REPORT OF REVISED DEFERRAL OF BUDGETARY RESOURCES—MESSAGE FROM THE PRESIDENT—PM 155

The PRESIDING OFFICER laid before the Senate the following message from the President of the United States, together with an accompanying report; referred jointly, pursuant to the order of January 30, 1975, as modified by the order of April 11, 1986, to the Committee on Appropriations, to the Committee on the Budget, and to the Committee on Finance.

To the Congress of the United States:

In accordance with the Congressional Budget and Impoundment Control Act of 1974, I herewith report one revised deferral of budgetary resources, totaling $7.4 million. The deferral affects the Social Security Administration.

WILLIAM J. CLINTON.

THE WHITE HOUSE, *June 24, 1996.*

EXECUTIVE AND OTHER COMMUNICATIONS

The following communications were laid before the Senate, together with accompanying papers, reports, and documents, which were referred as indicated:

EC–3108. A communication from the White House, President of the United States, transmitting, pursuant to law, a report concerning the presence of personnel from states of the former Soviet Union at the Juragua nuclear facility near Cienfuegos, Cuba; to the Committee on Foreign Relations.

EC–3109. A communication from the Administrator of the Agricultural Marketing Service, Department of Agriculture, transmitting, pursuant to law, the report of a rule relative to nectarines and peaches grown in California, received on June 20, 1996; to the Committee on Agriculture, Nutrition, and Forestry.

EC–3110. A communication from the Administrator of the Agricultural Marketing Service, Department of Agriculture, transmitting, pursuant to law, the report of a rule relative to Irish potatoes grown in Washington, received on June 19, 1996; to the Committee on Agriculture, Nutrition, and Forestry.

EC–3111. A communication from the Administrator of the Agricultural Marketing Service, Department of Agriculture, transmitting, pursuant to law, the report of a rule relative to limes and avacados grown in Florida, received on June 19, 1996; to the Committee on Agriculture, Nutrition, and Forestry.

EC–3112. A communication from the Administrator of the Agricultural Marketing Service, Department of Agriculture, transmitting, pursuant to law, the report of a final rule relative to grapes being grown in a designated area of Southeastern California, received on June 19 1996; to the Committee on Agriculture, Nutrition, and Forestry.

EC–3113. A communication from the Administrator of the Agricultural Marketing Service, Department of Agriculture, transmitting, pursuant to law, the report of a final rule relative to specialty crops, received on June 19, 1996; to the Committee on Agriculture, Nutrition, and Forestry.

EC–3114. A communication from the Congressional Review Coordinator of the Animal and Plant Health Inspection Service, Department of Agriculture, transmitting, pursuant to law, the report of a rule relative to Japanese Beetles, received on June 20, 1996; to the Committee on Agriculture, Nutrition, and Forestry.

EC–3115. A communication from the Under Secretary of Defense, transmitting, pursuant to law, the report of a violation of the Antideficiency Act, case number 92–84; to the Committee on Appropriations.

EC–3116. A communication from the Under Secretary of Defense, transmitting, pursuant to law, the report of a violation of the Antideficiency Act, case number 93–03; to the Committee on Appropriations.

EC–3117. A communication from the Acting Assistant Secretary of State (Legislative Affairs), transmitting, pursuant to law, a notice of intent to obligate funds, following the transfer, for the purpose of upgrading existing non-government television stations in Bosnia and Herzegovina; to the Committee on Appropriations.

EC–3118. A communication from the Acting Assistant Secretary of Legislative Affairs, Department of State, transmitting, pursuant to law, the description of property to be transferred to the Republic of Panama in 1996 and 1997; to the Committee on Armed Services.

EC–3119. A communication from the Secretary of Defense, transmitting, relative to the retirement of Lieutenant General Harold W. Blot, United States Marine Corps; to the Committee on Armed Services.

EC–3120. A communication from the Secretary of Defense, transmitting, relative to the retirement of Lieutenant General George R. Christmas, United States Marine Corps; to the Committee on Armed Services.

EC–3121. A communication from the Secretary of Defense, transmitting, relative to the retirement of Lieutenant General James A. Brabham, Jr., United States Marine Corps; to the Committee on Armed Services.

EC–3122. A communication from the Secretary of Defense, transmitting, relative to the retirement of Lieutenant General Arthur C. Blades, United States Marine Corps; to the Committee on Armed Services.

EC–3123. A communication from the Deputy Secretary of Defense, transmitting, pursuant to law, a report relative to the Defense Environmental Restoration Program; to the Committee on Armed Services.

EC–3124. A communication from the Under Secretary of Defense Acquisition and Technology, transmitting, pursuant to law, a report relative to the Amphibious Transport Dock Ship; to the Committee on Armed Services.

EC–3125. A communication from the Director of Financial Management and Deputy Chief Financial Officer, Department of the Interior, transmitting, pursuant to law, the Secretary's Report on Audit Followup; to the Committee on Energy and Natural Resources.

EC–3126. A communication from the Assistant Secretary, Lands and Minerals Management, Department of the Interior, transmitting, pursuant to law, the report of a final rule entitled ''Effective Dates of Permit Decisions'' (RIN1004–AB51), received on June 19, 1996; to the Committee on Energy and Natural Resources.

EC–3127. A communication from the Office of the Chairman, Surface Transportation Board, transmitting, pursuant to law, the report of a rule relative to being exempted from regulation of the construction and operation of connecting railroad track, received on June 14, 1996; to the Committee on Commerce, Science, and Transportation.

EC–3128. A communication from the Secretary of the Federal Trade Commission, transmitting, pursuant to law, the report of a final rule concerning energy consumption and water use, received on June 14, 1996; to the Committee on Commerce, Science, and Transportation.

EC–3129. A communication from the Program Management Officer, National Marine Fisheries Service, National Oceanic and Atmospheric Administration, Department of Commerce, transmitting, pursuant to law, the report of a final rule relative to Magnuson Act Provisions (RIN0648–AI17), received on June 19, 1996; to the Committee on Commerce, Science, and Transportation.

EC–3130. A communication from the Secretary of Transportation, transmitting, pursuant to law, a report entitled ''Regulatory Actions Affecting Tourist Railroads''; to the Committee on Commerce, Science, and Transportation.

EC–3131. A communication from the General Counsel, Department of Transportation, transmitting, pursuant to law, the report of four final rules concerning special local regulations (RIN2115–AE46, 2130–AA97), received on June 20, 1996; to the Committee on Commerce, Science, and Transportation.

EC–3132. A communication from the General Counsel of the Department of Transportation, transmitting, pursuant to law, the report of twenty-one final rules concerning airspace (RIN2120–AA66, AA64, A64, AF90, AA65), received on June 20, 1996; to the Committee on Commerce, Science, and Transportation.

INTRODUCTION OF BILLS AND JOINT RESOLUTIONS

The following bills and joint resolutions were introduced, read the first and second time by unanimous consent, and referred as indicated:

By Mr. DOMENICI:

S. 1898. A bill to protect the genetic privacy of individuals, and for other purposes; to the Committee on Labor and Human Resources.

