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NATIONAL DIABETES ADVISORY BOARD ACT, 1976

GOVERNMENT

CUMENTS

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HEARING
BEFORE THE
SUBCOMMITTEE ON HEALTH
OF THE
COMMITTEE ON
LABOR AND PUBLIC WELFARE
UNITED STATES SENATE
NINETY-FOURTH CONGRESS

SECOND SESSION
ON

S. 2910

TO ESTABLISH THE NATIONAL DIABETES ADVISORY
BOARD AND TO INSURE THE IMPLEMENTATION OF THE
LONG-RANGE PLAN TO COMBAT DIABETES

MAY 11, 1976



Printed for the use of the Committee on Labor and Public Welfare

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WASHINGTON : 1976

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NATIONAL DIABETES ADVISORY BOARD ACT, 1976

TUESDAY, MAY 11, 1976

U.S. SENATE,
SUBCOMMITTEE ON HEALTH OF THE
COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 9:38 a.m. in room 4232, Dirksen Senate Office Building, Senator Richard S. Schweiker presiding pro tempore.

Present: Senators Schweiker and Javits.

Senator SCHWEIKER. The Senate Health Subcommittee will please come to order.

First I would like to say that our chairman, Senator Kennedy, had planned to be here to open the meeting, but unfortunately he cannot be with us because of an urgent call to go to a bill signing at the White House. He asked me to express his regret for not being able to be here for the opening part.

But he did have a statement that he would like to insert in the record which I will give to the reporter at this time.

[The statement referred to follows:]

OPENING STATEMENT OF SENATOR EDWARD M. KENNEDY

This morning's hearing will consider the report of the National Diabetes Commission, and the recommendations which the Commission has made to mount a broad attack on the problem of diabetes.

Diabetes is one of the important diseases that afflict the American people. It is estimated that some 10 million Americans suffer from this disease, and that some 38,000 deaths each year are attributable to diabetes. Among the many unfortunate complications of diabetes is that the risk of blindness in a diabetic is 25 times that of the person who does not suffer from the disease.

The Commission's report makes it clear that we still do not know what causes diabetes, nor why the disease appears to be increasing in the United States. We do know, however, that the disease is more prevalent among women, among nonwhites, among the poor, and among overweight people.

It is clear that more research is needed on both the causes and therapy of this disease, of the type that led to the impressive clinical trials by National Eye Institute on the laser treatment of diabetic retinopathy.

My colleague, Senator Schweiker, has been in the forefront of the legislative activity to combat diabetes, first in the establishment of the Diabetes Commission in 1974, and now in taking the lead in introduc-

ing legislation to implement the recommendations of the Diabetes Commission, and in organizing the hearing on this subject this morning. I look forward to working with him on this important legislation, and am pleased to turn over the chair of the Health Subcommittee to him for this hearing.

Senator SCHWEIKER. I would like to express my thanks to the chairman, Senator Kennedy. In my diabetes work he has always been most cooperative and most supportive and he certainly was most willing to set up this day of hearings, and I am very indebted to him for that.

I would like to make a brief opening statement, and then we will hear from Dr. Carter, who is one of our key leaders in this area.

The purpose of the hearing today is to hear testimony concerning the National Diabetes Advisory Board Act, S. 2910, which I introduced February 2, 1976, along with Senator Williams, chairman of the committee, and Senator McGee. This bill would establish a National Diabetes Advisory Board and insure implementation of a long-range plan to combat diabetes.

Several years ago, I became aware of the increasing incidence of diabetes in our country. The incidence of diabetes is increasing at an alarming rate. Experts estimate that the number of people with diabetes will double every 15 years. The average American born today has a better than one in five chance of developing diabetes, unless a method of prevention is found.

At the same time, I was appalled to learn how little Federal money was being allocated for fighting this disease. It was clear to me that we needed expanded diabetes research programs to prevent and cure diabetes, and also better methods for treating the disease and its complications. It was essential that the Federal Government provide financial support to implement and coordinate effective programs aimed at problems related to diabetes.

Because of this concern, I introduced a bill which was passed in July 1974, creating the National Diabetes Research and Education Act. An important provision of this act established a National Commission on Diabetes charged with making specific recommendations for the organization and utilization of national resources for combating diabetes. The Commission, under the chairmanship of Dr. Oscar Crofford of Vanderbilt University, has brought to bear the resources of experts inside and outside Government. These have included research scientists, clinical physicians, directors of the National Institutes of Health, representatives of voluntary health organizations, and other health professionals and citizens vitally concerned with diabetes.

On December 10, 1975, the Commission presented to Congress its recommendations for the development of a long-range plan to combat diabetes. In addition to increased funding, the Commission recommended creation of nationwide diabetes research and education centers; coordination of Federal, State and local programs; and formation of a National Diabetes Advisory Board. The legislation before us today incorporates the Commission's recommendations.

The National Diabetes Advisory Board recommended by the Commission would "review, evaluate, and advise with regard to the imple-

mentation of the long-range plan to combat diabetes." The Board would provide an organizational focus for coordinating widely dispersed programs and resources.

The necessary research, education, and control programs involve diverse groups of Government agencies and private organizations. These include the National Institutes of Health, the Center for Disease Control, the Health Services Administration, the Health Resources Administration, other Federal agencies, State and local agencies, private industry, and voluntary health organizations. Each plays an important role. But no single coordinating body now exists which can evaluate implementation of the long-range plan. This is why we must create the National Diabetes Advisory Board.

[A copy of S. 2910 and introductory remarks of Senator Schweiker and Senator Williams follow:]

94TH CONGRESS
2D SESSION

S. 2910

IN THE SENATE OF THE UNITED STATES

FEBRUARY 2, 1976

Mr. SCHWEIKER (for himself, Mr. McGEE, and Mr. WILLIAMS) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

A BILL

To establish the National Diabetes Advisory Board and to insure the implementation of the long-range plan to combat diabetes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*
3 That this Act may be cited as the "National Diabetes Advi-
4 sory Board Act".

FINDINGS AND DECLARATION OF PURPOSE

6 SEC. 2. (a) The Congress finds that—

7 (1) the National Commission on Diabetes (here-
8 inafter referred to as the "Commission") has formulated
9 a long-range plan to combat diabetes (hereinafter
10 referred to as the "long-range plan") ;

II

1 (2) the ultimate goals of this long-range plan are
2 to discover means to prevent and to cure diabetes and its
3 complications and to improve the care and quality of
4 life of those individuals who now have or will get dia-
5 betes before the discovery of preventive measures and a
6 cure; and

7 (3) in order to insure the effective implementation
8 of the long-range plan it is necessary to have an orga-
9 nization with sufficient authority to—

10 (A) review, evaluate, and advise with regard
11 to the recommendations of the long-range plan; and

12 (B) coordinate the utilization of national
13 resources for diabetes research, education, and
14 treatment.

15 (b) It is the purpose of this Act to—

16 (1) establish a National Diabetes Advisory Board
17 to insure the implementation of the long-range plan to
18 combat diabetes, and

19 (2) insure the implementation of the long-range
20 plan to combat diabetes.

21 THE NATIONAL DIABETES ADVISORY BOARD

22 SEC. 3. (a) The Secretary of Health, Education, and
23 Welfare shall, within thirty days after the date of enactment
24 of this Act, establish a National Diabetes Advisory Board

1 (hereinafter referred to as the "Board") in accordance
2 with the requirements of this Act.

3 (b) The Board shall be composed of nineteen members
4 as follows:

5 (1) the Assistant Secretary for Health;

6 (2) the Director of the National Institutes of
7 Health;

8 (3) the Director of the National Institute of
9 Arthritis, Metabolism, and Digestive Diseases;

10 (4) the Director of the Center for Disease Control;

11 (5) the Administrator of the Health Services
12 Administration;

13 (6) the Administrator of the Health Resources
14 Administration;

15 (7) the Chairman of the Diabetes Mellitus Coordi-
16 nating Committee;

17 (8) seven members appointed by the Secretary of
18 Health, Education, and Welfare who are not in the em-
19 ployment of the Federal Government and who are physi-
20 cians, other health professionals, or scientists representing
21 the various specialties and disciplines involved with dia-
22 betes mellitus and related endocrine and metabolic
23 diseases;

24 (9) five members appointed by the Secretary of

1 Health, Education, and Welfare from the general public,
2 including at least one person with diabetes and one par-
3 ent of a diabetic child.

4 (c) The members of the Board shall select a Chairman
5 from among those members who are not employees of the
6 Federal Government.

7 (d) The Board shall—

8 (1) appoint and fix the compensation of an execu-
9 tive director, assistant director, and such additional
10 staff personnel, not to exceed three, as it deems neces-
11 sary for the performance of the Board functions, without
12 regard to the provisions of title 5, United States Code,
13 governing appointments in the competitive service, and
14 without regard to chapter 51 and subchapter III of chap-
15 ter 53 of such title relating to classification and General
16 Schedule pay rates, but at rates not in excess of the max-
17 imum rate for GS-18 of the General Schedule under sec-
18 tion 5332 of such title; and

19 (2) procure temporary and intermittent services to
20 the same extent as is authorized by section 3109 of title
21 5, United States Code.

22 (e) The Board is authorized—

23 (1) to adopt, amend, and repeal rules and regula-
24 tions governing the manner of its operations, organiza-
25 tion, and personnel;

1 (2) to enter into contracts or other arrangements
2 or modifications thereof, with any government, any de-
3 partment, agency, or independent instrumentality of the
4 United States, or with any person, firm, association, or
5 corporation, and such contracts or other arrangements,
6 or modifications thereof, may be entered into without
7 legal consideration, without performance or other bonds,
8 and without regard to section 3709 of the Revised
9 Statutes, as amended (41 U.S.C. 5) ;

10 (3) to make advance, progress, and other payments
11 which the Board deems necessary under this Act with-
12 out regard to the provisions of section 3648 of the
13 Revised Statutes, as amended (31 U.S.C. 529) ; and

14 (4) to take such other action as may be necessary
15 to carry out its functions under this section.

16 (f) The Office of the Assistant Secretary for Health
17 of the Department of Health, Education, and Welfare shall,
18 to the extent permitted by law and to the extent needed
19 to carry out the purposes of this Act, provide the Board
20 with necessary administrative services and facilities, includ-
21 ing but not limited to the services of professional and support
22 staff, necessary office space, and equipment.

23 (g) Members of the Board who are officers or em-
24 ployees of the Federal Government shall serve as members
25 of the Board without compensation in addition to that re-

1 ceived in their regular public employment. Members of the
2 Board who are not officials of the Federal Government shall
3 each receive the daily equivalent of the rate for Grade GS-18
4 of the General Schedule for each day (including traveltime)
5 they are engaged in the performance of their duties as mem-
6 bers of the Board. All members of the Board shall be entitled
7 to reimbursement for travel, subsistence, and other necessary
8 expenses incurred by them in the performance of their duties
9 as members of the Board.

10 (h) Of those individual members of the Board desig-
11 nated in paragraphs (8) and (9) of subsection (b), six shall
12 be appointed initially for terms of three years, to be suc-
13 ceeded by members appointed for two years, and six shall be
14 appointed initially for terms of two years, to be succeeded by
15 members appointed for three years.

16 (i) Only those individuals who are members of the
17 Board shall be permitted to vote on matters which require
18 decisions by the Board.

19 (j) The Board shall review, evaluate, and advise with
20 regard to the implementation of the long-range plan to com-
21 bat diabetes mellitus of the National Commission on Diabetes.
22 In carrying out this function the Board shall recommend
23 those additional administrative policies that it finds necessary
24 to insure—

1 (1) the success of the long-range plan to combat
2 diabetes mellitus; and

3 (2) the most effective utilization and organization
4 of national diabetes resources.

5 (k) (1) The Board may engage in and sponsor such
6 activities, collect such data, provide such technical assistance
7 as it deems necessary and advisable to enable it to perform
8 its duties under this Act.

9 (2) The Board may, from time to time, establish work-
10 ing committees composed of Board members and nonmem-
11 ber consultants with expertise in the particular areas ad-
12 dressed by such committees.

13 (1) The full Board shall hold regular quarterly meet-
14 ings. In addition, the full Board or any of its working com-
15 mittees may hold such additional meetings as are necessary
16 in order to enable the Board to carry out its activities.

17 (m) For each year that the Board is in operation, two
18 months prior to the transmission of the President's budget to
19 Congress, the Board shall submit simultaneously to both the
20 President and to Congress, an Annual Diabetes Report. Such
21 report shall—

22 (1) describe the Board activities for the prior year;
23 (2) describe and evaluate progress made during the
24 previous year in diabetes research, treatment, and edu-

1 cation with specific reference to the long-range plan to
2 combat diabetes mellitus;

3 (3) describe the Board's proposed activities for
4 the next year;

5 (4) include a detailed budget analysis of current
6 diabetes-related activities of the Federal Government;

7 (5) suggest recommended expenditures for the
8 forthcoming fiscal year;

9 (6) make recommendations for necessary legislation
10 to implement policy;

11 (7) discuss recommended technical refinements in
12 the long-range plan to combat diabetes mellitus neces-
13 sitated by developments in the field; and

14 (8) be made available to the public at the same
15 time it is transmitted to the President and the Congress.

16 (n) The Board shall cease to exist five years after the
17 date of its first meeting.

18 (o) There are authorized to be appropriated to carry
19 out the purposes of this section \$500,000 for fiscal year end-
20 ing June 30, 1976, and such sums as are necessary for each
21 of the four fiscal years thereafter.

22 DISTINGUISHED SCIENTIST GRANTS

23 SEC. 4. (a) The Secretary of Health, Education, and
24 Welfare (hereinafter referred to as the "Secretary") is au-

1 thorized to make grants to individual scientists who have
2 shown continuous and outstanding productivity in research
3 related to diabetes. The grants shall be made for the pur-
4 pose of enabling such scientists to continue research efforts
5 in areas such as basic research on insulin and related hor-
6 mones and metabolism, etiology of diabetes, obesity and
7 nutrition, and diabetic retinopathy and basic physiologic
8 studies of the eye as they relate to diabetes.

9 (b) The amount of each such grant made under sub-
10 section (a) shall not exceed \$35,000 per year.

11 (c) The Secretary shall, with the assistance of the
12 Directors of the National Institutes of Health, promulgate
13 rules and regulations governing the selection of those indi-
14 vidual scientists eligible to receive the grants under this sec-
15 tion. There are authorized to be appropriated \$175,000 for
16 fiscal year 1976, \$350,000 for fiscal year 1977, \$525,000
17 for fiscal year 1978, \$700,000 for fiscal year 1979, and
18 \$875,000 for fiscal year 1980 and each year thereafter.

19 FUNDS FOR DIABETES RESEARCH AND TRAINING

20 CENTERS

21 SEC. 5. Section 435 (c) of the Public Health Service
22 Act is amended to read as follows:

23 “(c) There are authorized to be appropriated to carry
24 out this section \$8,000,000 for fiscal year ending Septem-

- 1 ber 30, 1977, \$12,000,000 for fiscal year ending Septem-
- 2 ber 30, 1978, \$20,000,000 for fiscal year ending September
- 3 30, 1979, \$20,000,000 for fiscal year ending September 30,
- 4 1980, and \$20,000,000 for fiscal year ending September 30,
- 5 1981.”.

[From the Congressional Record—Senate, Feb. 2, 1976]

INTRODUCTORY REMARKS OF SENATOR SCHWEIKER

By Mr. SCHWEIKER (for himself, Mr. McGee, Mr. Williams) :

S. 2910. A bill to establish the National Diabetes Advisory Board and to insure the implementation of the long-range plan to combat diabetes. Referred to the Committee on Labor and Public Welfare.

