of our loved ones, colleagues and community members. While we have been waiting for the development of an effective early detection test—thousands of our sisters, including one-third of our founding board members, have lost their battle to ovarian cancer.

I am considered one of the lucky ones. When I was diagnosed 3 years ago, my two cancers—ovarian and endometrial—were found to be in early Stage 1 when I had the best chance for surviving beyond 5 years—something only 25 percent of women with this disease can claim. Like most women diagnosed in early stage ovarian cancer, my good fortune was not the result of my awareness of the symptoms, it was not the result of my awareness that I was at a higher risk, and it was not the result of having access to a currently non-existent early screening test. My good fortune was the lucky result of my perseverance with my doctor, and my subsequent treatment by the appropriate gynecologic oncologist specialist.

I have come to work for the Alliance to ensure that other women can have the opportunity to be as fortunate as I have been. We cannot rely on luck for our survival. All women should have access to treatment by a specialist. All women should have access to a valid and reliable screening test. We must deliver new and better treatments to patients and the physicians and nurses who treat patients with this disease tell us that until we have a test, we must continue to increase awareness

and educate women and health professionals about the signs and symptoms associated with this disease.

THE OVARIAN CANCER CONTROL INITIATIVE AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

As the statistics indicate, among the most urgent challenges in the ovarian cancer field are late detection and poor survival. The CDC's cancer program, with its strong capacity in epidemiology and excellent track record in public and professional education, is well positioned to address these problems. As the nation's leading prevention agency, the CDC plays an important role in translating and delivering at the community level what is learned from research, especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research.

Specifically, the CDC's Ovarian Cancer Control Initiative helps give all women the opportunity to survive ovarian cancer. Public awareness and education programs funded by the program make women and health professionals aware of the warning signs of ovarian cancer and examine survival trends based on care received, so they can better detect the cancer by identifying and understanding symptoms exhibited in early stages.

In addition, the CDC has a strong tradition of partnering with primary care physicians to combat two key barriers to early detection—recognition and diagnosis of the disease. Primary care physicians usually are the first to see women presenting with the disease. Increasing awareness and understanding of the signs and symptoms of ovarian cancer among these physicians can help improve early detection and survival rates.

Prompted by efforts from leaders of the Alliance and championed by Representative Rosa DeLauro—with bipartisan, bicameral support—Congress established the Ovarian Cancer Control Initiative at the CDC in November 1999. Congress' directive to the agency was to develop an appropriate public health response to ovarian cancer and conduct several public health activities targeted toward reducing ovarian cancer morbidity and mortality.

Currently, the Ovarian Cancer Control Initiative supports several national program grants, including three new CDC funded state initiatives:

- The Center for Health Promotion and Prevention Research at the University of Texas in Houston—Funded to conduct a study focusing on symptoms relating to early detection of ovarian cancer and staging distinctions.
- The School of Public Health at the University of Alabama at Birmingham—Funded to conduct a study focusing on barriers to early detection of ovarian cancer.
- The North American Association of Central Cancer Registries (NAACCR)—Funded to analyze and report data on ovarian cancer incidence by race, and to find new ways to improve accuracy of ovarian cancer incidence and mortality data among women who are neither Caucasian nor African American.
- The Department of Preventive Medicine at the University of Southern California—Funded for 1 year to analyze cancer registry data on borderline ovarian cancer cases in California.
- The Oklahoma University Health Sciences Center—Funded to conduct a 2-year, multiple component study of women experiencing possible ovarian cancer symptoms, how they seek treatment, and possible barriers to their medical care.
- Battelle Centers for Public Health and Evaluation—Funded to conduct a review of medical literature on clinical management of non-specific abdominal and pelvic symptoms potentially suspicious of ovarian cancer in older women. The review will provide the foundation for CDC funding to develop evidence-based guidelines for primary care providers to increase ovarian cancer cases detected in early stages.
- State tumor registries in California, Maryland, and New York—Each state received funding from the National Program of Cancer Registries to conduct a 3 year study to determine the proportion of women who had their initial surgery performed by a gynecologic oncologist and to detail aspects of the second course of treatment provided.

TAKING THE NEXT STEP IN PREVENTION AND AWARENESS

In only 5 years, the CDC's Ovarian Cancer Control Initiative, with its support of studies on early detection and underserved populations, has made an important contribution to a better understanding and awareness of the disease. However, without a screening test, it is clear that more needs to be done. Additional funding in fiscal year 2006 will enable the CDC to expand the reach and scope of its current ovarian

cancer initiatives to help advance our nation's efforts to reduce and prevent ovarian cancer morbidity and mortality. The allocation of \$9 million in fiscal year 2006 funding will continue the excellent progress being made and could expand the program's efforts to include:

- Development of a risk model for ovarian cancer like the model for breast cancer. This would help health care professionals identify high-risk women, who then could be monitored regularly. By helping health care providers to be “on alert,” they have the information and tools they need to catch the disease early and improve survival rates.
- Conduct an education campaign targeted to high-risk women to educate them about the signs and symptoms of ovarian cancer, the importance of regular monitoring, and strategies for risk reduction.
- Development and implementation of a national campaign to inform primary care physicians, who are usually the first to see women with symptoms, about ovarian cancer.
- Examination of the reasons why minority women have higher mortality rates and development of appropriate strategies for addressing this terrible health disparity.
- Conduct an education initiative targeted to health care professionals about best practices for treating the disease, especially referral to a gynecologic oncologist for optimal survival outcome.

#### A SUSTAINED COMMITMENT TO FUND CANCER RESEARCH

When funding stagnates or does not keep pace with inflation, progress in critical research programs is halted or slows significantly. Inadequate funding for the National Institutes of Health (NIH) and the National Cancer Institute (NCI) means smaller “trickle down” occurs for the lesser-known or less popular—yet terribly devastating—diseases like ovarian cancer. To ensure adequate funding for all types of cancer, particularly those most deadly and least understood, the Alliance joins the cancer community in asking for \$30.1 billion for NIH and \$6.17 billion for NCI in fiscal year 2006.

#### SUMMARY

The Alliance maintains a long-standing commitment to work with Congress, the Administration, and other policymakers and stakeholders to improve the survival rate from ovarian cancer through education, public policy, research, and communication. Please know that we appreciate and understand that our nation faces many challenges and Congress has limited resources to allocate, however, we are concerned that without increased funding to bolster and expand ovarian cancer education, awareness, and research efforts, the nation will continue to see growing numbers of women losing their battle with this terrible disease.

On behalf of the entire ovarian cancer community—patients, family members, clinicians and researchers—we thank you for your leadership and support of federal programs that seek to reduce and prevent suffering from ovarian cancer. Thank you in advance for your support of \$9 million in fiscal year 2006 funding for the CDC's Ovarian Cancer Control Initiative.

---

#### PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- \$250,000 within the Centers for Disease Control and Prevention (CDC) for a pulmonary hypertension awareness and education program.
- A 6 percent increase for the National Heart, Lung and Blood Institute (NHLBI) and the establishment of Pulmonary Hypertension Centers of Excellence at the Institute.
- \$30 million for the Health Resources and Services Administration's (HRSA) “Gift of Life Donation Initiative.”

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association.

I am Dr. Anne Caesar, a professor of medicine at Georgetown University and a pulmonary hypertension patient (PH). PH is a rare disorder involving both the heart and the lungs. The walls of the blood vessels that supply the lungs thicken and often constrict, making them unable to carry normal amounts of blood. The heart works harder to compensate and eventually can't keep up. Life is threatened. Currently, there is no cure. Symptoms of pulmonary hypertension include shortness of breath with minimal exertion, fatigue, chest pain, dizzy spells and fainting.

When PH occurs in the absence of a known cause, it is referred to as primary pulmonary hypertension (PPH). This term should not be construed to mean that because it has a single name it is a single disease. There are likely many unknown causes of PPH.

Secondary pulmonary hypertension (SPH) means the cause of the disease is known. Common causes of SPH are the breathing disorders emphysema and bronchitis. Other less frequent causes are scleroderma, CREST syndrome and systemic lupus. In addition, the use of diet drugs can lead to the disease.

While new treatments are available, unfortunately, PH is frequently misdiagnosed and often progresses to late stages by the time it is detected. Although PH is chronic and incurable with a poor survival rate, the new treatments becoming available are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients able to manage the disorder for 20 years or longer.

Eleven years ago, when three patients who were searching to end their own isolation founded this organization, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was not enough and as membership began to grow—driven by a newsletter written by patients and distributed by doctors—and as a community began to form, an 800 number support line was launched, support groups were established, a Scientific Advisory Board (SAB) was formed, a Patient's Guide to Pulmonary Hypertension was written, and a web site was launched.

Today, PHA includes:

- Over 5,000 patients, family members, and medical professionals.
- An international network of over 100 support groups.
- An active and growing patient telephone helpline.
- A new and fast-growing research fund. (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and fund five, five-year, mentored clinical research grants and PHA has awarded seven Young Researcher Grants.)
- A host of numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension—published quarterly and distributed to all cardiologists, pulmonologists and rheumatologists in the United States.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

PHA applauds the subcommittee for its leadership in encouraging CDC to initiate a professional and public PH awareness campaign. We continue to work with officials at the CDC to establish this important program which will better inform health care professionals and the general public about PH, its symptoms, and treatment options.

PHA knows that Americans are dying because of a lack of awareness of both pulmonary hypertension and recent advances in research and treatments. Most particularly, this is true among underserved populations. These are the least likely and the least able to see the three and four doctors it often takes to get a correct diagnosis. We believe that activities proposed below need to include special focus on reaching underserved populations and their medical services.

The following is a description of the specific initiatives we hope to launch in collaboration with CDC.

(1) Increasing awareness and understanding of PH among primary care physicians is critically important, because these practitioners are usually the first point of contact for PH patients. If the primary care doctor misses the symptoms, then the chance for early diagnosis depends upon the intuition and persistence of the patient. They have a chance, if they aggressively pursue diagnosis by trained and aware specialists. If they are not aggressive, or if they are in a health plan that requires their general practitioner to prescribe the referral, they are more likely to go undiagnosed until it is too late to control their illness. To increase awareness we propose to launch the following:

- Written and video diagnostic tools for placement on the Internet.
- Working with state health departments and clinic administrators to develop information for mailing to primary care physicians, medical schools and medical centers in the United States drawing their attention to the new web resources.
- A simplified and visually attractive print version of the proper diagnostic procedures, which will be targeted to primary care physicians, public health clinics, medical schools, and medical centers in the United States.

- Advertising in publications general practitioners and public health professionals are likely to read. The emphasis will be the importance of early diagnosis and the ease of accessing diagnostic tools via the Internet.
- Improvements to an already produced CD-ROM that explains pulmonary hypertension from a variety of perspectives. We would like to make these available to the medical community and patients through our web site on an as requested basis and at conferences and through targeted mailings.
- (2) Due to the advancements in treatment for PH, it is important that we also focus on educating cardiologists and pulmonologists. Our strategies for reaching cardiovascular specialists include:
  - Expansion of the first Pulmonary Hypertension Journal focused on educating a cardiologists and pulmonologists on issues related to the diagnosis and treatment of the illness.
  - Placement of additional detailed information on the illness on the web. The PH Journal and other publications will promote this availability.
  - Expansion of the medical section of PHA's international conference on pulmonary hypertension (the largest PH conference in the world).
  - Expansion of PHA's Pulmonary Hypertension Resource Network. This program is focused on increasing awareness and knowledge of PH among nurses, respiratory therapists, technicians and pharmacists through peer education.
- (3) Finally, PHA is committed to increasing PH awareness among the general public through the development of the following initiatives:
  - A series of 10, 15, and 30 second public service announcements on PH. These PSAs will be in both audio and video form.
  - A PH media relations manual.
  - An organ donation and transplant listing Awareness Campaign (unfortunately, many PH patients die before finding a suitable organ donor).
  - Expansion of awareness and information activities on PHA's web site.
  - Continuation of PH Awareness Month.

PHA and CDC have engaged in an ongoing dialogue about these and other strategies designed to increase awareness of PH. We are grateful for CDC's support of a DVD focused on the diagnosis of PH. However, despite repeated encouragement from the subcommittee, CDC has not established an ongoing awareness and education initiative on this devastating disease. Therefore, for fiscal year 2006, we encourage you to provide \$250,000 within CDC's Cardiovascular Disease program for the formal establishment of this important initiative.

#### NATIONAL HEART, LUNG AND BLOOD INSTITUTE

Mr. Chairman, PHA commends the leadership of the National Heart, Lung and Blood Institute (NHLBI) for its support of PH research. Three years ago, two separate groups of scientists funded by NHLBI simultaneously identified a genetic mutation associated with primary pulmonary hypertension.

The two groups independently reported that defects in the *BMPR2* gene, which regulates growth and development of the lung, are associated with PPH. The defects in the gene lead to the abnormal proliferation of cells in the lung characteristic on PPH.

Although both studies suggest that only one gene is involved in PPH, neither group identified the defects in *BMPR2* as the sole cause of PPH. In addition, since many people without a known family history of PPH get the disease, both groups suggested that other factors may interfere with control of the tissue growth. Now that we have pinpointed a gene, we can focus on learning how it works. Hopefully, that information will enable researchers to devise better treatments and perhaps eventually a preventive therapy or cure.

We greatly appreciate NHLBI's commitment to advancing research to better understand and ultimately cure this disease. Moreover, we applaud the subcommittee's strong support of PH research at the Institute. For fiscal year 2006, PHA recommends a 6 percent increase for NHLBI and the NIH overall. In addition, PHA recommends the establishment of three pulmonary hypertension "Centers of Excellence" at NHLBI to support the expansion of research, training and information dissemination. Finally, we encourage the establishment of a PH data system and clearinghouse at the Institute.

#### GIFT OF LIFE DONATION INITIATIVE AT HRSA

Mr. Chairman, PHA applauds the success of the Department of Health and Human Services "Gift of Life" Donation Initiative. Currently, there are three drugs that PH patients can be prescribed to help improve the quality of life with PH. Eventually, many patients must move toward lung or heart and lung transplan-

tation. PH is a difficult to diagnose illness and while patients often list soon after diagnosis, for many PH patients it is too late. This why PHA is developing the Bonnie's Gift Project.

Bonnie's Gift was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie was a PH patient herself. She battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use Bonnie's Gift as a way to disseminate information about PH, the importance of early listing, the importance of organ donation to our community and organ donation cards.

PHA has entered into a partnership with the "Gift of Life" Donation Initiative to increase awareness of the importance of organ donation and early listing within the PH community. For fiscal year 2006, PHA supports an appropriation of \$30 million for HRSA's Gift of Life program.

#### CONCLUSION

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. We look forward to continuing to work with you and the subcommittee to improve the lives of pulmonary hypertension patients. If you have any questions or would like additional information, please do not hesitate to contact me or the Pulmonary Hypertension Association's National Office.

---

#### PREPARED STATEMENT OF THE SOCIETY OF NUCLEAR MEDICINE

The Society of Nuclear Medicine (SNM) appreciates the opportunity to submit written testimony for the official record regarding federal funding for biomedical research in fiscal year 2006.

SNM is an international, scientific, and professional organization with more than 16,000 members dedicated to promoting the science, technology, and practical application of nuclear medicine. Over the last 50 years, since biomedical imaging first began, the Nuclear Medicine community has made groundbreaking discoveries thanks to the research and development that was facilitated at the National Institutes of Health (NIH). To that end, the Society strongly recommends sufficient levels of federal funding to sustain and seize new opportunities in biomedical research.

The Society of Nuclear Medicine stands ready to work with policymakers at the local, state, and federal levels to advance biomedical research policies and programs that will reduce and prevent suffering from disease.

#### WHAT IS NUCLEAR MEDICINE?

Nuclear Medicine is an established specialty that performs non-invasive molecular imaging procedures to diagnose and treat diseases, and also to determine the effectiveness of therapeutic treatments—whether surgical, chemical, or radiation. It contributes extensively to the treatments and diagnoses of patients with cancers of the brain, breast, blood, bone, bone marrow, liver, lungs, pancreas, thyroid, ovaries, and prostate. Molecular imaging continues to provide expert information to help doctors, technicians, and other health care personnel manage abnormalities of the heart, brain, and kidneys. In fact, recent advances in the detection and diagnosis of Alzheimer's disease can be attributed to Nuclear Medicine imaging procedures, specifically positron emission tomography (PET) scans. These advances—which were made possible by research from nuclear medicine professionals—helped lead the Centers for Medicaid and Medicare Services (CMS) to extend Medicare coverage to include PET scans for some beneficiaries who suffer from Alzheimer's and other dementia-related diseases.

CMS Administrator Mark B. McClellan announced the coverage by saying: "Together with outside experts and other agencies we examined the available data and determined that we ought to approve coverage for patients who've been worked up but whose diagnosis is uncertain."<sup>1</sup>

CMS' decision was also explained by Dr. Sean Tunis, CMS' Chief Medical Officer. He said: "The available evidence supports the conclusion that PET scans help to evaluate patients with progressive symptoms of dementia, but for whom a diagnosis remains unclear despite a thorough standard medical evaluation. We will also support the conduct of additional studies that will determine the value of PET scans

<sup>1</sup> CMS Press Release—Sept. 14, 2004—Medicare Posts Coverage Decision to Expand Coverage of PET Scans for Alzheimer's. <http://www.cms.hhs.gov/media/press/release.asp?Counter=1200>.

required in a broader population of Medicare beneficiaries who develop symptoms of dementia.”

The effect nuclear medicine has on people is far-reaching. Annually, more than 16 million men, women, and children require noninvasive molecular/nuclear medical procedures. These safe, cost-effective procedures include PET scans to diagnose and monitor treatments in cancer; cardiac stress tests that analyze heart function; bone scans for orthopedic injuries; and lung scans for blood clots. In addition, patients undergo procedures to diagnose liver and gall bladder functional abnormalities and to diagnose and treat hyperthyroidism and thyroid cancer.

#### SUSTAIN AND SEIZE RESEARCH OPPORTUNITIES

For decades, Americans and people from across the world have benefited from the strong federal investment in nuclear medicine and biomedical research at the National Institutes of Health. We can safely say, in the words CMS Administrator McClellan, “the technology is promising.”<sup>2</sup> The Society hopes that this subcommittee will continue its trend of forward thinking and federally fund NIH and the National Institute of Biomedical Imaging and Bioengineering (NIBIB) and the National Cancer Institute (NCI) at sufficient levels for fiscal year 2006.

SNM is proud to join its colleagues in the public health community in recommending that in fiscal year 2006, NIH is funded at a level totaling \$30.1 billion. This funding level will permit NIH to sustain and build upon its current research activities, which are a byproduct of the recent NIH budget doubling effort. Even a minimal decrease or slowed momentum of increased funding in NIH’s budget could cause severe disruption in the research activities and capabilities.

In 1946, the first successful nuclear magnetic resonance (NMR) experiments were performed. This led to the first nuclear magnetic resonance imaging (MRI) exam performed on a human being 31 years later in 1977. From the first MRI in 1977 to today, critical advances in technology have developed, allowing physicians, nuclear medicine technicians and other health care professionals to image in seconds what used to take hours, days, or even weeks. Research in biomedical imaging and bioengineering is progressing rapidly and recent technological advances have revolutionized the diagnosis and treatment of disease. In 2000, the National Institute of Biomedical Imaging and Bioengineering was created. This NIH institute, specifically focused on biomedical imaging and bioengineering, has made great strides in helping the health care community and its patients recognize and understand different diseases and disorders. Pancreatic transplantation, brain scans, improvement to epilepsy surgeries are just a few examples of how NIBIB research is helping diagnose and treat patients. In order for NIBIB to continue moving forward with its research, SNM requests \$350 million in federal funding for fiscal year 2006. This funding level will allow NIBIB to further its research, development, and application of emerging and breakthrough biomedical technologies that will facilitate improved disease detection, management, and prevention.

In addition, SNM advocates that another arm of NIH that uses molecular imaging, NCI, receive sufficient funding—\$5.21 billion—in fiscal year 2006. The American Cancer Society predicts that more than a million Americans will be diagnosed with cancer in 2005. We have made significant gains in the war on cancer, and there have been successful breakthroughs in diagnosing and treating this terrible disease. Currently PET scans are available to detect more than a dozen types of cancer. Cancer research is leading to new therapies that translate into longer survival and improved quality of life for cancer patients. Extraordinary advances in cancer research have resulted because of the strong commitment by the federal, state, and local governments in combating cancer. Effective prevention, early detection, and treatment methods for many cancers have resulted from this governmental interest, intervention and public education campaign. In order to continue making a strong case against cancer, SNM requests that the Committee allocate \$5.21 billion in federal funds for the NCI in fiscal year 2006.

#### CONCLUSION

As outlined above, SNM has a strong and vested interest in making sure that biomedical research in the United States is sufficiently funded. It is in everyone’s best interest that the federal government invests the needed dollars to continue the pursuit of medical breakthroughs in technology and science. Without the sufficient funding levels—which include \$30.1 billion for NIH, \$350 million for NIBIB, and

<sup>2</sup> CMS Press Release—Sept. 14, 2004—Medicare Posts Coverage Decision to Expand Coverage of PET Scans for Alzheimer’s. <http://www.cms.hhs.gov/media/press/release.asp?Counter=1200>.

\$5.21 billion for NCI—the positive effects and results of research and development are seriously compromised.

SNM stands ready to work with policymakers from both sides of the aisle to advance biomedical research and innovation to help reduce and prevent suffering from disease for all Americans. Again, on behalf of the members of SNM, I thank you for the opportunity to submit testimony regarding the absolute need for increased federal funding for biomedical research. I am available to answer any questions you may have.

---

PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION OF AMERICA

On behalf of the more than 70,000 individuals and their families who are affected by Spina Bifida, the Spina Bifida Association of America (SBAA) appreciates the opportunity to submit written testimony for the record regarding increased funding for the National Spina Bifida Program and other related Spina Bifida initiatives in fiscal year 2006. SBAA is the national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research, and service. The Association was founded in 1973 to address the needs of the Spina Bifida community and today serves as the representative of 57 chapters serving more than 125 communities nationwide. SBAA stands ready to work with Members of Congress and other stakeholders to ensure that our Nation takes all the steps necessary to reduce and prevent suffering from Spina Bifida.

BACKGROUND ON SPINA BIFIDA

Spina Bifida is a neural tube defect (NTD) and occurs when the spinal cord fails to close properly during the early stages of pregnancy, typically within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy—as the fetus grows—the spinal cord is exposed to the amniotic fluid which becomes increasingly toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida, from mild—with little or no noticeable disability—to severe—with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most children with it suffer from a host of physical, psychological, and educational challenges—including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls, which helps to relieve cranial pressure associated with spinal fluid that does not flow properly. We are pleased to report that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living long enough to become adults with Spina Bifida. These gains in longevity are principally due to breakthroughs in research, combined with improvements generally in health care and treatment. However, with this extended life expectancy, our Nation and people with Spina Bifida now face new challenges—education, job training, independent living, health care for secondary conditions, aging concerns, among others. Despite these gains, individuals and families affected by Spina Bifida face many challenges—physical, emotional, and financial.

Recent studies have shown that if all women of childbearing age were to consume 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy, the incidence of Spina Bifida could be reduced by up to 75 percent. However, even if we are successful in preventing the majority of Spina Bifida cases in the future, our Nation still must take steps to ensure that the tens of thousands of individuals living with Spina Bifida can live full, healthy, and productive lives. To ensure the highest quality-of-life possible, prevention interventions and treatment therapies must be identified, developed, and delivered to those in need.

COST OF SPINA BIFIDA

It is important to note that the lifetime costs associated with a typical case of Spina Bifida—including medical care, special education, therapy services, and loss of earnings—are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare Programs. Our Nation must do more to help reduce the emo-



tional, financial, and physical toll of Spina Bifida on the individuals and families affected. Efforts to reduce and prevent suffering from Spina Bifida help to save money and save lives.

#### IMPROVING QUALITY-OF-LIFE THROUGH THE NATIONAL SPINA BIFIDA PROGRAM

Secondary conditions associated with Spina Bifida include full or partial paralysis, neurological disorders, bladder and bowel control difficulties, learning disabilities, depression, latex allergy, obesity, skin breakdown, and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. Ensuring access to these services is essential to improving the quality-of-life for those born with this birth defect.

SBAA has worked with Members of Congress to ensure that our Nation is taking all the steps possible to prevent Spina Bifida and diminish suffering for those living with this condition. As part of this comprehensive effort, SBAA collaborated with Members of Congress and other interested parties to secure an essential increase in fiscal year 2005 funding for the National Spina Bifida Program at the National Center for Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). SBAA thanks the Members of the Subcommittee for their expression of support for this new and integral program by allocating \$3.6 million in fiscal year 2005.

The National Spina Bifida Program works on two critical levels—to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the 70,000 individuals and families affected by Spina Bifida. For example, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, which range from learning disabilities and depression to severe allergies and skin problems that make life difficult for these individuals. All of these problems can be treated or prevented, but only if those affected by Spina Bifida—and their caregivers—are properly educated and taught what they need to know to maintain the highest level of health and well-being possible.

Second, the National Spina Bifida Program offers benefits to those who live with Spina Bifida and their families by working to improve the outlook for a life challenged by this complicated birth defect—principally identifying potentially valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need. These secondary prevention activities represent a tangible quality-of-life difference to the 70,000 individuals living with Spina Bifida. With the goal being living well with Spina Bifida, the secondary prevention initiatives are focused on the creation and implementation of strategies to improve the quality-of-life. These quality-of-life efforts center on reaching the general population with Spina Bifida, advancing treatment of Spina Bifida and its related conditions, and working with adolescents living with Spina Bifida to address their specific academic, psycho-social, and vocational needs. In addition, the National Spina Bifida Program will create and implement a comprehensive program to assist teens with Spina Bifida in the development of life skills for independence, self-reliance, and success in the world.

SBAA advocates that the National Spina Bifida Program receive \$5.5 million in fiscal year 2006 so the NCBDDD can expand and continue to promote quality-of-life programs that support people with Spina Bifida so they can live fulfilling and productive lives. In its first three years, this program already has made a difference for our community and with additional resources it can expand its reach and provide additional assistance and hope to those with an affected loved one. Increasing funding for the National Spina Bifida Program will help ensure that our nation continues to mount a comprehensive effort to prevent and reduce suffering from Spina Bifida.

#### PREVENTING SPINA BIFIDA

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty million women are at-risk of having a child born with Spina Bifida and each year approximately 3,000 pregnancies in this country are affected by Spina Bifida, resulting in 1,500 births. As mentioned above, re-

search has found that the consumption of 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce incidence of Spina Bifida up to 75 percent. There are few public health challenges that our Nation can tackle and conquer by three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 25 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age—particularly those most at-risk for a Spina Bifida pregnancy—consume adequate amounts of folic acid.

The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain diet rich in folic acid. Since 1968, the CDC has led the Nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. Former CDC Director Jeff Koplan has stated that the agency's folic acid prevention campaign has reduced neural tube defect births by 20 percent. This public health success should be celebrated, but it is only half of the equation as approximately 3,000 pregnancies still are affected by this devastating birth defect. The Nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call—such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBAA works collaboratively with CDC and other nonprofits to increase awareness of the benefits of folic acid, particular for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves or those who have already conceived a baby with Spina Bifida). With additional funding in fiscal year 2006 these activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBAA advocates that Congress provide additional funding to CDC to allow for a particular public health education and awareness focus on at-risk populations (e.g. Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a \$5.5 million fiscal year 2006 allocation for the National Spina Bifida Program, SBAA supports a fiscal year 2006 allocation of \$135 million for the NCBDDD so the agency can enhance its programs and initiatives to prevent birth defects and developmental disabilities and promote health and wellness among people with disabilities.

#### IMPROVING HEALTH CARE FOR INDIVIDUALS WITH SPINA BIFIDA

The mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the outcomes and quality of health care; reduce its costs; improve patient safety; decrease medical errors; and broaden access to essential health services. The work conducted by the agency is vital to the evaluation of new treatments in order to ensure that individuals and their families living with Spina Bifida continue to receive the high quality health care that they need and deserve. SBAA recommends that AHRQ receive \$440 million in fiscal year 2006 so that it can continue to conduct follow-up efforts to evaluate Spina Bifida treatments, promulgate associated standards of care, and further the provision of evidence-based care stemming from the outcomes of the 2003 Spina Bifida Research Conference. A new partnership between the Centers for Disease Control and AHRQ to develop treatments for Spina Bifida brings new hope for families living with Spina Bifida.

#### SUSTAIN AND SEIZE SPINA BIFIDA RESEARCH OPPORTUNITIES

SBAA seeks to support individuals and families affected by Spina Bifida, maximize the prevention of Spina Bifida, and ensure that all babies born with Spina Bifida have the greatest chance of survival and the highest quality-of-life—through the lifespan. When families recently diagnosed with a Spina Bifida pregnancy contact SBAA, the organization puts them in touch with other families who have a child with the condition so they can learn of the joys and challenges of having a child with the birth defect. Unfortunately, traditionally when families are faced with a Spina Bifida diagnosis they have had two difficult options. The first is to continue the pregnancy with the expectation of multiple surgeries for the child after birth, uncertain life expectancy, and many physical and developmental challenges and complications. The second, unfortunately, is to terminate the pregnancy. Fortunately, now there may be an important and effective third option.