By Mr. STEVENS (for himself, Mr. LEAHY, and Mr. MURKOWSKI):

S. 1899. A bill entitled the Mollie Beattie Alaska Wilderness Area Act; to the Committee on Energy and Natural Resources.

By Mr. DORGAN (for himself, Mr. GRASSLEY, Mr. HARKIN, and Mr. ROCKEFELLER):

S. 1900. A bill to amend titles XVIII and XIX of the Social Security Act to permit a waiver of the prohibition of offering nurse aide training and competency evaluation programs in certain nursing facilities; to the Committee on Finance.

By Mr. DORGAN (for himself and Mr. GRASSLEY):

S. 1901. A bill to amend title XIX of the Social Security Act to repeal the requirement for annual resident review for nursing facilities under the Medicaid program and to require resident reviews for mentally ill or mentally retarded residents when there is a significant change in physical or mental condition; to the Committee on Finance.

STATEMENTS ON INTRODUCED BILLS AND JOINT RESOLUTIONS

By Mr. DOMENICI:

S. 1898. A bill to protect the genetic privacy of individuals, and for other purposes; to the Committee on Labor and Human Resources.

THE GENETIC CONFIDENTIALITY AND NONDISCRIMINATION ACT OF 1996

Mr. DOMENICI. Mr. President, I rise today to return a momentous issue to the forefront. This issue is genetics confidentiality and nondiscrimination. I am pleased to report that the human

genome project is proceeding rapidly to map and sequence the entire complement of human genes. These genes are coded in over 3 billion molecular building blocks of DNA.

Now, most people—and I must say most Members of the Congress—are not necessarily aware of the fact that since 1986, our Government has been involved in an annual program which has reached the size of about $138 to $140 million a year, which is divided one-third in the Department of Energy and two-thirds in the National Institutes of Health. That program spends that money by permitting various major American institutions to proceed to map certain chromosomes which are yielding fantastic information regarding diseases of the human species.

One might quickly recognize that if that is going on, it probably is also going on in the area of animals and in the area of agricultural products. And, yes, although the genome project is human, because of its tremendous success it is going on in the other areas also. So, in a very real sense, believe it or not, while all the discussion of late is about conventional health care proposals, it is entirely possible, in fact I believe probable, that within 25 to 40 years the entire delivery of health care will be built around genetics rather than what we are doing today. In fact, at certain conferences we have sat around and thought about what a hospital will probably look like when we have finally mapped and sequenced the entire chromosome system. It will not be anything like we have today.

So, in these 3 million molecular building blocks, we are busy locating the situs within that molecular system of most of the diseases that impede human progress and have this enormous impact on our well-being, our health, and thus our prosperity and the joy of living. Determining this entire code is going to provide scientists and doctors with a road map. This map will lead them to great discoveries and breakthroughs, as I have indicated, to prevent suffering and pain of diseases.

The human genome project stands to be one of humanity's greatest scientific achievements. Nonetheless, when the human genome was first brought to my attention in 1986, I recognized that it could catalyze revolutions, not just in science and medicine, but also in ethics and in law and society. That is why one will find, as part of the human genome funding, that there is money set aside specifically to address the ethical, legal, and social implications of this project.

There is literally a revolution occurring in genomic information, special information, information about our species, about our bodies, and, most important, about ourselves. Who should know this information? Should it be public? Should our doctors, our friends and our families, our insurers, our employers or even our very selves know every detail of our genetic blueprint? These are penetrating and provocative questions, and they are proactive, and they deeply concern many who know about them. I guarantee the Senate that there will be, with the passage of each year, more and more people concerned about them as the ramifications begin to unfold.

I am not one who says that, because of these serious ramifications, we should stop the progress of knowledge about human disease. But, obviously, if we do not do this carefully, the abuse could stop this progress. About that, there can be no doubt, for, if this kind of information is abused in a country like ours, there may be an enormous backlash. Frankly, I think that would be a pathetic response to one of the approaches to wellness with most potential that humankind has ever seen.

So, this genetic confidentiality and nondiscrimination is a monstrous issue, and I raise it today not as the first to raise it, for it is around. Certain Senators—led over time by Senator HATFIELD and, of late, a few others—are rising to the occasion and worrying about it.

The right for each individual to have some control over his or her most personal and most identifying information is what we are talking about. Indeed, I could change my name again and again and maybe some people would no longer be able to identify me, maybe some would, maybe some wish they could not. However, I can never, never change my genetic information. It will always be me, and yours will be you. People will always be able to identify this genetic information that is peculiar to each of us. Whether it comes from a drop of blood, the back of a postage stamp where saliva remains, or a pathology specimen, it is the person from whence the blood, the saliva, or whatever other piece of our anatomy is put to the pathology test.

So, along with my colleague, Senator SIMON, I am today introducing the Genetic Confidentiality and Nondiscrimination Act of 1996. This is a comprehensive and defining legislative vehicle. It is, indeed, needed to bolster the efforts of 19 States that have enacted some kind of information privacy statutes, as well as five of my colleagues who have introduced similar legislation, although substantially different. This bill in no way infringes on those efforts. Genetics privacy is a big issue, and many groups will have concern about specific provisions. There is much work to be done. There needs to be much more debate. I am certain the Chair is aware of that from this discussion thus far. My staff, as well as others, have worked very hard to craft the very best bill that we could.

I think from this point on we should not let time lapse. We should work together and get something done to make sure we do not punish and penalize the progress of this rather fantastic health research. Again, this bill is a comprehensive legislative vehicle that will be subject to exhaustive legislative review processes, with hearings and input from all sources and all points of view.

So let me briefly describe our bill. First, I send forward a summary to the desk and ask unanimous consent it be printed in the RECORD at the conclusion of my remarks.

The PRESIDING OFFICER. Without objection, it is so ordered.

(See exhibit 1.)

Mr. DOMENICI. The act itself will be known as the Genetic Confidentiality and Nondiscrimination Act of 1996. First, the bill defines genetic information as uniquely private and distinct from other personal information such as medical records. As I mentioned before, it is impossible to separate one's identity from one's genes. One's DNA also provides information about one's family. Genetic information carries significance and has great potential for misuse. Let me repeat. This information is of special significance and has great potential for misuse. Genetics transcends medicine and can penetrate many aspects of life, including employment, insurance, education, forensics, finance, and even one's self-perception.

Let me also make it perfectly clear that this bill does not make it illegal for a third party to collect, store, analyze, or even disclose an individual's genetic information. This bill requires that third parties obtain the individual's informed and written consent.

This legislation puts individuals in control of his or her genetic information. Some will object to that, but ultimately the question is going to be asked: If not the individual, who? Exceptions are provided in the bill for legitimate medical research, law enforcement activities, court-ordered analysis and purposes of identification of dead bodies or active duty military remains and, on the latter, we have already been hearing something about that.

Specifically, the purposes of this legislation are:

First, to define the circumstances under which genetic information may be created, stored, analyzed, or disclosed;

Second, to define the rights of individuals with respect to genetic information;

Third, to identify the responsibilities of third parties with respect to genetic information;

Fourth, to protect individuals from genetic discrimination with respect to insurance and employment. Just think of that one, the opportunity to discriminate because of genetic information if randomly delivered to people such as insurance carriers, employers, and many other institutions and individuals that could act based on it.