NATIONAL DIABETES ADVISORY BOARD ACT

Mr. SCHWEIKER. Mr. President, on behalf of myself, the distinguished Senator from Wyoming, Mr. McGee, and the distinguished chairman of the Committee on Labor and Public Welfare, Mr. Williams, I send to the desk for appropriate reference a bill to establish the National Diabetes Advisory Board and to insure the implementation of the long-range plan to combat diabetes.

In conjunction with our action here today Representative Tim Lee Carter, of Kentucky, Representative William Steiger, of Wisconsin, Representative Guy Vander Jagt, of Michigan, and Representative Andrew Maguire, of New Jersey, are introducing similar legislation in the other body.

Diabetes is the third most serious health problem facing our country today. The National Commission on Diabetes recently reported to Congress that over 10 million Americans suffer from this disease and that it is the leading cause of adult blindness, kidney disease, and heart problems. Yet for many years people have been told diabetes is a disease under control and not a major national problem.

The National Commission, created by the Diabetes Mellitus Research and Education Act of 1974, which we were proud to sponsor, has not only for the first time outlined the scope of the disease, in its report of December 10, 1975, but has also for the first time established a blueprint, defining what this Nation needs to do to mount a successful attack on diabetes. Some of the Commission's recommendations can be implemented by the National Institutes of Health under present authority; the NIH program is of major importance, and we will seek to assure that the Appropriations Committee recommends enough funds for this to occur.

The Commission has also recommended that a new administrative mechanism be created to oversee diabetes research and treatment efforts. This is necessary because diabetes is so broad in its impact that the traditional divisions of the National Institutes of Health may not allow for effectively coordinated research. In order to implement this recommendation, the bill we introduce today will establish the National Diabetes Advisory Board and insure the implementation of the long-range plan to combat diabetes prepared by the Commission.

The first section of the bill contains findings the Commission used to prepare a long-range plan to discover the means to prevent and cure diabetes, and to improve the quality of life for those who now have or will have diabetes. In order to implement the plan, the findings continue, it is necessary to have an organization with authority to coordinate the utilization of national resources for diabetes research, education, and treatment. It is then the purpose of our bill to establish a National Diabetes Advisory Board and to insure the implementation of the long-range plan to combat diabetes.

Section 3 of the bill creates the National Diabetes Advisory Board. This Board is composed of 19 members, including 7 designated health officials from the Department of Health, Education, and Welfare, 7 physicians or scientists designated by the Secretary of HEW, 5 representatives of the general public including at least 1 person with diabetes and 1 who is the parent of a diabetic child. The Board's power and authority are set out in the bill. Its most important function will be to review, evaluate, and advise the Federal Government with regard to implementation of the long-range plan. In doing this it will consult with experts in the field, both within and outside government, and it will have authority to acquire any technical assistance it may need. In addition, the Board will send to the President and Congress an annual diabetes report making both legislative and appropriations recommendations as well as describing the status of diabetes research in the previous year.

Section 4 of the bill creates distinguished scientist grants in the field of diabetes. One of the most serious drawbacks in present diabetes research has been the lack of qualified people to do that research. By these grants, to be administered by the Department of HEW, a core of scientific expertise will be created which will allow accelerated research in future years.

Section 5 authorizes funding for diabetes research and training centers. These centers, created in the 1974 Diabetes Act, have three principal functions: Performance of high quality research; generation of competent professional personnel familiar with diabetes; and translation of advances in the field of diabetes research into improved care for the diabetic. These centers are in no sense intended to be a means of providing massive health care delivery systems for the diabetic population in America.

Mr. President, this bill is a start toward implementation of the Diabetes Commission's report. There are some who question the advisability of creating a special board to oversee a single disease outside the normal NIH procedures. Normally I would agree, but diabetes is a special situation requiring special treatment. Diabetes research is currently being conducted by seven of the National Institutes of Health, and as we all know, everybody's responsibility is nobody's responsibility. Someone must have the job of overseeing the progress of diabetes research in this country. To solve this need, which does not exist in most other areas of medical science, this bill creates a National Advisory Board. I do not see this as a precedent which will be followed by many other diseases, but as an answer to a most unique medical situation.

Mr. President, I ask unanimous consent that the text of our bill be printed at this point in the RECORD, along with a summary of the long-range plan to combat diabetes prepared by the National Commission on Diabetes.

There being no objection, the bill and summary were ordered to be printed in the RECORD.

SUMMARY OF THE RECOMENDATIONS

To the Institutes of the National Institutes of Health:

That the National Institute of Arthritis, Metabolism, and Digestive Diseases—Increases its support of research efforts in basic endocrinology, metabolism, and nutrition, and apply the results of such research to the study of diabetic defects and the causes, prevention, and cure for diabetes.

Increase its support for research efforts in nutrition relating to diabetes and to obesity in persons with diabetes, and increase the number of its Obesity Centers to three to encourage such research and to train manpower in this area.

Establish an ad hoc advisory panel on transplantation and artificial devices and, commensurate with the panel's recommendations, increase support of research efforts in transplantation of the pancreas or islet cells and development of artificial devices.

Increase its support for research efforts in diabetic microangiopathy.

Initiate and support (with the National Heart and Lung Institute) a five-year study to assess the effect of treatment for juvenile-onset diabetes on the development of micro- and macrovascular complications.

Expand its ongoing intramural research program related to diabetes.

Expand its training fellowships and special awards in the area of diabetes-related studies.

Review all available research information resources in order to develop a system to provide a complete and up-to-date source of information on ongoing and proposed research relating to diabetes.

That the National Eye Institute—

Increase its support for research efforts on the causes and treatment of diabetic retinopathy.

Expand its ongoing intramural research program related to diabetes.

Expand its training fellowships and special awards in the area of diabetes-related studies.

That the National Institute of Neurological and Communicative Disorders and Stroke—

Increase its support for basic research relating to peripheral neuropathy, stroke, and other neural disorders prevalent in diabetes.

Expand its training fellowships and special awards in the area of diabetes-related studies.

That the National Institute of Dental Research—

Increase its support for research efforts on the dental complications of diabetes.

Expand its ongoing intramural research program related to diabetes.

Expand its training fellowships and special awards in the area of diabetes-related studies.

That, the National Institute for Child Health and Human Development—

Sponsor a long-term clinical study on the effects of infant feeding on the development of obesity and diabetes.

Increase its support for basic and clinical research efforts on pregnancy and diabetes, and sponsor a follow-up study of infants of mothers with diabetes.

Increase its support for research efforts on contraceptive agents and diabetes.

Expand its training fellowships and special awards in the area of diabetes-related studies.

That the National Heart and Lung Institute—

Increase its support for those research efforts in heart disease, peripheral vascular disease, atherosclerosis, hypertension, and blood coagulation that relate to diabetes morbidity and mortality, and increase its support for those research studies already under way which are unique to diabetic macroangiopathy.

Initiate and support (with the NIAMDD) a five-year clinical study to assess the effect of treatment for juvenile-onset diabetes on the development of micro- and macrovascular complications.

That appropriate Institutes of the NIH—

Establish research resource facilities to maintain research materials and animal models, and provide economical and efficient services necessary to meet the needs of diabetes research.

Be alert and receptive to the sponsorship of evaluation studies pertaining to diabetes treatment and education as a part of the NIH's competitively awarded research programs.

That the National Institutes of Health sponsor annual interdisciplinary workshops, symposia, and conferences on diabetes and its complications to encourage cross-fertilization of ideas and cooperative research efforts.

To the Secretary of Health, Education, and Welfare:

That the program for Diabetes Research and Training Centers be implemented immediately, in accordance with the Long-Range Plan, and that the responsibility for its supervision be delegated to the Director of the National Institutes of Health.

That the Diabetes Control Program be implemented immediately in accordance with the Long-Range Plan, and that the responsibility for its supervision be delegated to the Center for Disease Control.

That he instruct the relevant agencies of his department, and request other identified Federal Department: (1) to prepare a report with complete lists of services and resources within their organizations to meet the needs of the patient with diabetes and with proposals of how these and additional resources may be used for diabetes research, treatment, and education in light of the Long-Range Plan, and (2) to present this report to the Secretary and the National Diabetes Advisory Board.

To the Assistant Secretary for Health:

That he advise the identified agencies of the Public Health Service to address the problem of diabetes according to the recommendations of the Long-Range Plan.

That a National Diabetes Information and Education Clearinghouse be established as a central resource for educational materials and information.

That a National Diabetes Data Group be established to coordinate the collection and publication of diabetes data related to public health policy.

To Other Federal Agencies:

That the Administrator of the Veterans Administration increase the VA programs in the areas of research, education, and treatment of diabetes and request additional funds for these programs.

That the Social and Rehabilitation Service ensure that appropriate services are available to the underserved population with diabetes for which the Agency provides support.

That the Social Security Administration modify its guidelines for reimbursement of patients with diabetes to ensure that patient education expenses are included as reimbursable elements of patient care.

That the Department of Defense review its programs in light of the recommendations for other Federal Agencies in the Long-Range Plan.

That the Department of Agriculture expand its intramural research programs on nutrition for the diabetic population, and orient its Extension Service to disseminate diabetes-related health information.

That the Commission on Human Resources of the National Research Council, National Academy of Sciences, recognize the critical needs of diabetes research when identifying those areas eligible for National Research Service Awards.

That research funding agencies of the Public Health Service not mentioned previously (particularly the Health Resources Administration and the Health Services Administration), the grantees of these agencies, and the Veterans Administration be receptive to the sponsorship of evaluation studies pertaining to diabetes education and treatment as a part of their competitively awarded research programs.

To Others in the Diabetes Community:

That patient education be considered an essential element of treatment, and that all related activities promote this key concept.

That those organizations responsible for the development and conduct of continuing medical education programs increase the quality and number of such programs related to diabetes.

And Most Important, to the Congress:

That funds for increased diabetes research be appropriated to NIAMDD and other Institutes of the National Institutes of Health as detailed in the funding summary.

That the staff of the NIAMDD and other Institutes of the NIH be increased to meet the needs of the diabetes research program.

That increased funding support be provided to the General Clinical Research Centers Program of the Division of Research Resources of the NIH to ensure adequate resources for the clinical research needs of the Long-Range Plan.

That P.L. 93-354 be amended with respect to dates and duration of authorization for the Diabetes Research and Training Centers program and that funds for that program be appropriated.

That staff positions and funds be appropriated to the Center for Disease Control for the implementation and support of its Diabetes Control Program.

That appropriations be provided for (1) a National Diabetes Information and Education Clearinghouse, and (2) a National Diabetes Data Group.

That a National Diabetes Advisory Board be authorized and funded to review, evaluate, and advise with regard to the implementation of the Long-Range Plan, and that this Board be established in the Office of the Assistant Secretary for Health.

INTRODUCTORY REMARKS OF SENATOR WILLIAMS

Mr. WILLIAMS. Mr. President, I am pleased to join with my colleagues, the distinguished Senator from Pennsylvania (Mr. Schweiker) and the distinguished Senator from Wyoming (Mr. McGee), in introducing a bill to implement the recommendations of the National Commission on Diabetes.

More than a year ago, the Congress enacted the Diabetes Mellitus Research and Education Act of 1974, of which I was proud to be a principal sponsor. The purpose of this legislation was to establish a National Commission on Diabetes to develop a long-range plan defining what this Nation needs to do to mount a successful attack on diabetes.

On December 10, 1975, the Commission issued its report and the bill we are introducing today will help assure that these objectives will be accomplished.

Mr. President, diabetes is the third most serious health problem in the United States today. Over 10 million Americans suffer from this disease and it is the leading cause of adult blindness, kidney disease and heart disorders. Although there has been a visible Federal research effort to combat diabetes, it is clear from the Commission's report that much more needs to be done.

There is no question that some of the recommendations can be implemented by the National Institutes of Health under its current legislative authority. However, the Commission has made recommendations which require the Congress to act. This is especially true with respect to the need for a new mechanism to oversee diabetes research and treatment efforts which is so comprehensive in scope that the traditional NIH divisions may not by themselves allow for coordination in the absence of this bill. The bill would address these issues and others as follows:

The first section contains findings that it is necessary to have an organization with authority to coordinate the utilization of national resources for diabetes research, education, and treatment. It is then the purpose of our bill to establish a National Diabetes Advisory Board and to insure the implementation of the long-range plan to combat diabetes.

The second section creates the National Diabetes Advisory Board composed of 19 members, including 7 designated health officials from the Department of Health, Education, and Welfare, 7 physicians or scientists designated by the Secretary of HEW, 5 representatives of the general public including at least 1 person with diabetes and the parent of a diabetic child.

The Board's most important function will be to review, evaluate, and advise the Federal Government with regard to implementation of the long-range plan. In doing this it will consult with experts in the field, both within and outside Government, and it will have authority to acquire any technical assistance it may need. In addition, the Board will send to the President and Congress an annual diabetes report making both legislative and appropriations recommendations as well as describing the status of diabetes research in the previous year.

The third section of the bill creates distinguished scientists grants in the field of diabetes. These grants will assist in the development of a core of scientific expertise which will allow accelerated research in future years.

The final section authorizes funding for diabetes research and training centers. These centers, created in the 1974 Diabetes Act, have three principal functions: Performance of high quality research; generation of competent professional personnel familiar with diabetes; and translation of advances in the field of diabetes research into improved care for the diabetic. These centers are in no sense intended to be a means of providing massive health care delivery systems for the diabetic population in America.

Mr. President, diabetes research is currently being conducted by seven of the National Institutes of Health, and the job of overseeing the progress of diabetes research in this country must be carried out. I believe this legislation will accomplish that important purpose.

Senator SCHWEIKER. I am very happy to have as our first leadoff witness, Dr. Carter, a Member of the House, Dr. Carter, I might say, is a leader in this cause in his own right. He has done exceedingly well in leading legislation like this through the House and through our conferences, and he has been very dedicated and very motivated in this field.

Doctor, we appreciate your coming here as a sponsor of this legislation.

STATEMENT OF HON. TIM LEE CARTER, M.D., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF KENTUCKY

Dr. CARTER. Thank you, Mr. Chairman. It is certainly a pleasure to be here. I say good morning to everyone. I am glad to join you here today to testify in support of S. 2910, the National Diabetes Advisory Board Act.

As you know, I have introduced a companion bill on the House side which now has 81 cosponsors. It is indeed gratifying to see that this legislation enjoys such strong support in both Houses of Congress. Certainly much of the credit must go to Senators Schweiker, McGee, and Williams for their leadership here on the Senate side and for their longstanding commitment to the cause of diabetes. I am glad we are working together on this important initiative.

In fact, a bit of history deserves mention since it reveals the success of earlier dedicated efforts for the cause of diabetes. In 1974, the Congress recognized the importance of this disease with the passage of the Diabetes Mellitus Research and Education Act which created the National Commission on Diabetes.

I was proud to join as an original sponsor of that legislation which called for the development of a long-range plan to expand and coordinate research against diabetes and to advance activities in patient, professional, and public education about diabetes.

As a result of that mandate, the Commission has recently presented to the Congress a comprehensive and authoritative analysis on diabetes. This report documents the magnitude of the problem and provides a detailed blueprint for future actions with its long-range plan.

At this point, I would like to extend my congratulations to Dr. Oscar Crofford of Vanderbilt University School of Medicine who served as Chairman of the Diabetes Commission. He deserves to be commended for his key role in coordinating the resources and expertise necessary for the Commission's fine work.

Now, with the work of the Commission behind us, we have reached a key stage in our attack against diabetes and we must not lose any momentum in our efforts.

I am here today to urge that we move forward with the Commission's recommendations which include the establishment of a National Diabetes Advisory Board as proposed in this legislation.