Since the late 1990s, doctors at three U.S. hospitals—Children's Hospital of Philadelphia, Vanderbilt University Medical Center in Nashville, and the University of

California at San Francisco—have been operating before birth on fetuses diagnosed with Spina Bifida. In 2003, the University of North Carolina became the fourth hospital in the Nation to perform the in-utero operations. By closing the spinal lesion early in pregnancy, physicians believe they can minimize the damage created by fluid leaking from the spine, as well as limit by the harm done due to the spinal cord's contact with the amniotic fluid. Surgeons have found that closing the hole in the spine in this fashion before birth may correct breathing problems in 15 percent of the children receiving the procedure and may reduce the need for a shunt to drain fluid from the brain by between 33 percent and 50 percent.

To determine whether or not this new procedure is safer and more effective than the traditional post-birth surgery to address the condition, the National Institute of Child Health and Human Development (NICHD) is conducting a large study involving the Children's Hospital of Philadelphia, Vanderbilt University Medical Center, and the University of California at San Francisco. While these three institutions have undertaken preliminary studies of the in-utero surgery technique, the overall and long-term effectiveness of this approach as compared to traditional therapy remains unknown. Given the potential for this surgery to ameliorate many of the conditions associated with Spina Bifida, we must do a better job of studying and evaluating this procedure, educating health care providers about this surgery as a potential option, and making information about it available to more families facing a Spina Bifida pregnancy.

Our Nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). SBAA joins with the rest of the public health community in advocating that NIH receive \$30.1 billion in fiscal year 2006. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBAA urges the NIH to explore the following as they relate to individuals with Spina Bifida: assistive technology, in utero surgery, cost of care, women's and men's health, tethered cord, hydrocephalus, latex allergies, and other related factors.

#### CONCLUSION

SBAA stands ready to work with policymakers to advance policies that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views on funding for programs that will improve the quality-of-life for the 70,000 Americans and their families living with Spina Bifida and stand ready to answer any questions you may have.

#### PREPARED STATEMENT OF THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

(1) A 6 percent increase for all of the National Institutes of Health and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

(2) Encourage NIAMS to create and enhance academic and educational opportunities for the advancement of scientific investigation of skin health and dermatologic diseases.

(3) Encourage NIAMS to sponsor further burden of skin disease research and epidemiology activities to investigate general and skin-disease specific measures in order to generate data surrounding the incidence, prevalence, economic burden, quality of life, disability and handicaps attributable to these diseases.

(4) Promote the development of NIH-supported training resources dedicated to attract more individuals to careers in skin disease research.

Mr. Chairman, and members of the subcommittee—I am very grateful for this opportunity to testify on behalf of the Society for Investigative Dermatology. I am Dr. Kevin Cooper, Professor of Dermatology, Chairman and Director of the Skin Diseases Research Center at the Department of Dermatology at Case Western Reserve University. I have been a physician and investigator serving the VA for 20 years in a part time capacity as a component of my academic work. I also serve as President of the Society for Investigative Dermatology.

#### BACKGROUND

The Society for Investigative Dermatology has over 2000 members worldwide dedicated to the advancement and promotion of the sciences relevant to skin health and disease through education, advocacy, and the scholarly exchange of scientific information. Members include scientists and physician researchers from universities, hospitals, and industries committed to the science of dermatology. Each member

firmly believes that further research is critical to improved prevention, diagnosis, and treatment for the 3,000 different diseases of the skin, hair, and nails, which affect about 80 million Americans each year.

My purpose in being here today is to emphasize the need for increased funding for the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and to encourage follow-up to the "Burden of Skin Disease" workshop that took place in 2002. The workshop was held with the intention to investigate general and skin-disease specific measures in order to generate data surrounding the incidence, prevalence, economic burden, quality of life, disability and handicaps attributable to these diseases.

Good health depends on healthy skin. Much of what we see on the outside of the body is a reflection of a person's health inside. From the yellow of hepatitis, to the deep purple lesions of Kaposi's sarcoma—a common side effect of AIDS, from the sizeable skin lesions of lupus erythematosus, to the painful deformed nails which may occur in patients with severe arthritis and psoriasis—health disorders often show up first as problems on the skin's surface. Skin samples are often used to make genetic diagnoses of internal disorders and in the future, the skin may be a target for gene replacement.

Advances in cell biology allow us to understand the life cycle of skin and hair-producing cells and to explain how a malfunctioning immune system undermines the health of the body overall and the skin, in particular. Furthermore, the ongoing revolution in molecular and cell biology, genetics, immunology, information and laser technology provides unprecedented opportunities for achieving advances in basic research and medical treatment. We are becoming rapidly more adept at growing skin cells in the laboratory and at producing artificial skin. Increasingly, laser surgery is commonly replacing more invasive and traditional surgical methods.

I would like to thank you for the increase in funding the subcommittee provided in fiscal year 2004 for NIH overall and for NIAMS. This year, we recommend a 6 percent increase for the NIH budget, and a similar percentage increase for NIAMS, which would lead to a funding level of \$542 million for NIAMS. As the population ages and we live longer, dermatologists will be asked increasingly to treat cancers and other skin disorders that appear more often in aged individuals. Dermatologists will need to find new and better ways to help prevent and heal common conditions of the elderly, such as bed sores. Ulcers of the skin alone cost \$8 billion per year to diagnose and treat.

I would also like to thank the subcommittee for the inclusion of the conference report language in your fiscal year 2005 bill, calling for further attention to the numerous research opportunities and developments identified during the September 2002 Burden of Skin Disease workshop. Further exploration into the economic and social costs of skin disease in the U.S. population is necessary, as an analysis into many related areas has not been updated since 1979. More data must be collected to determine the prevalence of skin diseases and the disabilities they inflict upon those suffering from them. The translation of statistical data and methodology into improved bedside care must be a priority.

The costs to society for medical care and lost wages due to conditions of the skin, hair and nails is estimated to be in the billions annually. However, the costs to those suffering from these debilitating conditions are immeasurable: they encounter discomfort and pain, physical disfigurement, disability, dependency and death. Skin conditions affect an individual's ability to interact with others and compromise the self-confidence of those inflicted.

#### RESEARCH ADVANCES

The past two decades have seen explosive growth in technology and in increased sophistication in our understanding of the genetic and cellular mechanisms underlying many skin, hair and nail disorders. One consequence of these findings is a radical new paradigm shift in which the skin is now viewed as a complex organ that is intimately responsive to the immune system of the body. Several distinct cell types in the skin actively generate, regulate and perpetuate immune responses. Other important new research findings include the following:

- A gene responsible for the inherited form of basal cell carcinoma has been identified and may lead to new information as to the origins of skin cancer.
- A gene for an inherited form of hair loss has been discovered.
- A new protein that links collagen and vascular defects in scleroderma has been identified.
- Advances in the design of drug-delivery systems allow for sustained release of drugs through the skin, which will most likely lead to treatments that are more effective.

—Methods to grow real and artificial skin in laboratories are used to prepare skin grafts for burn victims.

The past two decades have focused on developing evaluation techniques such as clinical epidemiology, biostatistics, economics, and the quantitative social sciences used to determine the effectiveness of certain procedures and whether they contribute to the quality of life and health of both patients and society.

As you know, medical research organizations such as the Society for Investigative Dermatology work closely with patient support and advocacy groups. We are pleased to say for many years we have worked with the Coalition of Skin Diseases for Skin Disease Research. The many organizations that participate in the Coalition have been the best possible advocates for increased funding, as they understand that unless major research efforts are undertaken, advances in understanding and improvements in the health of patients will not occur. Every year, we participate with these organizations in advocating increased funding for the NIH and NIAMS. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.

---

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH AND THE  
WOMEN'S HEALTH RESEARCH COALITION

On the behalf of the Society for Women's Health Research and the Women's Health Research Coalition, we are pleased to submit testimony in support of increased funding for biomedical research, and more specifically women's health research.

The Society is the only national non-profit women's health organization whose mission is to improve the health of women through research, education, and advocacy. Founded in 1990, the Society brought to national attention the need for the appropriate inclusion of women in major medical research studies and the need for more information about conditions affecting women disproportionately, predominantly, or differently than men.

The Coalition was created by the Society in 1999 as a way to strengthen our grassroots advocacy with scientists and researchers and clinicians from across the country who are concerned and committed to improving women's health research. The Coalition now has more than 620 members from across the country, including leaders within the scientific community and medical researchers from many of the country's leading universities and medical centers, directors from various Centers of Excellence on Women's Health as well as leading voluntary health associations, and pharmaceutical and biotechnology companies.

The Society and the Coalition are committed to advancing the health status of women through the discovery of new and useful scientific knowledge. We believe that sustained funding for the women's health research programs that are conducted across the federal research agencies is necessary if we are to accommodate the health needs of the population and advance the nation's research capability. We urge your support for all these federal agencies and programs described below that are working to meet these goals.

NATIONAL INSTITUTES OF HEALTH

From decoding the human genome to elucidating the scientific components of human physiology, behavior, and disease, scientists are unearthing exciting new discoveries which have the potential to make our lives and the lives of our families longer, healthier, and safer. The National Institutes of Health (NIH) has made this all possible by conducting and supporting our nation's biomedical research. The world-class NIH researchers, scientists, and programs are dedicated to understanding how the human body works and to gain insight into countless diseases and disorders. Due to robust investment and support from Congress, NIH has made the United States the world leader in medical research and has had a direct and significant impact on women in science and on women's health research.

In planning for fiscal year 2006 funding for the NIH, the Administration has proposed a 0.5 percent increase. This proposed amount however will not keep pace with the Biomedical Research and Development Price Index. It is vital that United States' commitment to medical research be sustained in order not to erode the foundation created over the past several years and to continue to build upon promising research to enhance the quality of life for all Americans touched by illness and disease.

Therefore, to continue the momentum of scientific advancement and expedite the translation of research from the laboratory to the patient, the Society encourages an increase of six percent (6 percent) for the NIH, for a budget of at least \$30 billion for fiscal year 2006. In addition, we request that you strongly encourage the NIH to assure that women's health research receives resources sufficient to meet the health needs of Americans.

Scientists have long known of the anatomical differences between men and women, but only within the past decade have they begun to uncover significant biological and physiological differences. Sex differences have been found everywhere from the composition of bone matter and the experience of pain to the metabolism of certain drugs and the rate of neurotransmitter synthesis in the brain. Sex-based biology, the study of biological and physiological differences between men and women, has revolutionized the way that the scientific community views the sexes. The evidence is overwhelming, and as researchers continue to find more and more biological differences, they are gaining a greater understanding of the biological and physiological composition of both sexes.

Much of what is known about sex differences is the result of observational studies, or is descriptive evidence from studies that were not designed to obtain a careful comparison between females and males. The Society has long recognized that the inclusion of women in study populations by itself was insufficient to address the inequities in our knowledge of human biology and medicine, and that only by the careful study of sex differences at all levels, from genes to behavior, would science achieve the goal of optimal health care for both men and women. This has given rise to sex-based biology.

Many sex differences are already present at birth, whereas others develop later in life. These differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, coronary heart disease, autoimmune, mental health disorders, and other illnesses. Physiological and hormonal fluctuations may also play a role in the rate of drug metabolism and the effectiveness of response in females and males. This research needs to be supported and encouraged. Congress recognizes this importance and should support NIH at an appropriate level of funding and direct NIH to continue and expand this research into sex-based biology.

#### OFFICE OF RESEARCH ON WOMEN'S HEALTH

The NIH Office of Research on Women's Health (ORWH) has a fundamental role in improving women's health research at NIH. Within the Office of the Director, ORWH advises the NIH Director on matters relating to research on women's health; strengthens and enhances research related to diseases, disorders, and conditions that affect women; works to ensure that women are appropriately represented in biomedical and behavioral research studies supported by NIH; and develops opportunities for and supports recruitment, retention, re-entry and advancement of women in biomedical careers. ORWH works in partnership with the NIH Institutes and Centers to ensure that women's health research is part of the scientific framework and improve interdisciplinary research opportunities in women's health within NIH. ORWH's ambitious agenda encompasses issues that go far beyond reproductive capacity, cutting across and integrating scientific disciplines, medical specialties, psychosocial and behavioral factors, and environmental determinants in a multidisciplinary and collaborative approach. ORWH endeavors to address sex and gender perspectives of women's health and women's health research, as well as differences among special populations of women across the entire life span, from birth through adolescence, reproductive years, menopausal years and the more advanced, elderly years.

Two highly successful pioneering programs offered through ORWH that are critical to further advancing women's health research are Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR). These programs benefit both women's and men's health through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment.

The BIRCWH program is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. What makes BIRCWH so unique is that it bridges advanced training with research independence, as well as across scientific disciplines. Since 2000, 177 scholars have been trained in the 24 centers recording over 634 publications and 526 abstracts. The scholars have secured 40 NIH grants and 70 awards from industry and institutional sources.

The BIRCWH program offered at Magee Women's Hospital in Pittsburgh, for example, has been able to successfully support the transition of eight young faculty at the beginning of their careers. In the current environment young faculty are expected to generate their income by teaching, clinical care or grant support. However, being that they are new, grant support for salary is unlikely and they end up with heavy clinical and/or teaching loads—at just the time in their careers when they should be perfecting their recently developed research skills. The BIRCWH program allows young researchers at Magee to become established and ready to apply for extramural funding and salary support. Magee has also been able to provide additional mentoring, courses, and career guidance to young investigators in women's health research.

The SCOR program was established in 2001 and now has 11 centers throughout the country. ORWH, along with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Institute of Child Health and Human Development, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute on Drug Abuse, the National Institute of Mental Health, and the National Institute of Environmental Health Sciences, published a request for applications to create these centers as a way to meet some of the health promotion and disease prevention objectives outlined in the "Healthy People 2010" initiative, a Public Health Service-led national activity for setting priority areas.

The objective of the SCOR program is to expedite interdisciplinary development and application of new knowledge to human diseases, to learn more about the causes of these diseases, and to foster improved approaches to treatment and/or prevention. The program was designed to complement other federally supported programs addressing women's health issues such as BIRCWH.

The Institutes and Centers at the NIH, working with the ORWH, have identified many research priority areas to be undertaken by SCORs. Some of these include studying the influence of toxic environmental factors on women's health; examining the sex and/or gender factors in acute and chronic pain conditions or syndromes; undertaking studies to examine kidney disorders, including the impact of pregnancy, diabetes, and hypertension on renal function; studying urologic and urogynecologic disorders; examining the biological and behavioral risk factors, including sex and/or gender factors, in the development of mental disorders such as addictive behaviors, schizophrenia, mood, anxiety, and eating disorders; and the developmental biology of the vascular system and the role of the fetal environment in programming lifelong cardiovascular function.

We strongly encourage Congress to direct NIH to continue its support of ORWH and its programs. This step is needed to assure that advancements in discoveries of sex differences and, in particular, women's health that are long overdue are not lost. From the discovery and understanding of illness and diseases to the formulation of treatments, pain relief and potential cures, knowledge base gained from these important efforts must not be lost, as the benefits are of critical importance to all Americans, men and women.

#### WOMEN'S HEALTH OFFICES WITHIN DEPARTMENT OF HEALTH AND HUMAN SERVICES

In addition to the ORWH, there are several other offices throughout the Department of Health and Human Services (HHS) that enhance the focus of the government on women's health research. Agencies with offices, advisors or coordinators for women's health or women's health research are the Department of HHS, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Quality and Research, the Indian Health Service, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration, and the Centers for Medicare and Medicaid Services. There is a vital need for these agencies to be funded at levels adequate for them to perform their assigned missions.

We are grateful for the Committee's continuing support for the work of these entities. But with the exception of NIH and SAMSHA, none of these offices, advisors, or coordinators is statutorily authorized. Although an authorization does not guarantee an appropriation, having one makes it easier. The Society and its Coalition are addressing that issue in the appropriate venue through the Women's Health Office Act (H.R. 949 and S. 569). But, within your jurisdiction, we ask that the Committee Report clarify that Congress supports these offices and would like to see them continued and strengthened in the coming fiscal year.

The focus on women's health within HHS has been of critical importance to the advances made in women's health in the last decade. As previously mentioned, prior to the early-mid 1990's biomedical research had been firmly rooted in the male model—the belief that male biology (outside of the reproductive system) was rep-

representative of the species, and that where female biology differed from male biology it was “atypical” or “anomalous”. This led to a lack of knowledge about female biology that has significantly compromised women’s health. It is the offices, advisors and coordinators in the agencies listed above who played an essential role in trying to make up for time lost in the last decade. We have only just scratched the surface of understanding female biology. Now is the time to press ahead and make those discoveries and educate women about their health and the misinformation they have been given for years and these offices are critical to the success of this effort.

There are many wonderful programs that we could identify from these agencies but we would like to specifically mention two that have instrumental programs and initiatives that are vital to women’s health. The HHS Office on Women’s Health and the Agency for Healthcare Research and Quality each have a unique mission but are unified in advancing women’s health research.

#### HHS OFFICE OF WOMEN’S HEALTH

The HHS Office of Women’s Health is the government’s champion and focal point for women’s health issues, and works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. The HHS Office on Women’s Health coordinates women’s health efforts in HHS to eliminate disparities in health status and supports culturally sensitive educational programs that encourage women to take personal responsibility for their own health and wellness. A program initiated by the HHS Office on Women’s Health that is critical to women’s health is the National Centers of Excellence in Women’s Health (CoEs). Developed in 1996, this program offers a new model for university-based women’s health care. Selected on a competitive basis, the current twenty-one CoEs seek to improve the health of all women across the lifespan through the integration of comprehensive clinical health care, research, medical training, community outreach and public education, and medical school faculty leadership development.

Located in leading academic health centers across the United States and Puerto Rico, these Centers are developing new models for women’s health care that are setting standards beyond what is traditionally offered at hospital-sponsored women’s clinical health centers. The CoEs are able to reach a more diverse population of women, including more women of color and women beyond their reproductive years. In addition, the CoEs have a strong commitment to integrating research, education, and clinical care than most traditional women’s health centers.

A recent evaluation of the CoEs conducted by HHS Office of Women’s Health concluded that the CoEs provided comprehensive clinical preventive services, served a broader cross-section of women, reached underserved subpopulations, including minority and economically compromised communities, produced higher levels of patient satisfaction, and aided in mentoring more women in their professional roles as clinicians and/or researchers. However, the report also concluded that CoEs remain vulnerable to pressures including, obtaining adequate funding and having to compete for scarce resources.

Coalition member and Director of the University of Illinois Chicago National Center of Excellence in Women’s Health Stacie Geller, Ph.D., strongly believes that her CoE has been instrumental in promoting advancement and leadership opportunities for female researchers on campus and beyond. In addition, the University of Illinois Chicago CoE has improved healthcare for women with a “one-stop shopping” model within the medical center by incorporating an adolescent clinic, midlife practice, and a clinic designed to meet the needs of perimenopausal and postmenopausal women in the same facility. The CoE also works to reduce barriers to health care for underserved urban women, and partners with surrounding communities to disseminate health information.

Considering the advancements that have been made and those that still need to be achieved, we urge Congress to provide an increase of \$1.5 million for the HHS Office on Women’s Health to allow it to continue to sustain and expand the National Centers of Excellence in Women’s Health.

#### AGENCY FOR HEALTHCARE AND RESEARCH QUALITY

The Agency for Healthcare Research and Quality (AHRQ) is the lead Public Health Service agency focused on health care quality, including coordination of all federal quality improvement efforts and health services research. AHRQ’s work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of health care. This important information provided by AHRQ is brought to the attention of policymakers, health care providers, and consumers who can make a difference in the quality of health care women receive.



Congress has had an active role in the Agency's work, providing funding while adding responsibilities. This has allowed AHRQ to enhance its research on how to: reduce deaths from medical errors; improve access and quality of care; promote evidence based health care; eliminate racial and ethnic disparities; compile the first national report on quality; and assist in improving emergency responsiveness.

AHRQ has a valuable role in improving health care for women. Through AHRQ's research projects and findings, lives have been saved and underserved populations have been treated. For example, women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines that have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks.

While AHRQ has made great strides in women's health research, the Administration's budget for fiscal year 2006 could threaten life-saving research. If a budget request of \$319 million were enacted, AHRQ would be flat funded at fiscal year 2005 levels. In reality, AHRQ's funding has been kept flat for two years as the recent \$15 million increase is dedicated to a specific project. Flat funding prior to application of taps by Congress seriously jeopardizes the research and quality improvement programs that Congress demands or mandates from AHRQ. Congress through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 directed AHRQ to research comparative effectiveness of drugs and other products but provided no appropriated funds in fiscal year 2003 or 2004. In fiscal year 2005, AHRQ received \$15 million to conduct such extensive and important research, far less than is needed to do the project.

It is important that Congress continues its support for AHRQ by increasing their funding to \$443 million for fiscal year 2006. This will ensure that adequate resources are available for high priority research, including women's health care, gender-based analyses, Medicare, and health disparities.

In conclusion, Mr. Chairman, we thank you and this Committee for its strong record of support for medical and health services research and its unwavering commitment to the health of the nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

---

PREPARED STATEMENT OF THE UPPER COUNTY BRANCH OF THE MONTGOMERY COUNTY, MARYLAND STROKE CLUB

A STROKE SURVIVOR: A PERSONAL STORY

My name is Susan Emery. I am the presiding officer of the Upper County Branch of the Montgomery County Stroke Club and I am a stroke survivor.

Our club conducts education and support activities for stroke survivors, their family members, and caregivers. We serve people in the Maryland suburbs of Washington, D.C., and are fortunate to be in the same county as the National Institutes of Health. We have benefited on many occasions by the participation of NIH staff members in our membership meetings. They have been generous in sharing with us information about their research into stroke prevention and treatment.

On December 26, 1965 at the age of 9, I was playing a new game with my brother and a few friends at the kitchen table. That is the last thing that I remember. I was unconscious for the next two days. My mother first learned, incorrectly, that I had spinal meningitis. I was transferred to another hospital where my mother was told that I had little chance of survival. Yet, I am here, more than 37 years later, and I have survived a stroke.

People seldom associate strokes with children. These strokes are rare, but they do happen. There are about three cases of stroke per year in every 100,000 children under age 14. One of the difficulties in dealing with strokes in children is getting the right diagnosis quickly. There are often delays in diagnosis of childhood stroke.

I spent 2 weeks in the hospital and the following 4 months in intensive physical therapy. My 10th birthday was spent in the hospital, and I have a picture in my photo album of myself with my mother and a new friend. My right eye is turned down, my mouth is turned down, but I am still smiling. During the 4 months in therapy at Holy Cross in Detroit, I learned the basics: how to walk, how to talk, and how to move the fingers on my right hand. My mother followed the doctor's instructions and sent me back to school very quickly, where classmates helped me button and unbutton my coat and carry my books, and teachers taped papers to the desk so I could learn to write again. I survived that 4 months, and would never wish to repeat it.

I have been in therapy six times in my life. I need to tell you about the one time that was the most important to my family. I was 26 years old and had just had my first child. I kept her safe, for I knew my limitations. I always used my left hand to support her. But when she was 6 months old, she got to be a little heavy, and twice, as I was putting her on the floor to change her diaper, my right hand slipped from under her buttocks. She fell only inches in both cases and did not even notice. But I noticed. I went in for 2 or 3 months of therapy close to Denver, Colorado, where I was living at the time. Here for the first time, they helped my right hand and arm dexterity through occupational therapy. I also learned that I had aphasia—the inability to speak, write or understand spoken or written language because of brain injury—because I called things like cornucopias, unicorns instead of fruit baskets. Instead of the word being the same, I picked a word that sounded the same. These therapists in Colorado worked with my mind and my body and I will forever be in their debt.

Close to 15 years ago, I made a new life for myself in Maryland. Here, I have been an outpatient at the National Rehabilitation Hospital three times: once for my right foot, once for my Achilles tendon and once for my right knee. I have seen numerous physiatrists, all of whom are excellent in their field. I have also seen my fair share of therapists. Since I have had therapy off and on for most of my life, I can honestly say that the first few times you go in to see a therapist, you will come out hurting more than when you went in. But in the long run, they help tremendously.

On a work related note, I received a Bachelor of Science in 1978 from Michigan State University in Computer Science and worked for 12 years in the field. I started working in the telecommunications industry in 1990, and got a Master of Science from the University of Maryland, University College in Telecommunications Management. I now work for ITT Industries as a senior engineer on a contract supporting the Federal Aviation Administration's leased telecommunications activities, and have worked there for more than 6 years. I have done more than survive. I have become a productive member of society.

Stroke research has changed my life. Without the research carried out 40 to 50 years ago, I would not have benefited from electric shock therapy that made me understand the muscles that moved my fingers. Without research done 30 years ago, I may not have been able to understand how to exercise my hand for dexterity. Without research performed 10 years ago, the people around me would not understand that they need to get me to the hospital quickly if ever I have another stroke. Without current support, researchers may never understand how to stop strokes before they happen or how to make current stroke survivors live healthier lives.

Stroke remains America's No. 3 killer and a major cause of permanent disability. An estimated 5.4 million Americans live with the consequences of stroke and about 1 in 4 is permanently disabled. Yet, stroke research continues to receive a mere 1 percent of the National Institutes of Health budget. I strongly urge you to significantly increase funding for the National Institutes of Health-supported stroke research, particularly for National Institute of Neurological Disorders and Stroke-supported stroke research. NIH stroke research is essential to prevent strokes from happening to children and adults in the first place, and to advance recovery and rehabilitation of those who survive this potentially devastating illness.

---

#### DEPARTMENT OF EDUCATION

##### PREPARED STATEMENT OF THE ALAMO NAVAJO SCHOOL BOARD, INC.

The Alamo Navajo School Board, Inc. operates under resolution from the Alamo Navajo Community and from the Navajo Nation and was organized within the Alamo Navajo chapter community to establish and operate Federal and State programs that provide education, health and community development services to the people of Alamo under contracts, grants or cooperative agreements. We are responsible for operation of nearly all federal programs that serve the 2,000 Navajo people who live on the Alamo Reservation. Our 10-square mile reservation is isolated in south-central New Mexico, 250 miles from the Big Navajo Reservation, thus it is critical that we provide local services to persons living on the Alamo Reservation. On an annual basis, we operate over \$13 million of federal and state supported programs.

In summary our recommendations for the fiscal year 2006 Labor-HHS-Education and Related Agencies budget are:

—Reject the Administrations proposal to de-fund the Perkins vocational program and provide at least a modest increase;

- Direct the Department of Education to allow BIA-funded schools to apply directly for Library Literacy Grant funding;
- Reject the Administration's proposal to de-fund the Safe and Drug Free schools program and provide at least a modest increase;
- Allow Indian Head Start program to have the flexibility to allocate funds between their Early and regular Head Start programs;
- Support a four percent tribal allocation under the Head Start Program;
- Increase funding for the Workforce Investment Act;
- Reject the proposal to consolidate Supplemental Youth Services funding into a block grant which would probably cause the loss of Indian SYS funding;
- Reject the Administration's proposals to reallocate and/or rescind \$92 million of already-appropriated fiscal year 2006 CPB funds and to end forward funding for the CPB.
- Support continued and increased CPB support for Native radio.

#### VOCATIONAL EDUCATION

We operate a very successful and much-needed program funded through the Carl Perkins Vocational and Applied Technology Act and we strongly oppose the Administration's proposal to totally de-fund the Carl Perkins vocational education program. We are pleased that the House and Senate authorizing committees are proceeding with reauthorizing the Perkins Act, which sends a clear signal to the White House that Congress finds this a valuable program that should be continued.

We have been administering a Section 116 Perkins Act grant under which we are successfully helping Indian people access and complete postsecondary education. Our project is named Access-Retention-Completion (ARC) We are working toward development of a Navajo professional workforce that will enable people, if they so choose, to fill job needs on the Alamo Navajo Reservation that must now be filled by persons from outside the community. Under ARC, our students are able to gain academic and technical skills both on and off the reservation, via distance learning and on-site classes. The Alamo Navajo School Board has articulation agreements with several postsecondary institutions to offer classes both on and off reservation. We are able to help students with transportation to off-reservation education sites through the use of our 15-passenger van. We are making education more accessible and affordable for postsecondary students who are also parents. Our child care program provides pre-natal to early head start child care. We also have an after school tutoring program for older school-age children. Finally, we are providing support services to all postsecondary students through counseling, placement, advisement and facilitation.

While we feel very good about the development of our Access-Retention-Completion project, it takes more than four years to fully develop this multifaceted program. We are currently serving 83 students, with an 80 percent completion rate for on-site classes and 100 percent completion rate for students taking off-reservation classes. Our placement rate is 80 percent for on-site and 90 percent for off-reservation. Our students are about evenly split between on and off reservation programs. We also believe that our ARC project has the very real potential to be a model for other isolated communities—both Indian and non-Indian—and having several more years of assured funding would bring the necessary additional experience to serve as a model program.

#### IMPROVING LITERACY THROUGH SCHOOL LIBRARIES

The Alamo-Navajo School Board is excluded from applying for these much needed funds that would, as Congress intended, enable us to update our school library materials and media center equipment and assure an appropriately credentialed media specialist is on hand to assist our students. The Department of Education has taken the position that because the BIA-funded schools receive a 0.5 percent set-aside from the annual appropriations for this program, they cannot apply for discretionary grants as an LEA (local education agency) under the program operated by the Department. The average grant award under the Department's discretionary grant program ranges from \$150,000 to \$300,000.

In fiscal year 2005, the Department of Education transferred \$99,211 to the BIA for the use of the BIA-funded schools. The BIA, however, determined that instead of making the funds available—by discretionary or formula grant—to all of the 184 schools in the BIA school system, the entire fiscal year 2005 amount would be allocated to only two schools. The schools selected were on the BIA Center for School Improvement list for proposed restructuring, meaning they had not met adequate yearly progress (as required by the No Child Left Behind Act) despite earlier intervention.