Fifth, to establish uniform rules to protect genetic privacy and allow the advancement of research.

Today, there is clear and pressing need for Federal legislation on this issue. This Senator, along with Senator SIMON—and I am sure there will be others who will join us, but I have just not had enough time to get this circulated and get it out to other Senators; that will start today—but we are introducing this bill to motivate, consolidate,

and strengthen the process of getting something done in this very, very important area. I look forward to working with my House and Senate colleagues in bringing this issue, with broad bipartisan support, to an anxiously awaiting American public.

Mr. President, the call is now. Once again, the human genome project stands to be one of the greatest scientific and medical achievements of all time. And incidentally, I think one might wonder why we did not do this a long time ago. We constantly talk about the computer and what it permits us to do that we could not have done. It is patent and obvious that we could never ever have begun the process of mapping the 3 billion human genomes within the chromosome system of a human being without the computer system that has evolved in our country.

Without that, we would still be having researchers take on and study for their whole lifetime where the gene for multiple sclerosis might be. This is not to say many of those great research teams struggled mightily, and they did, and they found the situs for many of them and cures and drugs have resulted that ameliorate and sometimes cures.

But this offers science ultimately a map of all of the chromosomes, and then they will begin to sequence them in some kind of order. They will have a road map and then start to sequence them.

What they will have done, once they have finished, is give the great scientists an opportunity to focus in on the work to find where the mutation is that is causing breast cancer. Work is being done with families on just that subject, and the mutation is being isolated and people are being, in some instances, told whether they are going to get this cancer or not. It is rather amazing.

Where will all this end up? Let us hope, with an appropriate reservation of rights on disclosure, that it will end up in the right hands doing the right kind of things, making the right kind of progress that our great society is taking the lead in. I will say, though, so nobody thinks this is totally and singularly an American project. It is not. The French are doing great work. In some cases, they have a lead on America. Japan is doing some, and almost all of the industrialized nations are doing some. But our great genome project has moved ahead in a dramatic manner. It is ahead of schedule, it has cost much less than we expected and, consequently, it is time for us to do something now about this aspect of it.

Its wonderful promise may never be fully realized if the public is afraid of what someone else will do with their information. That is the reason that this becomes very important.

Mr. President, in addition to the matter for which I asked unanimous consent earlier, I ask unanimous consent that a number of news articles be printed in the RECORD, and I send the bill to the desk and ask for its appropriate referral.

There being no objection, the articles were ordered to be printed in the RECORD, as follows:

GENETIC PROPHECY AND GENETIC PRIVACY—CAN WE PRESENT THE DREAM FROM BECOMING A NIGHTMARE?

(By George J. Annas)

Would you want to know if you're likely to develop Alzheimer's disease later in life? Would you want your employer, your health insurer, your colleagues, or your family to know? Who should decide who should know, and how can public health practitioners use genetic information on predisposition to diseases like dementias and cancer for the public good without stigmatizing individuals?

In this issue's Health Law and Ethics, Mayeux and Schupf pose all of these questions and more in the context of apolipoprotein-E screening for Alzheimer's disease. Although the presence of the 4-type apolipoprotein E allele is not a test for Alzheimer's disease, Mayeux and Schupf's analysis suggests many of the issues we will face when tests for the genes that cause various types of Alzheimer's disease, such as early onset Alzheimer's, become available. They argue, persuasively I think, that population screening now ''would not only be impractical, but would be of no obvious benefit'' and ''without a clear-cut therapeutic option, early detection (by testing) at this point does not seem beneficial.'' They also properly stress the dangers of creating disease in the absence of symptoms, and the necessity for pre- and post-test counseling for any such probabilistic, presymptomatic genetic testing.

The central question presented by genetic screening and testing is whether genetic information is different in kind from other medical information (such as family history and cholesterol levels), and if so, whether this means that it should receive special legal protection. Stated another way, are Mayeux and Schupf correct in concluding that ''the genetic code of an individual should be protected and considered confidential information in all circumstances''? I think they are, but their conclusion with respect to genetic privacy deserves more analysis.

Genetic information can be considered uniquely private or personal information, even more personal than other medical information such as human immunodeficiency virus (HIV) status or mental health, for at least three reasons: it can predict an individual's likely medical future; it divulges personal information about one's parents, siblings, and children; and it has a history of being used to stigmatize and victimize individuals.

The highly personal nature of the information contained in one's deoxyribonucleic acid (DNA) can be illustrated by thinking of DNA as containing an individual's coded ''future diary.'' A diary is perhaps the most personal and private document a person can create. It contains a person's innermost thoughts and perceptions and is usually hidden and locked to assure its secrecy. Diaries describe the past. The information in one's genetic code can be thought of as a coded probabilistic future diary because it describes an important part of a person's unique future and, as such, can affect and undermine one's view of himself or herself and his or her life's possibilities. Unlike ordinary diaries that are created by the writer, the information contained in one's DNA, which is stable and can be stored for long periods of time, is largely unknown to the person. Most of the code cannot now be broken, but parts are being deciphered almost daily. As decoding techniques get better, and if one's DNA is deciphered without permission, another person could learn intimate details of the individuals likely future life that even the individual does not know.

Deciphering an individual's genetic code also provides the reader of that code with probabilistic health information about that individual's family, especially parents, siblings, and children. Finally, genetic information (and misinformation) has been used by governments (US) immigration and sterilization policies and Nazi racial hygiene policies, for example) to discriminate viciously against those perceived as genetically unfit and to restrict their reproductive decisions.

Mayeux and Schupf note my prior recommendations regarding regulating DNA banks. Although regulating such ''gene banks'' is necessary to protect genetic privacy, it is not sufficient. My colleagues Leonard Glantz and Patricia Roche and I now believe that we need federal legislation to protect individual privacy by protecting not only DNA samples, but also the genetic information obtained from analyzing DNA samples. To be effective, such legislation must govern activities at at least four points: collection of DNA, analysis of DNA, storage of DNA and information derived from it, and distribution of DNA samples and information derived from DNA samples. As a general rule, no collection or analysis of an individual's DNA should be permitted without an informed and voluntary authorization by the individual or his or her legal representative. Research on nonindentifiable DNA samples need not be inhibited; but research on DNA from identifiable individuals should proceed only with informed consent.

To codify these rules and make them uniform throughout the United States, we have drafted the ''Genetic Privacy Act of 1995,'' the core of which prohibits individuals from analyzing DNA samples unless they have verified that written authorization for the analysis has been given by the individual or his or her representative. The individual has the right to do the following:

Determine who may collect and analyze DNA;

Determine the purpose for which a DNA sample can be analyzed;

Know what information can reasonably be expected to be derived from the genetic analysis;

Order the destruction of DNA samples;

Delegate authority to another party to order the destruction of the DNA sample after death;

Refuse to permit the use of the DNA sample for research or commercial activities; and

Inspect and obtain copies of records containing information derived from genetic analysis of the DNA sample.