The purpose of this Board would be to review, evaluate, and advise with regard to the implementation of the long-range plan. The Board would serve as a visible focus point for all the various activities related to diabetes and would help assure that the initiative begun in 1974 is carried forward in the most effective manner.

Currently a wide range of efforts related to diabetes is already occurring at the National Institutes of Health within other Federal agencies and outside Government in a number of human service organizations. But because the scope of diabetes is so broad, I believe there is a need to oversee these activities and to coordinate implementation of the Commission's recommendations.

The Advisory Board proposed by this legislation will provide the mechanism needed to accomplish that purpose.

This legislation would also create distinguished scientist grants to be awarded to researchers who have demonstrated outstanding work in the field of diabetes. This provision is designed to contribute substantially to our Nation's research capability in the field of diabetes.

I also support the bill's extension of the authorizations for diabetes research and training centers. These centers, which were included in the original legislation by my amendment are a vital component of our attack against diabetes. They will provide a focal point for the

development of diabetes research and therapies, and will help develop needed experts in these areas.

Mr. Chairman, at this point, I would like to submit for the record a summary of the Commission's other recommendations which range from research and training to education and control programs. The Commission's work provides a comprehensive agenda for future efforts in this important field.

By now many of you are probably familiar with the statistics of the Commission's report, but I feel they merit brief review because of the seriousness and magnitude of this disease. Sometimes, I regret, numbers can lose their significance until we remember that we are talking about people whom we know and for whom we care.

Diabetes mellitus is indeed a major and serious health problem affecting more than 10 million Americans—in 5 percent of the population. Last year, as many as 300,000 deaths could be attributed to diabetes and its complications, thus making diabetes the third ranking cause of death after heart disease and cancer. In addition to the physical and emotional burden of this disease, it is estimated that the economic impact of diabetes on this Nation is more than 5 billion each year even without considering the cost of complications.

I have long maintained that research funding should be apportioned on the basis of the mortality, morbidity, and economic costs associated with a disease. And, in the case of diabetes, I feel it is imperative that we increase our research funding to reflect the magnitude of this problem and its impact on our people.

Recently we have witnessed an example of the kind of advances that can be achieved with the combination of economic support and scientific expertise. I am referring to the favorable results of a nationwide study on the treatment of diabetic retinopathy undertaken by the National Eye Institute. The results of that study have shown that treatment with powerful lasers can reduce the risk of blindness for patients with this disease. This scientific advance is an excellent illustration of how federally supported research in the field of diabetes can make a major contribution to the health of the American people.

However, despite this Nation's outstanding scientific expertise and its record of achievements, the problem of diabetes still lacks a cure and a means of prevention. Although there have been some advances in treatment including the possibility of a prolonged lifespan from insulin, these efforts have failed to prevent the number of people affected by this disease from growing. Perhaps most frightening is the evidence that the prevalence of diabetes appears to be increasing by 6 percent every year. At this rate, an American born today, living an average lifespan of 70 years, has a better than one in five chance of developing diabetes.

Given this situation I think our major objectives should be clear. We must continue to work toward improving current methods of treatment and management of diabetes as well as expanding our programs of patient and professional education.

We must find ways to translate research advances into health-care delivery and improved patient care.

And above all, we must continue to strive to develop a means of controlling and ultimately preventing diabetes.

As a member of the board of directors of the American Diabetes Association and as a Member of this Congress, I look forward to working with you and those who are committed to achieving these goals.

Thank you, Mr. Chairman.

Senator SCHWEIKER. Dr. Carter, I want to thank you for your testimony and for your support in this area, because the fact that you have 75 cosponsors shows you have not been letting any grass grow under your feet. I think that is a good start for both of us in this important legislation.

Do you have any idea at this point if we were to get some bill out in some form within the next few weeks, what opportunity we might have to get something going on the House side? I realize you are not the chairman of the committee. But supposing we could get a bill out that might have some chance of going all the way through, what chance might we have this year of doing something on the House side in your judgment?

Dr. CARTER. We have 81 cosponsors already, Senator, I feel that more will join. This list includes the chairman of the subcommittee. It is a case of necessity; we must proceed; we must get a bill out this year if possible.

Senator SCHWEIKER. I cannot ask more than that. Thank you very much. I appreciate your coming over here very much and taking time from your busy schedule and being with us. Thanks again.

Dr. CARTER. This is just very important on my list of "musts." I am happy to be here, thank you.

[The summary of the Commission's recommendations follows:]

Summary of the Recommendations

TO THE INSTITUTES OF THE NATIONAL INSTITUTES OF HEALTH:

- That the National Institute of Arthritis, Metabolism, and Digestive Diseases
 - Increase its support for research efforts in basic endocrinology, metabolism, and nutrition, and apply the results of such research to the study of diabetic defects and the causes, prevention, and cure for diabetes
 - Increase its support for research efforts in nutrition relating to diabetes and to obesity in persons with diabetes, and increase the number of its Obesity Centers to three to encourage such research and to train manpower in this area
 - Establish an ad hoc advisory panel on transplantation and artificial devices and, commensurate with the panel's recommendations, increase support of research efforts in transplantation of the pancreas or islet cells and development of artificial devices
 - Increase its support for research efforts in diabetic microangiopathy
 - Initiate and support (with the National Heart and Lung Institute) a five-year study to assess the effect of treatment for juvenile-onset diabetes on the development of micro- and macrovascular complications
 - Expand its ongoing intramural research program related to diabetes
 - Expand its training fellowships and special awards in the area of diabetes-related studies
 - Review all available research information resources in order to develop a system to provide a complete and up-to-date source of information on ongoing and proposed research relating to diabetes
- That the National Eye Institute
 - Increase its support for research efforts on the causes and treatment of diabetic retinopathy
 - Expand its ongoing intramural research program related to diabetes
 - Expand its training fellowships and special awards in the area of diabetes-related studies
- That the National Institute of Neurological and Communicative Disorders and Stroke
 - Increase its support for basic research relating to peripheral neuropathy, stroke, and other neural disorders prevalent in diabetes
 - Expand its training fellowships and special awards in the area of diabetes-related studies
- That the National Institute of Dental Research
 - Increase its support for research efforts on the dental complications of diabetes
 - Expand its ongoing intramural research program related to diabetes
 - Expand its training fellowships and special awards in the area of diabetes-related studies
- That the National Institute for Child Health and Human Development
 - Sponsor a long-term clinical study on the effects of infant feeding on the development of obesity and diabetes
 - Increase its support for basic and clinical research efforts on pregnancy and diabetes, and sponsor a follow-up study of infants of mothers with diabetes
 - Increase its support for research efforts on contraceptive agents and diabetes
 - Expand its training fellowships and special awards in the area of diabetes-related studies
- That the National Heart and Lung Institute
 - Increase its support for those research efforts in heart disease, peripheral vascular disease, atherosclerosis, hypertension, and blood coagulation that relate to diabetes morbidity and mortality, and increase its support for those research studies already under way which are unique to diabetic macroangiopathy
 - Initiate and support (with the NIAMDD) a five-year clinical study to assess the effect of treatment for juvenile-onset diabetes on the development of micro- and macrovascular complications
- That appropriate Institutes of the NIH
 - Establish research resource facilities to maintain research materials and animal models, and provide economical and efficient services necessary to meet the needs of diabetes research
 - Be alert and receptive to the sponsorship of evaluation studies pertaining to diabetes treatment and education as a part of the NIH's competitively awarded research programs
- That the National Institutes of Health sponsor annual interdisciplinary workshops, symposia, and conferences on diabetes and its complications to encourage cross-fertilization of ideas and cooperative research efforts

TO THE SECRETARY OF HEALTH, EDUCATION, AND WELFARE:

- That the program for Diabetes Research and Training Centers be implemented immediately, in accordance with the Long-Range Plan, and that the responsibility for its supervision be delegated to the Director of the National Institutes of Health

- That the Diabetes Control Program be implemented immediately in accordance with the Long-Range Plan, and that the responsibility for its supervision be delegated to the Center for Disease Control
- That he instruct the relevant agencies of his department, and request other identified Federal Departments: (1) to prepare a report with complete lists of services and resources within their organizations to meet the needs of the patient with diabetes and with proposals on how these and additional resources may be used for diabetes research, treatment, and education in light of the Long-Range Plan, and (2) to present this report to the Secretary and the National Diabetes Advisory Board

TO THE ASSISTANT SECRETARY FOR HEALTH:

- That he advise the identified agencies of the Public Health Service to address the problem of diabetes according to the recommendations of the Long-Range Plan
- That a National Diabetes Information and Education Clearinghouse be established as a central resource for educational materials and information
- That a National Diabetes Data Group be established to coordinate the collection and publication of diabetes data related to public health policy

TO OTHER FEDERAL AGENCIES:

- That the Administrator of the Veterans Administration increase the VA programs in the areas of research, education, and treatment of diabetes and request additional funds for these programs
- That the Social and Rehabilitation Service ensure that appropriate services are available to the underserved population with diabetes for which the Agency provides support
- That the Social Security Administration modify its guidelines for reimbursement of patients with diabetes to ensure that patient education expenses are included as reimbursable elements of patient care
- That the Department of Defense review its programs in light of the recommendations for other Federal Agencies in the Long-Range Plan
- That the Department of Agriculture expand its intramural research programs on nutrition for the diabetic population, and orient its Extension Service to disseminate diabetes-related health information
- That the Commission on Human Resources of the National Research Council, National Academy of Sciences, recognize the critical needs of diabetes research when identifying those areas eligible for National Research Service Awards
- That research funding agencies of the Public Health Service not mentioned previously (particularly the Health Resources Administration and the Health Services Administration), the grantees of these agencies, and the Veterans Administration be receptive to the sponsorship of evaluation studies pertaining to diabetes education and treatment as a part of their competitively awarded research programs

TO OTHERS IN THE DIABETES COMMUNITY:

- That patient education be considered an essential element of treatment, and that all related activities promote this key concept
- That those organizations responsible for the development and conduct of continuing medical education programs increase the quality and number of such programs related to diabetes

and, most important,

TO THE CONGRESS:

- That funds for increased diabetes research be appropriated to NIAMDD and other Institutes of the National Institutes of Health as detailed in the funding summary
- That the staff of the NIAMDD and other Institutes of the NIH be increased to meet the needs of the diabetes research program
- That increased funding support be provided to the General Clinical Research Centers Program of the Division of Research Resources of the NIH to ensure adequate resources for the clinical research needs of the Long-Range Plan
- That P.L. 93-354 be amended with respect to dates and duration of authorization for the Diabetes Research and Training Centers program and that funds for that program be appropriated
- That staff positions and funds be appropriated to the Center for Disease Control for the implementation and support of its Diabetes Control Program
- That appropriations be provided for (1) a National Diabetes Information and Education Clearinghouse, and (2) a National Diabetes Data Group
- That a National Diabetes Advisory Board be authorized and funded to review, evaluate, and advise with regard to the implementation of the Long-Range Plan, and that this Board be established in the Office of the Assistant Secretary for Health

Senator SCHWEIKER. Our next witness will be the administration witness, Deputy Assistant Secretary for Health Legislation, Gene Haislip; Dr. Donald Whedon, Director, National Institute of Arthritis, Metabolism, and Digestive Diseases; Dr. Robert Levy, Director, National Heart and Lung Institute; and Dr. Carl Kupfer, Director, National Eye Institute.

We hope you are going to tell us you will accept our bill.

STATEMENT OF GENE HAISLIP, DEPUTY ASSISTANT SECRETARY FOR HEALTH LEGISLATION; G. DONALD WHEDON, M.D., DIRECTOR, NATIONAL INSTITUTE OF ARTHRITIS, METABOLISM, AND DIGESTIVE DISEASES; ROBERT LEVY, M.D., DIRECTOR, NATIONAL HEART, LUNG, AND BLOOD INSTITUTE; CARL KUPFER, M.D., DIRECTOR, NATIONAL EYE INSTITUTE, A PANEL

Mr. HAISLIP. Dr. Dickson would like to extend his apologies. Unfortunately something arose very late in the evening last night which caused his absence. We apologize for that.

Senator SCHWEIKER. We understand. This schedule is prone to that kind of upset.

We are happy to have four distinguished substitutes.

Mr. HAISLIP. Thank you, sir. I have Directors of the Institutes which are principally involved in the Department's research effort with regard to diabetes. I would like to offer Dr. Dickson's statement for the record, and if I may, spend just a few minutes in summarizing some of the principal highlights of that statement.

Senator SCHWEIKER. Right. We certainly appreciate that. I have tried to request, and you are very graciously complying, that our witnesses submit their full statement for the record and highlight it or read that portion that will come up to about 10 minutes. You are very kind to follow that procedure. I appreciate it.

Mr. HAISLIP. The Department fully recognizes the importance of an active, aggressive effort to combat diabetes. It is a disease which affects perhaps 10 million people in our country, and it can have very serious repercussions. It is a disease which responds well to treatment in many cases, and perhaps one of the most unfortunate things is that there are a number of people who are unaware of how their problem can be successfully handled.

The Department's concern therefore is twofold. The first is to go forward with research to further control and prevent the disease and its adverse consequences, and second, to pursue programs so that people who suffer from diabetes may have the benefits that modern medicine now offers.

The Department opposes S. 2910, but our opposition is based on certain administrative concerns, as we see it—certainly not on the intent of the measure and certainly not insofar as the bill recognizes the crucial importance of progress in this area.

Before I deal with that, I would like to summarize briefly the history of the Department's efforts in the last several years, and some of the principal activities that are now in progress. I think it will help to underline why we feel the measure, as it is proposed, is not necessary.

A great deal of progress was achieved in 1974 with the passage of the National Diabetes Research and Education Act. This bill was a progressive measure which accomplished three principal things.

First, it established a National Commission on Diabetes to review the entire matter and to make recommendations in the areas of new programs, research, and further efforts.

Second, it established a Coordinating Committee to insure the coordination of the Federal Government's efforts in diabetes.

And third, it established diabetes as a principal program thrust of the Center for Disease Control, which I think is an accomplishment that will have significance for the future.

In short, the 1974 act, I believe, gave the programs in the Department a vital further impetus, and I think that impetus is still being carried forward. The Commission established by the act has made a number of recommendations. Some of them we recognize are embodied in this bill which we are opposing, but many of the others we regard as being extremely helpful and beneficial, and we have sought to include them within our present efforts.

The Department's principal research activity in diabetes is conducted by the National Institute of Arthritis, Metabolism and Digestive Diseases, headed by Dr. Whedon. In this area we are pursuing a varied program of research which is showing a great deal of progress. Dr. Whedon will elaborate on that further for you, if you so desire.

But I would like to point out also that there is other important research being undertaken by other Institutes of the National Institutes of Health, principally the National Heart, Lung, and Blood Institute, and the National Eye Institute.

Dr. Carter has detailed for you one of the recent breakthroughs which has been achieved through research sponsored by the National Eye Institute and which will have great impact on reducing the incidence of blindness resulting from diabetes to certain classes of persons. The Coordinating Committee we have found to be extremely helpful in insuring that the research activities of these three Institutes and the activities of other agencies of the Federal Government are coordinated into a meaningful program.

The bill S. 2910 would establish, in addition to other measures, an advisory board, which we feel is unnecessary because of the fact that the coordinating committee is achieving many of the purposes which the board would seek to accomplish.

Another problem that has concerned us with regard to the board is that it would be authorized to assume administrative and executive functions which would conflict with the management of programs now being pursued.