We understand that poorly performing schools require much assistance to enable them to help their students achieve academic success, and it is unlikely that the entire \$99,000 would be sufficient to correct the deficiencies experienced by just one BIA-funded school. Nonetheless, it is unfair to all BIA schools if the Department of Education excludes BIA-funded schools from the discretionary program and the BIA adopts a policy to restrict funds made available to a select few. We urge the Congress to direct the Department of Education to reconsider its exclusionary practice and allow the BIA-funded schools to apply directly to the Department for the Library Literacy grant funding.

#### SAFE AND DRUG FREE SCHOOLS AND COMMUNITIES

The Alamo-Navajo School Board strongly opposes the Administration's proposal to eliminate funding for the Safe and Drug Free Schools State Grants program (\$437.4 million in fiscal year 2005). Under the 1 percent set-aside for BIA-funded schools, we received \$29,000 that partially funded a school-home liaison who works directly with parents and community on matters identified by the school that would aid in ensuring a healthy learning environment.

As you are no doubt aware, alcohol and drug-related illnesses and crime levels in Native American communities greatly exceed the mainstream populations. By tapping all available sources of funds, we seek to provide our students the drug prevention and school safety programs that will help them develop the life skills that may enable them to live better, healthier lives. We urge Congress to reject the Administration's proposal to eliminate this valuable program and instead provide at least a modest increase.

#### HEAD START

The American Indian Head Start and Early Head Start programs receive a less than 3 percent share of the 13 percent set-aside for Indian, migrant, territorial, children with disabilities programs. In fiscal year 2004, that translated to \$161.6 million for Indian Head Start (ages 3–5 years) and \$27.5 million for Indian Early Head Start (ages 0–3 years), which served a combined total of nearly 24,000 children. Under the Administration's proposal, our programs would receive none of the requested \$45 million increase since all of it is targeted for pilot projects whereby states would consolidate Head Start and other state children's programs.

Although level funding in these constrained budgetary times may be viewed as a success, programs such as ours which are located in very rural areas are faced with rising costs that are greater than those located in more metropolitan areas, i.e., fuel costs for transportation, food, staff training. Level funding also does not address the increasing costs related to higher salaries for staff who achieve the high quality staff requirements of the program nor the unfunded mandate to install small child restraints in program vehicles (which cost \$6,000 but was not in our budget nor were we provided reimbursement from the national Head Start office).

Further, with the myriad and increasingly stringent requirements, small programs such as ours are losing the flexibility to structure our services to best meet the needs of our children. We need to be able to structure our Early Head Start and Head Start programs to the changing dynamics of our community yet current Head Start policies restrict us from being able to allocate our program funds to provide the services in accordance with the demographic changes. For instance, this year our Early Head Start has a waiting list which could result in an additional classroom of students while our enrollment for the Head Start program is less than anticipated. The logical reaction would be to respond to the need and utilize program funds to establish the necessary additional Early Head Start class but we were informed by the Head Start Grant office that even though we receive our Early Head Start/Head Start funds in one grant document, we must expend the monies under two separate budgets. Therefore, a number of Early Head Start eligible children in our community are not being served since there are no other early education programs available in our isolated area.

We ask that when Congress takes up the reauthorization of the Head Start Act, that (1) the Indian Head Start set-aside be increased from the present 2.8 percent to no less than 4 percent; and (2) provide program flexibility so that Indian Early Head Start/Head Start grant recipients may allocate funds between their Early and regular Head Start programs in the manner that best meet the needs of the population served.

#### WORKFORCE INVESTMENT ACT

The Alamo Navajo School Board receives funding under the Workforce Investment Act's Section 116 Program and the Supplemental Youth Services program. The Ad-

ministration has proposed level funding (\$54.2 million) for the Section 116 program which provides grants to Indian Tribes, Urban Indians, Hawaiians and Samoans. This program has been flat funded for years and we support the National Congress of American Indians request of \$75 million for the Section 116 program.

We oppose the Administration's proposal that the Supplemental Youth Services Program (of which the tribes receive \$1.5 percent allocation, or about \$15 million annually) be combined with three other streams of money and put into a block grant, with no obvious guarantee that the tribal money would be preserved. We are pleased that the House bill reauthorizing the WIA (H.R. 27) did not go along with this consolidation proposal and urge that the Appropriations Committee likewise reject this proposal and to provide an increase for Supplemental Youth Services which has been flat funded for years.

#### CORPORATION FOR PUBLIC BROADCASTING

The Alamo Navajo School Board is the licensee for a community radio station—KABR-AM in Magdalena, NM—which receives a modest amount of funding from CPB. We commend CPB for increasing funding for rural sole source radio stations—of which we are one. We also appreciate that CPB has provided start-up funds for a Center for Native American Radio which is to provide technical and other service to Indian radio stations. Our radio signal reaches approximately 13,000 people, including the Alamo population of 2,072. Of the 432 Alamo households, only 25 percent have telephones, and there is no cell phone service. So you can see what an important role our community radio station plays at Alamo Navajo.

There are currently 33 Indian-owned radio stations—all noncommercial—in thirteen states. Most are licensed to nonprofit organizations. We ask for this Committee's continued support of Native radio.

We are extremely concerned about the Administration's proposal to rescind \$10 million and divert an additional \$82 million of already appropriated fiscal year 2006 CPB funds to digital conversion and satellite interconnection. Such a rescission/diversion of funds would be a terrible setback for our station, which already runs on a shoe string. Should Congress approve the Administration's request and if it were applied across-the-board, we would be faced with a 25 percent reduction of CPB funds.

We ask Congress to again reject—as you have done the past four years—the Administration's proposal that the advance funding for CPB be eliminated.

Thank you for your consideration of concerns and recommendations of the Alamo Navajo School Board.

---

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) respectfully submits this statement highlighting funding priorities for nursing education and research programs in fiscal year 2006. AACN represents over 580 senior colleges and universities with baccalaureate and graduate nursing programs, and over 190,000 students and 10,000 faculty members. These institutions are responsible for educating about half of our nation's registered nurses (RNs) and all of the nurse faculty and researchers. Nursing represents the largest health profession in the nation, with approximately 2.7 million dedicated, trusted professionals delivering primary, acute, and chronic care to millions of Americans daily across the spectrum of settings.

#### THE NATIONWIDE NURSING SHORTAGE

Our country continues to be plagued by a shortage of nurses that is only expected to intensify in the future. While AACN is cognizant of the difficult budget environment in which the Subcommittee and the entire Congress must operate, patient safety is compromised without a sufficient number of RNs. Indeed, the American College of Healthcare Executives reported in 2004 that 72 percent of hospitals were experiencing a nursing shortage. Furthermore, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) found in 2002 that the nursing shortage contributes to nearly a quarter of all unexpected incidents that kill or injure hospitalized patients. Since nurses comprise the largest component of hospital staffs, shortages also result in emergency room overcrowding and diversions, increased wait time for or outright cancellation of surgeries, discontinued patient care programs or reduced service hours, and delayed discharges.

The U.S. Bureau of Labor Statistics (BLS) has projected that by 2012, our nation will need an additional 1.1 million new and replacement registered nurses. Despite nursing being identified by BLS as the fastest growing occupation, according to the

Health Resources and Services Administration (HRSA), the United States still will be roughly 800,000 nurses short in 2020, unless there is a significant and sustained increase in the number of nurses graduating each year and entering the workforce. There are nursing vacancies throughout all sectors of health care, including long-term care, home care, and public health. These alarming predictions are coupled with little change in the multitude of contributing factors such as the aging of America's population, the aging nurse workforce, high numbers of RN retirements, and the increasing demand for more intensive health care services by chronically ill, medically complex patients. It is clear that federal support must continue to play a critical role in the nation's effort to address the nursing shortage.

#### NURSING WORKFORCE DEVELOPMENT

Acknowledging the situation, Congress passed The Nurse Reinvestment Act of 2002. This legislation reauthorized and expanded Nursing Workforce Development programs, administered by HRSA under Title VIII of the Public Health Service Act, to address the inadequate supply and distribution of RNs across the country. These authorities fund nursing education and retention programs as well as support individual students in their nursing studies. The seven Title VIII grant and student programs stimulate innovation in nursing practice and bolster nursing education throughout the continuum, from entry-level preparation through graduate study. Thoughtful and well-written authorities, Title VIII programs are the largest source of federal funding for nursing education. In fiscal year 2004, these programs provided loan and scholarship support to over 28,000 student nurses.

Given the demonstrated need for these outstanding programs, past funding levels have been insufficient, receiving only \$150.67 million in fiscal year 2005. AACN respectfully requests \$175 million for Title VIII Nursing Workforce Development in fiscal year 2006, an additional \$24.33 million over fiscal year 2005. New monies would support these crucial Title VIII programs designed to help resolve the nursing shortage through education, recruitment, and retention efforts for the nursing workforce. During the last serious nursing shortage in 1974, Congress appropriated \$153 million for nursing education programs. Translated into today's dollars, that appropriation would total \$592 million, almost 4 times the current level.

#### COLLEGES OF NURSING RESPOND

The approximately 1,500 schools of nursing nationwide have been working diligently to expand enrollments. In fact, AACN found in a recent study that enrollments increased in 2004 by 15.5 percent for entry-level baccalaureate, master's, and doctoral nursing programs, over the 9.1 percent increase experienced in 2003. These increases are attributed to intensive marketing efforts by the private sector, public-private partnerships providing additional resources to expand capacity of nursing programs, and state legislation targeting funds towards nursing scholarships and loan repayment.

While impressive, these increases still cannot meet the demand. In the November 2003 issue of Health Affairs, Dr. Peter Buerhaus reported that nursing school enrollments would have to increase by at least 40 percent annually just to replace those nurses who retire, due to declining numbers of young RNs over the past 20 years. It is important to note that in spite of protracted efforts by colleges nationwide, AACN found that enrollments have increased only by a total of 53.5 percent over the last 5 years in entry-level baccalaureate programs.

In spite of increasing enrollments and the demonstrated need for RNs, U.S. colleges of nursing must still turn away eligible students. In 2004, AACN found that at least 32,797 qualified applicants were turned away, up sharply from over 18,000 in 2003. These students were turned away due to insufficient numbers of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Over 75 percent of the schools surveyed cited the faculty shortage as the primary barrier to increasing enrollments. Some of these qualified students are being placed on waiting lists that may be as long as 2 years.

#### BOTTLENECK: THE COEXISTING FACULTY SHORTAGE

AACN strongly believes that the most effective strategy for the resolution of the nursing shortage is addressing the underlying faculty shortage. HRSA reported in 2000 that just 9.6 percent of the RN workforce holds master's degrees, while only 0.6 percent holds doctorates. AACN found that more than half, 53.4 percent, of the nurse faculty vacancies in 2004 were for faculty positions requiring the doctoral degree. In 2003 AACN reported there were 10,500 full-time master's and doctorally prepared faculty teaching in baccalaureate and graduate nursing programs. Projections through 2012 show that the faculty pool will shrink by at least 2,000 as com-

pared to 2003, even after accounting for retirements, resignations, and additional entrants. Note that these figures do not take into account the need for faculty in new or expanded programs, but represent only present staffing requirements. If the faculty vacancy rate holds steady, it is expected the deficit of nurse faculty will swell to over 2,600 unfilled positions in 2012.

The situation is only expected to worsen with time. Faculty age continues to climb, narrowing the number of productive years nurse educators can teach. Significant numbers of faculty are expected to retire in the coming years, as the average age is 52. Likewise, there are not enough candidates in the pipeline to take their places. For example, an average of 410 individuals are awarded doctoral degrees in nursing each year, but almost a quarter, 23 percent, take jobs outside of academic nursing. Higher compensation in clinical and private sector settings lures current and potential nurse educators away from the classroom. The average salary of a nurse practitioner in an emergency department was \$80,697, according to the 2003 National Salary Survey of Nurse Practitioners. In contrast, AACN found that the average salary for a nurse faculty member was \$60,357 in 2003. Without sufficient nurse faculty, schools of nursing will not be able to expand their capacities to educate new generations of the nurses.

#### REVERSING THE TREND: THE NURSE FACULTY LOAN PROGRAM

This trend can be reversed—with your help. Additional appropriations for the Nurse Faculty Loan Program, Section 846A of Title VIII, will provide targeted assistance. Designed to help increase the number of nurse faculty, grants are provided to colleges of nursing in order to create a loan fund. To be eligible for these loans, students must be pursuing either a master's or doctoral degree on a full-time basis. Loan recipients will have up to 85 percent of their educational loans cancelled over a four-year period, if they agree to teach at a school of nursing. The loan is cancelled at a rate of 20 percent for the first three years, increasing to 25 percent in the final year. A student may receive a maximum loan award of \$30,000 per academic year for tuition, books, fees, laboratory expenses, and other reasonable educational costs. In fiscal year 2004, 61 grants were made to schools of nursing, which in turn supported a projected 419 future nurse faculty members. In fiscal year 2005, \$4.83 million was appropriated.

For example, if the current funding was doubled to almost \$10 million, based on this year's projections, colleges of nursing could educate over 800 future faculty. Though the student to faculty ratios vary by state, a common average is one faculty member for every ten students. Then one could surmise from that estimate that the doubled funding could help to educate over 800,000 future nurses.

#### OTHER SOURCES OF RELIEF

AACN would like to highlight the following programs in addition to the Nurse Faculty Loan Program: the Advanced Education Nursing program, the Workforce Diversity program, and the Nurse Education, Practice, and Retention program.

The Advanced Education Nursing program supports the majority of colleges of nursing that prepare graduate-level nurses to be primary care providers, some of whom become faculty. Receiving \$58.17 million in fiscal year 2005, this grant program helps schools of nursing, academic health centers, and other nonprofit entities improve the education and practice of nurse practitioners, nurse-midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and clinical nurse specialists. Out of the 149 applications received for this program in fiscal year 2004, 82 new grants were awarded to institutions and 75 previous awarded grants were continued. In addition, 408 schools of nursing received traineeship grants, which in turn directly supported 8,925 individual student nurses.

The health system's increasing demand for primary care, increased utilization of case management—particularly for chronic illnesses, prevention and cost-efficiency, and a shortage of physicians are driving the nation's need for nurse practitioners, certified nurse-midwives, and other RNs with graduate education and advanced clinical skills, known as advanced practice nurses (APNs). Mounting studies demonstrate the quality of APN care is at least equal to, and at times better than comparable physician services rendered by physicians, and often at lower cost. This is especially important, as the 78 million Baby Boomers age, their demand for health care services will skyrocket. AARP reported that the rate of physician office visits by those 65 and older jumped 22 percent from 1985 to 1999.

Workforce Diversity grants prepare disadvantaged students to become nurses. As the United States becomes ever more heterogeneous, it is imperative that the composition of our nursing workforce mirrors this shift. According to the U.S. Census Bureau, roughly 30 percent of the population was reported as a racial or ethnic mi-

nority in 2000, but by 2050 that percentage will jump to over 52 percent. This program awards grants to schools of nursing and other entities seeking to increase access to nursing education for disadvantaged students, including racial and ethnic minorities under-represented among RNs. The program provides scholarships or stipends, pre-entry preparation, and retention activities to enable students to complete their nursing education. In fiscal year 2004, 144 applications were submitted, from those 27 new grants were awarded and 35 previously awarded grants were continued. Under the scholarship program alone, 473 students each received \$7,000 scholarships. Workforce Diversity received \$16.27 million in fiscal year 2005.

The Nurse Education, Practice and Retention program helps schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and health care facilities strengthen programs that provide nursing education, facilitate innovations in nursing practice, and retention of the nursing workforce. Education grants are made to enable schools to expand enrollments in baccalaureate nursing programs, develop internship and residency programs, and provide for new technology. Practice grants are made to expand arrangements in non-institutional settings to improve primary health care in medically underserved communities, provide care for underserved populations, enhance practitioner skills, and develop cultural competencies. Retention grants are made to the Career Ladder program, which supports efforts to assist people to obtain the necessary education to either enter the profession or to advance within it; enhance patient care delivery systems through incorporation of best practices, and improved communication. In fiscal year 2004, 336 applications were submitted, from those, 40 new grants and 85 continuation grants were awarded. Nurse Education, Practice, and Retention received a total of \$36.48 million in fiscal year 2005.

#### NATIONAL INSTITUTE OF NURSING RESEARCH

One of the 27 Institutes and Centers at the National Institutes of Health (NIH), the efforts of the National Institute of Nursing Research (NINR) improve patient care and foster advances in nursing and other health professions' practice. These practices must be constantly updated and validated based on rigorous, peer-reviewed research. The outcomes-based findings derived from NINR research are important to the future of the health care system and its ability to deliver safe, cost-effective, and high quality care. Through grants, research training, and interdisciplinary collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life in those with chronic illness, and care for individuals at the end of life. To advance this research, AACN requests a funding level of \$160 million in fiscal year 2006, an additional \$21.91 million over the \$138.09 million NINR received in fiscal year 2005.

#### *NINR Addresses the Need for Translational and Clinical Research*

NINR emphasizes translational research, the means by which basic findings relating to behavior, molecules, and genes are tested in the clinical setting and translated into innovative medical practices and improvements in public health. This effort is incorporated into the NIH Roadmap for Medical Research. Under the framework of the Roadmap Initiative, NINR and nurse researchers are addressing the development of new interdisciplinary research teams and enhanced clinical research to move the overall NIH portfolio of social, behavioral, and medical research forward in this coordinated and cohesive effort.

#### *NINR Addresses the Shortage of Nurse Researchers and Faculty*

NINR allocates 8 percent of its budget, a high proportion when compared to other NIH institutes, to research training to help develop the pool of nurse researchers. In fiscal year 2004, NINR training dollars supported 88 individual researchers and provided 186 institutional awards, which in turn supported a number of nurse researchers at each site. Since nurse researchers often serve as faculty members for colleges of nursing, they are actively educating our next generation of RNs.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

While NIH supports biomedical research that improves health care by focusing on disease cause, cure, and prevention; the Agency for Healthcare Research and Quality (AHRQ) supports research from a systems perspective, collecting evidence-based information on health care outcomes. AHRQ research findings are used by patients, clinicians, health system decision makers, and public policymakers to guide healthcare delivery systems and patient care. The research supported by AHRQ not only improves the quality of health care services, but also helps people make more informed decisions about their healthcare. AACN joins the Friends of AHRQ in rec-



ommending a funding level of \$440 million for fiscal year 2006, an additional \$121 million over the fiscal year 2005 level of \$318.7 million.

*Health Systems Research at AHRQ Addresses Nurses' Role in Patient Safety*

AHRQ research has demonstrated that inefficient work processes, overwhelming work loads, extended work hours, and poor workplace designs create obstacles to providing patients safe, cost-effective, and high quality health care. The New England Journal of Medicine published a study of over 6 million patients in May, 2002 that found hospitalized patients had better outcomes when the majority of their nursing care was provided by RNs. Decreased hours of RN care, stemming from the nursing shortage, correlated with longer hospital stays, increased incidence of urinary tract infections and gastrointestinal bleeding, as well higher rates of pneumonia, shock, and cardiac arrest. When patients received additional hours of RN care, the death rates dropped for pneumonia, shock or cardiac arrest, upper gastrointestinal bleeding, sepsis, and deep venous thrombosis.

*AHRQ Research Demonstrates that Nurse Education Affects Patient Outcomes*

Another AHRQ study found that by employing a greater proportion of more highly educated nurses reduced the mortality and failure to rescue rates from life threatening complications. This extensive study in the September 2003 issue of the Journal of the American Medical Association found that surgical patients have a "substantial survival advantage" if treated in hospitals with higher proportions of nurses educated at the baccalaureate or higher degree level. In hospitals, a 10 percent increase in the proportion of nurses holding BSN degrees decreased the risk of patient death and failure to rescue by 5 percent.

CONCLUSION

Nurses can no longer simply give care to a patient at the bedside. They must evaluate research that promotes evidence-based practice and utilize technical innovations to provide quality patient care. To achieve this level of excellence, AACN recognizes that our nation desperately needs a dedicated, long-term vision for educating the new nursing workforce. Strategies must encompass state support, public-private sector initiatives, and increased federal funding for nursing education and research. Title VIII Nursing Workforce Development programs enable colleges of nursing to innovate and prepare students for the realities of caring for our nation's diverse population in many health care settings across the lifespan. NINR, NIH, and AHRQ provide the research that supports the evidence base for safe practice and quality care delivery. We ask the Subcommittee to graciously consider our appropriations requests for fiscal year 2006.

---

PREPARED STATEMENT OF THE AMERICAN CHEMICAL SOCIETY

Chairman Specter and other members of the Labor, Health and Human Services and Education Subcommittee, I appreciate the opportunity to submit written testimony on behalf of the American Chemical Society. The American Chemical Society (ACS) is the world's largest scientific society with over 159,000 members. We represent individual chemists and engineers in academia, industry, and government.

Mr. Chairman, the ACS recognizes that ensuring the continued economic supremacy and homeland security of this nation depends upon maintaining our global technological leadership. This leadership has resulted from the ready availability of a domestic workforce of highly trained scientists, technicians, engineers, and mathematicians (the STEM workforce). But today's high school students are not performing well in math and science overall, and a decreasing number of American students are pursuing college degrees in STEM fields. At the elementary school level, the recent PISA test showed that America's 15 year-olds perform below average in mathematics problem solving compared to their peers in other developed countries.

Thanks to your leadership, the Department of Education budget has increasingly reflected a commitment to remedy this situation through investments in a number of STEM initiatives from the K-12 to postsecondary level. These programs must continue to receive strong support in order to ensure a globally competitive U.S. workforce.

Central to this quest is ensuring the supply of qualified K-12 science and mathematics teachers. As you know, the Math and Science Partnerships, authorized in the No Child Left Behind Act at an increasing annual level to reach \$450 million by fiscal year 2007, are the sole source of dedicated DoEd K-12 math and science funding. This program supports valuable long-term, content-based continuing education

for math and science teachers—the type of training that research shows is most effective in improving student achievement.

Chairman Specter, we greatly appreciate your past support of the Partnership program which has grown from \$12.5 million in fiscal year 2002 to \$180 million in fiscal year 2005. We applaud you for this and urge you to work toward the authorized level by funding the program at the level of \$400 million in fiscal year 2006. Reaching the authorized level is critical, as the No Child Left Behind Act requires science testing to begin in the 2007–2008 school year.

ACS also urges you to reject the Administration's proposal to earmark its requested \$120 million increase in the program for a new high school mathematics initiative. This proposal strays from the intent of the No Child Left Behind Act, which seeks to address the equally critical needs in both math and science. A similar proposal was made by the Administration in the fiscal year 2005 budget and, in our view, wisely rejected by your Committee.

The ACS recognizes the value of encouraging chemists retiring early or those desiring a change from industry work to consider and train for a second career in high school teaching. To that end, we support the president's Adjunct Teacher Corps initiative, which brings experienced professionals with subject-matter knowledge into the classroom to teach part or full-time in areas of high need, including science and math. These professionals can offer valuable insights into the content and practical applications of their subject areas. We recommend that funding be provided to ensure adequate teacher development and to ensure effective communication of their expertise to their students.

On another front, the ACS opposes the Administration's proposal to eliminate the Vocational and Technical Education program. We feel it would have a very negative impact upon our technological leadership. In addition to scientists and engineers, the STEM workforce relies on highly trained technicians, of whom many enter the workforce through tech-prep programs that are currently supported under the Vocational and Technical Education program (\$110.7 million in fiscal year 2005). It is unrealistic to expect states to assume the burden of funding tech-prep programs through the new High School Intervention program, due to its emphasis on meeting academic state standards.

At the post-secondary level, the Department of Education provides incentives to students to pursue science and engineering occupations. The Graduate Assistance in Areas of National Need program (GAANN) is one such example. GAANN provides graduate and doctoral students with enhanced fellowship opportunities. We believe this program should support at least 1,200 fellowships, up from the 850 in fiscal year 2004 and the 721 fellowships that would be supported under the current budget request. This increased support is vital at a time when our nation must have the intellectual resources to respond to homeland security threats and maintain our economic growth.

Furthermore, we strongly support programs such as the Minority Science and Engineering Improvement program in order to increase the participation of underrepresented minorities in scientific and technological careers.

In closing, we appreciate your past support and leadership on behalf of the Department of Education's programs. We strongly believe that proactively investing in STEM education today, will pay real dividends with a more competitive, innovative and successful American workforce tomorrow.

---

#### PREPARED STATEMENT OF THE AMERICAN COLLEGE OF RHEUMATOLOGY

The American College of Rheumatology (ACR) is pleased to provide this statement for the record in support of the several important agencies and programs that address arthritis within the Department of Health and Human Services.

The ACR is an organization of physicians, health professionals and scientists that serves its members through programs of education, research and advocacy that foster excellence in the care of people with arthritis, rheumatic and musculoskeletal diseases.

Arthritis means swelling, pain and loss of motion in the joints of the body. There are more than 100 rheumatic diseases that cause this condition, which can sometimes be fatal, in both children and adults of all ages. One in three adults, or 70 million people in the United States, are affected by arthritis and other rheumatic conditions according to the Centers for Disease Control and Prevention (CDC). Arthritis and other chronic joint problems are the leading cause of disability among adults in the United States, costing more than \$86 billion a year in medical costs and lost productivity. These numbers and related costs are expected to increase as the U.S. population ages.

This burden will surely increase, possibly uncontrollably, as the baby boomer group continues to age. Although some forms of arthritis are predominant in older individuals, arthritis also affects children and adults of all ages. The number of individuals affected, as well as associated costs, will increase as the size of our elderly population continues its upswing.

Current research is providing breakthrough advances that have the potential to revolutionize our understanding of arthritis and rheumatic diseases, leading to more effective treatments, decreased costs and increased quality of life for patients suffering from these conditions. The federal government is doing critical medical research into the causes, treatment and prevention of arthritis and rheumatic diseases. The ACR urges the subcommittee to increase its investment in research and arthritis programs to further progress made in preventing, diagnosing and treating these prevalent diseases.

#### THE NATIONAL INSTITUTES OF HEALTH

The ACR supports a 2006 appropriation of \$30 billion for the National Institutes of Health (NIH) in order for it to carry out its goal to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability. The NIH disperses funding to the different institutes within it, including the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Allergy and Infectious Diseases (NIAID). Therefore, overall funding for NIH is extremely important to the federal medical research effort in arthritis and rheumatic diseases.

#### THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

The ACR strongly supports a 2006 appropriation of \$541.6 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), which leads the federal medical research effort in arthritis and rheumatic diseases. The NIAMS conducts research related to the causes, treatments and prevention of diseases of the bone, joints, muscle, skin and other connective tissues. The NIAMS sponsors research and research training at universities and medical centers throughout the United States. Research sponsored by the NIAMS leads to the development of more effective treatments, which leads to decreased costs and improved quality of life for patients suffering from rheumatic diseases.

#### THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

The ACR recommends a 2006 appropriation of \$4.667 billion for the National Institute of Allergy and Infectious Diseases (NIAID), which conducts research that strives to understand, treat, and ultimately prevent the myriad of infectious, immunologic, and allergic diseases. The NIAID's research focuses on the basic biology of the immune system and mechanisms of immunologic diseases including autoimmune disorders. To accomplish its goals, the NIAID carries out a wide range of basic, applied, and clinical investigations within its own laboratories, and provides research grant, contract, and cooperative agreement support to scientists at universities and other research institutions throughout the country and the world.

#### THE AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The ACR supports a 2006 appropriation of \$440 million for the Agency for Healthcare Research and Quality (AHRQ) to carry out its mission to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. AHRQ's health services research complements the biomedical research of the NIH by helping physicians, hospitals, purchasers and other stakeholders in health care delivery make informed decisions about what treatments work best, for whom, when, and at what costs.

#### THE NATIONAL ARTHRITIS ACTION PLAN

The ACR recommends a 2005 appropriation of \$15 million for the National Arthritis Action Plan (NAAP). The NAAP, housed within the CDC National Center for Chronic Disease Prevention and Health Promotion, helps deliver the advances made in the biomedical research system to millions of Americans who have arthritis. The NAAP is designed to increase recognition among the general public, people with arthritis and their families, medical care providers, and policy makers, of the impact of arthritis, what can be done to prevent or delay its onset, and what effective interventions and are available to reduce disability and improve the quality of life. The NAAP has made a tremendous impact in how state public health departments ad-

dress this national health problem, and with increased funding, programs could be established in more states and existing programs could be expanded.

#### IMPACT OF CONTINUING RESOLUTIONS ON MEDICAL RESEARCH

The ACR urges Congress to recognize the difficulties imposed on researchers by interruptions in the medical research funding cycle caused by delays in the federal appropriations process. Use of the continuing resolution mechanism to fund government operations in the absence of the normal appropriations process often causes federally funded researchers to halt their research until the appropriations process is resolved. These disruptions have the potential to not only significantly compromise the validity of the basic medical research being conducted, but can result in the unnecessary expenditure of federal funds to reactivate specific research studies. In order to preserve the integrity of federally supported medical research, the ACR urges Congress to minimize the use of continuing resolutions.

#### SUMMARY

The ACR appreciates the subcommittee's support for these important programs in recent years. As physicians involved in both research and specialized patient care, ACR members are acutely aware of the magnitude of the challenges that disease and disability place on the health care delivery system. The ACR encourages the subcommittee to provide a strong investment in the programs listed above for 2006 so that necessary research and programs to combat arthritis and related diseases can continue. These programs are critical to the development of more effective treatments, decreasing costs and improving the quality of life for patients suffering from rheumatic diseases.

---

#### PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) is grateful for the opportunity to provide testimony with regard to fiscal year 2006 appropriations for Federal programs that help to educate the future dental workforce, encourage the prevention of dental disease and provide access to oral health care for underserved populations. These programs are critical to academic dental institutions in fulfilling their primary mission to educate, conduct research and provide patient care. ADEA strongly urges Congress to enhance funding for the programs and preserve their fundamental structure.