A written summary of these principles (and other requirements under the act) must be supplied to the individual by the person who collects the DNA sample. The act requires that the person who holds private genetic information in the ordinary course of business keep such information confidential and prohibits the disclosure of private genetic information unless the individual has authorized the disclosure in writing, or unless the disclosure is limited to access by specified researchers for compiling data. Although the act itself does not prohibit the use of genetic information by employers and insurance companies (because this is a separate problem from privacy), it would be reasonable public policy to prohibit both employers and health insurance companies from using genetic information in making hiring and coverage decisions. Congress should act now to protect genetic privacy. While we

wait for congressional action, states can act, and private companies and practitioners can voluntarily adopt these privacy rules as their own.

The new genetics raises virtually every major health care policy question, as well as unique legal and ethical problems. How should screening for BRCA 1 and BRCA 2 (two ''breast cancer genes'') be introduced into medical and public health practice? Should we prohibit parents from authorizing the testing of minors or fetuses for breast cancer genes, or any other gene predisposing to a nonpreventable, late-onset disease? The Human Genome Project has devoted approximately $3 million a year for the past 5 years to exploring the legal, ethical, and social policy issues raised by the project. The Genetic Privacy Act is one of the products of this funding. In addition, the Institute of Medicine's Committee on Assessing Genetic Risks has made more than 225 specific recommendations dealing with genetic screening and testing, virtually all of which are reasonable. We know the privacy and policy issues that come with the new genetics. The challenge is to act now to try to maximize the good and minimize the harm that will come to all of us from our new genetic knowledge.

[From the Washington Post, May 12, 1996]

THIS MAP WON'T SHOW US THE WAY

(By Jessica Mathews)

The job of deciphering the 60,000 to 100,000 genes the human genome will be finished in less than 10 years. That may sound like a long time, but it isn't. Long before then, but it isn't. Long before then, at an accelerating pace, we will begin to be flooded with genetic information that can be as treacherous and unwelcome as it sometimes is lifesaving. We will need every minute to prepare for a revolution in medicine that will invade our privacy in unprecedented ways and challenge legal protections, social values, personal ethics and religious beliefs.

If the past is any measure, we won't be ready. With no societal consensus about how to approach the issues, most of the decisions will get bumped, as a last resort, to the courts where judges with no particular qualification nor preparation will have to decide, struggling to find some constitutional basis for resolving novel, moral dilemmas.

Think for a moment about a world in which genetic screening of people and fetuses is routine.

Suppose you knew you had a high risk of dying in 10 years? Should it be legal to keep that information to yourself when buying life insurance?

How would a managed-care provider treat a couple who refused preventive treatment. (an abortion) for a fetus that would require lifetime medical care?

What if screening revealed children's individual endowments of traits were now call intelligence. Would society demand educational tracking beginning in preschool?

How will prospective parents deal with the information in a fetal screen? Suppose it reveals a high risk of heart disease, or mental disorders, or obesity or undesirable temperament? Will pregnancy in this brave new world necessarily be a time of achingly difficult decisions? What will it mean for society when every child enters the world with hundreds of ''preexisting conditions''? What will it mean for religion when innate characteristics become a matter of choice?

Will the rich, who can afford repeated fetal screening and genetic interventions, begin to produce children who differ more and more from those of the poor?

Should prospective employers and insurers have access to an individual's genetic profile? What about prospective spouses? What about us—would we have a ''right'' not to know about ourselves?

Will we want all this information we can do very little about? Will we ever be able to meaningfully apply statistical risks to our own, individual cases? How will we cope with decades of enormous uncertainty as scientists sort out the interactions of tens of thousands of genes and the interactions of the resulting genetic propensities with the environment?

Where will we find enough genetic counselors who combine scientific knowledge, therapeutic insight, clerical compassion and the wisdom of Solomon? Should they just give the facts? If they do more, whose values will they be transmitting?

What about genetic alteration of germ cells, those that pass on traits to future generations? So have said that a line can be clearly drawn making these cells off limits. But suppose it becomes possible to alter the genes that give rise to familial predispositions to cancer and other diseases. Wouldn't we want to do that? Then aren't we facing an era of human eugenics?

The widespread unhappiness with having judges rule on the moral question of physician-assisted suicide offers a faint preview of what it would be like to leave such questions to the courts. In one of those cases, Andrew Kleinfeld, a dissenting judge on the 9th Circuit, made his own discomfort plain. ''The Founding Fathers did not establish the U.S. as a democratic republic,'' he wrote, ''so that elected officials could decide trivia, while all great questions would be decided by the judiciary.''

The alternative is to develop sufficient public understanding to address these choices through referendums and legislatively and, if possible, to do so in a way that avoids making genetic ethics into a political football like abortion. A small beginning has been made. The government-funded Human Genome Project wisely set aside a small fraction of its budget to study moral and ethical questions, so there are expert groups and advisory committees and a stream of scholarly papers. But that is not enough.

Nor is it enough to vaguely call—as I have in the past—for a ''broad public conversation'' on the subject. Without some sort of crisis it just won't happen. What is needed is a national commission of a new and different kind.

The usual mission for such a body is to serve either government or interested groups through fact-finding, research and expert advice. This one's client would be the public. Its job would be to find innovative ways to inform and stimulate public debate; to frame choices, to offer balanced pros and cons; to confront as many Americans as it can with the facts and the uncertainties and scientists' best guesses about where their work is leading. It should be nonpartisan and operate for as long as we need it.

The mapping of the human genome will be an enormous scientific achievement, at least on a par with nuclear fission, but much more personal. If it is, on balance, to improve our lives in the next few decades, we'll have to collectively think it through—in advance.

[From the Washington Post National Weekly Edition, June 3–9, 1996]

ALL IN THE GENES—THE NEW AVAILABILITY OF TESTS RAISES A HOST OF ETHICAL QUESTIONS

(By Rick Weiss)

When Ebenezer Scrooge got a sneak preview of his own demise, including views of his funeral that no one cared to attend, he had only to change his evil ways to revise the future. If only genetic testing offered such simple solutions.

New genetic tests are moving rapidly from research laboratories into doctors' offices, where they are being marketed as a way to predict people's chances of getting common diseases such as colon cancer, breast cancer and Alzheimer's disease.

But instead of offering clear views of the future and strategies for altering it, genetic tests have raised the specters of DNA-based discrimination and loss of health insurance, and the prospect of people learning just enough to scare them but not enough to cure them.

Now, as companies begin to market their new tests, scientists, patients' groups, health insurers and legislators are rushing to stake out positions on what restrictions, if any, should be placed on the commercialization and use of genetic tests. The strained positions some are taking reveal the extent to which science today is intermingled with politics and business.

Congress, for example, is preparing legislation that would prohibit genetic discrimination against some people—but not against others. The Food and Drug Administration, already on the defensive amid corporate claims of over-regulation, has declared it has the authority to regulate genetic tests but hastens to add that it has no plans to do so. And in perhaps the most unusual twist, many advocates of patients' rights who usually clamor for access to the latest cancer breakthroughs are asking that some genetic tests be kept from patients.