Further, we note that the proliferation of the advisory committees in general has been a problem and one which, in fact, the Congress itself has recommended against. While we realize that the establishment of the board would highlight the importance of diabetes and while we understand that the disease is certainly a serious one and worthy of emphasis, we also must recognize that, if there is established a board for each serious disease which afflicts man, we believe it really would cause problems in administration. This would not be beneficial to the pursuit of any of the programs, but would result in a morass of red-tape and confusion.

Thus, we have, as a general policy, opposed the proliferation of special committees or boards. Our opposition does not spring from failure to recognize the importance of highlighting the diabetes problem, a goal which we share with you.

The bill would do several other things. It would establish a system of awards to distinguished scientists. This is a type of program with which we have had some previous experience in the National Institutes of Health, and we have found that it is a more productive use of funds to directly support research selected for support on the basis of its merits, rather than make awards of the distinguished-scientist type. We think that is a provision of S. 2910 that would not be beneficial to our program.

Finally, the bill would seek to establish new priorities and levels of funding for research. I think it is certainly clear that more research on this and every other area of disease is desirable. It is really a question of determining priorities. I would simply point out that in addition to the work in diabetes, there is work that must go forward in research on diseases of all kinds, diseases which in many cases are of equal importance. At the present time, given current budgetary restraints which we must realistically recognize, we feel we are doing as much as we can. It is for all of these reasons we oppose S. 2910 as it now stands.

I suggest to you the progress we are making and the manner in which that progress is being coordinated is an adequate, aggressive response to the problem at this time and one that we would hope to improve on an annual basis. I would note Dr. Cooper is giving the matter his personal attention for the coming year.

The gentlemen who are with me and I will be glad to respond to any questions you might have. I thank you for your attention and for permitting me to summarize this statement.

Senator SCHWEIKER. How do you want to proceed next?

Mr. HAISLIP. We have no further statement to offer. We would be glad to respond to questions.

Senator SCHWEIKER. I will proceed with questions at this point.

Can you tell us a little bit more about how the Coordinating Committee has been functioning, how often does it meet, who makes up the membership? I know they have issued a report last year. Dr. Whedon, we would appreciate hearing anything you can tell us about it.

Dr. WHEDON. Yes, Senator, I am delighted to be here to answer your questions, particularly with regard to the Coordinating Committee. This was organized not long after the act was passed and signed. It has had a series of meetings in which the representatives of various Federal agencies having any programs related to diabetes have met. The committee members submitted information with regard to their respective activities and this was published in the report for fiscal year 1974.

Now, meanwhile, additional meetings have been held and we are getting close to the wire in the preparation of the report for fiscal year 1975, which I think will show an expanded and very intensive effort on the part of these various agencies.

You asked about the membership. It includes, of course, nine of the National Institutes of Health and representatives from the Center for Disease Control, the Health Services Administration, Health

Resources Administration, National Institute of Mental Health, Food and Drug Administration, Social and Rehabilitation Service, Social Security Administration, and the Department of Defense, Veterans' Administration, and Department of Agriculture. I feel that this committee clearly is an information exchange for what is going on in diabetes throughout Government.

The first stage of the effort of this committee has been to gather information on what everyone is doing. I think we are now moving gradually to a phase in which we may become truly effective as a coordinating body, and by exchanging information and opinions and through discussions we will be able to influence each other in what we do with respect to diabetes.

Senator SCHWEIKER. About how large a group would it be roughly in terms of numbers?

Dr. WHEDON. I would estimate that we have about 18 members.

Senator SCHWEIKER. What about its meetings? How often might it meet?

Dr. WHEDON. We have been meeting about every 2 months. I might say that as an indication of the level of importance the committee has, the chairman of this Coordinating Committee is Dr. Ronald LaMont-Havers, Deputy Director of the National Institutes of Health. The executive secretary is Dr. Krueger, who is director of the diabetes program within our Institute, and Executive Secretary of the Diabetes Commission.

This shows the continuity and importance which we place in this body.

Senator SCHWEIKER. I am going to ask all the Directors this question. Could you give me a rough percentage of how much of your Institute's work is devoted to diabetes research in some form? I guess the question would have to be in terms of the percentage of dollar commitment of your Institute, and I want to alert the heart and eye people to have a figure that you could give us in that same respect.

Dr. WHEDON. Well, the anticipated funding for research directly related to diabetes in the National Institute of Arthritis, Metabolism, and Digestive Diseases for fiscal year 1976 amounts to \$14½ million. This represents approximately 8 percent of the total funding of our Institute. I hasten to add, to make two additional points, that in addition to the diabetes program, we have vigorous and strong endocrinology and metabolism programs which are producing a lot of solid, fundamental information that is relative to diabetes.

The other point with respect to the 8 percent figure which I cited earlier is the broad number, the vast array of the responsibilities of this Institute. We are the Institute which covers most of the specialties of internal medicine, as well as some surgical. The main ones for which we are responsible, in addition to diabetes, are arthritic or rheumatic diseases, digestive diseases, kidney diseases, and hematology. Some of these programs, of course, are covered also by the Heart and Lung Institute and by some of the other Institutes.

Senator SCHWEIKER. Would you say there are any gaps at present in terms of research that are not filled either within your Institute or because it falls within the jurisdiction of overlap or duplications of others? How would you assess whether this is a problem or not?

Dr. WHEDON. I do not think, Senator, that this is a problem, except to add that proper coordination of the efforts of a number of different groups always is something that one should be concerned about.

I think the establishment of the Coordinating Committee has been a very positive step forward in the direction of improving the situation. At the same time there is nothing more important than close personal day-to-day telephone or other contacts between program managers in the various Institutes. I must say that the passage of the National Diabetes Act and the report of the National Diabetes Commission has intensified our concern for the importance of closer coordination and cooperation.

Senator SCHWEIKER. All right. Dr. Levy, how about the same question in terms of direct money with diabetes research? I realize a lot is basic research, which would spinoff in this. As I understand Dr. Whedon's answer, he gave me the figure of direct diabetes research. Can you give me a comparable figure?

Dr. LEVY. Thank you, Senator Schweiker. Defining direct support for diabetes research sometimes is difficult. In terms of diabetes unique research that deals specifically with diabetes or the effect of any process on the diabetic patient, it can be estimated that in 1975 the Institute provided between \$5½ and \$6 million for research. The figure for 1976 is not clear. It will probably be similar to 1975. In addition, the Institute has released a solicitation seeking more basic and clinical research grant proposals dealing with the cardiac and vascular aspects of diabetes. More studies on cardiovascular disease, as it affects and complicates the diabetic condition are necessary. We have been surprised by the response to this solicitation; in order to thoroughly review the 165 research grant applications we have received, we will probably fund this new program activity during the wedge period.

I imagine this will probably add somewhere between \$2 million and \$5 million to our program in diabetes and cardiovascular diseases.

Senator SCHWEIKER. A \$5½ million figure. This would represent less than 1 percent of your total budget.

Dr. LEVY. The \$5½ to \$6 million figure would represent closer to two percent of our budget. Our budget in 1975 was \$325 million.

Senator SCHWEIKER. Dr. Kupfer.

Dr. KUPFER. In terms of the National Eye Institute, you are aware of the fact that retinopathy is a very important public health problem. It probably ranks first or second as a leading cause for new adult blindness. As far as we are concerned, this is a problem that should command a significant amount—

Senator SCHWEIKER. We are finding that insulin may be contributing to that problem.

Dr. KUPFER. As far as newspaper accounts are concerned, I think I would agree with you, but I would prefer to look toward more scientifically valid data before one would accept such a statement as that.

This sort of presentation has had a long history. I think there are several in this room who could address themselves to this point very effectively.

Senator SCHWEIKER. I did not mean to sidetrack you. I was intrigued by the fact that some of the cures we give our diabetics today might well make them blind, which is why we have to put more effort in

finding out what we are doing for diabetes. You may not agree with that. If you do not, fine.

Dr. KUPFER. I would like to go on record saying there is no scientifically validated evidence whatsoever—particularly with respect to humans—that insulin has contributed to an increasing amount of blindness. We know that the involvement of the retina by the disease of diabetes is not related simply to the severity of the diabetes but is strongly related to the length of time that the individual has the disease. I think one of the major breakthroughs that followed the discovery of insulin is that diabetics have lived longer, and since they live longer and have had diabetes for a longer period of time, one might expect to have more patients developing eye complications. I think that would be the hypothesis that is substantiated by most of the data.

I really would like to reiterate strongly that there is no scientifically validated evidence at the present time that insulin contributes to the development of blindness.

Senator SCHWEIKER. There have been wire stories all over the country the last 2 days. I wanted to get the chance to set the record straight.

Dr. KUPFER. Thank you for bringing this up, so I can make it quite clear that there is no scientifically validated evidence for the inferences that have appeared in the press.

Senator SCHWEIKER. While Senator Javits is arriving, can you give us a figure on terms of commitment?

Dr. KUPFER. At the present time we are supporting approximately \$5 million in research in diabetes. This is about 10 percent of our overall budget, the budget of the National Eye Institute being approximately \$50 million. But perhaps another figure would be of interest to you. Retinal disease in general is a major problem. We are spending about \$15 million a year in supporting all research on retinal disease. Thus, so far as diabetic retinopathy is concerned, it accounts for about 30 percent of our entire effort in the area of retinal disease.

Senator SCHWEIKER. You have made some good advancement in the area of laser treatment of diabetic retinopathy. You might comment.

Dr. KUPFER. A cooperative study involving 15 cooperating eye research centers and over 1,700 patients has been going on for several years in which the question has been asked, can laser treatment of the diabetic retinopathy be a benefit? Just recently a month ago, a scientific publication appeared based on the data gathered during the first 2 years of followup on these patients, in which it has been conclusively shown that in certain types of diabetic retinopathy the rate to blindness can be cut by more than one-half. In other words there is significant beneficial effect of this treatment.

I would hasten to add this is not the end of concern with the patient having diabetic retinopathy. This form of therapy can only be used in certain patients with diabetic retinopathy. We are concerned with other groups of diabetic patients, not only in terms of those who are not eligible for photocoagulation, but in terms of basic research to prevent development of changes in the retina from diabetes. This effort is continuing and the clinical trial is also continuing on assessing photocoagulation.

Senator SCHWEIKER. I think it is a very encouraging and most constructive work.

I will interrupt at this moment. The ranking member of the Labor and Public Welfare Committee, Senator Javits, has been very helpful and very supportive of my efforts in this area here.

Senator JAVITS. Mr. Chairman, I came especially—I have to go to two markups—to thank the witnesses for giving their time and their interest to come here and help us, and to especially pay tribute, Mr. Chairman, to your leadership in fixing our attention on this very, very grave problem. It is the kind of problem I can say we are all interested in and have close experience—relatives and friends—which gives us a very acute personal realization of what is at stake. I have had friends who suffered all their lifetimes from this disease and who have been able to sustain life because of insulin and the other newer methods of treatment, and know we can go very much further.

I consider the bill introduced for a Commission or Advisory Board very innovative and would assure you, Mr. Chairman, and the witnesses, that I will give it most thorough and sympathetic attention within the total context of our health program in the Federal Government.

I understand that at least two witnesses, one is a very old and dear friend, Dina Merrill Robertson, will be testifying and the other, Mrs. Lurie, I understand, comes from New York, and is concerned with the work of the Juvenile Diabetes Foundation. I wish to commend them to the committee.

[Senator Javits' and Senator McGee's prepared statements follow:]

PREPARED STATEMENT OF SENATOR JACOB K. JAVITS

Mr. Chairman, I wish to welcome our distinguished witnesses who will help us to consider the important problem of diabetes. Since 1921 with Banting and Best's discovery of insulin, we have made great strides in the treatment of this disease. Nevertheless, much remains to be done: millions of our citizens are afflicted with diabetes; it has become one of the commonest causes of death in our adult population. In addition, diabetes accounts for much of the adult blindness as well as kidney and heart disease in the country.

I believe the Federal government should provide leadership in the development of research and service programs for the management of diabetes. We also have the difficult task of placing our concern for this tragic disease within the context of our national program for medical research and service. These hearings, as well as the hearings on the recent Report of the President's Biomedical Research, should provide us with invaluable assistance in our continuing effort to articulate an appropriate legislative national policy for health research and service.

PREPARED STATEMENT OF SENATOR GALE MCGEE

Mr. Chairman, as you know, there are several Members of Congress with vested interests in anything to do with the disease of diabetes mellitus. When it comes to the powers of Congress to deal with this disease, which has become the third most troublesome health problem in the United States, we elected officials who have diabetes would happily accept a charge of conflict of interest in our attempts to legislate the riddance of diabetes. Some may think it a bold statement that Congress could legislate the prevention, cure or elimination of a disease, but through prior actions of Congress and the rest of the government, that, I'm confident, is exactly what is happening.

This is not to say that the ultimate preventions, cures and eliminations will not come from the test tubes of science and that men of medicine will not be the ones who discover what we're after, but I would like to think that the people of this country through all their elected officials would be the ones to pave the way, if in no other way than providing for the test tubes and supporting the work of experts who we may gather in the fight against diabetes.

Through the passage of the McGee-Schweiker National Diabetes Research and Education Act we have taken the first step. The National Commission on Diabetes established by the Act filed with the Congress this year a comprehensive report on the magnitude of diabetes in the United States. Without taking the Committee's time on the Commission's report, let me just say that the magnitude of the disease is alarming, especially its complications which cause a multitude of other health problems affecting every vital bodily function.

Now that we have identified the many faces of the enemy, we are at the turning point where we must conquer that enemy.

S. 2910 notes that the National Commission on Diabetes has formulated a long-range plan to combat the enemy. The ultimate goals of this long-range plan are to discover means to prevent and cure diabetes and its complications and improve the care and quality of life of those individuals who now have or will get diabetes before the discovery of preventative measures and a cure. It is the purpose of this Act to establish a National Diabetes Advisory Board to insure implementation of the long-range plan.

To conserve time, Mr. Chairman, I'll not dwell on the specifics of S. 2910 as they relate to detailed membership and powers of the Advisory Board, as these matters will be thoroughly discussed as the bill progresses to law. My purpose here today has been to stress the importance of continuing along the path toward the cure for diabetes. It would be disastrous, not to mention senseless, to stop our efforts here; that would be like building a highway and then banning automobiles.

I need not dwell either on my support for this particular diabetes legislation as that should be well known. I would take this time to inform the Committee of the hundreds of letters and phone calls I have received from diabetics across the country in support of creating the National Diabetes Advisory Board. While these people have not escaped the disease, they have selfless intentions in their support of the long-range plan that others may escape. Their testimony, Mr. Chairman, would weigh heavily in the Committee's decision on S. 2910.

Before closing, there is one facet of diabetes which, in previous statements, I have not stressed enough; the severity of and priority that should be given to what's known as "juvenile diabetes."

The National Diabetes Mellitus Research and Education Act found and declared that "The severity of diabetes mellitus in children and most adolescents is greater than in adults, which in most cases involved greater problems in management of the disease."

Research needs are particularly urgent with regard to juvenile-onset diabetes. The Commission reported that about 50% of all children with diabetes now living will die of renal (kidney) disease within an average of 25 years after diagnosis of the disease.

At this point, Mr. Chairman, I ask that a few paragraphs on juvenile-onset diabetes from the December, 1975 issue of DIABETES FORECAST be inserted as my concluding testimony today.

If we leave nothing else in our efforts to combat diabetes, we must leave the children diabetic-free.

[The information referred to follows:]

[From Diabetes Forecast, December 1975 Special Edition]

COMPLICATIONS OF JUVENILE-ONSET DIABETES

Data on the complications of juvenile-onset diabetes indicate the following: among juveniles with diabetes followed for fifteen years or longer, 63% develop eye disease, of which 2% become totally blind; 20% develop high blood pressure; nearly 100% of those afflicted develop fibrosis and scarring of the renal glomeruli (impaired kidney function). About one half of the patients with juvenile-onset diabetes will die of kidney failure with an average life expectancy of 25 years after the diagnosis of diabetes. The problems are immense and cause untold suffering, loss of income, and destruction of family life as well as shortened life span.