ADEA is the premier national organization that speaks for dental education. It is dedicated to serving the needs of all 56 U.S. dental schools, nearly 730 dental residency programs and 550 allied dental programs, as well as the tens of thousands of faculty, dental residents and students engaged in training. It is at dental education institutions that future practitioners and researchers gain their knowledge; the majority of dental research is conducted; and significant dental care is provided to underserved low-income populations, including individuals covered by Medicaid and the State Children's Health Insurance Program (SCHIP).

Academic dentistry endeavors to address the oral health needs of the nation's uninsured, underinsured and publicly insured citizens. Profound disparities in the oral health of the nation's population have resulted in what the Surgeon General<sup>1</sup> called a "silent epidemic" of dental and oral diseases affecting the most vulnerable among us. These disparities, combined with the current shortage of dental school faculty, the scarcity of underrepresented minority dentists, and the need for targeted incentives to draw dentists to practice in rural and underserved communities, make our funding recommendations critically important.

The Administration's fiscal year 2006 budget proposal reduces by approximately 96 percent funding for Title VII Health Professions Programs and eliminates 100 percent of the funding for pediatric, general and public health dental residency programs. Title VII programs embody the federal government's commitment to educating the nation's future health care providers. Such programs focus on wide-ranging and important matters including interdisciplinary training, geriatric and rural health care, allied health education, advanced training for dental, allopathic and osteopathic residents. Eliminating funding for the programs will gravely weaken the health infrastructure of the nation.

Zeroing out funding for the dental residency training programs means that essential advanced education for dental residents and the oral health services they provide to underserved communities will be eliminated. Abandoning these programs

---

<sup>1</sup>Oral Health in America: A Report of the Surgeon General, 2000.

will intensify and contribute to the growing crisis in accessing oral health services as more states reduce Medicaid dental benefits for adults, the frail elderly and compromised patients. Furthermore, restrictions in Medicaid and SCHIP enrollment and eligibility have reduced access to oral health care for children.

As Congress wrestles with the fiscal year 2006 appropriations for federal agencies and programs of importance to dental education and research, ADEA respectfully urges that the following programs' funding be restored and enhanced at the levels recommended:

\$15 MILLION FOR TITLE VII GENERAL DENTISTRY AND PEDIATRIC DENTISTRY RESIDENCY TRAINING PROGRAMS

ADEA recommends that Congress restore and enhance funding for dental residency training programs. These programs are instrumental in educating dentists who work in underserved communities and treat Medicaid, SCHIP or other underserved populations, particularly those with special needs. Furthermore, dentists training in Title VII funded programs staff clinics that provide treatment at low or no cost.

\$19 MILLION FOR THE RYAN WHITE HIV/AIDS DENTAL REIMBURSEMENT PROGRAM OF THE RYAN WHITE CARE ACT (PART F)

The Dental Reimbursement and the Community-based Dental Partnerships programs, the smallest component of the CARE Act, are successful in increasing access and educating and training dental students, dental residents and allied dental students in the provision of care for patients afflicted with the disease. The Dental Reimbursement Program (DRP) accomplishes significant benefits for both patient care and education of future oral health practitioners.

Academic dental institutions (ADI) are safety net providers of oral and dental care for low-income, uninsured or underinsured immunocompromised patients who are prone to oral infections. A recent study<sup>2</sup> found that providing HIV/AIDS patients with regular diagnostic and preventive care reduced the need for more complex and costly services. Thus, two federal objectives—service to patients of limited means and education of future providers—are accomplished with this modest but important program.

\$420 MILLION FOR THE NATIONAL INSTITUTE FOR DENTAL AND CRANIOFACIAL RESEARCH (NIDCR)

NIDCR is the only Institute within the National Institutes of Health (NIH) whose mission is to improve oral, dental and craniofacial health through research, research training, and the dissemination of health information. Oral disease affects nearly every American. It is essential that Congress increase support for NIDCR's diverse and critical research initiatives. Of paramount importance is funding for clinical research and dental school research infrastructure. Among the ongoing research projects being conducted by dental researchers is work on saliva as a reliable diagnostic fluid to detect systemic diseases in a non-invasive way, including the detection of cancer-associated molecules associated with oral squamous cell carcinoma as well as research on how to engineer teeth in the laboratory and transplant them into the mouth to replace a missing or damaged tooth. In any future NIH reorganization NIDCR should remain independent.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

*\$18 million for the CDC Oral Health Program*

The CDC Oral Health Program supports state and community-based programs that work to prevent oral disease and reduce disparities in oral health. The program works with states to establish surveillance systems that provide valuable health information to assess the effectiveness of programs and target them to populations at greatest risk. Grants have been used to support basic state oral health services, including support for program leadership, monitoring oral health risk factors, and developing and evaluating prevention programs such as community fluoridation and school-based sealant programs. Federal funding is essential to maintain these programs.

*\$130 million for the CDC Prevention Block Grant*

\$3.5 million of this amount is for oral health projects. The President's budget eliminates the program completely. The funding is 50 percent of the CDC money

<sup>2</sup>Journal of the American Dental Association (133 JADA 1343).

that flows back to states for oral health programs. It is used by states to purchase and replace fluoridation equipment and to maintain a state dental presence.

\$10 MILLION FOR THE DENTAL HEALTH IMPROVEMENT ACT ENACTED AS PART OF THE  
HEALTH CARE SAFETY NET AMENDMENTS OF 2002 (PUBLIC LAW 107-251)

The Dental Health Improvement Act will help, when funded, to eliminate the disparities in oral health status and assure access to oral health services for low-income children. The law authorized \$50 million over 5 years for innovative state oral health care grants. Congress has not yet provided funding for this important federal-state partnership. The American Dental Association (ADA) and the American Academy of Pediatric Dentists (AAPD) join ADEA in requesting \$10 million for this program in fiscal year 2006.

Grants can be used for a variety of state initiatives including loan forgiveness programs for dentists serving in dental health professions shortage areas (HPSAs); grants or low-interest loans for dentists participating in Medicaid; dental faculty recruitment programs; and establishment or augmentation of a state dental officer position to coordinate oral health and access issues in the state. The program, when funded, will be a shining example of a true federal-state partnership, as states must agree to match at least 40 percent of any federal contributions under this grant.

\$135 MILLION FOR THE MINORITY AND DISADVANTAGED ASSISTANCE PROGRAMS IN THE  
HEALTH PROFESSIONS EDUCATION AND TRAINING PROGRAMS

The infrastructure that has been established by previous federal investment requires sustained and increased support to meet the challenges of diversifying the health care workforce, addressing student indebtedness, eliminating faculty shortages, and eradicating oral health care disparities in underserved communities.

The President's fiscal year 2006 budget eliminates funding for the Centers of Excellence (COE) program, the Health Careers Opportunity Program (HCOP), and the Faculty Loan Repayment Program (FLRP) and reduces by nearly 80 percent the funding for Scholarships for Disadvantaged Students (SDS). These programs are crucial if we are to address concerns with health disparities. The COE, HCOP and SDS programs are essential in assisting economically disadvantaged students enter and graduate from health professions schools. Underrepresented minority recruitment and retention in the health professions is a serious problem. In 2004, the first-year enrollment of underrepresented minority students in dental school was just 11.3 percent of the total first year dental student enrollment. In 1990, the percentage of underrepresented minority students in the first year class was 13.8 percent of the total first year enrollment. While the FLRP assists in recruiting and retaining faculty, it is of particular importance to academic dentistry as there is currently a faculty shortage. ADEA strongly urges Congress to continue investing in HCOP, COE, SDS, and FLRP so that the health professions can make strides in diversifying the future health care workforce.

\$213 MILLION FOR THE NATIONAL HEALTH SERVICE CORPS (NHSC)

The National Health Service Corps Scholarship and Loan Repayment Programs assist students with financing their health professions education while promoting primary care access to underserved areas. It is critical that the NHSC receive increased funding to meet the growing health care needs in the nation's rural and underserved communities. The President's budget proposal cuts \$5 million from the NHSC budget at a time when it is crucial to maintain a pipeline of health providers in health professions shortage areas.

\$108 MILLION FOR THE INDIAN HEALTH SERVICE (IHS) DENTAL PROGRAMS

Maintaining the health care infrastructure and supporting the health care workforce that provides care to the Alaska Native/American Indian (AN/AI) population is essential in meeting the needs of Indian people. The IHS Loan Repayment Program makes payments on health care worker's student loans while they provide care at one of 280 hospital sites located around the country. The IHS Scholarship program provides both hope and financial support to AN/AI students pursuing careers in the health professions. Without these programs access to care as well education for the AN/AI population will surely worsen.

\$1 MILLION FOR A MEDICAID COMMISSION TO STUDY AND RECOMMEND CHANGES TO  
MEDICAID

ADEA supports the amendment in the Senate's fiscal year 2006 Budget Resolution that halts further cuts to Medicaid and instead establishes a reserve fund of

\$1 million to establish a Medicaid Commission to study and recommend changes needed in Medicaid. While expenditures on dental care account for less than 1 percent of all Medicaid expenditures, 25 million children enrolled in Medicaid are eligible for needed dental care under the program. Medicaid accounts for almost a quarter of all dental expenditures for children under age 6 and provides the only guarantee of relief from dental pain and infections, restoration of teeth and dental health for millions of children on Medicaid. The Medicaid program is the only access that many of the poorest and sickest adults have to critical emergency oral health care.

In conclusion, the American Dental Education Association appreciates consideration of our fiscal year 2006 budget recommendations for dental education and research. A sustained federal commitment is needed to help meet the challenges oral disease poses among the nation's most vulnerable citizens including children. So too is the development of a partnership between the federal government and dental education programs to implement a national oral health plan that guarantees access to dental care for everyone, ensures continued dental health research, eliminates disparities, and eliminates workforce shortages.

---

PREPARED STATEMENT OF THE AMERICAN GEOLOGICAL INSTITUTE

To the Chairman and Members of the Subcommittee: Thank you for this opportunity to provide the American Geological Institute's perspective on fiscal year 2006 appropriations for the Department of Education's Mathematics and Science Partnership program.

In 1999, the Third International Math and Science Study found that the longer U.S. students are in school, the farther they fall behind in math and science proficiency in international comparisons. That prompted President Bush to propose the National Math and Science Partnership (MSP) program as part of No Child Left Behind. The goal of the partnership program is to strengthen K-12 science and math education by promoting a vision of education as a continuum that begins with the youngest learners and progresses through adulthood with teacher training. Among its activities, the program supports partnerships that unite K-12 schools, institutions of higher education and private industry.

Congress took the president's suggestion and authorized an MSP program at the National Science Foundation (NSF) and another partnership program at the Department of Education in 2002. These two acts of Congress were meant to fund two different types of partnerships to achieve the overall goal of highly qualified math and science teachers ensuring that all students have the basic knowledge to compete in the ever changing and competitive job market. The funds allocated for the NSF's MSPs go to the highest quality proposals chosen through a competitive peer-reviewed grant program. The program focuses on modeling, testing and identification of effective math-science activities. The funds allocated for the Department of Education MSPs go directly to the states as formula grants, providing funds to all states to replicate and then implement the best of the NSF partnerships throughout the country. Once states receive the money, they make competitive grants to local partnerships.

At a hearing in October 2003, the House Science Committee found that these new partnership programs are "on the right track toward improving math and science education." Testifying before the committee, M. Susana Navarro, executive director of the El Paso Collaborative for Academic Excellence MSP, said: "What the MSP now provides is an opportunity to bring together partners across the community, K-16, toward the shared development and implementation of high quality math and science content and instructional practices aimed at improving student achievement among all students."

Just 3 months after that hearing, President Bush released his budget proposal for fiscal year 2005, which phased out the NSF partnership programs and shifted the funding to the MSP companion program at the Department of Education. However, the \$120 million increase requested for 2005 was not slated to fund additional MSPs on the local level; instead it would have financed a new program focused on accelerating the math education of secondary-school students, especially those who are at risk of dropping out of school because they lack basic skills in math.

The Senate Labor, Health and Human Services and Education did not go along entirely with the President's plan last year. The MSPs would have received \$200 million, 4.5 percent less than the President requested but \$51 million or 34 percent more than fiscal year 2004 funding in the Senate version of the bill. The report stated, "These funds will be used to improve the performance of students in the areas of math and science by bringing math and science teachers in elementary and sec-

ondary schools together with scientists, mathematicians, and engineers to increase the teachers' subject-matter knowledge and improve their teaching skills."

We applauded the Subcommittee because it did not choose to fund math over science and, ultimately, Congress did not choose to fund math over science. In last year's omnibus bill, the Math and Science Partnership budget increased 16 percent over fiscal year 2004 levels to \$179 million and none of those funds were set-aside for one subject.

This year, the President has proposed something similar. The fiscal year 2006 budget proposal increases the MSPs to \$269 million, an increase of \$90.4 million, or 51 percent, over the fiscal year 2005 level. Although a large increase has been proposed, the President's plan restricts \$120 million for the Secondary Education Mathematics Initiative, a competitive grant program to be administered by the Department of Education. This creates a net decrease in funding available to the states in fiscal year 2006 compared to the fiscal year 2005 allocations.

The \$120 million in funds for Secondary Education Mathematics Initiative is part of the overall High School Initiative, which will expand the application of No Child Left Behind principles to improve high school education and raise achievement, particularly the achievement of students most at risk of failure. This new initiative combines a number of categorical programs in order to give states and districts more flexibility and contains stronger accountability mechanisms.

AGI believes the two MSPs are the most effective approach to rapidly improving the abilities of all students to enhance their future prospects regardless of their ultimate career goals. The two programs, designed and authorized by Congress, are complementary. AGI supports funding at NSF for competitive grants for teaching tools and teacher training and funding at the Department of Education for formula grants for implementation of these tools in K-12 education. The peer-review process in the NSF program should be safeguarded as should the formula grants for all states as administered by the Department of Education. Moreover, the program within the Department of Education should not suffer a net reduction in funding in order to support a new initiative for mathematics. These funds should serve the Math and Science Partnership with no earmarks or set-asides.

Thank you for the opportunity to present this testimony to the Subcommittee. If you would like any additional information, please contact me at 703-379-2480, ext. 228 voice, 703-379-7563 fax, rowan@agiweb.org, or 4220 King Street, Alexandria VA 22302-1502.

---

#### PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

Mr. Chairman and Members of the Subcommittee, on behalf of this Nation's 34 Tribal Colleges and Universities (TCUs), which compose the American Indian Higher Education Consortium (AIHEC), thank you for the opportunity to share our fiscal year 2006 funding requests for programs within the U.S. Department of Education, and the U.S. Department of Health and Human Services—Head Start program.

This statement will cover two areas: (a) background on the tribal colleges, and (b) justifications for our funding recommendations.

##### I. BACKGROUND ON TRIBAL COLLEGES

The Tribal College Movement began in 1968 with the establishment of Navajo Community College, now Diné College, in Tsaile, Arizona. Rapid growth of tribal colleges soon followed, primarily in the Northern Plains region. In 1972, the first six tribally controlled colleges established AIHEC to provide a support network for member institutions. Today, AIHEC represents 34 Tribal Colleges and Universities located in 12 states, which were begun specifically to serve the higher education needs of American Indians. Annually, these institutions serve upwards of 30,000 full-and part-time students from over 250 Federally-recognized tribes.

Currently, all but one of our colleges is accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide much needed high school completion (GED), basic remediation, job training, college preparatory courses, and adult education. Tribal colleges fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public-meeting places, and child care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.



Tribal colleges provide access to higher education for American Indians and others living in some of this Nation's most rural and economically depressed areas. These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs combine traditional teachings with conventional postsecondary courses and curricula. They have developed innovative means to address the needs of tribal populations and are successful in overcoming long-standing barriers to higher education for American Indians. Since the first tribal college was established on the Navajo reservation, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to and promoting achievement among students who may otherwise never have known postsecondary education success.

Despite their remarkable accomplishments, tribal colleges remain the most poorly funded institutions of higher education in the country. Persistently inadequate funding remains the most significant barrier to their success. Funding for basic institutional operations of 26 reservation based colleges is provided through Title I of the Tribally Controlled College or University Assistance Act (Public Law 95-471). Funding under the Act was first appropriated in 1981. Almost 25 years later, the funding level is at just 75 percent of the authorized level of \$6,000 per Indian student, which is defined as an enrolled member of a Federally recognized tribe. In fiscal year 2005, these colleges are receiving \$4,447 per full-time equivalent Indian student toward their institutions operating budgets. While mainstream institutions have had a foundation of stable state tax-based support, TCUs must rely on year-to-year Federal appropriations for their basic institutional operating funds. Because TCUs are located on Federal trust territories, states have no obligation to fund them even for the non-Indian state-resident students who account for approximately 20 percent of TCU enrollments. Yet, if these same students attended any other public institution in the state, the state would provide basic operating funds to the institution.

Inadequate funding has left many of our colleges with no choice but to continue to operate under severely distressed conditions. Although facilities initiatives of the last few years have resulted in widespread renovation and construction at TCUs, many colleges began in surplus trailers; cast-off buildings; and facilities with crumbling foundations, faulty wiring, and leaking roofs, and therefore have a long way to go. Sustaining quality academic programs is a challenge without a reliable source of facilities maintenance and construction funding.

As a result of more than 200 years of Federal Indian policy—including policies of termination, assimilation and relocation—many reservation residents live in abject poverty comparable to that found in Third World nations. Through the efforts of tribal colleges, American Indian communities receive services they need to reestablish themselves as responsible, productive, and self reliant.

## II. JUSTIFICATIONS

### A. *Higher Education Act*

The Higher Education Act Amendments of 1998 created a separate section within Title III, Part A, specifically for the Nation's Tribal Colleges and Universities (Section 316). Titles III and V programs support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. TCUs clearly fit this definition as they are among the most poorly funded institutions in America, yet they serve some of the most impoverished areas of the country. TCUs are victims of their own success. This year two new tribal colleges are eligible to compete for funding under Title III. Despite the increase in the size of the pool of eligible institutions, the President's fiscal year 2006 Budget recommends level funding for this vital program. We urge the Subcommittee to fund section 316 at \$32 million, an increase of \$8.2 million over fiscal year 2005 and the President's request, and we ask that report language included in since fiscal year 2003 be restated clarifying that funds not needed to support continuation grants or new planning or implementation grants be available for facilities renovation and construction grants.

The importance of Pell grants to our students cannot be overstated. Department of Education figures show that at the majority of all tribal college students receive Pell grants, primarily because student income levels are so low and our students have far less access to other sources of aid than students at mainstream institutions. Within the Tribal College system, Pell grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping people gain access to higher education and become active, productive mem-

bers of the workforce. We urge Congress to fund this critical program at the highest possible level.

*B. Carl D. Perkins Vocational & Applied Technology Education Act*

*Tribally-Controlled Postsecondary Vocational Institutions.*—Section 117 of the Perkins Act provides basic operating funds for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Crownpoint Institute of Technology in Crownpoint, New Mexico. We urge that Congress fund this program at \$8.5 million. Included in both the House and Senate reauthorization bills, which are being considered in the 109th Congress is language waiving section 117 grantees from having to utilize a restricted indirect cost rate, since the timeline for enactment of the reauthorizing legislation is uncertain, we ask that you reiterate the language that has been included in this appropriations measure since fiscal year 2002 stating that Section 117 Perkins grantees need not utilize restricted indirect cost rate.

The President's fiscal year 2006 budget once again proposes the elimination of the Native American Program Section 116, which reserves 1.25 percent of appropriated funding to support Indian vocational programs. We strongly urge Congress to continue this program, which is vital to the survival of vocational education programs being offered at TCUs.

*C. Greater Support of Indian Education Programs*

*American Indian Adult and Basic Education.*—This section supports adult education programs for American Indians offered by TCUs, state and local education agencies, Indian tribes, institutions, and agencies. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, learn to read. According to a 1995 survey conducted by the Carnegie Foundation for the Advancement of Teaching, 20 percent of the participating students had completed a tribal college GED program before beginning higher education classes at the tribal college. At some schools, the percentage is even higher. Clearly, there is a tremendous need for basic educational programs, and TCUs need funding to support these crucial activities. Tribal colleges respectfully request that Congress appropriate \$5 million to meet the ever increasing demand for basic adult education and remediation program services.

*American Indian Teacher Corps.*—American Indians are severely under-represented in the teaching and school administrator ranks nationally. These competitive programs, aimed at producing new American Indian teachers and school administrators for schools serving American Indian students, support the recruitment, training, and in-service professional development programs for Indians to become effective teachers and school administrators, and in doing so excellent role models for Indian children. We believe that the TCUs are the ideal catalysts for these initiatives because of our current work in this area and the existing articulation agreements TCUs hold with 4-year degree awarding institutions. We request that Congress support these programs at \$10 million and \$5 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.

*D. Department of Health and Human Services/Administration for Children & Families/Head Start*

*Tribal Colleges and Universities (TCU) Head Start Partnership Program.*—The TCU/Head Start partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. New graduates of these programs can help meet the mandate that 50 percent of all program teachers earn an associate degree in Early Childhood Development or a related discipline. More importantly, this program has afforded American Indian children Head Start programs of the highest quality. A clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funding made available for the TCU/Head Start partnership. Since fiscal year 1999, the first year of the program, a total of just 15 tribal colleges have been able to participate in this valuable program. Some colleges were awarded 3-year grants, others 5-year grants, and in fiscal year 2002 there were no new grants funded at all. In fiscal year 2003, funding for eight new grants was made available, but in fiscal year 2004, only two new awards could be made because of the lack of adequate funds. The President's fiscal year 2006 budget includes a total request of \$6.9 billion for Head Start Programs. We request Congress direct the Head Start Bureau to designate a minimum of \$5 million for the TCU/Head Start Partnership program, to ensure that this critical program can be continued

and be expanded so that all TCUs might participate in the TCU- Head Start partnership program.

### III. CONCLUSION

Tribal colleges and universities are bringing education to thousands of American Indians. The modest Federal investment in the TCUs has paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. Tribal colleges need your help if they are to sustain and grow their programs and achieve their missions.

Thank you again for this opportunity to present our funding recommendations. We respectfully ask the Members of this Subcommittee for their continued support of the Nation's tribal colleges and universities and full consideration of their fiscal year 2006 appropriations needs and recommendations.

#### PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Mr. Chairman, thank you very much for the opportunity to present the views of the Association of Minority Health Professions Schools (AMHPS). I am Dr. John E. Maupin, President of Meharry Medical College in Nashville, Tennessee and President of AMHPS.

AMHPS is comprised of the nation's 12 historically black medical, dental, pharmacy, and veterinary. Combined, our institutions have graduated 50 percent of African-American physicians and dentists, 60 percent of all the nation's African-American pharmacists, and 75 percent of the African-American veterinarians.

Mr. Chairman, historically black health professions institutions are addressing a pressing national need in carrying out their mission of training minorities in the health professions. While African-Americans represent approximately 15 percent of the U.S. population, only 2-3 percent of the nation's health professions workforce is African-American. Studies have demonstrated that when African Americans and other minorities are trained in minority institutions, they are much more likely to: (1) serve in medically underserved areas, (2) care for minorities, and (3) accept patients who are Medicaid dependent or otherwise poor.

This is important Mr. Chairman because the gap in health status between our nation's minority and majority populations continues to widen due in part to the lack of access to quality health care services in minority communities. As a result, we believe it is imperative that the federal commitment to training African Americans and other minorities in the health professions remains strong.

In spite of our proven success in training health professionals, and the important contribution these professionals make, our institutions continue to face a financial struggle inherent to our mission. The financial challenges facing the majority of our students affect our institutions in numerous ways. For example, we are unable to depend on tuition as a means by which to respond to any discontinuation of federal support. Moreover, the patient populations served by the AMHPS institutions are overwhelmingly poor. As a result, our institutions cannot rely on patient care income at a time when the average medical school gets 40-60 percent of its operating revenue from health care services.

Mr. Chairman, before I present AMHPS's appropriations recommendations for fiscal year 2006, I would like to express my sincere appreciation for your leadership in restoring funding for the Health Resources and Services Administration's health professions training programs in fiscal year 2005. For many of our schools, support from these programs represent the difference between our doors being open or closed. We cannot overstate our gratitude for your leadership in this area.

#### FISCAL YEAR 2006 RECOMMENDATIONS FOR FEDERAL PROGRAMS OF INTEREST TO AMHPS

##### *Health Resources and Services Administration*

##### *Health Professions Training*

The health professions training programs administered by the Health Resources and Services Administration are the only federal initiatives designed to address the longstanding under-representation of minority individuals in health careers. HRSA's Minority Centers of Excellence, Health Careers Opportunity Program, and Scholarships for Disadvantaged Students, support health professions institutions with a historic mission and commitment to increasing the number of minorities in the health professions.

Mr. Chairman, our schools and students greatly appreciate the subcommittee's consistent support of these important programs. However, we are very disappointed

that the administration's budget all but eliminates funding again this year for health professions programs focused on diversity in the workforce. For fiscal year 2006, AMHPS joins with the Health Professions Nursing and Education Coalition in recommending a funding level of at least \$300 million for Title VII health professions training programs.

For the health professions programs specifically focused on enhancing minority representation in the health care workforce AMHPS recommendations are as follows:

*Minority Centers of Excellence*

The purpose of the Minority Centers of Excellence program (COE) is to assist schools that train minority health professionals by supporting programs of excellence in health professions education at those institutions. The COE program focuses on improving student recruitment and performance; improving curricula and cultural competence of graduates; facilitating faculty/student research on minority health issues; and training students to provide health services to minority individuals by providing clinical teaching at community-based health facilities.

For fiscal year 2006, AMHPS recommends a funding level of \$40 million for Minority Centers of Excellence (an increase of \$6.1 million over fiscal year 2005).

*Health Careers Opportunity Program*

Grants made to health professions schools and educational entities under the Health Careers Opportunity Program (HCOP) enhance the ability of individuals from disadvantaged backgrounds to improve their competitiveness to enter and graduate from health professions schools. HCOP funds activities that are designed to develop a more competitive applicant pool through partnerships with institutions of higher education, school districts, and other community based entities. HCOP also provides for mentoring, counseling, primary care exposure activities and information regarding careers in a primary care discipline. Sources of financial aid are provided to students as well as assistance in entering into the health professions school

For fiscal year 2006, AMHPS recommends a funding level of \$40 million for the Health Careers and Opportunities Program (an increase of \$4.1 million over fiscal year 2005).

*Scholarships for Disadvantaged Students*

The Scholarships for Disadvantaged Students program was established to make scholarship funds available to eligible students from disadvantaged backgrounds who are enrolled (or accepted for enrollment) as full-time students. To be eligible for funding, a school must have in place a program to recruit and retain students from disadvantaged backgrounds (including racial and ethnic minorities) and demonstrate that the program has achieved success based on the number or percentage of disadvantaged students who graduate from the school.

For fiscal year 2006, AMHPS recommends a funding level of \$55 million for the Scholarships for Disadvantaged Students program (an increase of \$7.5 million over fiscal year 2005).

HEALTHY COMMUNITIES ACCESS PROGRAM

Mr. Chairman, as you know, Congress passed legislation last year in 2003 to reauthorize the Community Health Centers program. Included in this important measure was a provision which established a demonstration authority within the Healthy Community Access Program to foster greater collaboration between historically black health professions and federally qualified CHC's. Specifically, this provision:

(1) Establishes a demonstration program for the development of research infrastructure at historically black health professions schools affiliated with federally qualified Community Health Centers.

(2) Establishes joint and collaborative programs of medical research and data collection between historically black health professions schools and federally qualified Community Health Centers with the goal of improving the health status of medically underserved populations.

(3) Supports the cost of patient care, data collection, and academic training resulting from these partnerships.

Mr. Chairman, Meharry Medical College and other members of our Association successfully applied for funding under this new demonstration authority in fiscal year 2005. These funds are making an important contribution at all of our institutions. For fiscal year 2006, we encourage the subcommittee to restore funding for the Health Communities Access Program to \$83 million.

## NATIONAL INSTITUTES OF HEALTH

*The National Center on Minority Health and Health Disparities*

Established in 2000 by the Minority Health and Health Disparities Research and Education Act (Public Law 106–525), the National Center on Minority Health and Health Disparities at NIH is charged with addressing the longstanding health status gap between minority and majority populations. The National Center has the authority to:

- Directly support biomedical research, training, and information dissemination focused on eliminating health status disparities.
- Serve in a leadership capacity in developing a comprehensive plan for minority health research at NIH.
- Participate as an equal when NIH institute and center directors meet to determine research policy.
- Support the enhancement of biomedical research capacity at minority health professions institutions through a “Research Endowment” program.
- Support the development of health professions institutions with a history and mission of serving minority and medically underserved communities through a “Centers of Excellence” program.

For fiscal year 2006, AMHPS recommends a funding level of \$250 million for the National Center. This is an increase of \$53 million. This new funding will enable the Center to support all of its new programs and begin to meet the challenge of eliminating health status disparities within minority and medically underserved communities.

*Extramural Facilities Construction*

Mr. Chairman, if we are to take full advantage of the historic increases in biomedical research funding that Congress has provided to NIH, it is critical that our nation’s research infrastructure remain strong.

Under legislation passed in 2001, the authorization level for the Extramural Facility Construction program at the National Center for Research Resources was increased from \$150 million to \$250 million. In addition, the law maintains the 25 percent set-aside for Institutions of Emerging Excellence (many of which are minority institutions) for funding up to \$50 million and allows the NCRR director to waive the matching requirement for participation in the program.