The National Breast Cancer Coalition, for example, a patients' rights group, opposes open marketing of a test for the so-called breast cancer gene, BRCA1. At the risk of sounding as paternalistic as the doctors they often fight against, members say the test's generally ambiguous results may trigger unnecessary panic in many women while reassuring others who should remain vigliant.

''There's a real dilemma among feminist scholars on this,'' says June Peters, a genetic counselor at the National Institutes of Health. ''You need to build in safeguards,'' she says, since profit-driven companies do not necessarily share the same interests as patients. ''At the same time, there is the feeling, 'I am an adult and I can take care of these decisions myself.'''

Genetic tests differ from many medical tests because they often provide very vague answers, such as, ''You have a gene that gives you a 70 percent chance of getting breast cancer in the next 20 years.'' That uncertainty can be all the more frsutrating because in most cases there is nothing a person can do to prevent the predicted disease from occurring.

Moreover, people can reduce their risk of getting heart disease or cancer by changing unhealthful habits such as overeating or smoking, but they are stuck with their genes. And with legal protections still not fully established, the information gleaned from genetic tests today is as easily used against people as for them.

''You can't choose your genes,'' says Francis Collins, director of the National Center for Human Genome Research. ''So you shouldn't be discriminated against on the basis of those genes.''

The stakes are high on both sides of the issue. The fledging genetic testing industry, which foresees soaring profits in the next few years, is pushing hard to get its tests to market, arguing that patients have the right to learn about their own genes even if the information is incomplete or inconclusive. Similarly, health insurers desperately want the right to peek at their clients' genes to help predict their medical fates—and to set their insurance rates accordingly—in part because they are afraid that people who discover they have faulty genes may try to take out large policies.

On the other hand, many scientists, doctors and patients' groups argue that, at least for now, most gene testing should be limited to research studies designed to gather more information about how to make the most of this new resource. Studies could keep track of how people with various ''bad'' genes fare over the years, settling the question of which genetic glitches really matter and which are less important.

Studies also could compare different preventive treatments to see whether it is worthwhile, for example, to remove a person's colon just because a genetic test reveals a very high risk of colon cancer, or whether that individual can safely put off surgery until a cancer is actually found. Extra time also would allow Congress and other institutions to devise safeguards against the misuse of genetic information.

With these concerns in mind, several prestigious scientific organizations—including the American Society for Human Genetics, the National Advisory Council for Human Genome Research and the National Action Plan on Breast Cancer, which is coordinated by the U.S. Public Health Service—have come out against commercialization of the BRCA1 test, the first crude predictor of cancer risk to come on the market.

Scores of genetic tests have been developed for dozens of diseases. Some are used to diagnose existing conditions and others are used in healthy people to predict the odds that a disease will occur. The tests, usually done with a drop of blood, look for ''misspellings'' in a person's DNA—the strands of genetic material that spell out in biological code the instructions for making products the body needs.

Many genetic tests—especially those for rare diseases—can predict with certainty a person's fate. Everyone who tests positive for the genetic defect associated with Huntingdon's disease, for example, will get the fatal neurodegenerative disease, probably in midlife.

But many other genetic tests—especially those for more common diseases such as cancer and Alzheimer's disease—offer far less definite predictions. The breast cancer test, which looks for a spelling error in the BRCA1 gene, is one such test. It is now making its way onto the market in three different formats, ranging from ''research only'' to open marketing.

Increasing numbers of women are asking for the test because they are under the impression that those who have a mutation in the BRCA1 gene have an 85 percent chance of getting breast cancer, as well as an elevated risk of ovarian cancer.

But what should a woman do if she tests positive? No preventive strategies have been shown to help—not even preemptive removal of both breasts, since tumors may still develop in nearby chest tissues. More frequent mammograms to watch for the first sign of cancer may be useless or even dangerous, since there is evidence that some women with this mutation may be especially prone to DNA damage and cancer from X-rays.

To further complicate the issue, more than 130 mutations have been found in the breast cancer gene. Some are probably meaningless, and others deadly, but most have not been studied yet. Standard gene tests available today detect only one or a few of the more common mutations, so a negative test doesn't guarantee safety.

Most important, many women seem not to realize that it is only if a woman has a clear family history of breast cancer—usually defined as two or more close relatives with the disease—that the BRCA1 mutation confers 85 percent odds of getting breast cancer.

The vast majority of women do not come from cancer-prone families, and for them the risk of having a BRCA1 mutation remains completely unknown.

That is not to say the test is useless. For some carefully selected women already diagnosed with breast cancer, a positive test can indicate the need for more aggressive therapy.

And for a woman whose mother or sister had breast cancer from a BRCA1 mutation, a negative test can provide some reassurance. What remains unproved, however, is that the test has any value for the more than 95 percent of women who do not fit into those categories.

A federally funded study of thousands of women, ongoing in the Washington, D.C.-Baltimore area, will begin to answer the question of what a positive BRCA1 test really means. But because it is research, and the results of the study will take time to interpret, the women will not be told whether they have the mutation.

Meanwhile, the Genetics & IVF Institute, of Fairfax, Va., recently started offering the BRCA1 test to women willing to pay about $300. The clinic has been criticized by some doctors and ethicists for making the test available to women who might have little or nothing to gain from it. Its medical director, Joseph Schulman, declined to be interviewed for this story.

A third option, praised by several doctors as a good compromise, is underway at OncorMed, of Gaithersburg, Md. The company offers BRCA1 testing and results to women who are willing to follow certain rules prepared by an independent research review board. Women must be referred for counseling before and after the test is performed. Results must be given by the doctor in person, and the doctor must follow up with patient about three months later. The company also must compile data from its experience to determine which aspects of the gene-testing process need improvement.

At a recent meeting in Baltimore of a federal task force on gene testing, some participants questioned whether the companies marketing genetic tests should be the ones to decide who gets tested and what information they receive or whether some sort of regulatory oversight should be imposed.

The question of oversight is made more difficult because laboratory testing already is regulated in a patchwork manner, and none of the patches quite applies to genetic tests.

Medical testing is regulated in part by an act of Congress, the Clinical Laboratory Improvement Amendments of 1988. But CLIA stipulates only that laboratory tests must be scientifically accurate—that is, a test for a BRCA1 mutation must be good at finding BRCA1 mutations. It does not require that a test have any proven usefulness for patients. The FDA reviews and approves the relatively simple test ''kits'' that are sold for use in commercial laboratories or at home. At times it has even required that counseling be given with test results, as it did with the approval of a home AIDS test early last month.

But genetic tests are too new and complicated to be sold as kits. Most genetic tests are ''home brew'' tests, developed inhouse by the companies that do the testing. The FDA has the authority to regulate such tests, says Deputy Commissioner Mary K. Pendergast, but it has never done so. ''We would not be able to take it on,'' she says, ''without stopping other things we are doing now.''

Congress could help protect test recipients by making it illegal for insurers and employers to discriminate on the basis of genetic information. Both the House and Senate versions of the health care bill that is soon to be considered by a conference committee contain language that would prohibit some forms of genetic discrimination.

The bills would preclude companies from using genetic information to deny an insured person continued insurance when that person changes health plans. But they offer little or no protection to people who do not yet have insurance and are trying to get it. And other safeguards are far from complete.