The National Commission on Diabetes recommends that the National Heart and Lung Institute and the National Institute of Arthritis, Metabolism, and Digestive Diseases initiate and support a five-year clinical study to assess the effect of treatment of juvenile-onset diabetes on the development of microvascular and macrovascular complications.

Whether or not the major complications of diabetes are correlated with the wide variations of blood glucose levels which occur in juvenile diabetes is a subject of continued debate. Advocates of rigid control of glucose levels appears to have preliminary evidence to support their claim that such control lessens or delays the appearance of most complications. On the other hand, diabetologists who favor less rigid or "loose" control cite anecdotal evidence to the contrary. This controversy can only be resolved by a well-controlled clinical study of "tight" versus "loose" control of juvenile diabetes to compare the effects that each has on the development of microvascular and macrovascular complications. The need to resolve this problem is immediate since wide-scale use of alternative therapies (e.g., transplantation or artificial devices) is not likely to impact the majority of diabetic patients for many years.

Such a study requires extensive preliminary planning, careful long-term monitoring and evaluation, and effective administration. An advisory group should be established as an integral part of the project to assist with all of these functions.

Senator SCHWEIKER. Thank you very much, Senator Javits. I certainly appreciate your help and support and encouragement in this area.

Now I think I would like to ask a few questions of the Secretary. You oppose the structure and the form of what the Commission has come up with, and what our bill supports. The thing that most concerns me is that diabetes, unlike any other disease that we are confronted with in the whole country today, has a unique quality in that it is dissected through our Institutes of Health and through our different research programs, and fragmented and compartmentalized. Having completed a 15-month study of the CIA, and its departmentalization, and its problems there. I see a very similar analogy here. The compartmentalization of research we have witnessed here this morning, where one Institute has 8 percent and one has 2 percent, and so on, is really a unique problem. I think it calls for unique answers. Now if you do not like or do not agree with the structure we set up, what structure, Mr. Secretary, can we use to overcome what I think is a severe limitation. I think the reason frankly that diabetes has not been getting the attention it deserves as the third largest killer in this country is because of the inherent fragmentation of the disease in our health service structure.

Mr. HAISLIP. I would like to try to respond to that. I think that effective coordination depends really on two things: The first is there must be a mechanism, and I think that we have such a mechanism in the Coordinating Committee; and the second is there must be—

Senator SCHWEIKER. Coordinating Committee you are talking about?

Mr. HAISLIP. Yes. The second is there must be strong leadership and interest in the program at the top. I would suggest to you that we have that in Dr. Cooper, our Assistant Secretary for Health. I know he takes a personal and very strong interest in this, and I know that he undertakes to coordinate his programs effectively; the people who are involved meet on a frequent basis, and Dr. Cooper is a person, you know, who is heard. He does not whisper to his staff.

I think that strong leadership is important, and I think that we do have a tool in the Coordinating Committee. Now one of the particular problems that we have with the Board proposed in S. 2910 is in addition to what I am suggesting to you, it does have operational aspects which can lead to problems of administration. I think it is always a wise thing to indicate clearly where administrative authority resides so that decisions can be made in expeditious fashion. I am

sure you are well aware that one of the problems we have in the Department of Health, Education, and Welfare is making decisions expeditiously and seeing that they are implemented. It is a great problem, the length of time, the amount of staff resources that are eaten away by circulating paper through boards, and committees, and offices, and what have you.

It is a problem with which we are concerned and with which Secretary Mathews is concerned. It is not easy to make government effective. I am afraid that is what my personal experience suggests.

What I emphasize is that Dr. Cooper is taking a forceful lead here, and we do have an effective implementing mechanism in the Coordinating Committee so that the bill would only complicate and not aid current efforts. That is really the basis of our opposition. I hope you will regard that as a satisfactory answer.

Dr. WHEDON. May I speak to that? I would like to amplify that, if I may, and make a couple of additional points. One is that we in medical research administration are not against technical, scientific advice, and even advice of a policy nature. It is not only useful but it is valuable, and I would say in some cases essential. As far as advisory groups go, we have no objection. What we have here, however, is a provision in the bill that would vest in the Board certain authorities which are not ordinarily assigned to advisory bodies.

For example, the Board would be given authority to contract for services, make payment for services, engage in and be responsible for such activities, collect such data, provide such technical assistance as it seems necessary, and advisable. I understand, Senator, that this is in conflict with the Federal Advisory Committee Act.

The bill further authorizes an operating budget for the Board in the amount of \$500,000. This is a very sizable sum, and the various activities which are suggested in the bill for its operation in my view are directly in conflict with, duplicative of, and therefore counterproductive to what the Institutes are supposed to do in furthering their activities in diabetes. Such an arrangement would be particularly prone jeopardize the effectiveness of the newly appointed Associate Director for Diabetes, because those are the things he is supposed to do.

Senator SCHWEIKER. Let me ask you this. If we would accept your criticism that it does not meet the National Advisory Committee Act and revise the bill to meet the guidelines and the criteria of the National Advisory Committee Act that you would support it?

Mr. HAISLIP. I think that would certainly respond to that particular problem. It would be wrong for me to mislead you that there are not problems with other provisions, but that would certainly clear up one difficulty, since an advisory board, as a means of providing an extra dimension of expertise and advice is not something that the Department opposes.

Senator SCHWEIKER. Is that a "maybe" or what is that?

Mr. HAISLIP. Senator, I think other problems would still remain. That is really the best answer I can give you.

Senator SCHWEIKER. What concerns me, Mr. Secretary, is that here we have the third ranking disease. We spend \$763 million, roughly, on cancer, \$200 million on heart, and maybe that is even a low estimate, depending on how you break it down, and \$43 million on

diabetes: \$763 million, \$200 million, and \$43 million. In my judgment, diabetes is way underfunded. And if you put it in terms of amount spent per diabetic individual versus the others, I think it would be even more unfavorable. I think frankly it is a result not because of any direct plan or program, but just because it is caught between the grooves on the boardwalk, and it falls neither here, nor here, nor here. This is the heart of what we are discussing here.

I commend the Coordinating Committee concept. I think it is important for the reason I just stated to have a Diabetes Mellitus Coordinating Committee. I think it is important and I think it is necessary. I think that is a very important function. That is an in-house function. That is an in-government function, an inside function. Should we not have some outside help here? That is the part I think we are missing. I have no criticism or complaints about the Coordinating Committee. It was part of my original bill. I do not think it fills the gap that we need now.

Now frankly some of the people in the movement have asked me to introduce a bill to set up a National Institute of Diabetes as their answer to this problem. I realize the problem that makes. I realize the problem that creates. But I see their point. When you look at \$763 million, \$200 million, and \$43 million, they have a pretty valid point. It, to me, says we have to do something especially unique, to get the "out of house" commitment and coordination that we do not have. It seems to me some kind of group, whether it is an advisory group that meets with standards that we have laid down, and other legislation, or whether it is this particular proposal, I feel something is needed, because we are not here asking for an Institute of Diabetes. We do not want to complicate the problems of the new Associate Director. I want to compliment Dr. Whedon on that. I think we have a good choice there.

We want to give him support. I hope you will very seriously look at this bill and consider whether there are some modifications consistent with the Federal Advisory Committee Act that would fill the void.

This bill talks about training programs. The problem exists because we do not have diabetes training programs in the same sense as we do in some other diseases. Diabetes gets lost between the boards again. And we are suffering here along with clinicians and researchers in diabetes, for just the same reason, segmented, fragmented health problems. Wherever you look, you are dealing with blindness, kidney failure, heart attacks, stroke, you are dealing with complications of pregnancy and reproduction for diabetics, all across the board, and no other disease has it. That is why I think we need a unique solution to this problem.

Mr. Secretary, do you have any further response? It may be just a matter of taking a second look at your own criticism of saying it does not meet the Federal Advisory Committee Act, something that would meet that act that would fill your bill—

Mr. Haislip. It is difficult to respond to what you said. Whereas I think the gentlemen with me can take pride in what progress we have made, more progress needs to be made. I do not think anyone denies that. I think what we are trying to suggest to you is we do have a viable program. We certainly need to make it even better with time. When you have not solved a problem, there is always a need to do more.

Senator SCHWEIKER. I think you do have a viable program under the conditions and structure with which you are operating now, and, I acknowledge that. But I think that is part of the problem right there, that it is under conditions of fragmentation you are operating with now. I think it is a structural defect here. It is hard to put your finger on it.

Mr. HAISLIP. One of the things I suggest to you is that fragmentation in terms of pursuing programs in several institutes, and in fact probably in several agencies, is going to be necessary, simply because the disease and its manifestations do cut across the board. I suspect that some of the money being expended on research which have direct impact on diabetes cannot be clearly identified in relation to that program, simply because research on heart disease and various other types of diseases can and does often prove relevant. I think that kind of fragmentation perhaps cannot be avoided.

What would be inexcusable, and what we are seeking to assure, does not occur, is for the research to be conducted in a vacuum without coordination, without knowledge of the other components, without a cross-fertilization.

What I am suggesting is that given strong leadership, which I think we have, and given a coordinating mechanism which I think we have, we can see to it that needless fragmentation does not occur. But there is no denying that more work needs to be done in this area, and it is a very important area; we do not deny that.

Senator SCHWEIKER. Would you give us—Dr. Whedon—you wanted to respond?

Dr. WHEDON. May I respond further and try to make it perfectly clear that as Secretary Haislip stated in his opening remarks, that we have no quarrel with the basic intent of this legislation. And to be more specific, we do need advice. We do look for outside opinion and recommendations, and I think the work of the Commission thus far has been very valuable in this respect; particularly, some of the work groups on research have given us some clues as to extraordinarily good directions in which we should go. We intend to go further with that.

Further, specifically, our Associate Director would expect to have—we intend to have him get outside advice. An advisory group of this sort could be very helpful. The objection I have to the one proposed here is its operational character almost, you might say, a miniagency, one which seems to be in conflict with our own authorities.

Senator SCHWEICKER. I gather from what you say then, Doctor, you would be willing to talk with your diabetic groups and our staffs, to see if we could possibly approach the problem in a way that would meet your criteria, would solve the need they see, and that I see. That is fair enough. I think we should take a look at this point. I think that is a fairly constructive statement and I appreciate it.

One question, and this is probably to Dr. Whedon—what is the total amount of approved but unfunded diabetes related research and training grants? Can you give us that figure that has been approved but not funded?

Dr. WHEDON. Senator, for fiscal year 1976, the total amount of approved but unfunded diabetes research and training grants is \$2,024,000, of which \$1,623,000 is for 34 research grants and \$401,000 is for 24 training grants.

There clearly are many good training applications that we have received that we have been unable to fund and we feel training is extremely important. We wish we were in a position to fund them.

Senator SCHWEIKER. Along with that, I would like to ask each of the Institutes whether they have enough trained clinical laboratory researchers to follow some of the promising leads that are available now in diabetes research. Dr. Whedon, how would you answer the question? Are there enough trained clinical and laboratory researchers to follow the leads, some of the promising leads that are coming to the forefront now in diabetic research, in your Institute?

Dr. WHEDON. I feel very strongly that there are not enough. We could do more. I think as Secretary Haislip has said, I think we have had a good effective organization, we have a particularly strong intramural research group in diabetes, in our Institute. But there are good ideas which do come in in the form of research grant applications, and we fund them to the extent of our resources. I think our answer is that we are doing all we can within the resources that we have.

Senator SCHWEIKER. Dr. Kupfer, how about your response to that question?

Dr. KUPFER. As you know, we have had an ongoing review of our program by the National Advisory Eye Council, and of course they have been particularly interested in the area of diabetes. Whereas it seems that all research opportunities are being taken advantage of, what we are concerned with is the rate with which this research is moving forward, and the limiting factor is manpower. We have done everything possible to try to expedite the entry of researchers into the area of diabetes. I might just mention as recently as a month ago we made an arrangement with a leading diabetes research group in the country to help train an individual in the NEI's own Biometry and Epidemiology Division. Subsequent to this training, he will return to the extramural community and hopefully carry on this research.

We would like to be able to attract more people into diabetic retinopathy research, because perhaps the key to finding out the cause of disease in the retina may be of great help in knowing what is going on in other tissue systems.

Senator SCHWEIKER. Dr. Levy.

Dr. LEVY. I would like to respond to this question by going back and responding in part to an earlier question and that is to talk about the statement that the NHLBI is only spending 2 percent of its dollars in diabetes. It is very difficult to talk about dollars related to a specific disease. Our Institute staff has been and is well aware of the relationship of diabetes to cardiovascular disease. Cardiovascular disease is the major reason why the lifespan of the diabetic is cut by one-third.

We can estimate that close to \$100 million of our program in arteriosclerosis, hypertension, et cetera, can and will likely impact on future care and prevention activities for the diabetic. For example, we have clinical trials now that are trying to determine the effectiveness of decreasing risk factors in preventing heart attack. Diabetes is one of the four major risk factors for heart attack, others being high blood pressure, high cholesterol, and smoking. If we can show in these trials that stopping smoking, lower blood pressure, lower cholesterol, will decrease risk, it will immediately impact on the diabetic, because we will have immediate therapy that will decrease the risk of the diabetic patient.

We are doing a good deal. Manpower is a limitation. There is a limitation in all our programs, especially those involved in clinical investigation; that we could do more is probably spoken to by the responsiveness of the community to our recent solicitation. But we can do so much within resources, and without competing priorities.

Senator SCHWEIKER. All right. I probably have taken a little more time than I should have with this. It looks like we might have some possibilities of coming together in some of these areas, so I want to thank you, Mr. Secretary, and your associates and Directors of the Institutes for your participation here today, and appreciate very much your taking time to come up here.

Mr. HATSLIP. Thank you.

[The prepared statement of Mr. Dickson follows:]



FOR RELEASE ONLY UPON DELIVERY

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

STATEMENT

BY

JAMES F. DICKSON III, M.D.

DEPUTY ASSISTANT SECRETARY FOR HEALTH

BEFORE THE

SUBCOMMITTEE ON HEALTH

COMMITTEE ON LABOR AND PUBLIC WELFARE

UNITED STATES SENATE

TUESDAY, MAY 11, 1976

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to present the views of the Department of Health, Education, and Welfare on S. 2910, a bill designed to establish the National Diabetes Advisory Board and to insure the implementation of the long-range plan to combat diabetes.

As you know, this Department and the Subcommittee have not been in complete agreement regarding specific mechanisms for expanding our diabetes programs. As I will discuss in greater detail later, we have taken a number of positive steps on our own initiative as well as in response to Congressional directives and suggestions from the professional community and members of the public concerned with diabetes. However, the Department opposes enactment of S. 2910 because we believe the mechanisms created would be inappropriate and authorization levels would be excessive.

Current Activities

The "National Diabetes Mellitus Research and Education Act" established a National Commission on Diabetes charged with

responsibility for formulating a long-range plan to combat diabetes mellitus with specific recommendations for utilization and organization of national resources. The Act also established a Diabetes Mellitus Coordinating Committee, authorized diabetes research and training centers, and added diabetes to the disease control programs administered by the Center for Disease Control.

If I may summarize briefly the status of activities under the Act, the report of the National Commission on Diabetes was submitted in December 1975. Included among the recommendations were proposals also embodied in S. 2910: establishment of a National Diabetes Advisory Board; authorization for a new program of distinguished scientist grants; and extension of authorizations for diabetes research training centers. In addition, the Commission made a number of recommendations related to programs of the various Institutes of the National Institutes of Health (NIH). For the most part those recommendations have been extremely helpful, and the Institutes hope to pursue them to the extent permitted by available resources.