Unfortunately, funding for the Extramural Facility Construction program was cut from \$119 million in fiscal year 2004 to \$30 million in fiscal year 2005. AMHPS encourages the subcommittee to prioritize support for this important program in fiscal year 2006 by restoring funding to the fiscal year 2004 level.

*Research Centers at Minority Institutions*

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, AMHPS recommends that funding for this important program grow at the same rate as NIH overall in fiscal year 2005.

## STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS—DEPARTMENT OF EDUCATION

The Department of Education’s Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to AMHPS institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities.

For fiscal year 2006, AMHPS recommends an appropriation of \$65 million (an increase of \$6.5 million over fiscal year 2005) to continue the vital support that this program provides to historically black graduate institutions.

## HHS OFFICE OF MINORITY HEALTH

The HHS Office of Minority Health (OMH) has the potential to play a critical role in addressing health status disparities throughout the country. Unfortunately, the office does not currently have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations. For fiscal year 2006, AMHPS recommends a funding level of \$65 million for the Office, with \$10 million designated for the following programs

focused on medically underserved communities and capacity building for the training of minorities in health professions:

(1) OMH sponsored programs to assist medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals;

(2) Assistance to minority institutions in acquiring real property to expand their campuses to increase the capacity to train minorities for medical careers;

(3) Support of conferences for high school and undergraduate students to pursue health professions careers; and

(4) Support for cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

Once again, thank you for the opportunity to present the views of the Association of Minority Health Professions Schools. We look forward to working with you in support of these important programs.

---

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY CENTERS ON  
DISABILITIES

Mr. Chairman, on behalf of the Association of University Centers on Disabilities, I am pleased to submit this written testimony for the record both as a means to thank you for the Committee's support of our Centers in fiscal year 2005, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs). The network of UCEDDs is a showcase for unique and effective models for developing approaches and gathering new knowledge in the field of developmental disabilities and sharing this knowledge both nationally and internationally, as well as in our own states to improve the lives of people with developmental and other disabilities. I am Fred Palmer, Director of the Boling Center for Developmental Disabilities, Tennessee's University Center for Excellence in Developmental Disabilities at the University of Tennessee Health Science Center, and President of the Association of University Centers on Disabilities.

The mission of the UCEDDs is to advance policy and practice, for and with people with developmental and other disabilities, their families and communities. As a network of 61 interdisciplinary Centers across the United States and its Territories, we work to ensure full participation in all aspects of living for individuals with disabilities.

Since the early 1960s, when Congress established a small number of research centers to study mental retardation, we have grown into a national network where each University Center has developed its own area(s) of expertise based on the needs of the local community, state, and evolving expectations of people with disabilities nationwide to be more included in community life. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106-402) we currently focus our work on serving as a national education and training, service and information resource and research entity for our nation.

We are extremely grateful that in fiscal year 2005, the Congress increased funding for the UCEDDs by \$5 million, bringing our current funding to \$31.5 million. This increase has provided us with an opportunity that has not existed in over a decade—the opportunity to increase the number of Centers in our network in order to better serve people with disabilities. With this money, we will establish three new Centers in states where there is a large minority population and/or difficulties reaching people with disabilities due to geographic hardships. The increased funding also provides each current Center with additional dollars to conduct research and provide community supports and services as outlined in the DD Act, essentially funding each current Center at the level authorized in 2000. Additionally, the increased funding allows the Administration on Developmental Disabilities to compete one or two small National Training Initiative grants which allow the grantee to conduct community-based training on a topical area of national significance.

We are respectfully seeking an appropriation of \$37 million for the network of Centers for fiscal year 2006. This increase will allow funding for the three new Centers to be increased to the same funding as the existing 61 Centers, as well as to continue our ability to establish additional Center grants in the five states that currently have unserved and underserved populations, and support for four new Centers that specialize in minority health disparities and education issues.

AUCD believes that all people with disabilities must have the opportunity to maximize their potential, and have equal and meaningful access to all programs that help people be part of community life. We have been honored and pleased to

work with President Bush and his Administration to carry out initiatives established in the New Freedom Initiative. Through Executive Order 12317, "Community-Based Alternatives for Individuals with Disabilities" we are working at the state and national level to implement programs and secure funding to rebalance the system of care for individuals with disabilities and their families. We believe that the country is at a turning point in time that can truly change the way that individuals with disabilities are perceived and treated. By helping states rebalance their service systems to serve people in the community first, as opposed to institutional settings, we are truly working to achieve the President's goals set forward in the Executive Order.

The UCEDDs focus their work in a concerted effort through the areas of education and training at the university and community level; research, both basic and applied; and service provision at the individual and family level. Please allow me this opportunity to provide you with some examples.

*Education.*—Quality of life in the community for individuals with disabilities depends upon well-trained professionals. Positioned within the university, UCEDDs educate professionals-in-training in interdisciplinary approaches and provide continuing education for professionals practicing in multiple fields relating to disabilities. Whether the focus is on leadership, direct service, clinical or other personnel training, these pre-service and continuing education programs are geared to the needs of students, fellows, and practicing professionals and have been essential in raising and defining the educational standards of service across health, education, employment and social service systems. Further, they have increased the capacity of States to be responsive to the needs of individuals with disabilities.

Each year, UCEDDs provide education and training to approximately 500,000 health, education, mental health, and policy-making professionals, as well as people with disabilities and their families. UCEDDs in communities nationwide provide this essential education and training.

For example, one issue that Centers focus on nationally is positive behavioral supports. One UCEDD in Oregon houses the Center on Positive Behavioral Intervention and Support. The Center assists local schools in identifying, adapting, and sustaining effective behavioral practices, including school-wide discipline programs. Results from their replication efforts in over 400 schools nationwide indicate that their technical assistance and research has enhanced schools' capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction.

Through a partnership with the Centers for Disease Control and Prevention (CDC), the network of UCEDDs are designing and disseminating training materials on Down Syndrome and Spina Bifida. Educational modules are being designed for use in medical schools for training physicians in recognition and recommended treatments for these two conditions. Materials from these efforts will be disseminated to medical schools throughout the country.

*Research.*—UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. From basic research to applied research and policy analysis, University Centers work to link research to public policy and professional practice. By studying areas such as brain development, autism spectrum disorders, and early literacy, UCEDD researchers are learning how children and adults learn and how best to teach them. UCEDDs lead in developing and evaluating new ideas and promising practices that improve the lives of children and adults with disabilities and their families and increase their access to quality services. Many participate in federally established research projects to study and disseminate information on the causes and prevention of disabilities and chronic conditions.

One example of how research impacts upon policy and practice is a collaborative effort between one UCEDD and its state Department of Education and Department of Health and Human Services. Together they are studying the issues of access to, and retention in, high quality childcare for all children throughout the state. This multi-year, interdepartmental initiative is studying ways to develop a coordinated system of inclusive childcare and early education for all children, including those who are at risk due to poverty, disability, social-emotional and behavioral challenges, abuse, or language and cultural differences. By implementing and studying various systems of support for childcare providers, the UCEDD will be able to inform policymakers in areas such as staff development and retention of childcare staff, providing childcare support to TANF families, inclusive childcare support for children with disabilities, and supporting children in foster care.

*Service.*—UCEDDs provide direct services and supports to people with developmental and other disabilities, their families, and communities, including state-of-the-art diagnosis, evaluation, and support services for children and adults with dis-

abilities in health care, cognitive development, behavior disorders, education, daily living, and work skills. Moreover, through technical assistance to other providers, they magnify the impact of their programs, reducing disparities among individuals and communities.

In Ohio, one UCEDD is working with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are in urban areas, families in Appalachia were traveling 100 miles to the city for multiple evaluations by individual disciplines. This resulted in a great expense in time and money for the family. The Center now sends teams of providers to rural areas to provide interdisciplinary care to families. They provide evaluation of children, training for local healthcare providers, and support for the families through a system of rural clinics. These clinics are improving access of needed services to families and providers and help local providers to better diagnose developmental disabilities such as cerebral palsy, fetal alcohol syndrome, autism and other genetic disorders.

UCEDDs also lead in improving the lives of people with disabilities through new technologies. More than 20 UCEDDs including those in Pennsylvania, Iowa, Texas, and Utah provide services that help individuals assess their technology needs and get the equipment they need to read, hear, speak, write, learn, work, play, and fully participate in their communities.

*Responding to National Needs.*—UCEDDs are equipped to respond quickly to emerging national needs. We are currently expanding our work in the area of aging and disability. As we continue to see people with disabilities living longer, aging parents need community support to ensure the safety and well-being of their adult aged children when they can no longer care for them and communities must be prepared. UCEDDs are working in communities on many aging-related projects and working with the White House Conference on Aging to ensure that aging and disability is part of the national dialogue. We continue to work with the federal government on policies and initiatives on emergency preparedness for people with developmental and other disabilities sharing much of our expertise and experience that came with the September 11 disaster. Other national issues that have been addressed by UCEDDs have included treatment and diagnosis of Autism and Related Spectrum Disorders, reading disorders in children, design and dissemination of training programs for direct support personnel in developmental disabilities, provision of training in methods to support employment for individuals with disabilities and improvement of housing options for individuals with disabilities and their families.

I again ask that you consider our request for \$37 million for the network of UCEDDs so that we may expand our network to more adequately serve our nation's growing population of Americans with developmental and related disabilities and to address our nation's health disparities.

Thank you for the opportunity to share this information about the UCEDDs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

---

PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND  
SCIENCE

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2006

1. A 6 percent increase for all institutes and centers at the National Institutes of Health (NIH), specifically the National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).

2. Urge NCI to continue to support the establishment of collaborative minority health comprehensive cancer centers at historically minority institutions in collaboration with existing NCI cancer centers. Continue to urge NCRR and NCMHD to collaborate on the establishment of a cancer center at a historically minority institution.

3. Urge the Department of Health and Human Services, particularly the Office of Minority Health (OMH), to develop a focused effort on faculty support to address the residency training programs at minority medical institutions.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present you with testimony. Charles R. Drew University is one of four predominantly minority medical schools in the country, and the only one located west of the Mississippi River.



Charles R. Drew University of Medicine and Science is located in the Watts-section of South Central Los Angeles, and has a mission of rendering quality medical education to underrepresented minority students, and, through its affiliation with the University of California Los Angeles (UCLA) at the co-located King-Drew Medical Center, Drew provides valuable health care services to the medically underserved community. Through innovative basic science, clinical, and health services research programs, Drew University works to address the health and social issues that strike hardest and deepest among inner city and minority populations.

The population of this medically underserved community is predominately African American and Hispanic. Many of these people would be without health care if not for the services provided by the King-Drew Medical Center and Charles R. Drew University of Medicine and Science. This record of service has led Charles R. Drew University (in partnership with UCLA School of Medicine) to be designated as a Health Resources and Services Administration Minority Center of Excellence.

#### A RESPONSE TO HEALTH DISPARITIES

Racial and ethnic disparities in health outcomes for a multitude of major diseases in minority and underserved communities continue to plague this nation that was built on a premise of equality. As articulated in the Institute of Medicine report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care", this problem is not getting better on its own. For example, African American males develop cancer fifteen percent more frequently than white males. Similarly, African American women are not as likely as white women to develop breast cancer, but are much more likely to die from the disease once it is detected. In fact, according to the American Cancer Society, those who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care, typically experience high cancer incidence and mortality rates. Despite these devastating statistics, we are still not doing enough to try to combat cancer in our communities.

In response to these findings and the high cancer rate in our own community, Charles R. Drew University of Medicine and Science proposes that a Minority Health Comprehensive Cancer Center be built on its campus.

The Center would specialize in providing not only medical treatment services for the community, but would also serve as a research facility, focusing on prevention and the development of new strategies in the fight against cancer.

Mr. Chairman, the support that this subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers has and continues to be invaluable to our University and our community. The dream of a state of the art facility to aid in the fight against cancer in our underserved community would be impossible without the resources of NIH.

To help facilitate the establishment of a Minority Health Comprehensive Cancer Center at Charles R. Drew University of Medicine and Science, the University is seeking support from the National Institutes of Health's National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).

#### ACADEMIC RENEWAL AND CLINICAL FACULTY RECRUITMENT

Some of the major challenges faced in sustaining high quality graduate medical education programs in "safety-net" medical centers with missions focused on the medically underserved, are directly related to the lack of sufficient numbers of clinical faculty highly trained in academic medicine. To address these challenges, a plan for academic enrichment is proposed.

The plan is a strategic initiative to position Charles R. Drew University in the first decade of the 21st Century, as a leader in Urban Academic Health Sciences with an emphasis on training physicians and other health professionals to meet the needs of the medically underserved. The Plan for Academic Enrichment is an opportunity to enhance the impact of Charles R. Drew University as a national center of excellence in meeting the national, state, and local challenge of preparing a diverse complement of excellent physicians and other health professionals to close the health disparity gap by affording culturally sensitive quality care to the medically underserved and economically disadvantaged. A central component of the plan is the enrichment of academic excellence through the recruitment of new, highly qualified clinical teaching faculty, with solid research skills, to be members of the Charles R. Drew College of Medicine faculty to strengthen both the graduate and undergraduate medical education programs.

## CONCLUSION

Despite our knowledge about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the “gap” continues to widen in most instances. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventive care and/or research is completely inaccessible either due to distance or lack of facilities and expertise. This is a critical loss of untapped potential in both physical and intellectual contributions to the entire society.

Even though institutions like Drew are ideally situated (by location, population, and institutional commitment) for the study of conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, this cancer center will facilitate translation of insights gained through research into greater understanding of disparities in cancer incidence, morbidity and mortality and ultimately to improved outcomes.

We look forward to working with you to lessen the burden of cancer for all Americans through greater understanding of cancer, its causes, and its cures. We also look forward to working with the Department of Health and Human Services to address the residency training program issues at Charles R. Drew University.

Mr. Chairman, thank you for the opportunity to present on behalf of Charles R. Drew University of Medicine and Science.

---

PREPARED STATEMENT OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION (CSAVR)

Mr. Chairman and Members of the Senate Appropriations Subcommittee: This testimony is submitted on behalf of the Council of State Administrators of Vocational Rehabilitation (CSAVR) in conjunction with the hearing held on March 2, 2005 before the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

The CSAVR is composed of the chief administrators of the State Vocational Rehabilitation (VR) Agencies serving individuals with physical and/or mental disabilities in the United States, the District of Columbia and the Territories. These agencies constitute the state partners in the State-Federal Program of Rehabilitation Services provided under Title 1 of the Rehabilitation Act of 1973, as amended. State VR agencies provide individualized services and supports to eligible individuals with significant disabilities that are required for them to go to work. These services may include, but are not limited to, counseling and guidance, job training, higher education, physical and mental restoration services, and assistive technology. Over 1 million individuals with disabilities are served annually. In fiscal year 2004, these agencies placed over 213,000 individuals with disabilities into competitive employment.

The CSAVR, founded in 1940 to furnish input into the State-Federal Rehabilitation Program, provides a forum for state administrators to study, deliberate, and act upon matters affecting the rehabilitation and employment of individuals with disabilities. The Council serves as a resource for the formulation and expression of the collective points of view of state rehabilitation agencies on all issues affecting the provision of quality employment and rehabilitation services to persons with significant disabilities.

For fiscal year 2006, CSAVR recommends an increase in the Vocational Rehabilitation (VR) appropriation of \$125 million above the President’s budget request for fiscal year 2006. While the President’s budget proposes a 3.2 percent increase in funding for the Public VR program, an increase of approximately 1.2 percent above the mandated CPI called for in law, this increase is based on the elimination of several smaller programs (Supported Employment (SE), Projects With Industry (PWI), and Migrant and Seasonal Farm Workers (MSFW), with an assumption that VR will continue to provide services, under Title 1 of the Rehabilitation Act, to the individuals previously served under these programs. The President’s budget request for fiscal year 2006 is between \$22 and \$25 million less than the consolidated funding for these three programs; thus, VR would need additional funding for services to accommodate for the elimination of these programs. In addition to the proposed elimination of the SE, PWI, and MSFW programs, which CSAVR does not support, H.R. 27, the House bill to reauthorize the Workforce Investment Act (WIA), expands the requirements for VR to provide transition services to students with disabilities. CSAVR also anticipates that S. 9, the Senate bill to reauthorize the WIA, will include expanded transition requirements, when it is reintroduced as a free-standing bill. Based on the significant internal and external challenges facing the Public VR

Program, (i.e., staffing shortages, state budget shortfalls, increased numbers of consumers seeking services, and increased service expectations, the CSAVR believes that an increased appropriation of \$125 million above the President's budget request for VR, for fiscal year 2006, is an appropriate recommendation.

#### THE PUBLIC VOCATIONAL REHABILITATION PROGRAM

The Public VR Program is one of the most cost-effective programs ever created by Congress. It enables hundreds of thousands of individuals with disabilities to go to work each year and become tax-paying citizens. In fiscal year 2004, the VR Program assisted over 1 million individuals with disabilities who wanted to work, by providing them with the job skills, training and support services they needed to become employed. Of those served, more than 213,000 entered into competitive employment. Funding for the VR Program requires a state match of 21.3 percent, and creates a state-federal partnership that has worked effectively for more than 85 years, and has assisted over 15 million individuals with disabilities to engage in employment and become tax-paying citizens.

The Rehabilitation Act mandates that the annual Federal appropriation for the VR Program grow at a rate at least equal to the change in the Consumer Price Index (CPI) over the previous fiscal year. While the mandate was intended to create a floor for the VR appropriation, Congress has not appropriated funds above the mandated CPI increase since 1999. This is particularly problematic because the formula used to distribute these funds, which is based on a state's per capita income and population, results in significant variations in the increases in individual State's allotments. When the increase is limited to the CPI increase and the formula is applied, not all states receive increases that are equal to the annual rate of inflation. In fiscal year 2005, 30 states did not receive the 1.977 percent required CPI increase in their state allotment.

#### CHALLENGES FACING THE PUBLIC VR PROGRAM

Over the last several years, the Public VR Program has faced a number of external challenges that have been compounded by the minimal increases in Federal funding.

##### *Special Education*

Between 1990 and 2004, the federal appropriation for special education increased by approximately 333 percent. During the same time period, the federal appropriation for the Public VR Program increased by only 22 percent. As a result of these very significant increases in special education funding, an ever-increasing number of special education students are exiting the education system and seeking adult services, including Vocational Rehabilitation, in order to participate in post secondary education, job training, and/or to go to work. In addition, the House passed the Job Training Improvement Act in March 2005, which adds additional responsibilities to State VR agencies for the provision of transition services, beyond those presently required by current law. The Senate bill, S. 9, is also anticipated to add new transition responsibilities for VR when it is reintroduced. These additional requirements, if implemented effectively, will place a tremendous burden on the fiscal and personnel resources of State VR agencies, many of which are already sorely under-funded to meet the needs of adults with significant disabilities who are seeking employment.

##### *Impact of the Workforce Investment Act of 1998 (WIA)*

The Public VR Program is a mandatory partner in the WIA and, as such, is required to contribute significant resources to support the infrastructure and other costs associated with the operation of the One-Stop Centers. While VR's involvement in State Workforce Investment Systems is critically important, WIA has placed yet another financial burden on an already strained program, further reducing the percentage of VR funds that are available to provide services and supports to eligible individuals with disabilities. In addition, the House bill to reauthorize the WIA, H.R. 27, proposes to take significant resources from the Public VR Program far beyond the resources contributed to the One-Stop Centers under current law. The Senate bill, S. 9, also requires additional resources from VR to fund the infrastructure costs and other common costs associated with the operation of One-Stop Centers.

##### *Impact of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA)*

The TWWIIA was designed to address disincentives to work found in the Social Security Disability Insurance Program (SSDI) and the Supplemental Security Income Program (SSI), and to increase employment opportunities for individuals en-

rolled in these programs. Research has shown that less than one-half of one percent of these individuals leaves the Social Security disability rolls each year as a result of paid employment. The provisions in TWWIA that provide extended Medicare and Medicaid coverage to such individuals, when they enter or return to the workforce, are expected to encourage more beneficiaries to seek employment. Despite the establishment of a network of private providers to offer employment services to beneficiaries, the majority of beneficiaries, 90 percent, continue to seek services from State VR Agencies. With only minimal increases in VR funding over the last decade, this situation creates yet another challenge for the Public VR Program.

*Temporary Assistance for Needy Families (TANF)*

Most states have had significant success in reducing their TANF, or welfare to work caseloads. While TANF caseloads have been shrinking, the composition of the remaining caseload has changed. A 2002 General Accounting Office (GAO) report found that individuals with disabilities and their family members represent approximately 44 percent of the remaining TANF population. Since many of these individuals have multiple and significant barriers to employment, state welfare agencies are increasingly turning to State VR Agencies for assistance in serving these individuals. With only minimal increases in funding, and 42 State VR Agencies operating under an Order of Selection, a system of prioritization whereby individuals with the most significant disabilities are served first, it is becoming increasingly difficult, if not impossible, for State VR Agencies to serve the increased numbers of TANF referrals.

As stated earlier, the Public VR Program is one of the most cost-effective programs ever created by Congress. Evidence of its success is further established by:

- A 2002 Longitudinal Study of the Public VR Program which provided evidenced based research that the VR Program is effective in putting people with disabilities to work in good jobs with opportunities for advancement.
- A fiscal year 2005 Program Assessment Rating Tool (PART), developed by the Office of Management and Budget (OMB) to rate program performance, rated the VR Program favorably, and in general, successful in meeting its program goal.
- A report by the Social Security Administration, released annually, that provides detailed information on the funds disbursed to State VR Agencies, based on their successfully serving beneficiaries on Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). In fiscal year 2004 SSA projected a \$470.3 million savings to the Trust Fund by the VR Program, and established that every \$1.00 that SSA spends on VR results in a \$6.00 savings.

In this era of federal and state budget deficits, and an increase in the unemployment rate for individuals with disabilities, we urge you to consider an increase in funding for the Public VR Program, through which you can be assured to have positive outcomes, based on the three factors mentioned above.

Our nation's ability to be competitive in a global economy depends on the quality of our workforce. According to a report released by the Department of Labor, Employment & Training Administration, during the fiscal year 2005 Budget Briefing, the American workforce will be vastly different than it is today, as the 21st century unfolds. Integrating all available workers into the workforce, including workers with significant disabilities, will be required for employers to meet the demands of the 21st century economy. Significant numbers of large and small employers have acknowledged that hiring individuals with disabilities makes good business sense. It provides them with dependable workers and access to a market of individuals with spending power, which has historically been untapped. These same employers also have long-standing, positive relationships with VR, to whom they look to provide them with qualified workers with disabilities. Integrating all available workers into the workforce, including workers with disabilities, will require significant resources. VR's positive relationships with employers, who rely heavily on the Public VR Program to meet their hiring needs, further emphasizes and documents the need for additional resources for VR.

---

PREPARED STATEMENT OF THE FLORIDA DEPARTMENT OF EDUCATION

Chairman Specter, and other distinguished members of the Subcommittee: My name is Carlos R. Saavedra. I am the Director of the Adult Migrant Program and Services Section of the Florida Department of Education and submit my testimony for consideration by the Subcommittee regarding the Workforce Investment Act, Title I, Section 167 National Farmworker Jobs Program. The Florida Department of Education is the grantee for the National Farmworker Jobs Program and has op-

erated this program successfully for past years, under the aegis of the Office of Economic Development, the Comprehensive Employment and Training Act, and the Jobs Training Partnership Act.

As you are aware, the President's budget for 2006 proposes to eliminate the National Farmworker Jobs Program. This action appears to be prompted by a reduction in the United States Department of Labor's Employment and Training budget; the conviction that farmworkers will receive similar services through the One-Stop Centers and the local One-Stop Systems; and the belief that the National Farmworker Jobs Program is ineffective and duplicates other programs.

There are many issues that remain to be addressed and resolved first if the One-Stop Centers and the One-Stop Systems are to fulfill the mandate to serve migrant and seasonal farmworkers as part of their universe of clients. At the very least, state and local workforce boards will need to deal with issues of program performance and the manner for reaching farmworkers with services. Farmworkers live and work in the margins of small rural towns, where the One-Stop Systems have limited representation.

As regards performance, local workforce boards and their service providers currently receive few, if any, incentives from the state workforce boards to serve farmworkers and other populations with special needs. Consequently, providers feel obliged to job place many clients in the shortest time possible, with little consideration of their need for remedial education and customized skills training, which farmworkers and other special population with special needs require. Under current conditions, local workforce boards and their providers see little or no benefit to enrolling individuals with extremely low education levels and high mobility rates, as is the case with migrant farmworkers. This is the current state of services to migrant and seasonal farmworkers via the One-Stop Centers and the One-Stop Delivery System in many states where farmworkers are a significant part of the overall workforce.

As regards farmworkers' access to services, the degree and mix of employment, training and supportive services that farmworkers receive in their communities today is possible because of funding by the National Farmworker Jobs Program. The National Farmworker Jobs Program supports customized service strategies with bilingual and bicultural staff that serve as a bridge between the farmworker community and the services and those educational programs offered by community and faith-based organizations and public institutions that are attuned to the needs of youth and adult learners. It is worth noting that the National Farmworker Jobs Program has high performance standards and outcome measures that are consistently met or exceeded. The outcomes for the Farmworker Jobs and Education Program, as Florida's National Farmworker Jobs Program is known, compares very favorably with national, state and local outcomes of other employment and training programs.

In closing, I would like to share with the Subcommittee the story of one individual who benefited from Florida's Farmworker Jobs and Education Program and who was recently recognized by the Florida Department of Education as an "All American Success".

Thank you for the opportunity to address this issue and ask that the Subcommittee consider farmworkers among those for whom continued federal support is essential.

---

PREPARED STATEMENT OF GALLAUDET UNIVERSITY

Mr. Chairman and members of the Committee: I would like to express my appreciation to you and to Congress for the generous support that we received in fiscal year 2005 to continue maintaining and enhancing academic programs and salaries at Gallaudet University. I am especially grateful that Congress continues to support us during these challenging times. I would like to provide you with some details concerning our request for fiscal year 2006. In my testimony last year, I discussed ongoing efforts by Gallaudet to diversify our sources of revenue and support, and I also want to bring you up to date on this issue.

It is important to note that the proportion of the Federal appropriation for Gallaudet University as a part of our total budget was 17 percentage points less in 2004 than it was in 1981. During the 1980's and 1990's, we coped with limitations on Federal support by increasing our tuition charges at a rate that exceeded growth in the Consumer Price Index (CPI) during that period. However, in light of concerns expressed by members of Congress and others, we have limited the increase in tuition charges for fiscal year 2006 to 3 percent, commensurate with general inflation. Very significantly, we have also reduced staffing since 1989 by 20 percent. In addi-

tion, we have changed our strategy for funding major construction and renovation projects. When I became President in 1988, every building on the Kendall Green campus had been constructed with 100 percent Federal funding. Since I became President, every major construction or renovation project we have conducted has been supported either by cost-sharing with the Federal government or by private fundraising alone. For example, the buildings constructed here most recently, the Kellogg Conference Hotel at Gallaudet University and the Student Academic Center, were constructed without any additional Federal appropriations. In 2003, we completed a 4-year, \$40 million capital campaign, and much of that funding went to support construction of the Student Academic Center and growth in our endowment. We have begun fundraising for a much-needed new facility to house our language and communication programs, and I am pleased to inform you that in November of last year we received a \$5 million gift for this project from the Sorenson family of Utah. I believe, therefore, that we have been very responsible in our requests for Federal support and that we have done everything we could to seek additional sources of funding during a period when Congress has faced funding limitations.

Because of Congress' ongoing support of Gallaudet in fiscal year 2005, we have been able to maintain a competitive pay structure for our employees while retaining the flexibility to meet the needs of a changing student body. Given the unique student population we serve and the communication skills our employees are expected to possess, retaining skilled employees is very critical to our mission. Gallaudet employees received general pay increases of 2 percent in fiscal year 2003, 3 percent in fiscal year 2004, and 2 percent in fiscal year 2005, increases that are below what Federal employees in the region received during the same timeframe, but in line with increases in the CPI. It will be important for Gallaudet to ensure that our employees receive a 3 percent pay increase in fiscal year 2006, commensurate with current increases in inflation. We are also requesting support for inflationary increases in non-salary areas, especially in the cost of utilities, insurance, and other professional fees.

The administration budget for fiscal year 2006 includes \$104.557 million for Gallaudet, the same as our current year fiscal year 2005 appropriation. I have carefully analyzed our fiscal year 2006 funding needs and have determined that in order to award a 3 percent salary increase to our faculty and staff, and to meet other inflation-driven increases, we need an increase of only \$3.1 million, 3 percent above our current appropriation.

While this minimal increase would allow us to continue with current programs, it would not allow us to invest in programs that the University considers of critical importance. Our three priorities for fiscal year 2006 include the following:

*Initiatives to increase accessibility to information from outside and from within the University campus—\$975,000*

Information technology continues to be the "great equalizer" that levels the playing field for those who are deaf or hard of hearing. Ever-increasing access to visual media and the growing proliferation of text-based communication provides more opportunities for deaf and hard of hearing people in different aspects of society. Therefore, it is essential that Gallaudet continue to invest in information technology that will provide these kinds of opportunities for our students.

This funding will support the replacement of computers used daily by students in the digital learning center at the Student Academic Center, in student services programs, and in classrooms. It will also support upgrades to the University's Web presence and to student e-portfolio systems, which allow students to document their academic progress, receive feedback from their instructors, and present themselves electronically to potential employers.

Finally, Gallaudet owns the largest and most unique collection of deafness-related materials in the world. Support will be given to the digitization of Gallaudet's unique archives. Digitizing these archives will make them more accessible to scholars and students at the University, as well as scholars from outside the Gallaudet community.