''These bills would require that insurers offer a policy, but they don't cover pricing, so we can expect to see discriminatory pricing,'' says Wendy McGoodwin, executive director of the Council for Responsible Genetics, an advocacy group in Cambridge, Mass. ''And it has no impact whatsoever on life insurance or disability insurance.''

According to many experts, the last hope for intelligent guidance on the gene-testing issue may be a federal task force convened last year by the National Institutes of Health and the Department of Energy.

The task force, with representatives from the medical profession, the testing and insurance industries and patients' rights groups, is preparing a wide-ranging report on the ethical, legal and social implications of genetic testing, due to be completed by the end of the year. But consensus has been difficult to achieve.

At a task force meeting in April, representatives of the biotechnology industry said it is the doctor's job to make sure that patients understand the risks and benefits of being tested. Doctors said they were still getting up to speed in genetics and would be unable to stem the tide of patient demand if testing were not subject to regulatory restrictions. And insurers said they would go out of business if they were restricted from having access to genetic information.

Given the lack of agreement, some suspect the field will simply grow like any other ''buyer beware'' market as more and more tests become available.

''Physicians are soon likely to confront extremely awkward situations,'' Harvard scientists Ruth Hubbard and Richard Lewontin wrote recently in the New England Journal of Medicine. ''Physicians need to recognize the limitations of the new information * * * and the commercial pressures behind the speed with which preliminary scientific data are being turned into tests.''

Mr. DOMENICI. I yield the floor.

EXHIBIT 1

THE GENETICS CONFIDENTIALITY AND NONDISCRIMINATION ACT—SUMMARY

Sec. 1.—Short title: The ''Genetics Confidentiality and Nondiscrimination Act of 1996''

Sec. 2.—Findings: The DNA molecule contains an individual's genetic information that is uniquely private and inseparable from one's identity. Genetic information is being rapidly sequenced and understood. Genetic information carries special significance. It provides information about one's family, and, more importantly, provides information about one's self and one's self perception. Genetic information has been misused, harming individuals through stigmatization and discrimination. The potential for misuse is tremendous as genetics transcends medicine and has the potential to penetrate many aspects of life including employment, insurance, finance, and education. Genetic information should not be collected. stored, analyzed, nor disclosed without the individual's authorization. Current legal protections for genetic information are inadequate. Uniform rules for collection, storage and use of DNA samples and genetic information are needed to protect individual privacy and prevent discrimination, such as in employment and insurance, while permitting legitimate medical research.

Purposes: This legislation will: (1) define circumstances under which genetic information may be created, stored, analyzed, or disclosed: (2) define rights of individuals and

persons with respect to genetic information; (3) define responsibilities of others with respect to genetic information; (4) protect individuals from genetic discrimination; (5) establish uniform rules that protect individual genetic privacy and allow the advancement of genetic research; and (6) establish effective mechanisms to enforce the rights and responsibilities defined in this Act.

Sec. 3.—Definitions: Genetic information—means any the information that may derive from an individual or a family member about genes, gene products, inherited characteristics. Such term includes DNA sequence information including that which is derived from the alteration, mutation, or polymorphism of DNA or the presence or absence of a specific DNA marker or markers. Individual—means the source of the DNA sample including body, body parts, or bodily fluids from whom the DNA sample originated. Research—means systematic scientific (including social science) investigation that includes development, testing, and evaluation, designed or developed to contribute to original generalizable knowledge.

TITLE I.—COLLECTION, STORAGE, AND ANALYSIS OF DNA SAMPLES

Secs. 101–105 prohibit collection, storage, or analysis of genetic information, unless written, informed consent has been obtained from the individual (exceptions in the bill are provided for identification of dead bodies or active-duty remains, law enforcement purposes, purposes pursuant to court-ordered analysis, and some research purposes).

TITLE II—DISCLOSURE OF GENETIC INFORMATION

Secs. 201–205 describe the written authorization necessary to disclose genetic information. It also describes the protection, inspection, amendment, and disclosure of records containing genetic information. This part also provides exceptions for compulsory disclosure in any judicial, legislative, administrative proceeding, as well as court-order purposes. (The bill also provides some exceptions for research purposes under Title V.)

TITLE III.—DISCRIMINATION PROHIBITED

Secs. 301–302 prohibit genetic discrimination by employers and insurers.

TITLE IV.—EXCEPTIONS FOR IDENTIFICATION AND COURT-ORDERED ANALYSIS

Secs. 401–404 provide exceptions for identification of dead bodies and active-duty military remains, law enforcement purposes, and activities pursuant to court-ordered analysis.

TITLE V.—RESEARCH ACTIVITIES

Secs. 501–503 restate the need for researchers to obtain informed consent from individuals who participate in research. It provides exceptions for obtaining, storing, and analyzing genetic information for research purposes. It specifies: conditions for genetic analysis, safeguards against disclosures, limitations on minors (requires parental consent), destruction of DNA samples upon completion of the project (unless permission is given to maintain them), protections regarding pedigree analysis and family linkage studies, and the research subjects' right to obtain information. This part also specifies conditions for disclosure of genetic information for research purposes, allows limited access to genetic information for epidemiologic uses, and provides exceptions for DNA samples collected from individuals prior to the effective date of this Act.

TITLE VI.—MINORS

Sec. 601 provides conditions for collection and analysis of genetic information from minors. Essentially, the bill requires a parent, guardian to consent to the individual's participation in research and that the analysis benefits the individual.

TITLE VII.—MISCELLANEOUS

Secs. 701–702 require employers to annually notify employees who maintain DNA samples or genetic information of their responsibilities under this Act. It also provides for continuity of privacy of genetic information upon transfer of ownership or discontinuation of services.

TITLE VIII.—ENFORCEMENT

Secs. 801–802 provide civil penalties of $50,000 for negligent violation or $100,000 for willful violation; both per incident. No criminal penalties are specified. Injunctive relief and private right of action are also provided. There is a six year statute of limitations.

TITLE IX.—EFFECTIVE DATES, APPLICABILITY AND RELATIONSHIPS TO OTHER LAWS

Proposed effective date is January 1, 1997. Nineteen States have enacted genetics privacy or nondiscrimination legislation; this Act would only serve to strengthen existing State laws.

By Mr. STEVENS (for himself, Mr. LEAHY and Mr. MURKOWSKI):

S. 1899. A bill entitled the ''Mollie Beattie Alaska Wilderness Area Act''; to the Committee on Energy and Natural Resources.

THE MOLLIE BEATTIE ALASKA WILDERNESS AREA ACT

Mr. STEVENS. Mr. President, I am here today with a heavy heart to introduce a bill that I would like to have called the Mollie Beattie Alaska Wilderness Area Act. My colleague from Alaska, Mr. MURKOWSKI joins me in my remarks and as an original sponsor of this legislation.

I want to make a few remarks about Mollie, who has served well as the Director of Fish and Wildlife Service for this administration. I believe my colleague in the House, DON YOUNG, will introduce similar legislation. As the Senate knows, Mollie Beattie is gravely ill—so ill that she decided to step down from her position as Director of the Fish and Wildlife Service. We are now informed that Mollie's situation is worsening.