With regard to other provisions of the Act, NIH plans to issue guidelines for establishment of research centers in the near future. The Diabetes Coordinating Committee was established in November 1974 and submitted its first report in October 1975.

Diabetes research at the National Institutes of Health is centered in the National Institute of Arthritis, Metabolism, and Digestive Diseases (NIAMDD). Other NIH components, most important among them the National Heart, Lung and Blood Institute (NHLBI) and the National Eye Institute (NEI), also conduct and support research in long-range complications of the disease such as heart attacks, stroke, neurologic defects, peripheral vascular disease, and blindness. Because many Institutes are involved in diabetes-related research, coordination within the NIH is strengthened and augmented by the recently created Diabetes Mellitus Coordinating Committee which includes representation not only from involved Institutes at NIH, but also from all other Federal agencies with diabetes-related activities.

The NIAMDD is primarily responsible for basic research into the endocrinologic, metabolic, and nutritional aspects of diabetes. Recently, NIAMDD intramural scientists have reported an important finding which may lead to a better understanding of insulin resistance (inability of insulin blood levels to proportionally affect blood glucose in diabetic patients). These investigators have evidence that there is a serum factor in some patients which may alter cell surface insulin receptor activity, thereby causing impaired insulin binding, a condition which inhibits insulin from exerting its blood-glucose lowering effect.

Extramurally, the NIAMDD is supporting pioneering research on the elucidation of the multi-hormonal interactions which are hallmarks of diabetes. Support is continuing for research on the role of the high blood glucagon levels in diabetics, and its relationship to the hormone somatostatin. Somatostatin characteristically suppresses many hormones including insulin and glucagon, and this new area of diabetes research holds much promise for our understanding of aspects of the basic biological mechanisms in diabetes. The nutritional aspect, while long recognized as important, also is beginning

to emerge as a research area in its own right. The NIAMDD is planning expansion of its Obesity Centers and continued support of basic research in nutrition. Other diabetes-related efforts of the NIAMDD include increased support for research on transplantation of islet cells; and epidemiological studies to elucidate the role of microangiopathy in the manifestation of complications of diabetes; and plans for a contract program for the development of an artificial pancreas.

Other institutes, most notably NHLBI and NEI carry out significant diabetes-related research. The NHLBI supports approximately \$6 million in grant-supported research directly involving cardiovascular disease in patients with diabetes or in animal research involving diabetes.

The NHLBI is fully aware of the role that diabetes plays in dramatically shortening the life expectancy of diabetes since it is cardiovascular disease that is the major element in this premature mortality. Indeed, the Institute has been responsible for the support over the years of several major epidemiological studies that have documented the cardiovascular complications of diabetes and particularly its role as a risk-factor promoting heart attack in men and women, its association with increased sudden cardiac death, and its aggravation of cardiac failure.

This year the Institute solicited applications for research in the broad area of cardiovascular disease in diabetes. Some 270 investigators have told us that they intend to apply to this solicitation for new research. We have received responses from persons in all the major clinical and basic science disciplines. Yesterday, May 10, was our deadline for receipt of applications. I cannot say today exactly how many responses we had but we are heartened by the large response and we expect that this single solicitation will increase our funding this year in the area of diabetes from approximately \$6 million to about \$9 million. Clearly, the projection of these amounts into future years will be modified by current experience but it will obviously be larger than we have anticipated. In our view, the additional research holds real promise of contributing to the cardiovascular well-being of the diabetic patient and for taking into account his or her special needs in cardiovascular diagnosis, treatment, and preventive cardiology.

The National Eye Institute is also making significant progress in diabetes research. I am pleased to report that the recent Diabetic Retinopathy Study has shown that treatment through a technique called photocoagulation has

reduced by more than one half the risk of blindness in certain persons suffering diabetic retinopathy. The study, funded first by NEI in 1971, involved 1,720 patients represented an unprecedented cooperative effort among ophthalmologists, internists, biostatisticians, technicians, and administrative personnel. The NEI has made a major effort to inform physicians throughout the country as well as the general public of the results of the study. A copy of a scientific paper presenting these results was mailed to each of 10,000 practicing ophthalmologists in the United States and 3,000 physicians specializing in diabetes four weeks in advance of its publication in an ophthalmic journal.

It is noteworthy that the results of the Diabetic Retinopathy Study are already being accepted by the medical and scientific community. This may be attributed to the unceasing efforts on the part of all participants to assure that the study's design and execution incorporated the highest possible standards of ethical, scientific, and medical practice.

S. 2910

Turning to the legislation now before the Subcommittee, I would like to discuss the Department's views on S. 2910.

National Diabetes Advisory Board

S. 2910 would establish a National Diabetes Advisory Board composed of 19 members, including the Assistant Secretary for Health; the Director of the National Institutes of Health; the Director of the National Institute of Arthritis, Metabolism, and Digestive Diseases; the Director of the Center for Disease Control; the Administrators of the Health Services Administration and the Health Resources Administration; the Chairman of the Diabetes Mellitus Coordinating Committee; seven health or health research professionals not employed by the Federal government; and five persons from the general public.

The Board is to review, evaluate, and advise on the implementation of the long-range plan to combat diabetes mellitus, and to submit an Annual Diabetes Report simultaneously to the President and the Congress. Among other items, the Report would: describe progress made during the previous year in diabetes research, treatment, and education; include a detailed budget analysis of diabetes-related activities of the Federal government; recommend expenditures for the next fiscal year; and recommend necessary legislation to implement policy.

Mr. Chairman, the Department recognizes the magnitude and importance of health problems associated with diabetes, as well as the cross-cutting nature of diabetes activities involving many components of HEW and other agencies. It may be of interest to you that in the current Forward Plan for NIH the Director, NIH, singled out diabetes as an example of an activity requiring high level formal program coordination. We do not, however, share the view that establishment of a quasi-operational Board is a necessary or desirable means of ensuring better coordination or visibility for diabetes activities.

The Department has a number of concerns with the proposal for a National Diabetes Board which we would like to share with the Subcommittee.

We already have underway a multifaceted approach to diabetes research, training, and treatment programs. While we are also acutely aware that similar arguments can be advanced in support of special advisory groups for other diseases or health problems, we do not believe the proposed Board is desirable for the following reasons:

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1. As you may know, the National Commission on Arthritis is expected to make a similar recommendation in its forthcoming report. Similar study commissions on epilepsy and Huntington's disease have recently been chartered, as directed by the Congress. It is our view that proliferation of advisory bodies such as the proposed Board would create major problems of program management within the Department, particularly in the context of duplicative or conflicting relationships with the various statutory advisory councils charged with responsibility for recommending grant awards and advising on program policy. Further, the proliferation of advisory committees with overlapping jurisdictions is in contradiction to the intent of Congress, expressed in the Federal Advisory Committee Act, to limit the number of such Committees to a minimum.
2. S. 2910 would direct the Board to "review, evaluate, and advise" with regard to implementation of the diabetes long-range plan. Proposed membership of the Board would include Federal officials responsible for the programs being evaluated by the Board. This would create a potential conflict of interest which is clearly inappropriate.

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3. S. 2910 would vest in the Board certain authorities not ordinarily assigned to advisory bodies, for example, authority to contract for services, make payments for services, and "engage in and sponsor such activities, collect such data, provide such technical assistance as it deems necessary and advisable...." This is also in conflict with the Federal Advisory Committee Act. The bill furthermore authorizes an operating budget for the Board. We object to these provisions because the Board would not be subject to the customary agency oversight of procurement practices. We also object to the establishment of an advisory committee which would pre-empt operational responsibilities of Federal officials.

Diabetes Research and Training Centers

S. 2910 would reauthorize FY 1977 appropriations authorizations for diabetes research and training centers. It would also provide new authorization levels for this purpose of \$12 million for FY 1978 and \$20 million for each of the three succeeding fiscal years. In our view, these authorization levels are both excessive and unnecessary, since center programs may be conducted under other general authorities.

Distinguished Scientist Grants

S. 2910 would also authorize distinguished scientist grant awards of \$35,000 per year to be made to individual scientists who have shown outstanding productivity in diabetes-related research. Authorization levels for distinguished scientist grants would be \$175,000 for FY 1976; \$350,000 for FY 1977; \$525,000 for FY 1978; \$700,000 for FY 1979; and \$875,000 for FY 1980 and succeeding years.

The Department opposes the establishment of distinguished scientist grants as inappropriate. Support for scientists, based on scientifically meritorious research proposals, is available through the regular grant peer review process. As a matter of policy, we believe that payment should be for the time and effort devoted to pursuit of approved scientific projects. The distinguished scientist grant would be similar to the Research Career Awards program which, after thorough study and review, NIH terminated because it was not directly related to the scientific merit of the individual's ongoing research.

Conclusion

In summary, Mr. Chairman, we are opposed to enactment of S. 2910. We are, however, moving ahead on a variety of exciting and promising activities in diabetes, and we believe that significant progress has been made in coordinating this complex task. My colleagues and I would be happy to answer any questions you or other members of the Subcommittee may have.

Senator SCHWEIKER. Our next witness is Dr. Crofford, Chairman, National Commission on Diabetes. I am very proud of the work that Dr. Crofford's commission has done. I certainly feel that his work in the Commission has advanced the cause of diabetes measurably, by defining the problem in a very basic and meaningful way that the country can understand and probably did not know before.

STATEMENT OF OSCAR B. CROFFORD, M.D., CHAIRMAN, NATIONAL COMMISSION OF DIABETES; DIRECTOR, DIABETES-ENDOCRINOLOGY CENTER, SERVING AS ADDISON B. SCOVILLE PROFESSOR OF MEDICINE, VANDERBILT UNIVERSITY SCHOOL OF MEDICINE, NASHVILLE, TENN.

Dr. CROFFORD. Thank you very much for those kind remarks, Senator Schweiker. Obviously this was a group effort. We have had over 300 people helping in the preparation of this report, and I think that the public interest, the interest of the Congress, and the interest of the entire diabetes community has contributed to the momentum that we are seeing in the diabetes area at the present time. I certainly hope that that momentum will not be lost.

To begin my statement, let me state that my name is Oscar B. Crofford. I am a doctor of medicine and serve as the Addison B. Scoville Professor of Medicine at the Vanderbilt University Medical School in Nashville, Tenn. For the past 14 months I have served as Chairman of the National Commission on Diabetes and I am grateful to the subcommittee for allowing me to appear as a witness this morning. I respectfully request that my statement be made a part of the official record, and I would only try to summarize at this time.

Senator SCHWEIKER. Without objection, it will be inserted at the conclusion of your testimony.

Dr. CROFFORD. The National Commission on Diabetes was established by the 93d Congress to develop a long-range plan to combat diabetes. That report was delivered to the Congress on December 10, 1975. As conceived by the Commission, the diabetes plan calls for more basic research, better training of skilled manpower, and more efficient use of existing agencies to care for patients who already have diabetes or who may develop diabetes before a cure is found. The fourth component of the plan is the establishment of the National Diabetes Advisory Board. This Board will evaluate progress and advise the Government and the public with respect to the implementation of all components of the plan.

I would now like to respond to some specific questions concerning this legislation.

1. Why did the Commission propose a National Diabetes Advisory Board instead of a new National Institute of Diabetes?

The Commission concluded that it would be unsound, scientifically, to isolate research in diabetes from the ongoing, diabetes-related research programs of other Institutes. A Diabetes Institute would cost more money, expand the Federal bureaucracy and be inconsistent with the recommendations of the President's Biomedical Research Panel. Finally, and again in agreement with the President's Biomedical Research Panel, the Commission did not wish an Institute of the NIH to shoulder the responsibility of implementing those aspects of the

long-range plan dealing with treatment and education since we view research rather than health care delivery as the principal mission of the National Institutes of Health.

2. What will the National Diabetes Advisory Board really do?

The Board will meet quarterly to review, evaluate, and advise with respect to the implementation of all components of the long-range plan to combat diabetes. It will submit a concise annual report simultaneously to the Congress and to the administration. This will keep the diabetes plan up to date.

3. Could not this be done by an existing NIH Institute, Council, or advisory body?

No. There is no existing advisory body that is equipped to evaluate progress in implementing the diabetes plan in the broad array of Federal agencies that are involved. Many of the involved agencies are not even a part of NIH.

4. What about the Diabetes Mellitus Coordinating Committee?

The Coordinating Committee is made up entirely of Federal employees and will be a valuable resource for the Advisory Board. It is our hope that the Coordinating Committee will compile information concerning the diabetes-related activities of all of the Federal agencies. The Advisory Board will evaluate these data in preparing its annual report to the Congress. The Advisory Board report, however, will not be limited to the activities of Federal agencies reporting on and evaluating their own progress. It will include the progress made by State and local health agencies, voluntary health agencies, pharmaceutical companies and organizations of nurses, dietitians, doctors, and others that are participating in the long-range plan to combat diabetes.

5. Is the proposed National Diabetes Advisory Board, in reality, a miniagency with substantial operational authority?

Absolutely not. The Board is strictly advisory. Naturally the advice is worthless if it is not based on solid, up-to-date facts. This requires the Board to hold meetings, to establish its own working subcommittees and have some degree of staff assistance. Let me emphasize, however, that these provisions are for the sole purpose of permitting the Board to serve in a meaningful advisory capacity. It operates nothing except its own affairs.

6. Is the budget excessive?

The budget is our best estimate of the true cost of carrying out the functions ascribed to the Board. The legislation gives the Board backup authority and backup resources to assure that it is able to perform its duties. If adequate staff resources are provided by the Office of the Assistant Secretary for Health and if every agency sponsors its own workshops and provides the Board with timely and accurate data then the budget would be excessive. However, our experience with the Commission indicates that many Federal agencies are not equipped to provide the needed information. Quite simply, the Commission had to compile its own information. It would make a mockery of the Board to establish it without providing the resources necessary for its work.

7. What about the question of precedent? Should every disease have an Advisory Board?

Of course not. But diabetes is not like "every disease." There is a National Cancer Institute and a Heart Lung Institute with their

own Advisory Panels and Councils, but there is no diabetes institute or diabetes council. The diabetes programs fall within the scope of at least seven Institutes. There is already a National Institute of Arthritis, Metabolism and Digestive Diseases. Arthritis and digestive diseases are important illnesses, but quite frankly, they do not cause blindness, and stroke, and heart attacks, and kidney failure, and the complications of pregnancy and childbirth that are seen with diabetes and need not be dealt with in the same way. Diabetes is unique in producing severe complications in so many different organs.

8. Why locate the Diabetes Advisory Board in the Office of the Assistant Secretary for Health rather than at NIH?

The long-range plan to combat diabetes calls for more basic research to discover the cause and cure for diabetes and research is the mission of the National Institutes of Health. But the plan also provides care for those who already have diabetes or will develop diabetes before a cure is found, and we do not view clinical care as the principal mission of the NIH. The long-range plan to combat diabetes calls for activities by the Health Resources Administration, the Health Services Administration, the American Diabetes Association, the Juvenile Diabetes Foundation, and a number of other Federal, State, local, and voluntary health agencies. All of these agencies are outside the National Institutes of Health.

There is no ideal location for the National Diabetes Advisory Board but having viewed the alternatives, the Commission concluded that the best location for the Board is in the Office of the Assistant Secretary for Health.

9. What about the composition of the Board?

As conceived by the Commission, the Board would have representatives from the general public, from the health professions and from both the administrative and legislative branches of Government. In S. 2910 the legislative representatives have been omitted because someone questioned whether such a Board violates the principle of separation of powers. Since the Board would have only an advisory role, I do not believe this is a valid issue and would prefer to see S. 2910 modified to put the legislative representatives back on the Board.