*Initiatives to enhance University programs for deaf students from non-traditional and diverse backgrounds—\$300,000*

Gallaudet continues to seek ways to reach out to and create a more positive educational climate for deaf students from non-traditional and diverse backgrounds. Demographic trends point to a growing number of students of color as well as a growing number of deaf students who are placed in educational settings where sign language is not the primary mode of communication.

Gallaudet recognizes that teacher preparation is essential in supporting students of color. In order for the teachers to capitalize on the expertise that Gallaudet has

to offer, we seek to offer a regional distance education degree program that will allow teachers to receive training and earn a degree from Gallaudet without their having to come to Washington, D.C. to earn all their credits.

In public education today, more deaf students are placed in educational settings where sign language is not the primary mode of communication. We believe it is important to have sufficient support for students with such backgrounds who come to Gallaudet to help them make the transition to a direct communication environment. It is also important for those who are undecided about which college to attend to understand that there is a strong program in place to help with such transition. The additional funding will let Gallaudet study optimal ways to enhance real-time captioning. In addition, it will support upgrading of the New Signers Program that provides sign language instruction to new students with weak or no signing skills.

*Improvements to the Theatre Arts Department, including renovations of the Elstad Auditorium and Annex—\$950,000*

Funding will enhance student learning by improving and expanding the Theatre Arts program at Gallaudet and by updating and expanding the Elstad Auditorium and Annex. As an institution that promotes the visual arts, we must provide a solid theatre arts experience to our students. Further, as the world's only university in which all programs and services are specifically designed to accommodate deaf and hard of hearing students, Gallaudet needs a first rate arena to promote direct access for a broad audience.

Changes in technology in the last thirty years have been very significant, and we are falling behind in our technical theatre. Lighting and sound systems are outdated, as are computer programming, costume shop equipment, and the set workshop. The building is not wired for classrooms to have direct access to the information network, and the box office is not wired to enable the use of effective and efficient ticketing programs.

Access to theatre for deaf and hard of hearing people is often limited to one or two interpreted performances in area productions. The improvements to the Gallaudet University Theatre Arts program and facilities would enable direct access by a broader audience, as well as allow for opportunities for us to partner with other theatre companies, such as the nationally acclaimed Arena Stage, to produce unique visual performances. Students would experience "smart" classrooms and learn how to use state-of-the-art theatrical technology. In addition, the deaf and hard-of-hearing community would have direct access to many theatrical performances. Finally, hearing audiences would be attracted to and exposed to deaf theatre.

*Total Program Requests—\$2,225,000*

The total request for Gallaudet University, including these three critical program priorities is \$109.9 million, representing a 5 percent increase from our fiscal year 2005 appropriation. This increase would have a significantly positive impact on the University's ability to meet the increasing and changing needs of our students and those in the field of deaf education.

I appreciate the challenges that Congress faces in making appropriations decisions for fiscal year 2006, but experience has shown that Gallaudet provides an outstanding return on the Federal dollars that are invested here in terms of the educated and productive deaf community that the nation enjoys as a result.

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND THE ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2006

(1) A 6 percent increase for the National Library of Medicine at the National Institutes of Health and support for NLM'S urgent facility construction needs.

(2) Continued support for the Medical Library community's role in NLM'S outreach, telemedicine and health information technology initiatives.

Mr. Chairman, thank you for the opportunity to testify today on behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) regarding the fiscal year 2006 budget for the National Library of Medicine. I am Logan Ludwig, Associate Dean for Library and Telehealth Services at Loyola University Strich School of Medicine in Maywood, Illinois.

Established in 1898, MLA is a nonprofit, educational organization of more than 1,100 institutions and 3,600 individual members in the health sciences information field, committed to educating health information professionals, supporting health information research, promoting access to the world's health sciences information, and working to ensure that the best health information is available to all.

AAHSL is comprised of the directors of libraries of 142 accredited United States and Canadian medical schools belonging to the Association of American Medical Colleges. Together, MLA and AAHSL address health information issues and legislative matters of importance to the medical community through a joint task force.

Mr. Chairman, the National Library of Medicine, on the campus of the National Institutes of Health in Bethesda, Maryland, is the world's largest medical library. The Library collects materials in all areas of biomedicine and health care, as well as works on biomedical aspects of technology, the humanities, and the physical, life, and social sciences. The collections stand at 5.8 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. Housed within the library is one of the world's finest medical history collections of old and rare medical works. The Library's collection may be accessed in the reading room or requested on interlibrary loan. NLM is a national resource for all U.S. health science libraries through a National Network of Libraries of Medicine. Increasingly, it is becoming an international resource for world-wide research collaboration.

With respect to the Library's budget for the coming fiscal year, I would like to touch briefly on four issues: (1) the growing demand for NLM's basic services; (2) NLM's outreach and education services; (3) NLM's telemedicine and informatics activities; and (4) NLM's facility needs.

#### THE GROWING DEMAND FOR NLM'S BASIC SERVICES

Mr. Chairman, it is a tribute to NLM that the demand for its services continues to steadily increase each year. An average of 500 million Internet searches are performed annually on NLM's MEDLINE database, which provides access to the world's most up-to-date health care information. MEDLINEplus, NLM's extensive electronic information resource for the general public, is viewed approximately 200 million times a year. This activity dwarfs previous usage of NLM's bibliographic services, whether electronic or print. Moreover, researchers, scholars, librarians, physicians, healthcare providers from around the world, and the general public rely heavily on NLM and its National Network of Libraries of Medicine to deliver health care information everyday that is necessary to improve the quality of our nation's healthcare system.

NLM also plays a critical role in maintaining the integrity of the world's largest collection of medical books and journals. Increasingly, this current and historical information is in digital form. This has fundamentally changed how the library operates—how and what it collects, how it preserves information, and how it disseminates biomedical knowledge. NLM, as a national library responsible for preserving the scholarly record of biomedicine, is developing a strategy for selecting, organizing, and ensuring permanent access to digital information. Regardless of the format in which the materials are received, ensuring their availability for future generations remains the highest priority of the Library.

Mr. Chairman, simply stated, NLM is a national treasure. I can tell you that without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's healthcare providers, educators, researchers and patients have come to expect.

Recognizing the invaluable role that NLM plays in our health care delivery system, the Medical Library Association and the Association of Academic Health Sciences Libraries join with the Ad Hoc Group for Medical Research Funding in recommending a 6 percent increase for NLM and NIH overall in fiscal year 2006.

#### OUTREACH AND EDUCATION

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities, designed to educate medical librarians, health care professionals and the general public about NLM's services, are an essential part of the Library's mission.

The Library has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. We were pleased that the Committee again last year recognized the need for NLM to coordinate its outreach activities with the medical library community.

#### *PubMed Central*

The medical library community also applauds NLM for its leadership in establishing PubMed Central, an online repository for life science articles. Introduced in 2000, PubMed Central was created by NLM's National Center for Biotechnology Information and evolved from an electronic publishing concept proposed by former



NIH Director Dr. Harold Varmus. The site houses articles from some 100 journals including the Proceedings of the National Academy of Sciences and Molecular Biology of the Cell.

The medical library community believes that health sciences librarians should continue to play a key role in further development of PubMed Central and we are pleased that medical librarians are members of the NLM PubMed Central Advisory Committee. Because of the high level of expertise health information specialists have in the organization, collection and dissemination of medical literature, we believe our community can assist NLM with issues related to copyright, fair use, and information classification on the PubMed Central site. We look forward to continuing our collaboration with the Library as this exciting project continues to evolve this year.

#### *MEDLINEplus*

NLM estimates that the public conducts 30 percent of all MEDLINE searching. MEDLINEplus [<http://www.nlm.nih.gov/medlineplus/>], a source of authoritative, full-text health information resources from the NIH institutes and a variety of non-Federal sources, has grown tremendously in its coverage of health and its usage by the public. In January 2003, two million unique users searched more than 600 "health topics" that contain detailed consumer-focused information on various diseases and health conditions. Recent additions to MEDLINEplus include illustrated interactive patient tutorials, a daily news feed from the public media on health-related topics, and the NIHSeniorHealth site [<http://nihseniorhealth.gov/>], a collaborative project between NLM and the National Institute on Aging.

#### *Clinical Trials*

Mr. Chairman, I also want to comment on another relatively new service offered by NLM—its clinical trials database [<http://www.clinicaltrials.gov>]. This listing of more than 7,000 federal and privately funded trials for serious or life-threatening diseases was launched in February of 2000 and currently logs more than 2 million page hits per month. The clinical trials database is a free and invaluable resource to patients and families interested in participating in cutting edge treatments for serious illnesses. The medical library community congratulates NLM for its leadership in creating ClinicalTrials.gov and looks forward to assisting the Library in advancing this important initiative.

Mr. Chairman, we applaud the success of NLM's outreach initiatives and look forward to continuing our work with the Library again in fiscal year 2006 on these important programs.

#### TELEMEDICINE AND MEDICAL INFORMATICS

Mr. Chairman, telemedicine continues to hold great promise for dramatically increasing the delivery of health care to underserved communities across the country and throughout the world. NLM has sponsored over 50 innovative telemedicine related projects in recent years, including 21 multi-year projects in various rural and urban medically underserved communities. These sites serve as models for:

- Evaluating the impact of telemedicine on cost, quality, and access to health care;
- Assessing various approaches to ensuring the confidentiality of health data transmitted via electronic networks; and
- Testing emerging health data standards.

It is clear that telemedicine and medical informatics program such as the Visible Human Project [[http://www.nlm.nih.gov/research/visible/visible\\_human.html](http://www.nlm.nih.gov/research/visible/visible_human.html)]  
—male and female data sets consisting of MRI, CT, and photographic cryosection images totaling 50 gigabytes and licenses to scientists at more than 1,700 institutions around the world—will play a major role in the delivery of health care and research in the 21st Century.

We are pleased that NLM has begun a new program to support informatics research that addresses information management problems relevant to disaster management. Medical librarians and health information specialists have an important role to play in supporting these cutting edge technologies, and we encourage Congress and NLM to continue their strong support of telemedicine and other medical informatics initiatives.

#### NLM'S FACILITY NEEDS

Mr. Chairman, over the past two decades NLM has assumed several new responsibilities, particularly in the areas of biotechnology, health services research, high performance computing, and consumer health. As a result, the Library has had tre-

mendous growth in its basic functions related to the acquisition, organization, and preservation of an ever-expanding collection of biomedical literature.

This increase in the volume of biomedical information as well as expansion of personnel (NLM currently houses over 1,100 people in a facility built to accommodate 650) has resulted in a serious shortage of space at the Library. In addition, NLM's National Center for Biotechnology Information [<http://www.ncbi.nlm.nih.gov>] builds sophisticated data management tools for processing and analyzing enormous amounts of genetic information critical to advancing the Human Genome Project.

In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. The medical library community is pleased that Congress appropriated the necessary architectural and engineering funds for facility expansion at NLM in 2003.

We encourage the subcommittee to continue to provide the resources necessary to acquire a new facility and to support the Library's health information programs.

Mr. Chairman, thank you again for the opportunity to present the views of the medical library community.

---

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

OVERVIEW

The National Association of Children's Hospitals (N.A.C.H.) is pleased to have the opportunity to submit the following statement for the hearing record in support of the Children's Hospitals' Graduate Medical Education (CHGME) Payment Program in the Health Resources and Services Administration (HRSA).

On behalf of the nation's 60 independent children's teaching hospitals, N.A.C.H. very much appreciates the Subcommittee's early and continuing commitment over several years to provide full, equitable GME funding for these hospitals, giving them a level of federal support for their teaching programs that seeks to be comparable to what all other teaching hospitals receive through Medicare.

We also appreciate the Subcommittee's support for level funding of \$303 million for fiscal year 2005—the amount requested by President Bush and recommended by N.A.C.H. Ultimately, this funding was reduced to \$301 million, or less than level funding, by a 0.8 percent across the board reduction in non-defense, non-homeland security discretionary spending programs in the final conference report.

For fiscal year 2006, we respectfully request an adjustment recognizing the cost of inflation for CHGME, which would result in total funding of \$309 million, so that these institutions will have the resources necessary to train and educate the nation's pediatric workforce. Such an adjustment is important for a program with both wage-related and medical teaching costs associated with it. Given the challenges that the Subcommittee faces, we hope that at a minimum the program can at least be maintained at level funding and not lose further ground in fiscal year 2006.

N.A.C.H. is a not-for-profit trade association, representing more than 125 children's hospitals across the country. Its members include independent acute care children's hospitals, acute care children's hospitals organized within larger medical centers, and independent children's specialty and rehabilitation hospitals. N.A.C.H. seeks to serve its member hospitals' ability to fulfill their four-fold missions of clinical care, education, research and advocacy devoted to the health and well being of all children in their communities.

Children's hospitals are regional and national centers of excellence for children with serious and complex conditions. They are centers of biomedical and health services research for children, and they serve as the major training centers for future pediatric researchers, as well as a significant number of our children's doctors. These institutions are major safety net providers, serving a disproportionate share of children from low-income families, and they are also advocates for the public health of all children.

Although they represent less than 5 percent of all hospitals in the country, the three major types of children's hospitals provide 41 percent of the inpatient care for all children, 42 percent of the inpatient care for children assisted by Medicaid, and the vast majority of hospital care for children with serious conditions such as cancer or heart defects.

BACKGROUND: THE NEED FOR CHILDREN'S HOSPITALS GME

While they account for less than 1 percent of all hospitals, the independent children's teaching hospitals alone train nearly 30 percent of all pediatricians, half of all pediatric specialists and a majority of future pediatric researchers. They also pro-

vide required pediatric rotations for many other residents. They train about 4,000 residents annually, and the need for these training programs is even more heightened by the growing evidence of shortages in pediatric specialists around the country.

Prior to initial funding of the CHGME program for fiscal year 2000, these hospitals were facing enormous challenges to their ability to maintain their training programs. The increasingly price competitive medical marketplace was resulting in more and more payers failing to cover the costs of care, including the costs associated with teaching.

The independent children's hospitals were essentially left out of what had become the one major source of GME financing for other teaching hospitals, Medicare, because they see few if any Medicare patients. They received only 1/200th (or less than 0.5 percent) of the federal GME support that all other teaching hospitals received under Medicare.

This lack of GME financing, combined with the financial challenges stemming from their other missions, was threatening their teaching programs, as well as other important services.

*Integral Safety Net Institutions.*—In addition to their teaching missions, the independent children's hospitals are a significant part of the health care safety net for low-income children. In fiscal year 2003, children assisted by Medicaid represented, on average, 47 percent of all discharges from free-standing acute care children's hospitals and accounted for about 50 percent of all inpatient days of care. Yet Medicaid, on average, reimbursed 80 percent of the cost of care provided. Without disproportionate share hospital payments, those reimbursements would only cover, on average, 73 percent of the cost of care. The shortfalls in Medicaid payments for outpatient and physician care are even greater. . The independent children's hospitals also are essential providers of care for seriously and chronically ill children. They devote more than 75 percent of their care to children with one or more chronic or congenital conditions. They provide the vast majority of inpatient care to children with many serious illnesses—from children with cancer or cerebral palsy, for example, to children needing heart surgery or organ transplants. In some regions, they are the only source of pediatric specialty care. The severity and complexity of illness and the services and resources that these institutions must maintain to assure access to this quality care for all children are also often inadequately reimbursed.

*Mounting Financial Pressures.*—The CHGME program, and its relatively quick progress to full funding in fiscal year 2002, came at a critical time. In 1997, when Congress first considered establishing CHGME, a growing number of independent children's teaching hospitals had financial losses, and many more faced mounting financial pressures. More than 10 percent had negative total margins, more than 20 percent had negative operating margins, and nearly 60 percent had negative patient care margins. Some of the nation's most prominent children's hospitals were at financial risk. Thanks to the CHGME program, these hospitals have been able to maintain and strengthen their training programs.

Continuing this critical CHGME funding is more important for these hospitals than ever in light of state budget shortfalls in many states and the resulting pressures for significant reductions in state Medicaid spending. Because children's hospitals devote such a substantial portion of their care to children from low-income families, they are especially affected by cutbacks in state Medicaid programs.

*Pediatric Workforce Development.*—The important role the CHGME program plays in the continual development of our nation's pediatric workforce is not lost on the larger pediatric community, including the American Academy of Pediatrics and Association of Medical School Pediatric Department Chairs. The pediatric community supports this program and recognizes that CHGME is critical not only to the future of the individual hospitals, but also to provision of children's health care and advancements in pediatric medicine overall.

Lastly, many of the independent children's hospitals are a vital part of the emergency and critical care services in their communities and regions. They are part of the emergency response system that must be in place for public health emergencies. Expenses associated with preparedness add to their continuing costs in meeting children's needs.

#### CONGRESSIONAL RESPONSE

In the absence of any movement toward broader GME financing reform, Congress in 1999 authorized the Children's Hospitals' GME discretionary grant program to address the existing inequity in GME financing for the independent children's hospitals. The legislation was reauthorized in 2000 through fiscal year 2005 and provided \$285 million through fiscal year 2001 and such sums as may be necessary in

the years beyond.<sup>1</sup> Congress passed the initial authorization as part of the “Healthcare Research and Quality Act of 1999” and the reauthorization as part of the “Children’s Health Act of 2000.”

With the support of this Subcommittee, Congress appropriated initial funding for the program in fiscal year 2000, before the enactment of its authorization. Following enactment, Congress moved substantially toward full funding for the program in fiscal year 2001 and completed that goal, providing \$285 million in fiscal year 2002, \$290 million in fiscal year 2003, \$303 million in fiscal year 2004 and \$301 million in fiscal year 2005. (In the last 2 fiscal years, the funding levels are net of across-the-board reductions in all non-defense, non-homeland security discretionary appropriations.) The annual CHGME appropriations represent an extraordinary achievement for the future of children’s health care as well as for the nation’s independent children’s teaching hospitals.

*Health Resources and Services Administration.*—The CHGME funding appropriated by Congress is distributed through HRSA to 60 children’s hospitals according to a formula based on the number and type of full-time equivalent (FTE) residents trained, in accordance with Medicare rules, as well as the complexity of care and intensity of teaching the hospitals provide. Consistent with the authorizing legislation, HRSA allocates the annual appropriation in bi-weekly periodic payments to eligible independent children’s hospitals.

*“Adequate” Rating From Administration.*—The Office of Management and Budget gave CHGME an “adequate” rating in 2003, using its Program Assessment Rating Tool (PART). The PART review said CHGME has a “clear purpose,” is “effectively targeted,” has specific “long-term performance measures” that focus on outcomes, and holds grantees “accountable for cost, schedule, and performance results.”

#### FISCAL YEAR 2006 REQUEST

N.A.C.H. respectfully requests that the Subcommittee continue equitable GME funding for the independent children’s hospitals by providing \$309 million for the program in fiscal year 2006, which would provide an adjustment for inflation over current funding. We, of course, hope that such an adjustment could be provided, since it is particularly important for a program that includes both wage-related and medical teaching costs. Given the challenges that the Subcommittee faces, we hope that the program at least can be maintained at level funding and not lose further ground in fiscal year 2006.

Adequate, equitable funding for CHGME is an ongoing need. Children’s hospitals continue to train new pediatric residents and researchers every year. Children’s hospitals have appreciated very much the congressional support they have received, including the attainment of the program’s authorized full funding level in fiscal year 2002 and continuation of full funding with an inflation adjustment in fiscal year 2003 and fiscal year 2004. Now, N.A.C.H. asks Congress to maintain this progress by providing \$309 million in fiscal year 2006.

Support for a strong investment in GME at independent children’s teaching hospitals is consistent with the repeated concern the Subcommittee has expressed for the health and well-being of our nation’s children—through education, health and social welfare programs. It also is consistent with the Subcommittee’s repeated emphasis on the importance of enhanced investment in the National Institutes of Health (NIH) overall, and in NIH support for pediatric research in particular, for which we are very grateful.

The CHGME funding has been essential to the ability of the independent children’s hospitals to sustain their GME programs. At the same time, it has enabled them to do so without sacrificing support for other critically important services that also rely on hospital subsidy, such as many specialty and critical care services, child abuse prevention and treatment services, poison control centers, services to low-income children with inadequate or no coverage, mental health and dental services, and community advocacy, such as immunization and motor vehicle safety campaigns.

In conclusion, the Children’s Hospitals GME Payment Program is an invaluable investment in children’s health. The future of the pediatric workforce and children’s access to quality pediatric care, including specialty and critical care services, could not be assured without it. Again, N.A.C.H. and the nation’s independent children’s

<sup>1</sup>The Lewin Group, an independent health policy analysis firm calculated in 1998 that independent children’s teaching hospitals should receive approximately \$285 million in federal GME support for nearly 60 institutions to achieve parity with the financial compensation provided through Medicare for GME support to other teaching hospitals.

teaching hospitals are deeply grateful to the Chairman and the Subcommittee for your continuing leadership on behalf of the teaching missions of children's hospitals.

For further information, please contact Peters D. Willson, vice president for public policy, N.A.C.H., at 703/797-6006 or pwillson@nachri.org.

#### PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

1. Increase funding for the health professions and nursing education programs under Title VII and Title VIII of the Public Health Service Act to at least \$550 million for fiscal year 2006.

2. Restore funding for Area Health Education Centers (AHECs) to fiscal year 2003 level of \$33.1 million.

3. Restore funding for Health Education Training Centers (HETCs) to fiscal year 2003 level of \$4.3 million.

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the National AHEC Organization.

I am Linda Kanzleiter, and I work for the Pennsylvania Statewide AHEC Program and am a member of the National AHEC Organization (NAO). NAO is the professional organization representing the Area Health Education Centers (AHECs) and Health Education Training Centers (HETCs). Together, we seek to enhance access to quality health care, particularly primary care and preventative care, by improving the supply and distribution of health care professionals through community—academic partnerships

##### PERSISTENT WORKFORCE SHORTAGES

Mr. Chairman, contrary to what may be commonly understood, persistent and severe shortages exist in a number of health professions. Chronic shortages exist for all health professions in many of our nation's underserved communities, and substantial shortages exist in all communities for some professions such as nursing, pharmacy, and certain allied health fields. While the supply of physicians in the non-primary care specialties may well be adequate, supply and distribution problems for primary care physicians, nurses, and many allied health professionals are undermining access and quality in many of our nation's communities.

Historically, the supply of and demand for health care professionals has waxed and waned in a manner that produced cycles of shortage and excess. However, it is reasonable to believe that the current shortages are of a different and more persistent nature. First, the breadth and depth of shortages are greater than at any time in the past. More disciplines are in short supply, more sites of care (hospitals, nursing homes, home care agencies, and clinics) are experiencing shortages, and the duration of vacancies is longer. Second, the demand for health care services is steadily and inexorably increasing due to the aging population and the advances in medical technology. Third, the health care provider population is aging itself. Fourth, the resources with which the health care industry might respond to shortages are inadequate to the challenges. Due to the squeeze of managed care, provider institutions are unable to increase salaries, and due to cuts in government funding, educational institutions are unable to expand class sizes. Finally, the career opportunities available to women, who dominate the health care professions, have expanded greatly.

Health care workforce shortages are occurring in a context of an increasingly aged population with greater needs for health care services. In addition, health technology steadily produces advances that require a higher level of training and sophistication on the part of health care providers. These trends are occurring at time when the number and the level of academic preparedness of students entering the health professions are decreasing.

In addition, minority and disadvantaged populations are egregiously under represented in the health professions. Given the demographic trends in the United States, minority populations constitute a major untapped source of future health care professionals.

##### THE ROLE OF AHECS

Mr. Chairman, the AHEC/HETC network is the federal government's most flexible and efficient mechanism for addressing a wide and evolving variety of health care issues on a local level. Through AHECs and HETCs, national initiatives can be targeted to the areas of greatest need and molded to the particular issues confronting individual communities. Whether the issue is the nursing shortage, bioter-

rorism preparedness, access for the uninsured, or recruiting under-represented minority students into the health professions, AHECs and HETCs, where they exist, can assemble the appropriate local collaboration and apply federal, state, and local resources in a precise and cost-effective manner.

Since our inception almost thirty years ago, AHECs have partnered with local, state, and federal initiatives and educational institutions in providing clinical training opportunities to health professions and nursing students in rural and underserved communities. We bring the resources of academic health centers to bear in addressing the health care needs of these communities. Currently, there are 48 AHEC programs and 180 centers located in 43 states and the District of Columbia. AHEC programs are based at schools of medicine, which are the federal AHEC grant recipients, and are implemented through the regional offices (centers), each of which serves a defined geographic area.

#### AHEC PROGRAMS PERFORM FOUR BASIC FUNCTIONS:

1. They develop and support the community based training of health professions students, particularly in underserved rural and urban areas. Exposing health professions students to underserved communities increases the likelihood that they will return to these communities to practice.

When considering access, Pennsylvania faces some unique challenges. For example, The Pennsylvania Department of Health estimates that about 1,259,441 people in our Commonwealth do not have health insurance of any kind. Of that number, 109,883 are persons within the five counties we serve. The National Association of Community Health Centers estimates that, in Pennsylvania, at least 1,479,087 people are "without a primary care provider". This figure represents more than 12 percent of Pennsylvania's total population (12,281,054). This number is likely higher because eight counties, including Carbon & Lehigh, were not included in their data.

Pennsylvania AHECs have developed a network of over 972 health care training sites, 3,632 students and residents, and 1,045 on-site preceptors providing service to patients at these training centers.

2. They provide continuing education and other services that improve the quality of community-based health care. Improving the quality of care also enhances the retention of providers in underserved communities, particularly community health centers.

A crucial part of our mission in Pennsylvania involves linking fourth year medical students with Medical Preceptors, mentors and teachers in the community. Our goal is to help facilitate the process that allows the students to become familiar with the issues encountered in rural communities. The student can also begin to establish relationships, which will prove beneficial should they decide to practice in a rural area. In this way, Pennsylvania AHECs support the viability and, often, the continued, independent existence of small community hospitals.

The Northeast Pennsylvania Area Health Education Center surveyed physicians in the rural counties it serves to clarify issues surrounding continuing education. The overwhelming response was that there was a desire for more information about bioterrorism, and that it should be accessible online. The Pennsylvania Department of Health subsequently created the Learning Management System (LMS), a web-based system for education and information-sharing regarding bioterrorism and other public health issues. The LMS delivers emergency preparedness training and access to up to date information to the hands of health professionals, day or night. The LMS serves as an information library, a forum for discussion groups, and means of surveying program content online.

3. They recruit under-represented minority students into the health professions through a variety of programs targeted at elementary through high schools. Minority students are grossly under-represented in the health professions and are more likely to practice in underserved communities.

The Northwest Pennsylvania AHEC has developed a program called the Great Hospital Adventure Puppet Presentation. The multi-media presentation includes a live puppet show, video movie, coloring book, classroom poster, and an interactive question and answer session. This program promotes health career awareness and encourages healthy behaviors for children aged four to nine. The classroom materials and activities emphasize non-traditional gender roles and multi-cultural images. The goal of the presentation is to attract children of all genders, backgrounds and cultures to health professions.

The Northeast Pennsylvania AHEC established a summer camp called "Exploring Careers in Health" for high school students who demonstrate a strong interest in medicine or health care. The camp is a weeklong program held on the campus of Keystone College. Students must apply for admission, and the camp provides an in-

depth look at the health care field by participation in workshops with health professionals, hands-on activities, and field trips. Students are encouraged to explore numerous career choices as health professionals.

Additionally, the Northeast Pennsylvania sponsors a program for area teachers and guidance counselors called "Seeds for Success." The program offers an overview of health career opportunities at colleges, universities and post-secondary institutions in the surrounding area. The response to the program was overwhelmingly positive.

4. They facilitate and support practitioners, facilities, and community based organizations in addressing critical local health issues in a timely and efficient manner.

Only 13 percent of primary care physicians in Pennsylvania serve in rural communities. However, 42 of the state's 67 counties are predominantly rural and 7 counties are completely rural. These startling facts are the driving force behind the health care professions workforce development resolution.

#### THE ROLE OF HETCS

The HETC programs were created to address the public health needs of severely underserved populations in border and non-border areas. Currently, HETC programs exist in 12 states and are supported by a combination of federal, state, and local funding, the majority of which comes from non-federal sources.

Because the majority of preventable health problems are due to health behaviors and the environment, HETCs focus on community health education and health provider training programs in areas with severely underserved populations. HETCs target minority groups, disadvantaged communities, and communities with diverse culture and languages.

#### COLLABORATIVE EFFORTS

Virtually all AHEC and HETC programs are collaborative in nature. They routinely partner with a wide variety of federal, state, and locally funded programs. Examples of these collaborations include health professions schools, primary care residency programs, community health centers, primary care associations, geriatric education centers, the National Health Service Corps, public health departments, health career opportunity programs, school districts, and foundations.

Additionally, AHECs and HETCs often go beyond their core functions to undertake a wide variety of innovative programs, tailored to specific health issues affecting the communities they serve. Because health issues vary from community to community, the programs of each AHEC and HETC also vary considerably. AHECs and HETCs respond to changing health and health workforce needs in a flexible and timely manner. Examples of current issues for which we are directing our resources are:

1. *The nursing shortage.*—Currently, AHECs and HETCs are working with schools of nursing, state nursing associations, and others to increase the number of qualified applicants to nursing schools, increase minority enrollment in nursing schools, expand the number of community-based nursing training sites, and re-train nurses who wish to re-enter the profession.