It may seem strange for me to be here talking about Mollie Beattie. She opposed many of the things that I believe in, as far as Alaska public lands are concerned. But I am introducing this bill to designate the 8 million acres of wilderness within the 19 million acre Arctic National Wildlife Refuge as the ''Mollie Beattie Alaska Wilderness Area.''

Under my legislation, the Secretary of the Interior would be directed to place a monument on a portion of the wilderness, so that people entering the wilderness might remember and honor Mollie Beattie's contribution to the conservation of fish and wildlife.

Now, Mollie Beattie opposed us on some things, and she worked with us on some things. But the reason I like her is she was always honest with us. We knew where she stood. And she listened. As a matter of fact, as days went on, we thought maybe she was listening to us more and we might be able to find some middle ground between the position she had taken and our own.

And so I was saddened, and I came to the floor and said so, when Mollie stepped down from her position as the Director of the Fish and Wildlife Service. In Mollie's departure from the Service, the American people are losing a leader of depth of knowledge and life experience.

Mollie, by the way, was the first woman to serve as the Director of the Fish and Wildlife Service. During the Eisenhower administration, I served in the Interior Department for almost 5 years, and I know of the mission of that service and its continuing benefit to the American public.

Mollie was and is a champion of resource conservation. I do not think we really had any disagreement as to the end result that we sought, but perhaps some of the means to get there.

She came to the Fish and Wildlife Service from the Richard A. Snelling Center for Government in Vermont, where she was the executive director. Prior to that, she served in several Vermont State land management agencies. I am happy that the senior Senator from Vermont, Mr. LEAHY, and the junior Senator, Mr. JEFFORDS, have asked to cosponsor the bill that I will send to the desk in a few moments.

In her last major speech as Director of the Fish and Wildlife Service, Mollie recalled releasing Hope, a rehabilitated bald eagle, as a highlight of her career. Her career has had many high moments. She has focussed on reconnecting the American people to the wildlife around them. Those of us who have worked with Mollie really are saddened to learn about her condition. We send her and her husband, Rick, our sincerest sentiments and really want him to know that, from a professional point of view, his wife has enjoyed the greatest of friendships in the Congress regardless of party.

There being no objection, the bill was ordered to be printed in the RECORD, as follows:

S. 1899

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SEC. 1. SHORT TITLE.—This Act may be cited as the ''Mollie Beattie Alaska Wilderness Area Act.''

SEC. 2. MOLLIE BEATTIE ALASKA WILDERNESS AREA.—Amend P.L. 96–487 by striking Section 702(3) and inserting in lieu thereof the following:

''(3) Arctic National Wildlife Refuge Wilderness of approximately eight million acres as generally depicted on a map entitled ''Arctic National Wildlife Refuge'' dated August 1980. That portion of the Arctic National Wildlife Refuge Wilderness located in the Brooks Range on a map to be prepared by the Secretary of the Interior shall be named and appropriately identified as the ''Mollie Beattie Alaska Wilderness Area'';''

SEC. 3. PLACEMENT OF MONUMENT.—The Secretary of the Interior shall place a monument in honor of Mollie Beattie's contributions to fish, wildlife, and waterfowl conservation and management at the entrance to the Mollie Beattie Alaska Wilderness Area or another suitable location he designates. Such sums as may be necessary are authorized for the placement of such monument.

Mr. JEFFORDS. Mr. President, today we dedicate a beautiful area of Alaska as the Mollie Beattie Fish and Wildlife Refuge. More than any person this century, Mollie has led the fight to protect our Nation's natural heritage. Her dedication to preserving wildlife and wildlife habitat and her spirit and enthusiasm in accomplishing this important goal will be appreciated by generations to come.

Mollie and I share much in common. We both love the wild, appreciate its complexity and beauty and value that it contributes to our lives. We also recognize the importance of protecting fragile ecosystems, from wetlands to forests. Finally, we both love Vermont and have worked together to preserve its distinctive character.

I have followed Mollie's career throughout her time in Vermont and here in Washington. A resident of Vermont since 1968, Mollie used her calm and determined manner and her knowledge of animals, plants, and natural resources to institute policies which today are a model of environmental protection. As a reporter, a University of Vermont professor and the developer of an experimental game bird habitat, Mollie strove to integrate her values into each position and left behind a legacy of success.

As Commissioner of the Vermont Department of Forests, Parks, and Recreation in the late 1980's, Mollie oversaw all of Vermont's public lands, including wildlife habitat areas and 48 State parks. In 1989, she became Deputy Secretary for Vermont's Agency of Natural Resources, caring for forests, public lands, water quality, air quality, and wildlife. After a stop over as Executive Director of the Richard A. Snelling Center for Government in Burlington, Mollie was nominated by President Clinton to serve as Director of the U.S. Fish and Wildlife Service. I have never known, in my 22 years representing Vermont, a person with greater dedication to preserving our Nation's wildlife.

I remember soon after her appointment, Mollie came to visit me here in the Senate. We spent time discussing the future of the refuge system and prospects for Endangered Species Act reform. We also reviewed our Nation's ability to curb the unnecessary slaughter of tigers, rhinos, elephants, and species rapidly disappearing from other countries. Her commitment to ending the rapid loss of species was remarkable. Since her arrival here in Washington, she recognized the importance of our Nation's wildlife refuge system and has been successful in protecting these vital resources. She did so effectively and I assure you that our children and their children will forever cherish this determined woman's work.

During her tenure at the Fish and Wildlife Service, Mollie visited Alaska several times and shared with me some of her special memories of the State. These visits made a remarkable impression on Mollie, especially her trip to the Arctic Refuge two summers ago. I can think of no better tribute than to name the 8 million acres of wilderness in the Arctic Refuge after Mollie. This area captures the ideals and beauty that Mollie strove to protect while at the Fish and Wildlife Service.

Mr. President, I want to thank Mollie Beattie on behalf of all my colleagues in the U.S. Senate and all Americans for all that she has done to make America a more beautiful Nation.

By Mr. DORGAN (for himself, Mr. GRASSLEY, Mr. HARKIN, and Mr. ROCKEFELLER):

S. 1900. A bill to amend title XVIII and XIX of the Social Security Act to permit a waiver of the prohibition of offering nurse aide training and competency evaluation programs in certain nursing facilities; to the Committee on Finance.

By Mr. DORGAN (for himself and Mr. GRASSLEY):

S. 1901. A bill to amend title XIX of the Social Security Act to repeal the requirement for annual resident review for nursing facilities under the Medicaid program and to require resident reviews for mentally ill or mentally retarded residents when there is a significant change in physical or mental condition; to the Committee on Finance.

LONG-TERM-CARE LEGISLATION

Mr. DORGAN. Mr. President, today I am introducing legislation that will relieve nursing homes of unnecessary regulation without jeopardizing the high quality of care nursing home residents receive. These two bills, which enjoy bipartisan support, will improve long-term care in this country by giving nursing homes the flexibility they need to focus scarce resources on providing quality care.