One final point about the Board. The position of Associate Director for Diabetes for the National Institute of Arthritis, Metabolism and Digestive Diseases was unfilled at the time the Commission report was prepared. With the position now filled it would be highly desirable for the person who holds that office to relate directly to the Board either by being a voting member, an ex officio member or by serving as the Executive Director for the Board. These last comments are my personal opinions and not those of the full Commission since the question was not considered in detail during the Commission's deliberations.

In the minute remaining let me now turn briefly to the other two aspects of S. 2910.

10. What about the distinguished scientists program?

The Commission proposed the establishment of a limited number of distinguished scientists awards, each limited to one nonrenewable 10-year term. The recipients would be drawn from those individuals who have demonstrated continuous and outstanding research productivity.

The purpose is to provide an incentive for experienced investigators to continue their research, rather than assuming administrative positions when they are between the ages of 35 and 45—a decade that is potentially the most productive. Such a program would help attract and maintain a pool of highly talented health scientists into the field of diabetes research.

11. Would such a program not draw physicians into research and away from primary care?

When the distinguished scientist award program is fully operational (in 1981) there will be only 25 positions—5 appointed each year (1977–1981). This is a very small percentage of the 14,000 physicians graduated from American medical schools each year. Besides we must continue to train teachers and scientists as well as practicing physicians.

12. What about the diabetes research and training centers program?

The diabetes research and training centers program was authorized by Public Law 93–354, the “National Diabetes Mellitus Research and Education Act.” The scope and cost of the program, as described in detail by the Commission, is fully consistent with that already authorized. Only the dates are changed. The dates have been moved forward by 27 months. This is necessary because of the change in the Federal fiscal year and because the program will only begin in fiscal year 1977 even though the original 3-year authorization began with fiscal year 1975.

In conclusion, Mr. Chairman, let me thank you for allowing me to make these statements in behalf of the National Commission on Diabetes. We consider S. 2910 to be essential to the full implementation of the long-range plan to combat diabetes and add our strongest endorsement.

Senator SCHWEIKER. Let me say, Dr. Crofford, that you have certainly summed up very succinctly, and ably, and articulately, the Commission’s arguments as to why the bill is before us.

I am sorry the administration witnesses are not here to hear some of this, because I think it goes right to some of the points they raised. And you very succinctly came down very hard on some of the issues at hand.

Having heard the previous dialog prior to your writing up your statement, do you have any supplemental remarks that you might want to make in reference to any of the points that were made a few moments ago?

I know you pretty well covered it, actually.

Dr. CROFFORD. Well, I tried to anticipate most of their—

Senator SCHWEIKER. You certainly did very well, yes.

Dr. CROFFORD [continuing]. Points.

I would add that one of the most constructive suggestions is the one that you made.

The position of the administration and the position of the Commission is really not as far apart as it would seem. Obviously, the Board must have the authority to collect data on which to give meaningful advice.

I do not consider that to be “operational authority,” and I don’t think they do either. The dollar resources, obviously, will have to be appropriated to some agency of the Government, and I believe that I

could sit down, representing the Commission, with the appropriate members of your staff and with the appropriate representatives from the administration, and assist you in modifying the bill in a way which would meet most of the administration's objections and still answer the need as perceived by the Commission and by yourself.

Senator SCHWEIKER. I certainly think it is, too.

And I would certainly suggest, in view of what has happened here this morning, that we immediately begin this process.

In addition to my staff, I think we probably should invite Dr. Carter's staff to participate in this process. I think it would be very productive and I think it would also do something which is a concern of mine. Our timeframe in this legislative year, while it isn't too late, is late. And I think this may well overcome some of the obstacles that we can perceive—a White House veto and otherwise—that we can avoid by this route.

So, I think it is very helpful.

Dr. CROFFORD. It says in the bill, that the staff resources needed by the Board will be provided by the Secretary. It is subtle wording, like who shall determine what the Board needs.

Obviously, if the Secretary does provide a staff to meet all the needs, then I think we could make some changes in the budget, because we have budgeted amounts for staff needs. And I think there are subtleties in the wording of the legislation which could be worked out to assure you, and to assure the Board and assure Dr. Carter that the administrative needs will be met by the Secretary's office, which could alter the budget.

And just as Dr. Whedon said, his institute and the other institutes plan to hold workshops and get scientists together, and that is fine. Insofar as they do those things, then it would be unnecessary for the Board to sponsor such activities.

Obviously, the Board does not intend to duplicate the activities that the institutes undertake. Rather, the Board has to be assured that if the institutes do not—for one reason or the other—stage and hold the proper workshops, that it has some sort of backup mechanisms for assuring that this can be achieved.

So, there, again, I think a compromise position would be possible.

Senator SCHWEIKER. All right, Dr. Crofford, we thank you very much. And once again, you have played a very positive, dynamic role. And we are very grateful and will follow up with your latest suggestion.

Dr. CROFFORD. Thank you, Senator.

[The prepared statement of Dr. Crofford follows:]

STATEMENT OF

OSCAR B. CROFFORD, M.D.

Chairman, National Commission on Diabetes

Addison B. Scoville Professor of Medicine
Vanderbilt University School of Medicine
Nashville, Tennessee 37232

PRESENTED AT A HEARING

Before the

HEALTH SUBCOMMITTEE

of the

COMMITTEE ON LABOR AND PUBLIC WELFARE

UNITED STATES SENATE

94th Congress

2nd Session

Subject: The National Diabetes Advisory
Board Act, S-2910

May 11, 1976

Mr. Chairman and distinguished members of the Subcommittee:

My name is Oscar B. Crofford. I am a doctor of medicine and serve as the Addison B. Scoville Professor of Medicine at the Vanderbilt University Medical School in Nashville, Tennessee. For the past 14 months I have served as Chairman of the National Commission on Diabetes and I am grateful to the Subcommittee for allowing me to appear as a witness this morning. I respectfully request that my statement be made a part of the official record.

The National Commission on Diabetes was established by the 93rd Congress to develop a Long-Range Plan to Combat Diabetes. That report was delivered to the Congress on December 10, 1975. As conceived by the Commission, the Diabetes Plan calls for more basic research, better training of skilled manpower and more efficient use of existing agencies to care for patients who already have diabetes or who may develop diabetes before a cure is found. The fourth component of the Plan is the establishment of the National Diabetes Advisory Board. This Board will evaluate progress and advise the Government and the public with respect to the implementation of all components of the Plan.

I am pleased to report today that within the limits of existing authorizations and dollar resources, Government agencies are already moving ahead. Let me cite some examples: 1) the appointment of the Associate Director for Diabetes of the National Institute of Arthritis, Metabolism and Digestive Diseases; 2) a special emphasis grant program relating diabetes and heart disease sponsored by the National Heart Lung Institute; 3) the remarkable progress on the treatment of diabetic retinopathy recently reported by the National Eye Institute; 4) the appointment of a new staff member by the Center for Disease Control in Atlanta to help develop the diabetes control program of the CDC; 5) a workshop on diabetes with the Mental Health Agency; and 6) a workshop in diabetes with Dr. Endicott and other representatives from the Health Resources Administration

and a workshop with the Health Services Administration already scheduled. More is to come for the Diabetes Plan is already beginning to pay off.

With respect to appropriations for diabetes research, both houses of Congress are working hard to modify the FY'77 appropriations bill to provide the dollar resources needed for full implementation of the Diabetes Plan.

What is now needed is the final step -- the passage of this piece of legislation. This bill (S-2910) is an integral part of the Long-Range Plan to Combat Diabetes since it provides the authorization for those aspects of the Plan where authorization does not already exist. It is my firm conviction that if S-2910 should fail, the entire Plan will fail because the Diabetes Plan was built with four interlocking parts and -- quite simply -- this is the fourth and final part.

I would now like to respond to some specific questions concerning this legislation.

1) *Why did the Commission propose a National Diabetes Advisory Board instead of a new National Institute of Diabetes?*

The Commission concluded that it would be unsound scientifically to isolate research in diabetes from the on-going, diabetes-related research programs of other Institutes. A Diabetes Institute would cost more money, expand the Federal bureaucracy and be inconsistent with the recommendations of the President's Biomedical Research Panel. Finally, and again in agreement with the President's Biomedical Research Panel, the Commission did not wish an Institute of the NIH to shoulder the responsibility of implementing those aspects of the Long-Range Plan dealing with treatment and education since we view research rather than health care delivery as the principal mission of the National Institutes of Health.

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The Coordinating Committee is made up entirely of Federal employees and will be a valuable resource for the Advisory Board. It is our hope that the Coordinating Committee will compile information concerning the diabetes-related activities of all of the Federal agencies. The Advisory Board will evaluate these data in preparing its annual report to the Congress. The Advisory Board Report, however, will not be limited to the activities of Federal agencies reporting on and evaluating their own progress. It will include the progress made by state and local health agencies, voluntary health agencies, pharmaceutical companies and organizations of nurses, dietitians, doctors and others that are participating in the Long-Range Plan to Combat Diabetes.

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7) What about the question of precedent? Should every disease have an Advisory Board?

Of course not. But diabetes is not like "every disease." There is a National Cancer Institute and a Heart Lung Institute with their own Advisory Panels and Councils, but there is no Diabetes Institute or Diabetes Council. The Diabetes programs fall within the scope of at least seven Institutes. There is already a National Institute of Arthritis, Metabolism and Digestive Diseases. Arthritis and digestive diseases are important illnesses, but quite frankly, they do not cause blindness, and stroke, and heart attacks, and kidney failure, and the complications of pregnancy and childbirth that are seen with diabetes and need not be dealt with in the same way. Diabetes is unique in producing severe complications in so many different organs.

5.

8) Why Locate the Diabetes Advisory Board in the Office of the Assistant Secretary for Health rather than at NIH?

The Long-Range Plan to Combat Diabetes calls for more basic research to discover the cause and cure for Diabetes and research is the mission of the National Institutes of Health. But the Plan also provides care for those who already have diabetes or will develop diabetes before a cure is found, and we do not view clinical care as the principal mission of the NIH. The Long-Range Plan to Combat Diabetes calls for activities by the Health Resources Administration, the Health Services Administration, the American Diabetes Association, the Juvenile Diabetes Foundation and a number of other Federal, state, local and voluntary health agencies. All of these agencies are outside the National Institutes of Health.

There is no ideal location for the National Diabetes Advisory Board but having viewed the alternatives, the Commission concluded that the best location for the Board is in the Office of the Assistant Secretary for Health.

9) What about the composition of the Board?

As conceived by the Commission, the Board would have representatives from the general public, from the health professions and from both the administrative and legislative branches of government. In S-2910 the legislative representatives have been omitted because someone questioned whether such a Board violates the principle of separation of powers. Since the Board would have only an advisory role, I do not believe this is a valid issue and would prefer to see S-2910 modified to put the legislative representatives back on the Board.

One final point about the Board. The position of Associate Director for Diabetes for the National Institute of Arthritis, Metabolism and Digestive Diseases was unfilled at the time the Commission Report was prepared. With the position

now filled it would be highly desirable for the person who holds that office to relate directly to the Board either by being a voting member, an ex officio member or by serving as the Executive Director for the Board. These last comments are my personal opinions and not those of the full Commission since the question was not considered in detail during the Commission's deliberations.

In the minute remaining let me now turn briefly to the other two aspects of S-2910.

10) *What about the Distinguished Scientists Program?*

The Commission proposed the establishment of a limited number of Distinguished Scientists Awards, each limited to one non-renewable 10 year term. The recipients would be drawn from those individuals who have demonstrated continuous and outstanding research productivity. The purpose is to provide an incentive for experienced investigators to continue their research, rather than assuming administrative positions when they are between the ages of 35 and 45 -- a decade that is potentially the most productive. Such a program would help attract and maintain a pool of highly talented health scientists into the field of diabetes research.

11) *Would such a program not draw physicians into research and away from primary care?*

When the Distinguished Scientist Award program is fully operational (in 1981) there will be only 25 positions -- five appointed each year (1977-1981). This is a very small percentage of the 14,000 physicians graduated from American Medical Schools each year. Besides we must continue to train teachers and scientists as well as practicing physicians.

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The Diabetes Research and Training Centers program was authorized by Public Law 93-354, the "National Diabetes Mellitus Research and Education Act." The scope and cost of the program, as described in detail by the Commission, is fully consistent with that already authorized. Only the dates are changed. The dates have been moved forward by 27 months. This is necessary because of the change in the Federal fiscal year and because the program will only begin in FY'77 even though the original three year authorization began with FY'75.

In conclusion, Mr. Chairman, let me thank you for allowing me to make these statements in behalf of the National Commission on Diabetes. We consider S-2910 to be essential to the full implementation of the Long-Range Plan to Combat Diabetes and add our strongest endorsement.

Senator SCHWEIKER. We will call as our next witness Dr. George F. Cahill, President of the American Diabetes Association and Director of the Elliott P. Joslin Research Laboratory at Harvard University Medical School.

Dr. Cahill.

STATEMENT OF GEORGE F. CAHILL, JR., M.D., PRESIDENT, AMERICAN DIABETES ASSOCIATION AND DIRECTOR, ELLIOTT P. JOSLIN RESEARCH LABORATORY, HARVARD UNIVERSITY MEDICAL SCHOOL ACCOMPANIED BY DONNELL D. ETZWILER, M.D., PRESIDENT-ELECT, AMERICAN DIABETES ASSOCIATION, ST. LOUIS PARK MEDICAL CENTER

Dr. CAHILL. This is Dr. Etzwiler from the University of Minnesota, Minneapolis, who is the president-elect of the American Diabetes Association.

Senator SCHWEIKER. I want to say, having met you before and having worked with you, I am very glad to see the life and vigor that I think your leadership and some others have brought to the ADA.

I think you really have made a great effort in this area. You have been one of the leaders in your movement to elevate the effectiveness, and vigor and strength of your organization.

Dr. CAHILL. Thank you, Senator, very much for those kind comments.

I have a formal document, which has been turned into your staff, but I would like, with your permission, instead of reading from that to make a few very brief, off-the-cuff comments. If I could, sir.

Senator SCHWEIKER. Your statement will be inserted at the conclusion of your testimony.

Dr. CAHILL. First, thank you tremendously for your input and the initial legislation that started this whole ball rolling.

I think the administration already presented our case, although they were taking the other side. Because it is very clear that the changes in funding of the institutes that they recommend was largely due to pressures—in fact, majorly due to pressures—that your original legislation put forth.

So, we already have evidence before us that an outside advisory body can perform an awful lot of good. And the idea of setting up the Advisory Board is obviously to keep this going. So it now no longer falls back into the obscurity that diabetes had some 5–10 years ago—as we all know only too well.

I am sorry Mr. Haislip had to run. Of course, his departure was already evidence of the confusion and convulsion that people within the Government have in trying to get some program going through.

But I would like to ask the Coordinating Committee is how much input they have had from non-Government witnesses during their meetings. And I know the answer; it is very minimal.

There are obviously two reasons: one is the Commission is still in action, so they don't need it.

And I think, as Dr. Whedon has stated, that they will be drawing in on other people. But I don't think that they could ever get the mileage that the Commission has had in catalyzing efforts without hav-

ing formal membership, which means setting up a continual advisory board.

So I think those facts speak for themselves.

Senator SCHWEIKER. At the time when we wrote this bill the Coordinating Committee was strictly put in as an inhouse coordinating body.

It was our concept here in this committee, and that was its purpose and objective

So to say that it can really do more than that is really not a portrayal of its legislative history or the origin of it. And we had the Commission itself as the outside body, so right from the beginning it was never intended to be what some people are saying it is.