The Northcentral Pennsylvania AHEC facilitated the Nursing Forum, titled *Joining Healing Hands: Communication, Collaboration, and Teambuilding*, to enhance regional nursing recruitment and retention efforts within their 10 county region on Friday, February 27, 2004 in Lewisburg, Union County. Participating nurses, nurse administrators, healthcare representatives, and nursing educators explored ways to strengthen communication, leadership skills, and teamwork to create a shared vision and commitment to quality healthcare. Skill sets encouraged at the forum promoted a shared commitment to quality healthcare, fostered positive outcomes, encouraged inclusion of collaborative educational efforts, and supported the recruitment and retention of a diversified workforce.

2. *Bioterrorism education.*—Currently, AHECs and HETCs are working with public health departments to educate health and public health professionals on surveillance, reporting, risk communication, treatment, and other responses to the threat of bioterrorism.

3. *The National Health Service Corps (NHSC).*—AHECs and HETCs undertake a variety of programs related to the placement and support of NHSC scholars and loan repayment recipients.

The Pennsylvania State University AHEC has actively supported the NHSC "SEARCH" program by interviewing prospective students, recommending community preceptors, and monitoring placements of students each summer in rural and underserved sites.

4. *Expansion of community health centers.*—AHECs and HETCs are collaborating with health professions schools, primary care associations, and community health centers to increase the supply of providers willing and able to work in community health centers. In addition, AHECs/HETCs are working directly with CHC providers to improve the quality of care.

JUSTIFICATION FOR FUNDING RECOMMENDATIONS

Mr. Chairman, I respectfully ask the Subcommittee to support our recommendations to increase funding for the health professions and nursing education programs under Title VII and Title VIII of the Public Health Service Act to at least \$550 million for fiscal year 2006. Our recommendations are consistent with those of the Health Professions and Nursing Education Coalition (HPNEC).

The AHEC and HETC programs improve access to primary and preventative care through community partnerships, linking the resources of academic health centers with local communities. AHECs and HETCs have proven to be responsive and efficient models for addressing an ever-changing variety of community health issues.

However, AHECs and HETCs have not yet fully realized their potential to be a nationwide infrastructure for local training and information dissemination. In order to realize that potential additional federal investment is required. That is why we are requesting that in fiscal year 2006, you restore funding to fiscal year 2003 levels of \$33.4 million for AHECs and \$4.3 million for HETCs.

PREPARED STATEMENT OF THE STATE EDUCATIONAL TECHNOLOGY DIRECTORS  
ASSOCIATION (SETDA)

NCLB TITLE II, PART D: ENHANCING EDUCATION THROUGH TECHNOLOGY

On behalf of SETDA representing all fifty states, DC, and American Samoa, we encourage you to restore NCLB Title II, Part D—Enhancing Education through Technology (EETT) program to its fiscal year 2004 funding level of \$692 million. In fiscal year 2005, this program sustained a 28 percent cut, which has not yet been realized in schools across the country due to the grant award cycle. This testimony documents how states leverage EETT funding to ensure the ability of states, districts, and schools to implement all Titles within NCLB, specifically:

- Enhancing data systems to ensure that educators can utilize real-time data to inform sound instructional decisions and ensure that states are able to meet AYP.
- Closing the achievement gap by providing access to software, online resources, and virtual learning aligned to academic standards for instruction and learning.
- Supporting the development of highly qualified teachers by providing online courses, communities of practice, and virtual communication that ensure flexibility and access.

The data and examples illustrate how forty-nine states and DC (representing 99 percent of federal education technology funding) utilize EETT funding. 81 percent of school districts in this country receive and use EETT funding. States maintain 5 percent for technical assistance and administration and disseminate the remaining 95 percent equally between two programs:

1. The Formula Grant Program by which high need districts receive an allotment based upon poverty rates.
2. The Competitive Grant Program through which states establish areas of focus for districts to compete for the grants. Each grantee must include at least one high need district.

THE MYTH OF EETT

Some believe that EETT is utilized primarily to purchase computers or “the boxes in the back of the classroom.” The SETDA National Trends Report and examples provided demonstrate that this is not the case. The majority of this funding supports the purchase of curriculum, provides professional development to ensure teachers are highly qualified, and builds systems for assessment, data and accountability mechanisms. Some grantees may use small amounts of the funding to purchase hardware integral to the students’ education, i.e. laptops that children in rural areas bring home to expand learning opportunities; however the overwhelming majority of the funding is utilized to support the successful implementation of NCLB that is highlighted below.



## MEETING AYP AND IMPROVING STUDENT ACHIEVEMENT THROUGH DATA SYSTEMS

*Key Facts*

Data management and accountability requirements are steadily rising and states have a limited capacity for meeting these requirements. EETT funds are the only source of federal funding for most states to use in developing the data systems needed to report AYP results mandated through NCLB. These funds are being used toward data systems that impact both instructional and administrative aspects of education. On the instructional side, the National Trends Report cites many examples of EETT funds being used to train teachers in understanding how to use data effectively to individualize learning and to make real-time modifications to instruction in order to best meet the needs of every learner. The report also cites multiple examples of state and district-wide data management systems that allow for increased accountability and reporting.

While professional development and student achievement are still extremely important in EETT, the program has seen a tremendous increase in the number of states (78 percent) that are using these technology funds for three other key NCLB priorities—assessment, outreach to parents, and data-driven decision-making.

*Examples*

The Philadelphia Instructional Management System (IMS) is part of the School District of Philadelphia's comprehensive reform effort that includes new resources, a standardized curriculum, after school programs, and professional development. IMS provides teachers and administrators with immediate data on student learning aligned to State and District standards. A benchmark assessment, given every five weeks, allows teachers to differentiate instruction, provide immediate remediation, and identify those students who need additional assistance. Teachers, coaches, and administrators have access to student performance data through an online system. This system also provides suggested resources and strategies teachers can use to meet unique student needs. In 2003, before these technology tools were provided to teachers, only 9 of the 40 initial participating schools had met AYP; and 15 were identified for Corrective Action. At the end of the 2004 school year, 25 schools met their AYP targets, and only 10 remained in Corrective Action II.

In Vermont, school districts are using EETT funds to develop local student data systems or to join the statewide Vermont Data Consortium which is working with the Department of Education to create a statewide Education Data Warehouse. These data efforts support teachers using data to inform instruction and facilitate reporting of AYP data.

States are finding that as they make more and more data available, teachers need help in understanding and using this data to inform their teaching and to help individualize and improve student learning. A good example of this is in the Blackfoot School District in Idaho where EETT funds are used with particular attention to K–12 mathematics. Through this program, teachers use data to identify student needs and then use technology to meet these needs. They are also able to provide ongoing professional development for teachers that otherwise would have been impossible without the Title II D funds.

Maryland is using EETT funds for curriculum management systems. If a child is not mastering certain standards, this provides them with lesson plans and remediation activities to help get them up to par.

## HELPING TO CLOSE THE ACHIEVEMENT GAP

*Key Facts*

The requirement for EETT funds to be targeted to high need districts ensures that students who are most at risk will benefit from additional opportunities. EETT funds are helping to close the achievement gap by providing students with access to software, web courses, and virtual learning opportunities that are aligned to state standards. This is particularly important in areas where teachers in certain disciplines are difficult to find, such as foreign language, Advanced Placement (AP), or higher level science and math courses. With access to online opportunities, students in rural or high need areas have opportunities similar to other students in the state.

Many states have steered EETT funds to core-curricular areas, such as reading, math and science, by establishing content priorities in their competitive grant processes: 74 percent of states created funding priorities in reading or writing, while 38 percent focused on mathematics.

*Examples*

The Missouri eMINTS program provides classrooms with advanced software, intense professional development and Internet access to support standards-based in-

struction. Three years of data from a quasi-experimental evaluation of the eMINTS program showed a significant improvement in third and fourth grade achievement on the Missouri Assessment Program (MAP) test results for African Americans. The study also noted that the achievement gap was closed between those African American students who participated in the program and White students who did not. The success of the eMINTS program is now being replicated in the state of Utah.

Researcher Dale Mann (ASBO, 2003) cited a direct correlation between pupil performance and technology in instruction through West Virginia’s Basic Skills/Computer Education program. The study found that while per capita income had not changed between 1991 and 1998, the infusion of technology was the single factor that accounted for the state moving from 33rd among the states for student achievement to 11th.

In Virginia, EETT funds have been used to develop an online Advanced Placement school. This program provides benefits to Virginia’s students who are most in need, primarily rural and urban students, who otherwise would not have access to AP teachers or courses. A similar West Virginia project provides foreign language opportunities using online technologies. Preliminary findings through a scientifically-based research evaluation indicate that courses delivered online are as effective as courses delivered face to face—expanding the opportunities for closing the achievement gap between students in remote areas.

In region 4 of New York City, EETT funds have allowed student access to Cyber English, Social Studies, Math and Science classes. High schools are no longer limited by time and space and learning has become a 24/7 activity. This model has improved school attendance, engaged previously uninterested students, allowed students from diverse neighborhoods to collaborate, and finally provided parents a vehicle for becoming involved in their teenager’s education.

In North Carolina, the cuts will result in a limitation on nine very successful Community Technology Learning Centers. These centers have offered after-school and weekend programs for needy students and their parents. Most of these centers will either close or drastically scale back their services without EETT funding.

North Dakota has established a rural consortium to implement the “Unified Education Project (UEP), which focuses on creating individualized learning plans for each student based on his or her strengths and weaknesses. Using an electronic portfolio, the UEP helps teachers track needs and provide appropriate instruction and remediation, allows the students to view standards and expectations and assess their own work accordingly, and encourages parent communication. The UEP allows for individualized instruction to ensure that schools and districts can meet AYP.

IMPROVING TEACHER TRAINING, RETENTION, AND RECRUITMENT

*Key Facts*

EETT requires that at least 25 percent (\$147,000,000) of all EETT funds be used for professional development purposes, although most states use considerably more. EETT funds help to increase the access by providing online options that give teachers anytime, anyplace access to quality professional development. This is critical to ensure that teachers have the opportunity to increase content knowledge, improve instruction, and become highly qualified teachers.

*Examples*

Algebra I is often a predictor for success in high school and beyond. Louisiana implemented an on-line Algebra I course to provide additional opportunities for student achievement. Preliminary evaluations indicate that students in the on-line course, with similar pre-test scores are showing more significant achievement gains compared to the control group as indicated below:

Group	Pre-test (fall) mean	Post-test (spring) mean
Algebra I Online Students .....	13.3	17.2
Control Students .....	13.4	15.6

In Nevada, a middle school science partnership is beginning to show evidence of closing the achievement gap in participating schools. The partnerships between the University of Nevada, Reno and five rural Nevada school districts provides professional development to teachers to make them better able to assess their students and use technology to increase student achievement in math. The ability of these teachers to have access to the rigorous university research and the professional development to effectively bring about increases in student achievement in science.

The North Carolina IMPACT Model Schools Grant provides personnel, connectivity, hardware, software, and professional development to impact teaching and learning to improve student achievement in participating elementary or middle schools. One initial finding from this evaluation is that participating schools have dramatically improved their ability to attract and retain teachers. Teachers who are scheduled to retire often choose to stay in these IMPACT schools, others request transfers into them, and new teachers clamor to be hired. "These teachers like the way technology is changing the way they teach, and the enthusiasm with which their students approach learning," says Frances Bryant Bradburn, Director of Instructional Technology for the North Carolina Department of Public Instruction.

In the center of Wyoming, there are many small, rural school districts that do not have the capacity to create aggressive staff development plans. The local Board of Cooperative Education Services formed a partnership between six districts focused on helping teachers to improve instruction through learning environments. For the first time, classes are using smart boards, establishing wireless connections, conducting Internet research, and attending compressed video classes.

In Massachusetts, reports from independent evaluators of the EETT grant projects and the year-end reports submitted by grant recipients show substantial improvement in teacher technology literacy. The use of the state's online interactive Technology Self-Assessment Tool (TSAT) helps in measuring the progress of teachers' technology skills in the different levels. For example, in a Gloucester Public Schools' project, there was an increase from 8.5 percent to 27 percent in the number of educators at the Proficient level and a decrease from 33.5 percent to 20 percent in number at the Early Technology level (the lowest level).

Iowa utilized EETT funds to implement comprehensive professional development programs for teachers targeted at core subject areas. Initial results from one consortium focusing on mathematics demonstrate an increase in student achievement among 4th grade students compared to the control group. Iowa is seeing similar results in reading throughout the state.

#### IMPACT OF CUTTING EETT

Education technology is about more than technology—it's about education. The EETT program supports every tenet and goal of the No Child Left Behind Act. It would be impossible to effectively implement NCLB without the technical expertise and leadership the EETT program brings. As representatives of the states and districts who make the most critical use of educational technology, we urge you to restore the funding to \$692 million, the funding level that was in place before the Omnibus appropriations in November 2004.

Not only does EETT help improve student achievement through technology, it is an efficient use of federal funds. Dale Mann (ASBO, 2003) notes that districts have two options when trying to increase reading scores by one month in grade-level gains: decreasing class size or utilizing technology. Class-size reduction would cost approximately \$636 per student per year compared to \$86 for instructional technology. EETT provides additional opportunities to help increase student achievement.

The targeted funds for educational technology that are available through the EETT program are still very much needed as we work to ensure that all students are ready to compete in the global economy. It is unrealistic to assume that these technology funds and the leadership and innovation that accompany them would be effectively managed through other existing education title programs such as Title I and Title IIA. These Title programs have not received additional funds to pay for the mission critical technology components of their initiatives. Other Title programs, unlike EETT, support narrowly defined student populations and training purposes rather than the broader mission of supporting all students and all programs as EETT currently does. Finally, the leadership and expertise needed to implement successful data driven decision making, curriculum management systems, online professional development, and reporting processes for NCLB would be lost if there was an attempt to subsume educational technology planning and implementation under these already established programs.

About SETDA—<http://www.setda.org>

The State Educational Technology Directors Association (SETDA) is the principal association representing the state directors for educational technology. SETDA's membership includes educational technology directors and staff from the state departments of education of all fifty states, the District of Columbia and American Samoa.

PREPARED STATEMENT OF THE NATIONAL EDUCATION KNOWLEDGE INDUSTRY  
ASSOCIATION

NEKIA appreciates the opportunity to inform the Subcommittee of NEKIA's appropriations proposals for fiscal year 2006. The mission of our association is to advance the development and utilization of research-based knowledge for the improvement of the academic performance of all children. NEKIA's members are committed to finding new and better ways to support and expand high-quality education research, development, dissemination, technical assistance, and evaluation at the federal, regional, state, tribal, and local levels.

Our appropriations proposals seek greater federal investments that will support the use of research-based knowledge in America's K-12 classrooms and spur the implementation of the No Child Left Behind Act and the Education Sciences Reform Act. These two laws ushered in a new era of evidence-based education in which classroom teachers are required to use instructional practices based on scientifically based research. Our proposals for fiscal year 2006 are also designed to address both greater demand for evidence-based education and under-funded supply.

NEKIA'S PROPOSALS ARE BASED ON THREE CRITICAL POINTS

1. *Now is the time to enhance and expand the federal system of education research, development, dissemination, and technical assistance.*—Federally supported programs—specifically the Regional Educational Labs, the R&D Centers, the Comprehensive Centers and Comprehensive School Reform—are playing a vital role in meeting the tremendous needs for research-based practices and technical assistance. Each of these programs fills a unique role in the spectrum of knowledge utilization—from basic research to applied research, from development and dissemination to technical assistance, and ultimately student achievement. Given that more than 20,000 U.S. public schools are not making adequate yearly progress and 10,000 schools are in need of improvement under the No Child Left Behind Act, we must become more aggressive in using research-based education solutions in the classroom.

NEKIA's members are fully supporting the implementation of No Child Left Behind through applied research, development, dissemination, technical assistance, and evaluation programs. For example:

2. *Current federal support for education research, development, dissemination, and technical assistance lags far behind other federal research investments.*—While the No Child Left Behind Act clearly requires educators to use instructional practices and innovations supported by research, the Department of Education spends less than one percent of its budget on research, development, and statistics. Education is a \$745 billion industry representing an estimated 7.2 percent of the gross domestic product. However, only 0.03 percent is spent on research and development. That is only three cents for every hundred dollars spent on education. In comparison, other agencies' R&D budgets as percentage of their discretionary spending: Defense, 17 percent; NASA, 68 percent; Energy, 37 percent; HHS, 42 percent; NSF, 74 percent; and Agriculture, 4.6 percent. In other words, the Department of Education's research budget has been and remains among the smallest of any federal agency.

3. *To address this capacity crisis we urge Congress to double its investments in education knowledge utilization over the next 3 years.*—Not only would increased investments help meet demand, they would also address a number of high priorities such as:

- Improving teacher quality by providing research based information on best practices to teacher training institutions as well as information and technical assistance to schools districts implementing professional development programs.
- Helping special populations of students meet state adequate yearly progress goals. These special populations include English language learners, special needs children, and students in rural areas.
- Working with educators to interpret and manage a variety of data about student performance and classroom instruction.
- Scaling up school improvement efforts at the local level so that reform efforts in single schools can expand to districtwide initiatives.

To adequately respond to the capacity crisis and meet these priorities, NEKIA proposes the following investments:

*Priority Investment.—Fund the Regional Educational Laboratories at \$70 million—an increase of \$3 million over fiscal year 2005*

The Regional Educational Laboratories are the nation's key institutions for applied education research and development that respond to the needs of educators and policy makers. A 2000 Department of Education independent evaluation found

that educators considered the labs among the most trusted institutions in the nation for research support and reported they were highly responsive to customers. They are also highly responsive to local and regional needs. Regional governing boards—representing educators, parents, and businesses from each state of each lab region—set research and development priorities for each lab. The ability to respond to customers in their regions helps keep the laboratories' work focused on real world needs and creating valid research, development, tools and assistance in the successful implementation of the No Child Left Behind Act. Without the Regional Labs, the chain is broken. Without the regional labs, the link between basic research and technical assistance would cease to exist.

Unfortunately, the Regional Education Lab program is at risk. The President's budget for fiscal year 2005 proposes to eliminate funding for the program. Last year, the Administration proposed eliminating the labs. Fortunately, Congress acted in a bipartisan way to fund it. We hope Congress will do so again for fiscal year 2006.

*Priority Investment.—Fund the Research and Development Centers (included in the Research, Development, and Dissemination Line) at \$170 million—an increase of \$5 million over fiscal year 2005*

The centers address enduring issues of national significance in education through sustained and focused research programs. They address specific topics such as early childhood development and learning, student learning and achievement, at-risk students, adult learning, and education policy. The research done by the R&D centers is used by regional labs to develop programs, strategies and assessment tools which in turn are adapted by technical assistance providers (Comprehensive Centers) for the training and tools to implement their own programs to assist districts and schools.

*Priority Investment.—Fund the Comprehensive Regional Assistance Centers at \$60 million—an increase of \$3 million over fiscal year 2005*

The purpose of Title II of the Education Sciences Reform Act (ESRA) and specifically the newly reformed Comprehensive Centers program authorized within it, is to serve as part of a national technical assistance and dissemination system, which provides comprehensive technical assistance services to states, districts, tribes and schools in administering and implementing school reform efforts under No Child Left Behind. Their focus is to help schools and districts improve opportunities for all children to meet content and performance standards. Next year (fiscal year 2006), the 20 new centers will be fully operational. The new centers will include the scope of work of the current Comprehensive Regional Assistance Centers, the Eisenhower Regional Mathematics and Science Consortia, and the Regional Technology in Education Consortia.

*Priority Investment.—Fund the Comprehensive School Reform program at \$233 million—an increase of \$30 million over last year*

Comprehensive School Reform targets the neediest schools. Forty-five percent of CSR schools have poverty rates of 75 percent or greater—almost double the rate of Title I schools. And, almost half (46 percent) of CSR schools are low performing at the time of funding. CSR schools have baseline achievement scores lower than Title I school wide programs (in reading and math) at the time of funding. Finally, CSR Schools address the whole school and are more likely to use research-based models and measurable goals for student performance. Unfortunately, the Comprehensive School Reform program is at risk. The President's budget for fiscal year 2005 proposes to eliminate funding for the program. We hope Congress will act in a bipartisan fashion to preserve it.

NEKIA is very heartened by the continuing interest Congress shows in the work of our member organizations to provide the research-based tools our children and teachers need to succeed. If we are to ensure even greater success for all our children, we must increase the federal investment in knowledge utilization efforts.

Thank you. We appreciate your consideration of our proposals.

---

PREPARED STATEMENT OF THE SCIENCE, TECHNOLOGY, ENGINEERING, AND  
MATHEMATICS (STEM) EDUCATION COALITION

On behalf of the science, technology, engineering, mathematics, education and business groups listed here, we thank you for your efforts to secure \$179 million for the fiscal year 2005 Math and Science Partnership program at the U.S. Department of Education (ED). The STEM (Science, Technology, Engineering, and Mathematics) Education Coalition greatly appreciates your continued support to improve STEM education at all levels.

It is imperative that the work continues and additional funding be provided to the ED MSPs so we can ensure that all students receive a world-class education in science and math. We understand in these tight fiscal times, Congress is unable to provide the NCLB authorization of \$450 million for the MSPs, but we do support substantial increases in order to prepare for the science assessments that will be required in 2007. Therefore, we urge you to support the President's request of \$269 million for the fiscal year 2006 Math and Science Partnerships under Title II, Part B of NCLB.

Additionally, we urge you to oppose the creation of a new initiative that would redirect \$120 million of the funds away from the ED state-based MSP programs to create a new federal grant program. This would require a change to the NCLB statute, cut funds to the states, and greatly reduce state flexibility to meet their most critical needs.

Funding for the ED MSPs goes directly to the states as formula block grants. States provide these funds through competitive grants to local partnerships of schools, higher education institutions and others for reform efforts to meet the NCLB math and science education obligations. Most grants go to high-need districts so they can strengthen teacher professional development and increase student performance in science, mathematics, and technology.

In summary, we strongly urge Congress to fund the fiscal year 2006 ED Math and Science Partnerships at \$269 million and to oppose efforts to redirect \$120 million of these funds away from the states.

If we can provide any additional information or answer questions, please contact Patti Curtis at 202.785.7385.

---

#### PREPARED STATEMENT OF TEACH FOR AMERICA

Mr. Chairman, Senator Harkin and Members of the Subcommittee: Thank you for the opportunity to submit testimony regarding the President's fiscal year 2006 budget proposal, which includes \$4 million for Teach For America under the Corporation for National and Community Service. Mr. Chairman and Senator Harkin, I applaud your commitment to national service and desire to help AmeriCorps realize its full potential.

I would like to take this opportunity to discuss Teach For America and our current growth plans. I will also focus on the \$4 million line item in the President's fiscal year 2006 budget under the Corporation for National and Community Service and explain why it is critical to Teach For America's ability to grow to scale.

As you know, Teach For America is the national corps of outstanding recent college graduates of all academic majors who commit 2 years to teach in urban and rural public schools and become lifelong leaders in the effort to ensure that all children in our nation have an equal chance in life. We are a private, national non-profit organization, as well as one of the original AmeriCorps programs. Our teachers receive a salary from their local school district as well as education awards through AmeriCorps. These education awards can be used for graduate level education courses necessary to obtain teacher certification, to pay back qualified student loans, or for future education.

Since 1990, when I founded Teach For America, our organization has grown from 500 corps members teaching in 5 regions to what will soon be 3,200 corps members teaching in 22 regions during the 2005–2006 school year. Teach For America corps members are having an impact throughout our nation, from St. Louis to Philadelphia, and from New Mexico's Navajo Nation to the Rio Grande Valley in South Texas.

#### TEACH FOR AMERICA MEETS CRITICAL NEEDS

Our mission is to build a movement to eliminate the educational inequality that exists in our country today. By the age of nine, children in low-income areas are already three grade levels behind in reading ability (Source: National Center of Education Statistics, 2000). As these children progress in the educational system, this achievement gap only widens, to the point that a child who grows up in a low-income community is seven times less likely to graduate from college than a child growing up in a more privileged area (Source: Education Trust, 1998).

Our corps members help close the achievement gap for the students they reach during their 2-year commitment. At the same time, they gain insight and added commitment that shapes them into an important leadership force, working from inside of education and from other sectors, for long-term change.

## OUR PROGRAM

We recruit the most highly sought-after college graduates of all academic majors, career interests, and backgrounds from leading colleges and universities. We then select corps members who demonstrate records of achievement and leadership, as well as a commitment to expanding opportunity for children in low-income areas.

Admission to Teach For America is highly selective, with approximately 12 percent of our applicants gaining admission to the corps. Of our 2004 corps members, 93 percent held leadership positions on their campuses or in their communities. They earned average SAT scores of 1,310 and average GPAs of 3.5. In addition, 31 percent of corps members are people of color.

This year, 17,319 young people applied for only 2,000 slots as first year teachers. At many top schools, Teach For America is considered one of the most prestigious post-graduate opportunities. This year, 12 percent of Spelman's senior class applied to the corps. And at top, larger universities, Teach For America attracted significant portions of the student body: 12 percent of Yale's seniors applied, as did 8 percent of seniors at Princeton and Harvard. All are competing for the opportunity to teach in America's neediest schools.

Corps members are selected into Teach For America if they demonstrate strong leadership characteristics such as achievement orientation, critical thinking, personal responsibility for success, and the ability to influence and motivate others, as well as high expectations for students and families in low-income communities and the desire to work relentlessly toward this particular mission.

Those selected attend a summer training institute where corps members teach in local public summer schools and participate in a full afternoon and evening schedule of professional development activities. We aim to ensure that corps members internalize the overarching approach utilized by the most successful teachers in urban and rural areas; and that they gain skills in instructional planning and delivery; building a strong classroom culture; literacy development; and teaching the specific content-area and grade-level they will be teaching.

Following the institute, corps members assume teaching positions in school districts in 22 urban and rural areas. They are clustered in schools and receive extensive ongoing support and professional development through Teach For America and through local teacher education programs.

Following their 2-year commitments, corps members can remain in teaching (and about 60 percent teach for at least a third year). We expect that they will ask themselves how they can have the greatest possible impact on the challenges they and their students experienced during their 2 years, and we provide a network of resources and support that they can tap into as they continue working in educational and social reform throughout their lives.

## IMMEDIATE IMPACT ON COMMUNITIES AND STUDENT ACHIEVEMENT

Our success in recruiting and preparing exceptional classroom teachers has led education policy makers to highlight our impact on disadvantaged communities. Teach For America corps members impact the academic prospects of their students during their first 2 years in the classroom and continue to impact the quality of education in low-income communities beyond their initial commitments.

A 2004 independent study by Mathematica Policy Research, Inc revealed Teach For America corps members in elementary grades affected greater gains than would typically be expected in a year. The study also showed corps members even outpaced fully certified and veteran teachers in their schools in moving their students ahead academically. To put corps members' value-added in context, Mathematica concludes the impact of having a Teach For America teacher compared to a non-Teach For America teacher (including veteran and certified teachers) is 65 percent of the impact of reducing class size from 23 to 15 students (and is substantially less expensive). The impact of having a corps member versus another novice teacher is greater than the impact of reducing class size by eighty students. This study essentially replicated the results from an earlier study on Teach For America's impact by Stanford's Center for Research in Education Outcomes.

Another way we evaluate corps member impact is through a bi-annual survey of principal satisfaction conducted by Kane, Parsons & Associates, Inc., an independent research firm. In a June 2004 survey by Kane, Parsons & Associates, principals credit Teach For America teachers as having positive effects on their schools and on student achievement. Nearly three out of four principals reported that corps members are more effective than their other beginning teachers. And principals rated corps members as good or excellent on multiple indicators of effective teaching, including:

—90 percent—Instructional planning

- 95 percent—Motivation and dedication to teaching
- 96 percent—Achievement orientation and drive to succeed
- 93 percent—Working with other faculty and administrators
- 92 percent—Having high expectations for students; and
- 93 percent—Assuming responsibility for student achievement.

#### LONG-TERM IMPACT

Teach For America is building a force of leaders and citizens with a lifelong commitment to addressing the issues they witness during their 2 years of service. Education Week, a leading national journal of K–12 education, profiled Teach For America’s alumni in an article titled “Most Likely To Succeed” and called Teach For America a “leader-making machine.”

According to a survey conducted in the fall of 2004, our alumni are deeply influenced by their Teach For America experience:

- Nationally, 63 percent of our alumni are working full-time in education, 39 percent as K–12 teachers and 28 percent as administrators, 4 percent in higher education, and 9 percent in education-related non-profits and other positions in the field of education; and
- Nearly 200 Teach For America alumni have founded a school or a non-profit organization.

Even more striking is the extent to which Teach For America alumni have already assumed leadership in the broader effort to improve education—they are running many of the most highly acclaimed charter schools in the country; they are turning around major urban schools as principals; they are winning some of the highest accolades teachers can win (as state and city teachers of the year); they are serving on school boards and advising Governors and Members of Congress on education policy; and they are leading model education reform, public health and economic development initiatives.

#### TEACH FOR AMERICA NEEDS INCREASED FUNDING TO GROW TO SCALE

Teach For America is in the midst of a 5-year expansion plan to more than double the size of its teacher corps. Currently, Teach For America has over 3,000 teachers in 22 communities and a budget of under \$39 million. In the 2006–2007 school year, Teach For America will have nearly 3,500 corps members and will need to raise a budget in excess of \$50 million. At that scale, Teach For America teachers will reach more than 300,000 public school students every day in this country’s lowest-income neighborhoods.

Seventy-five percent of our funding comes from private sources, much of it from the local communities where our teachers teach. We have a highly diversified base of more than 2,000 private donors from all over the country. Top donors include Don and Doris Fisher’s Pisces Foundation; the Broad Foundation; New Profit; the Atlantic Philanthropies; and Wachovia Corporation.