I have long believed that the Federal Government has an important role to play in ensuring against the kinds of abuses that occurred in some areas of the country prior to enactment of Federal nursing home standards. I do not believe that those abuses were the norm in nursing homes. In fact, nursing homes in my State of North Dakota have a strong record of providing quality care, and I believe that this was the case in most nursing homes.

But it is clear that some nursing homes did not meet that high standard, and many States were far too slow to respond. To address that critical problem, I supported and continue to support minimum Federal quality standards. Our first priority in nursing home legislation must be the quality of care provided to residents, and we should not pass any laws that would compromise that goal.

However, I believe that some of our efforts to regulate nursing homes have not resulted in greater quality of care for residents. In some cases, by imposing unnecessary burdens and diverting scarce resources in nursing facilities, these laws and regulations can hinder the delivery of quality care. The legislation I am offering today will address two such instances.

NURSE-AIDE TRAINING PROGRAM

The first bill I am introducing has enjoyed broad bipartisan support during the 104th Congress. I am joined in offering this bill by Senator GRASSLEY and Senator HARKIN. This bill would exempt rural nursing facilities from the possibility of termination of their nurse-aide training programs for reasons unrelated to the quality of the training program

Simply put, this is a commonsense amendment. In rural areas all over the country, nursing facilities offer people an opportunity to learn the basic nursing and personal care skills needed to become a certified nurse aide. In return, those who participate in a nurse-aide training program help nursing facilities meet their staffing needs and allow the nursing staff to focus more on administering quality nursing care.

Nurse-aide training programs are especially important in rural areas like my State of North Dakota, where potential nurse aides might have to travel hundreds of miles for training if it is not available at the nursing facility in their community. These nurse-aide training programs comply with strict guidelines related to the amount of training necessary and determination of competency for certification.

Despite these safeguards, current law allows programs to be terminated for up to 2 years if a facility has been cited for a deficiency or assessed a civil money penalty for reasons completely unrelated to the quality of the nurse-aide training program. In North Dakota, this could result in real hardship not just for the nursing facility and potential nurse aides, but for the nursing home residents who rely on nurse aides for their day-to-day care.

Under my bill, rural areas would be exempt from termination of nurse-aide training programs in these specific instances only if: first, no other program is offered within a reasonable distance of the facility; second, the State assures that an adequate environment exists for operating the program; and third, the State provides notice of the determination and assurances to the State long-term care ombudsman.

Congress included this exception for rural nurse-aide training programs in the Balanced Budget Act passed last December, and the President included it in his 1997 budget proposal.

ANNUAL RESIDENT REVIEWS

The second bill I am introducing today relates to the pre-admission screening and annual resident review [PASARR] requirements enacted as part of OBRA '87. Senator GRASSLEY joins me in introducing this bill, which also has bipartisan support and was included in the President's balanced budget proposal.

PASARR was enacted to prevent inappropriate placements of residents with mental health or developmental disabilities. The need for assessments to determine whether a mental health

or developmental disability exists is critical, and we still have some way to go in ensuring that residents with these problems receive appropriate placement and treatment in all cases.

However, the annual resident review process duplicates other mandatory assessments and has not resulted in identifying inappropriate placements or improving the quality of care for nursing home residents. The current law adds an average of $700,000 to State costs for long-term care and diverts valuable nursing facility resources. We must continue to work to ensure that nursing home residents receive the quality care they need, but we should not do so by placing unnecessary or ineffective burdens on nursing facilities and their staffs.

My bill would retain the pre-admission screening for each resident, but would repeal the annual resident review requirement for each patient. This would go a long way toward streamlining the regulatory process and allowing nursing homes to focus more time on providing quality care.

I hope my colleagues will join me in supporting these sound policy proposals.

ADDITIONAL COSPONSORS

S. 814

At the request of Mr. MCCAIN, the name of the Senator from Maine [Ms. SNOWE] was added as a cosponsor of S. 814, a bill to provide for the reorganization of the Bureau of Indian Affairs, and for other purposes.

S. 1607

At the request of Mrs. FEINSTEIN, the name of the Senator from Missouri [Mr. ASHCROFT] was added as a cosponsor of S. 1607, a bill to control access to precursor chemicals used to manufacture methamphetamine and other illicit narcotics, and for other purposes.

S. 1799

At the request of Ms. SNOWE, the name of the Senator from Vermont [Mr. JEFFORDS] was added as a cosponsor of S. 1799, a bill to promote greater equity in the delivery of health care services to American women through expanded research on women's health issues and through improved access to health care services, including preventive health services.

S. 1806

At the request of Mr. D'AMATO, the name of the Senator from Iowa [Mr. GRASSLEY] was added as a cosponsor of S. 1806, a bill to amend the Federal Food, Drug, and Cosmetic Act to clarify that any dietary supplement that claims to produce euphoria, heightened awareness or similar mental or psychological effects shall be treated as a drug under the act, and for other purposes.

SENATE RESOLUTION 270

At the request of Mr. LIEBERMAN, the names of the Senator from Utah [Mr. HATCH], and the Senator from Michigan [Mr. LEVIN] were added as cosponsors of Senate Resolution 270, a resolution urging continued and increased United States support for the efforts of the International Criminal Tribunal for the former Yugoslavia to bring to justice the perpetrators of gross violations of international law in the former Yugoslavia.

AMENDMENTS SUBMITTED

THE SENATE CAMPAIGN FINANCE REFORM ACT OF 1996

HOLLINGS AMENDMENT NO. 4093

(Ordered to lie on the table.)

Mr. HOLLINGS submitted an amendment intended to be proposed by him to the bill (S. 1219) to reform the financing of Federal elections, and for other purposes; as follows:

At the appropriate place insert the following:

SEC. . SENSE OF THE SENATE THAT CONGRESS SHOULD ADOPT A JOINT RESOLUTION PROPOSING AN AMENDMENT TO THE CONSTITUTION THAT WOULD EMPOWER CONGRESS AND THE STATES TO SET REASONABLE LIMITS ON CAMPAIGN EXPENDITURES

It is the sense of the Senate that Congress should adopt a joint resolution proposing an amendment to the Constitution that would—

(1) empower Congress to set reasonable limits on campaign expenditures by, in support of, or in opposition to any candidate in any primary, general, or other election for Federal office; and

(2) empower the States to set reasonable limits on campaign expenditures by, in support of, or in opposition to any candidate in any primary, general, or other election for State or local office,

(3) empower local governments of general jurisdiction to set reasonable limits on campaign expenditures by, in support of, or in opposition to any candidate in any primary, general or other election for office in that government.

BUMPERS AMENDMENT NO. 4094

(Ordered to lie on the table.)

Mr. BUMPERS submitted an amendment intended to be proposed by him to the bill, S. 1219, supra; as follows:

In lieu of the matter proposed to be inserted, insert the following:

SECTION 1. SHORT TITLE; AMENDMENT OF CAMPAIGN ACT; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the ''Senate Campaign Financing and Spending Reform Act''.

(b) AMENDMENT OF FECA.—When used in this Act, the term ''FECA'' means the Federal Election Campaign Act of 1971 (2 U.S.C. 431 et seq.).

(c) TABLE OF CONTENTS.—