To raise our expanded budget, we must significantly increase our private funding base while growing our federal funding proportionately. With adequate federal funding, we can expand to reach more communities and engage more recent college graduates while continuing to provide highly qualified teachers for America’s neediest classrooms. The Corporation for National and Community Service’s \$4 million fiscal year 2006 budget line item would allow us to maintain our current ratio of federal to private funding and enable us to execute our growth plan.

#### CONCLUSION

I hope you will agree that we have demonstrated all the characteristics of an exemplary AmeriCorps program: we recruit talented young people into competitive positions in critical areas of public need; we have a significant impact in the communities we serve; we influence the civic commitment and career path of our corps members; and we leverage our public support for significant private resources. As we continue our efforts to more than double in size and reach hundreds of thousands of children each year, we seek your support so that Teach For America can expand its scale and impact. Mr. Chairman and Members of the Subcommittee, we hope you will support the President’s request for \$4 million for Teach for America in the fiscal year 2006 budget.



## PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

## SUMMARY OF REQUEST

For 36 years United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from throughout the nation. Our request for fiscal year 2006 funding for tribally controlled postsecondary vocational institutions as authorized under Section 117 of the Carl Perkins Vocational and Applied Technology Act is:

- \$8.5 million under Section 117 of the Perkins Act, which is \$1.1 million over the fiscal year 2005 enacted level of \$7,406,250. This funding is essential to our survival, as we receive no state-appropriated vocational education monies.
- Ensure that the provision that has been included since fiscal year 2002 in the Labor-HHS Education Appropriations Acts that waived the regulatory requirement that we utilize a restricted indirect cost rate is continued.
- Funding for renovation of our facilities, many of which are original to the Fort Abraham Lincoln army installation. A recent study commissioned by the Department of Education shows a facility need for UTTC of \$49 million.
- We support the recommendations of the American Indian Higher Education Consortium, including \$32 million for the Strengthening Developing Institutions Program for tribal colleges (Section 316).

## RESTRICTED INDIRECT COST ISSUE

Beginning in fiscal year 2002 the Labor-HHS-Education Appropriations Act provided that notwithstanding any law or regulation, that Section 117 Perkins grantees are not required to utilize a restricted indirect cost rate. We thank you for taking this action, and ask that it be continued in the fiscal year 2006 Act. We also point out that the pending Perkins reauthorization bills, S.250 and H.R. 366, contain a provision that would exempt Section 117 grantees from the requirement to utilize a restricted indirect cost rate.

In 2001, the Department of Education, for the first time, directed Indian grantees (both Section 116 and 117 grantees) to apply a “restricted indirect cost rate” to their grants. This means each tribal grantee must obtain another indirect cost rate—exclusively for its Perkins Act grant—from its cognizant federal agency (which in most cases is the Inspector General for the Department of the Interior.)

The Department gave two reasons for applying a restricted rate to these Perkins Act Indian programs: (1) The 1998 Amendments to the Perkins Act (Sec. 311(a)) prohibits the use of Perkins Act grant funds to supplant non-federal funds expended for vocational/technical programs. This “supplement, not supplant” limitation previously applied to State grants, only; and (2) A long-standing Department of Education regulation (promulgated years before the 1998 Perkins Amendments) automatically applies the restricted indirect cost rate requirement to any Department of Education grant program with a “supplement, not supplant” provision.

UTTC has no quarrel with the bases and objectives of the “supplement, not supplant” rule and seeks no change to this statutory provision. The primary targets of this rule are States and possibly local government entities that run vocational education programs with State or local funds.

By contrast, however, UTTC has little or no ability to violate this rule, as we have no source of non-federal funds to operate vocational education programs. Unlike States, we have no tax base and no source of non-federal funds to maintain a vocational education program. We depend on federal funding for our vocational/technical education program operations. Despite our inability to violate the supplanting prohibition, we are, nonetheless, being disadvantaged by a Department of Education regulation intended to enforce the prohibition against States who do have the ability to supplant.

—*Impact of new requirement on grantees.*—Under DoEd regulations, a “restricted indirect cost rate” makes unallowable certain indirect costs that are considered allowable by other federal programs. Primarily, these are costs that DoEd believes the grantee would otherwise incur if it did not receive a Perkins grant, such as the cost of the grantee’s chief officer and heads of departments who report to the CEO, as well as the costs of maintaining offices for these personnel.

Prohibiting the Perkins grant from contributing its appropriate share to the grantee’s indirect cost pool will most likely mean that other federal programs operated by the grantee would be expected to pick up a great share of the indirect cost pool. This outcome may well result in objections from the other program agencies that do not want to bear costs properly attributable to the Perkins grant.

We are caught between conflicting federal agency requirements and will find ourselves unable to recover the necessary share of indirect costs attributable to each of the federal programs we operate.

#### UTTC PERFORMANCE INDICATORS

UTTC has:

- An 85 percent retention rate
- A placement rate of 95 percent (job placement and going on to 4-year institutions)
- A projected return on federal investment of 11 to 1 (2003 study comparing the projected earnings generated over a 29-year period of UTTC Associate of Applied Science graduates with the cost of educating them.)
- The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable—10 years or until 2011—and with no stipulations. We are also the only tribal college accredited to offer on-line associate degrees.

*The demand for our services is growing and we are serving more students.*—For the 2003–2004 school year we enrolled 661 Indian students. For the 2004–2005 school year we enrolled 753 Indian students, for an increase of 13 percent over the prior year. The 753 Indian students we enrolled are from 54 tribes and 22 states. The majority of our students are from the Great Plains states, an area that, according to the 2001 BIA Labor Force Report, has an Indian reservation jobless rate of 75 percent. UTTC is proud that we have an annual placement rate of 95 percent. We hope to enroll 2000 adult students by 2008.

In addition, as of the 2004–2005 year, we have served 257 students in our Theodore Jamerson Elementary school, and 226 children in our infant-toddler and preschool programs.

The total population for whom we provided direct services to in the 2004–2005 academic year is 1,236. This is an increase in our overall total population of 17 percent from the 2003–2004 school year.

*UTTC course offerings and partnerships with other educational institutions.*—We offer 17 AAS degrees, 5 of which have been approved to be offered on-line, and 11 certificate degrees. We are accredited by the North Central Association of Colleges and Schools. Our course which has the highest number of students is the Licensed Practical Nursing program.

We are very excited about the recent additions to our course offerings, and the particular relevance they hold for Indian communities. These programs are: (1) Injury Prevention, (2) On-Line Education, (3) Nutrition and Food Services, (4) Tribal Government Management, (5) Tourism, and (6) Tribal Environmental Science.

*Tribal Environmental Science.*—Our newest course offering is Tribal Environmental Science. It is being established through a National Science Foundation Tribal College and Universities Program grant. The 5-year project will support UTTC in planning and implementing an innovative environmental science program. The program is slated to be developed by this summer, beginning with a three week intense student skill-building program. The course work will lead to a 2-year associate of applied science degree in Tribal Environmental Science.

*Injury Prevention.*—Through our Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population. We received assistance through Indian Health Service to establish the only degree-granting Injury Prevention program in the nation. Injuries are the number one cause of mortality among Native people for ages 1–44 and the third for overall death rates.

*On-Line Education.*—We are working to bridge the “digital divide” by providing web-based education and Interactive Video Network courses from our North Dakota campus to American Indians residing at other remote sites and as well as to students on our campus. This semester have 45 students, a number of whom are campus-based, taking on-line courses. We are accredited by the North Central Association of Colleges and Schools to provide on-line associate degrees. This approval is required in order for us to offer federal financial aid to students enrolled in these on-line courses.

On-line courses provide the scheduling flexibility students need, especially those students with young children. Our on-line education is currently provided in the areas of Early Childhood Education, Injury Prevention, Health Information Technology, Nutrition and Food Service and Elementary Education. We are the only tribal college accredited to offer on-line associate degrees.

*Computer Technicians.*—In the second year of implementation, the Computer Support Technician program is at maximum student capacity. In order to keep up with

student demand, we will need more classrooms, equipment and instructors. Our program includes all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

*Nutrition and Food Services.*—UTTTC will meet the challenge of fighting diabetes in Indian Country through education. As this Subcommittee knows, the rate of diabetes is very high in Indian Country, with some tribal areas experiencing the highest incidence of diabetes in the world. About half of Indian adults have diabetes (Diabetes in American Indians and Alaska Natives, NIH Publication 99-4567, October 1999).

We offer a Nutrition and Food Services Associate of Applied Science degree in an effort to increase the number of Indians with expertise in nutrition and dietetics. Currently, there are only a handful of Indian professionals in the country with training in these areas. Future improvement plans include offering a Nutrition and Food Services degree with a strong emphasis on diabetes education and traditional food preparation.

We also established the United Tribes Diabetes Education Center to assist local tribal communities and our students and staff in decreasing the prevalence of diabetes by providing diabetes educational programs, materials and training. We published and made available tribal food guides to our on-campus community and to tribes.

*Tribal Government Management / Tourism.*—Another of our new programs is tribal government management designed to help tribal leaders be more effective administrators. We continue to refine our curricula for this program.

A recently established education program is tribal tourism management. We developed the core curricula for the tourism program and are partnering with three other tribal colleges (Sitting Bull, Fort Berthold, and Turtle Mountain) in this offering. The development of the tribal tourism program was timed to coincide with the planned activities of the national Lewis and Clark Bicentennial in 2003.

*Job Training and Economic Development.*—UTTTC is a designated Minority Business Center serving Montana, South Dakota and North Dakota. We also administer a Workforce Investment Act program and an internship program with private employers.

Economic Development Administration funding was made available to open a "University Center." The Center is used to help create economic development opportunities in tribal communities. While most states have such centers, this center is the first-ever tribal center.

*Upcoming Endeavors.*—We are seeking to develop a Memorandum of Understanding with the BIA's Police Academy in New Mexico that would allow our criminal justice program to be recognized for the purpose of BIA and Tribal police certification, so that Tribal members from the BIA regions in the Northern Plains, Northwest, Rocky Mountain, and Midwest areas would not have to travel so far from their families to receive training. Our criminal justice program is accredited and recognized as meeting the requirements of most police departments in our region.

We are also interested in developing training programs that would assist the BIA in the area of provision of trust services. We have several technology disciplines and instructors that are capable of providing those kinds of services with minimum of additional training. We also provide training in health records technology that fit within the training needs of the Indian Health Service.

*Department of Education Study Documents our Facility/Housing Needs.*—The 1998 Vocational Education and Applied Technology Act required the Department of Education to study the facilities, housing and training needs of our institution. That report was published in November 2000 ("Assessment of Training and Housing Needs within Tribally Controlled Postsecondary Vocational Institutions, November 2000, American Institute of Research"). The report identified the need for \$17 million for the renovation of existing housing and instructional buildings and \$30 million for the construction of housing and instructional facilities.

We continue to identify housing as our greatest need. We have a current waiting list of 64 families. Some families must wait from 1 to 3 years for admittance due to lack of available housing. In 2003-2004, we were forced to find housing off campus for 52 families. In 2004-2005 we housed 105 families off campus, a 50 percent increase over the prior year. In order to accommodate the enrollment increase, UTTTC partners with local renters and two county housing authorities (Burleigh, Morton).

UTTTC has a new 86-bed single-student dormitory on campus. It is already completely full as are all of our other dormitories and student housing. To build the dormitory, we formed an alliance with the U.S. Department of Education, the U.S. Department of Agriculture, the American Indian College Fund, the Shakopee-Mdewakanton Sioux Tribe and other sources for funding. Our new dormitory has

at the same time created new challenges such as shortages in classroom, office and other support facility space. However, more housing must be built to accommodate those on the waiting list and to meet expected increased enrollment. We also have housing which needs renovation to meet safety codes.

Thank you for your consideration of our request. We cannot survive without the basic vocational education funds that come through the Department of Education's Perkins funds. They are essential to the operation of our campus and essential to the welfare of Indian people throughout the Great Plains region and beyond.

---

#### RELATED AGENCIES

##### PREPARED STATEMENT OF THE NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

Thank you for the opportunity to submit testimony to this Subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the President and CEO of the National Federation of Community Broadcasters, I speak on behalf of nearly 257 community radio stations and related organizations across the country. Nearly half our members are rural stations and half are minority controlled stations. In addition, our members include many of the new Low Power FM stations that are putting new local voices on the airwaves. NFCB is the sole national organization representing this group of stations which provide service in the smallest communities of this country as well as the largest metropolitan areas.

In summary, the points we wish to make to this Subcommittee are that NFCB:

- Requests \$430 million in funding for CPB for fiscal year 2008, a \$30 million increase over the fiscal year 2006 advance appropriation;
- Requests \$45 million in fiscal year 2005 for conversion of public radio and television to digital broadcasting. Also supports funding for the Public TV interconnection system;
- Requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fundraising by public broadcasters;
- Requests report language to ensure that CPB utilizes digital funds it receives for radio as well as television needs;
- Supports CPB activities in facilitating programming and services to Native American and Latino radio stations;
- Supports CPB's efforts to help public radio stations utilize new distribution technologies and requests that the Subcommittee ensure that these technologies are available to all public radio services and not just the ones with the greatest resources.

*Community Radio fully supports \$430 million in federal funding for the Corporation for Public Broadcasting in fiscal year 2008.*—Federal support distributed through CPB is an essential resource for rural stations and for those stations serving minority communities. These stations provide critical, life-saving information to their listeners and are often in communities with very small populations and limited economic bases, thus the community is unable to financially support the station without federal funds.

In larger towns and cities, sustaining grants from CPB enable Community Radio stations to provide a reliable source of noncommercial programming about the communities themselves. Local programming is an increasingly rare commodity in a nation that is dominated by national program services and concentrated ownership of the media.

For the past 29 years, CPB appropriations have been enacted 2 years in advance. This insulation has allowed public broadcasting to grow into a respected, independent, national resource that leverages its federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the federal funds. Most importantly, the insulation that advance funding provides “go[es] a long way toward eliminating both the risk of and the appearance of undue interference with and control of public broadcasting.” (House Report 94–245.)

For the last few years, CPB has increased support to rural stations and committed resources to help public radio take advantage of new technologies such as the Internet, satellite radio and digital broadcasting. We commend these activities which we feel provide better service to the American people but want to be sure that the smaller stations with more limited resources are not left out of this technological transition. We ask that the Subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system utilize the new technologies, particularly rural and minority stations.

NFCB commends CPB for the leadership it has shown in supporting and fostering the programming services to Latino stations and to Native American stations. For example, Satélite Radio Bilingüe provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues in Spanish of particular interest to the Latino population. At the same time, American Indian Radio on Satellite (AIROS) is distributing programming for the Native American stations, arguably the fastest growing group of stations. There are now over 30 stations controlled by and serving Native Americans, primarily on Indian reservations.

This year CPB funded the establishment of the Center for Native American Public Radio (CNAPR). Based on a comprehensive assessment of the Native American Radio System, CNAPR will develop new funding sources for stations and programming; provide direct services to the Native Radio System; encourage collaborations; and represent the Native Radio System. These stations are critical in serving local isolated communities (all but one are on Indian Reservations) and in preserving cultures that are in danger of being lost. CPB's assessment recognized that ". . . Native Radio faces enormous challenges and operates in very difficult environments." CPB funding is critical to these rural, minority stations. CPB's funding of the Intertribal Native Radio Summit in 2001 helped to pull these isolated stations together into a system of stations that can support each other. The CPB assessment goes on to say "Nevertheless, the Native Radio system is relatively new, fragile and still needs help building its capacity at this time in its development." The Center for Native American Public Radio promises to leverage additional, new funding to ensure that these stations can continue to provide essential services to their communities.

CPB also funded a Summit for Latino Public Radio which took place in September 2002 in Rohnert Park, California, home of the first Latino Public Radio station. These Summits have expanded the circle of support for Native and Latino Public Radio and identified projects that will improve efficiency among the stations through collaborations and explore new ways of reaching the target audiences.

CPB plays a very important role for the public and Community Radio system. They are the convener of discussions on critical issues facing us as a system. They support research so that we have a better understanding of how we are serving listeners. And they provide funding to programming, new ventures, expansion to new listeners, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with new distribution technologies and media consolidation. An example of this support is the grant that NFCB received to update and publish our Public Radio Legal Handbook online. This provides easy-to-read information to stations about complying with governmental regulations so that stations can function legally and use their precious resources for programming instead of legal fees.

*Finally, Community Radio supports \$45 million in fiscal year 2006 for conversion to digital broadcasting by public radio and television.*—It is critical that this digital funding be in addition to the on-going operational support that CPB provides. The President's proposal that digital money should be taken from the fiscal year 2006 CPB appropriation would effectively cut stations' grants by more than 25 percent. This would have a devastating impact as stations trying to recover from hard economic times. And it would come at a time when the local voices of community and public radio are especially important to notify and support people during emergency situations and to help communities deal with the loss of loved ones—things that commercial radio is no longer able to do because of media consolidation.

While public television's digital conversion needs are mandated by the FCC, public radio is converting to digital to provide more public service and to keep up with what commercial radio is doing. The Federal Communications Commission has approved a standard for digital radio transmission. CPB has provided funding for 301 transmitters in 42 states to convert to digital, is supporting additional research on AM radio conversion, and is working with radio transmitter and receiver manufacturers to build in the capacity to provide a second channel of programming. Most exciting to public and community radio is the encouraging results of tests that National Public Radio has conducted, with funding from CPB, that indicate that stations can broadcast two high-quality signals, even while they continue to provide the analog signal. The development of second audio channels will potentially double the public service that public radio can provide, particularly in service to unserved and underserved communities. This initial funding still leaves more than 500 radio transmitters that will ultimately need to convert to digital or be left behind.

Federal funds distributed by the CPB should be available to all public radio stations eligible for Federal equipment support through the Public Telecommunications Facilities Program (PTFP) of the National Telecommunications and Information Agency of the Department of Commerce. In previous years, Federal support for pub-

lic radio has been distributed through the PTFP grant program. The PTFP criteria for funding are exacting, but allow for wider participation among public stations. Stations eligible for PTFP funding and not for CPB funding include small-budget, rural and minority controlled stations and the new Low Power FM service.

Community Radio also supports funding for the public television interconnection system. Interconnection is vital to the delivery of the high quality programming that public broadcasting provides to the American people.

We appreciate Congress' direction to CPB that it utilize its digital conversion fund for both radio and television and ask that you ensure that the funds are used for both media. Congress stated, with regard to fiscal year 2000 digital conversion funds:

"The required (digital) conversion will impose enormous costs on both individual stations and the public broadcasting system as a whole. Because television and radio infrastructures are closely linked, the conversion of television to digital will create immediate costs not only for television, *but also for public radio stations* (emphasis added). Therefore, the Committee has included \$15,000,000 to assist radio stations and television stations in the conversion to digitalization . . . ." (S. Rpt. 105-300)

This is a period of tremendous change. Digital is transforming the way we do things; new distribution avenues like digital satellite broadcasting and the Internet are changing how we define the business we are in; the concentration of ownership in commercial radio makes public radio in general, and Community Radio in particular, more important as a local voice than we have ever been. New Low Power FM stations are providing new local voices in their communities. Community radio is providing essential local emergency information, programming about the local impact of the major global events taking place, culturally appropriate information and entertainment in the language of the native culture, as well as helping to preserve cultures that are dying out.

During this time, the role of CPB as a convener of the system becomes even more important. The funding that it provides will allow the smaller stations to participate along with the larger stations which have more resources, as we move into a new era of communications.

Thank you for your consideration of our testimony. If the Subcommittee has any questions or needs to follow-up on any of the points expressed above, please contact: Carol Pierson, President and CEO, National Federation of Community Broadcasters, Telephone: 510 451-8200 Fax: 510-451-8208 E-mail: carol@nfcfb.org

The NFCB is a 30-year-old grassroots organization which was established by, and continues to be supported by, our member stations. Large and small, rural and urban, the NFCB member stations are distinguished by their commitment to local programming, community participation and support. NFCB's 257 members come from across the United States, from Alaska to Florida, from every major market to the smallest Native American reservation. While the urban member stations provide alternative programming to communities that include New York, Minneapolis, San Francisco and other major markets, the rural members are often the sole source of local and national daily news and information in their communities. NFCB's membership reflects the true diversity of the American population: 41 percent of the members serve rural communities and 46 percent are minority radio services.

On Community Radio stations' airwaves examples of localism abound: on KWSO in Warm Springs, Oregon, you will hear morning drive programs in their Native language; throughout the California farming areas in the central valley, Radio Bilingüe programs five stations targeting low-income farm workers; in Chevak, Alaska, on KCUK you will hear the local weather reports and public service announcements in Cup'ik/Yup'ik Eskimo; in Dunmore, West Virginia, you will hear coverage of the local school board and county commission meetings; KABR in Alamo, New Mexico serves its small isolated Native American population with programming almost exclusively in Navajo; and on WWOZ you can hear the sounds and culture of New Orleans throughout the day and night.

In 1949 the first Community Radio station went on the air. From that day forward, Community Radio stations have been reliant on their local community for support. Today, many stations are partially funded through the Corporation for Public Broadcasting grant programs. CPB funds represent under 10 percent of the larger stations' budgets, but can represent up to 50 percent of the budget of the smallest rural stations.

PREPARED STATEMENT OF THE NATIONAL MINORITY PUBLIC BROADCASTING  
CONSORTIA

- National Asian American Telecommunications Association
- National Black Programming Consortium
- Latino Public Broadcasting Project
- Native American Public Telecommunications
- Pacific Islanders in Communications

The National Minority Public Broadcasting Consortia (Minority Consortia) submits this statement on the fiscal year 2008 appropriation for the Corporation for Public Broadcasting (CPB) and CPB's fiscal year 2006 digital conversion funding. Our primary missions are to bring a significant amount of programming from our communities into the mainstream of PBS and public broadcasting. In summary, we ask the Committee to:

- Encourage CPB to increase its efforts for diverse programming with commensurate increases for minority programming and the Minority Consortia;
- Encourage CPB to continue its support for the Native radio system;
- Reject the Administration's proposal to end advance funding for the Corporation for Public Broadcasting;
- Reject the Administration's proposal to divert \$82 million of already-appropriated fiscal year 2006 funds to digital conversion and satellite interconnection and to rescind an additional \$10 million;
- Recommend at least \$430 million for CPB core funding for fiscal year 2008, a \$30 million increase over fiscal year 2007;
- Support CPB's request of \$45 million in fiscal year 2006 funds for digital conversion, but require that some of it be made available to independent producers. Also support CPB request of \$52 million for the interconnection system for public radio and television.

We are dismayed at the Administration's continued proposals regarding public broadcasting. The quality gap between network television and public television has never been wider, and it continues to grow with each new "reality" show. Administration proposals to end forward funding of CPB and to divert already appropriated funds would dramatically reduce the development of programming for public broadcasting.

*Advance Funding.*—We strongly oppose the Administration's proposal that the advance funding for CPB be eliminated, a proposal that would stop CPB funding for two years. We appreciate that Congress has rejected this proposal each of the last four years. Reasons to continue advance funding for CPB include:

- The production of programming for public broadcasting usually takes several years and substantial lead time is needed for planning.
- Public broadcasting programs are supported by multiple funding sources, and two years advance knowledge of the amount of federal funding allows CPB to better leverage its federal funds to bring in other sources of revenue.
- The Minority Consortia administers a significant amount of CPB programming monies, and elimination of advance funding would negatively affect our organizations' planning and fundraising activities.

*Proposed Diversion of Fiscal Year 2006 CPB Funds.*—We are extremely concerned about the Administration's proposal to rescind \$10 million and divert an additional \$82 million of already appropriated fiscal year 2006 CPB funds to digital conversion and satellite interconnection. Such a rescission/diversion of funds would wreck havoc on our organizations and the independent producers that we help support as well as many radio and television stations. We would be faced with a 25 percent reduction of CPB funds should Congress approve this proposal by the Administration.

*CPB Fiscal Year 2008 Appropriation.*—We support a fiscal year 2008 federal appropriation for CPB of at least \$430 million. This would be a reasonable, albeit modest, contribution toward our national treasure of public broadcasting. The debate of the past several years regarding public television and public radio has highlighted the great esteem in which they are held.

Public broadcasting, including PBS and NPR, is particularly important for our nation's growing minority and ethnic communities. While there is a niche in the commercial broadcast and cable world for quality programming about our communities and our concerns, it is in the public broadcasting industry where minority communities and producers are more able to bring quality programming for national audiences. Additionally, public television and radio is universally available.

*Digital Conversion Assistance.*—We support CPB's request for \$45 million in fiscal year 2006 funds for digital conversion funding for CPB.

With stations able to broadcast on multiple channels, there will be a need for a tremendous amount of new, quality public broadcasting programming. There are

costs involved in the conversion which go beyond the significant equipment and hardware needs of stations. It will also take additional money to produce programming for digital broadcast. All producers face these new, higher costs.

Part of the equation in bringing more high quality diverse programming to public broadcasting is that independent producers be able to transition to digital production. Federal funding for digital conversion should include assistance for independent producers.

*About the National Minority Public Broadcasting Consortia.*—With primary funding from the Corporation for Public Broadcasting, the Minority Consortia serves as an important component of American public television. By training and mentoring the next generation of minority producers and program managers we are able to ensure the future strength of public television and radio television programming from our communities. Individually, each Consortia organization is engaged in cultivating ongoing relationships with the independent producer community by providing technical assistance, program funding, programming support and distribution. We also provide numerous hours of programming to individual public television and radio stations.

Through our outreach we help bring an awareness of the value of public media among communities which have historically been untapped by public television. Through innovative outreach campaigns, local screenings of works destined for public television, and promotion of web-based information and programming, communities of color are embraced rather than ignored. The Minority Consortia's work in educational distribution further increases the value of public television programming by sharing its works with thousands of students.

While the Consortia organizations work on projects specific to their communities, the five organizations also work collaboratively. One example is our joint effort on the public television four-part series, *Matters of Race* that aired in the Fall of 2003. That series explored the complexity of our rapidly changing multiracial, multicultural society in America. The project resulted in more than television programming. The project was designed so that modules could be pulled out for classroom use. It was also formatted for radio broadcast and for the internet, and included extended interviews. This project provided a great opportunity for extensive and diverse community outreach and collaboration throughout its development, distribution, and use.

We also worked with American Public Television on 6 one-hour programs (named *Colorvision*) featuring the work of Native American, Asian American, Pacific Islander, Latino and African American filmmakers and television producers. It is now in national distribution for all public television stations.

The programming we, both as individual organizations and collaboratively, help bring to public television is beyond the production reach of most local television stations. We support the bill's proposal for increased funding for the production of local programming but believe there is also a great need for increased funding for major programming efforts such as those we and other independent producers undertake.

From 1997 to 2002, the Minority Consortia delivered over 88.5 hours of quality public television programming. Collectively, we have also funded 250 projects and 440 producers/directors. These accomplishments have been recognized with over 123 prestigious national and regional awards, including numerous Emmys. While most of our work is focused on film, of note is that the Native American Public Telecommunications (NAPT) also works in the area of public radio. NAPT developed the Native American public radio satellite network (AIROS) that provides live radio streaming 24 hours a day to over 70 Native American and mainstream public radio stations in the United States (including Alaska).

*CPB Funds for the Minority Consortia.*—The National Minority Public Broadcasting Consortia currently receives funds from two portions of the CPB budget, organization support funds from the Systems Support and programming funds from the Television Programming sections. CPB financial support is critical to the work of our organizations. We believe that we make a major contribution to public broadcasting with a very modest amount of funding, but there is so much more that should be done.

The organizational support funds we receive from CPB are used not only for operations requirements but for also for a broad array of programming support activities and for outreach to our communities. We received \$2 million in fiscal year 2005 CPB funds for organizational support (\$400,000 for each organization). This represents 0.51 percent of the fiscal year 2005 CPB appropriation. We have received only very small increases in operations support funds in the past several years.

The programming funds we receive from CPB are re-granted to producers, used for purchase of broadcast rights and other related programming activities. Each organization solicits applications from our communities for these programming funds.



We received \$3.1 million in fiscal year 2005 CPB funds for programming (\$636,363 for each organization). This represents 0.81 percent of the fiscal year 2004 CPB appropriation. Our CPB programming funds have remained virtually flat over the past nine years, despite increases in CPB appropriations.

The Minority Consortia works closely with CPB. We value our relationship with CPB and appreciate the financial and technical assistance provided to us by that organization. We do not doubt CPB's commitment to increasing the diversity of programming on public television and radio but also believe they can do more with the resources at hand. The oft-stated commitment of CPB and Congress for increased multicultural programming combined with seven years of funding increases should translate into significant progress. We ask this Committee to urge CPB to increase its support for the Minority Consortia as part of an effort to bring more quality multicultural programming to public television.

*Native Radio.*—Native American Public Telecommunications—one of the five Minority Consortia organizations—works with both the radio and television sides of public broadcasting. NAPT operates American Indian Radio on Satellite (AIROS) which distributes programming to Native-owned and other radio stations. Koahnic Broadcasting Corporation, headquartered in Alaska, also produces and distributes Native American programming.

Native-owned radio is the fastest growing area of community radio. There are currently 33 Native-owned stations, all but one of which is located in Indian country. We greatly appreciate CPB's central role in the establishment late last year of the Center for Native American Public Radio (CNAPR), an organization that will provide technical and other services to Native radio stations. CNAPR's mission also includes developing new sources of revenue for the Indian radio system and being an advocate for Native radio. CPB is providing \$1.5 million over a three-year period for CNAPR.

We ask that this Committee urge CPB to continue its support for Native radio.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and thank you for your long time support of our work on behalf of our communities.