Go ahead.

Dr. CAHILL. Now the next thing is the precedent for other diseases. And now I would like to wear the hat of the physician rather than as an advocate directly for diabetes. There is no other disease that cuts across so many lines of medicine.

Tuberculosis and syphilis were the two global diseases. And thank God, we just about got rid of both of those.

In other words, there is no other disease that hits the central nervous system, the periphery, the heart, the kidneys, the eyes, in addition to the emotional problems of having a chronic disease. This is unique to diabetes.

And the concern that Mr. Haislip made, saying that this would set a precedent is completely wrong. There is no other disease. And thank God, there is not any that touches so many important systems.

So we are standing unique when we are speaking for diabetes, because I don't think we will be setting up a precedent for any other advisory board, that already doesn't fall within a given institute.

We are not recommending a new institute; we are not recommending a new operating body.

We are purely recommending, within the present structure, advisory body. But as Dr. Crofford said, if you need an advisory body you have to have some funds, some staff to be able to collect the information from which one can give the advice. And that is why the budget has been written in, as you did write in.

So that we are agreeing with their concept, I believe, in the fullest.

Now, another comment I would like to echo concerning the working with the present structure is what Dr. Crofford touched on. Dr. Whedon has been able to attract a very competent young man to be the Associate Director for Diabetes with his Institute.

And to have this man serve either as a voting member or possibly—and I would be speaking now for myself, as the executive director of the advisory panel—would place no conflict. In other words, it would really, if anything—

Senator SCHWEIKER. I think that is an important point. You see absolutely no conflict with the new man coming in and the concept embodied here in terms of their respective roles.

Dr. CAHILL. It would be autocatalytic, really.

There couldn't be a better way to do things, and I would like to speak to that now in the last 2 or 3 minutes, and then I would like, with your permission, sir, to have Dr. Etzwiler defend why this has

to go beyond the NIH. It is much broader than the NIH, again because of the problem with diabetes.

What I would like to speak to is the career awards, for 1 minute.

When we met with the workshops—for example, the workshop on the neuropathy of diabetes, one-fifth of all diabetics get symptomatic neurologic diabetes; their feet hurt, they scream at night. It is a hell of a problem, in just so many words.

In the entire world, there are probably only four or five people dealing with peripheral diabetic neuropathy in a very basic, fundamental approach. This is absolutely amazing.

And the reason is because there is a very limited but small amount of money, true. But people don't want to get into a specific area unless they realize they will have support for a long term. And to be able to attract competent scientists, one has to secure some limited period of time for them to work in this job. A 10-year pull is very reasonable.

And this is why we are not recommending to set up career life awards, which were set up 5, 10, 15 years ago and then rejected as being not practical. We are setting up a 10-year pull, or trying to urge that we set up a 10-year pull, whereby biochemists, physiologists can be pulled into these relatively obscure areas of disease. Otherwise, we are going to get no one.

In other words, it is really kind of a luring of competent people, and I don't see how it is going to be done without some more permanent, long-range support—not “completely permanent”—I should say 10-year pulls for these investigators. Because simply to learn the technology takes 5 to 6 years in many of these fields.

This also goes for Dr. Kupfer's field in the National Eye Institute. Research ophthalmologists, only one or two—at the most—a year go into research, let alone into the diabetes problems.

And to get a very enthusiastic young investigator, you have to offer him some limited time of security to go into this research effort.

This is why I feel personally, as a researcher, very strongly that these 10-year career awards be implemented.

That is essentially my summation.

I would like now, if I could, with your permission, sir, to ask Dr. Etzwiler—I am more of a test-tube scientist. He is a person, or “people-kind” of a scientist who deals primarily with the problem of taking care of the diabetic and seek research developments, in this area. Thank you very much.

Senator SCHWEIKER. Thank you very much, Dr. Cahill. We will be delighted to hear from Dr. Etzwiler.

[The prepared statement of Dr. Cahill follows:]



American
Diabetes
Association, Inc.

Statement of

GEORGE F. CAHILL, JR., M.D.

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PRESENTED AT A HEARING

before the

SUBCOMMITTEE ON HEALTH

of the

COMMITTEE ON LABOR AND PUBLIC WELFARE

UNITED STATES SENATE

94th Congress

2nd Session

Subject: S.2910

May 11, 1976

Mr. Chairman and distinguished members of the Subcommittee:

I am George Cahill, a physician, current President of the American Diabetes Association, and a Professor of Medicine at Harvard, whose major responsibility is the scientific direction of research efforts as well as teaching in areas relating to diseases of metabolism, especially diabetes. I also was a member of the National Commission on Diabetes and with Dr. Paul Lacy and Mrs. Leatrice Ducat was responsible for the research aspects of the Commission's hearings and the report.

I want to comment today as a researcher on the problems of diabetes and the need to implement the Commission's recommendations in S.2910 to carry out the long-range plan to combat diabetes. Diabetes has a major impact on our health -- a crossroads of all sorts of problems virtually affecting every organ in the body. Diabetes is the leading cause of blindness in adults. It also is a major factor in heart attacks, strokes and kidney disease. It can cause gangrene and subsequent amputation of limbs.

Because of this systemic nature, diabetes is a unique disease, calling for a unique approach to solving its problems. The typical NIH approach does not meet the needs of diabetes because basically the Institutes are divided by organs, or disease entities. But diabetes cross-cuts the Institutes --

- The National Institute of Arthritis, Metabolism and Digestive Diseases is the base for the greatest amount of research into basic endocrinology, metabolism and nutrition. Currently under investigation are the synthesis of insulin and other mechanisms for increasing the world's insulin supply; interaction among hormones with possible relationships to diabetes, including somatostatin and growth hormone; the mechanisms and role of viruses in the etiology of diabetes; the genetic factors which could identify those persons with a genetic predisposition

for diabetes and eventually prevent the disorder; the epidemiological studies of discrete populations needed to further elucidate our understanding of diabetes; research in nutrition and obesity; and approaches to transplantation and management of diabetes with artificial devices.

- The Heart and Lung Institute is conducting research on diseases of the large blood vessels, with important implications for all other complications of diabetes. The vascular system is the central focus for many of the complications of diabetes. Atherosclerosis, which is part of the usual aging process, is markedly accelerated in the diabetic patient, both juvenile-onset and maturity-onset. Recent surveys indicate that the risk of cardiovascular events at any given age is two to five times higher for the diabetic individual than the nondiabetic.

- The National Eye Institute is studying diabetic retinopathy: the basic pathology of diabetic retinopathy involves changes in the vascular structure of the eye which are progressive and may ultimately lead to blindness. These changes are similar to those that occur in other organs, especially the kidney. The relatively less complex organ structure of the eye provides a unique opportunity for more easily accessible tissue to study the pathological processes of microangiopathy in the retinal vessels, including thickening and basic biochemistry of the basement membrane, and the clinical effectiveness of therapeutic agents.

- The Child Health and Human Development Institute has an important role to play: with insulin therapy and extended life span has come the recognition that pregnancy poses serious threats to the life of the diabetic mother. Close control of diabetes during pregnancy has decreased maternal mortality to near normal but the survival rate for offspring is still substantially lower than in normal pregnancies. Evidence indicates that those babies that do survive have a higher

incidence of congenital abnormalities. In addition, studies are necessary regarding "gestational" diabetes, a form of the disease which occurs only while the mother is pregnant. Contraceptive techniques for diabetic women is an area that requires additional study. Currently these studies are not taking place.

- The National Institute of Neurological and Communicative Disorders and Stroke is studying diabetic neuropathy, the diverse abnormalities that occur in peripheral nerves of the diabetic. All individuals with diabetes have some demonstrable alteration in their peripheral nerves. Approximately one-fourth are symptomatic and one half of these symptoms are severe enough to cause partial or total disability, accompanied by intense pain and eventual loss of sensation. The anesthetized extremities are susceptible to injury and ulceration, which may contribute, in many cases, to loss of the affected extremity.

- The Dental Research Institute is looking into the incidence of serious periodontal disease among individuals with diabetes, estimated to be as much as three times higher than among normal individuals. Generally the disease is more serious and progresses more rapidly in diabetic patients. This may be related to the predisposition of diabetic patients to develop loss of bone throughout the body -- generalized osteoporosis. Periodontal disease causes serious difficulties in mastication and other discomforts and problems such as infection. In addition, it can be a serious financial burden, since periodontal care is expensive and is generally not covered by most third-party payment systems.

All this research is being conducted without much opportunity for coordination or interagency contact within NIH. Add to this problem the fact that extensive and very important research is conducted through the Veterans Administration; the fact that the Health Resources Administration, the Health Services Administration, and the Alcohol, Drug Abuse and Mental Health Administration are also in a position to undertake meaningful research responsibilities, and

nongovernmental bodies are also conducting research and other programs -- and you are faced, as the Commission was, without any way to guarantee coordination and evaluation of these efforts.

The obvious suggestion was the formulation of a National Diabetes Institute, but the Commission decided that such an effort ultimately would be counterproductive. Isolating research in diabetes from research programs for other diseases could greatly decrease the scope and effectiveness of diabetes-related research. Also, the Commission did not favor establishment of a National Diabetes Institute with the responsibility of coordinating and implementing those aspects of the long-range plan dealing with treatment and education, since these functions are not traditionally the main focus of NIH.

It is pertinent here to comment on the report of the Biomedical Research Panel. Essentially the panel has recommended few structural changes in NIH. At no point has it directed its attention to the severe problems I have described regarding diabetes research -- the problems of a major disease area, the research into which is spread throughout many NIH Institutes. The panel has focused on more general policy matters. The panel has recommended that there be no further Institutes created and that, to the contrary, the existing 11 Institutes be consolidated in order to limit the span of management required of the Director of NIH. Consistent with this attempt to consolidate activities and strengthen the managerial capacity of the system, the panel has recommended a Presidential Biomedical Research Panel in lieu of the Cancer Panel and a new NIH Advisory Board to advise on matters of program balance and organization. Clearly, the focus of these recommendations is on maintenance of stability in the system.

The panel does direct itself to diabetes research on page 34 of the report, but only to reemphasize one of its major points: the need for NIH to focus on developing knowledge through research and not to become too involved in patient care.

The National Commission on Diabetes did just that; it urged NIH to concentrate on research. For example, it did not recommend an "NIH Diabetes Control Program." The Diabetes Centers programs which the Commission supported are not to be patient care centers. The American Diabetes Association also supports this same policy for NIH diabetes activities. In deciding against a separate Institute for Diabetes, the Commission cast its lot with improving the working of the present Institutes. For the moment the ADA also takes this position. But, we are very troubled by the failure of the NIH system to deal responsively with the management of research efforts for major diseases whose causes and effects are being researched throughout the various Institutes of NIH. We are likewise troubled by the failure of the President's Panel to deal with this matter, as evidenced by its brief discussion of the issue on page 34 of the report.

Research on major diseases done by many Institutes creates not only the problems of failure to coordinate research, but also the far more serious problems of 1) neglect in time of scarce resources, and 2) lack of accountability. Neglect because it is basic bureaucratic instinct to let someone else spend his Institute's money on diabetes, and lack of accountability because the diabetes effort is varied in at least seven or eight Institutes rather than being highly visible in one. This problem is not unique to us but common to management systems generally.

We believe that S.2910 poses an effective answer to the problem of managing diabetes research and is consistent with the general recommendations of the President's Panel. It does not call for a new Institute. S.2910 seeks simply to strengthen the present NIH system. The system is strengthened through the creation of a body to shed light on the activities of the many Institutes and agencies concerned with diabetes; to coordinate those activities; and to stimulate needed

innovations. It should also serve to bridge the gap between research and practice by assisting in the dissemination of new information and linking the programs of the NIH with the Center for Disease Control, the Diabetes Research and Training Centers, and the other elements of the long-range plan.

The Commission's proposal to create a National Diabetes Advisory Board came after careful study of all alternatives available to fulfill the mandate of Congress to organize national resources to combat diabetes. Why is the Board necessary from the standpoint of research? Because the present system does not meet the needs of diabetes. For example, the Commission's attempt to find out what diabetes-related extramural research was being carried out by each Institute were successful only after the Commission brought in a health economist as a consultant to work with the NIH Division of Research Grants. NIH was not able to provide an answer to an obvious need of the Commission.

Also, the current bureaucracy within the government is so large and so fragmented that the top officials are just not in a position to focus on the problems of interagency contact, let alone contact with nongovernmental participants. Because of this, there is no way that a group composed only of NIH, or Federal, representatives can look over the current research levels of all the Institutes, and make meaningful recommendations concerning promising areas that should be funded in a particular Institute. The National Institute of Allergy and Infectious Disease, for example, reported to the Commission last week that although they are very interested in research on chronic and degenerative diseases with possible viral implications, the Institute at the present time is not supporting any work on the viral etiology of diabetes. There is exciting new research on the possibility that viruses are a factor in triggering diabetes. The whole area is absolutely explosive right now. A National Diabetes Advisory Board with the operational authority specified in S.2910 would be in a position to call this

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lack of funding to the attention of the Institute and urge that they make every effort to invite grant applications on this area.

Very bluntly, the problems of diabetes are so enormous that a purely advisory board would not be in a position to see that the recommendations of the Commission, and the Congress, were being carried out. If we are to take advantage of the myriad research opportunities now available in the field of diabetes, we must be sure there is some oversight group with the authority to do more than advise -- a group with the authority to engage in and sponsor its own complementary activities, and with the responsibility to report annually to both the President and the Congress.

The two other sections of S.2910 are also vitally important to the success of the long-range plan.

The authorization for Distinguished Scientist Grants would fill a great void in the current status of diabetes researchers. A field of research that has appropriate financial support draws investigators into it. The converse is also true: a field that is not well supported -- and we all know that diabetes has not been well funded -- finds that after their initial training period the most promising investigators are transferring their talents to other areas because they cannot find the funds to support their research. This is a tragic waste of gifted physicians and scientists deeply involved in the problems of diabetes. The limited number of Distinguished Scientist Grants, to be given to those individuals who have demonstrated continuous and outstanding research productivity, would ensure that the diabetes research community would have a level of mature and highly experienced research investigators. The Commission's findings indicate that diabetes and its complications are this nation's third leading cause of death -- behind cardiovascular disease and cancer. And yet there are not enough funds presently available to keep investigators in this area.

The third section of S.2910 would amend the authorization for the Diabetes Research and Training Centers established in Public Law 93-354. Because of the length of time taken to establish the National Commission on Diabetes, the dates in the Law are no longer relevant. The Commission considers the Centers to be a microcosm of the entire long-range plan. Their research and training programs will eventually provide the skilled health professionals and new treatment techniques needed by all agencies and systems involved in diabetes health care. The Centers will also benefit from the other components of the long-range plan -- through new research, new information and educational programs, and a more coordinated approach to the problem of diabetes.

In conclusion, I would like to emphasize the care and attention the Commission paid to drawing up this long-range plan to combat diabetes. As many programs as possible were placed in existing agencies in a deliberate attempt to work within the present structure. S.2910 is necessary to the fulfillment of this plan, a coordinated attack which would represent all segments of the diabetes community.

The American Diabetes Association totally endorses this proposed legislation and respectfully urges the favorable action of this Subcommittee.

Senator SCHWEIKER. Please go ahead, Dr. Etzwiler.

Dr. ETZWILER. Senator Schweiker, I, too, would like to tell you that I appreciate all the efforts and leadership that you have provided in this area. And I, too, have prepared a statement which has been submitted to you, and I would like—

Senator SCHWEIKER. Without objection, it will be inserted at the conclusion of your testimony.

Dr. ETZWILER. Thank you. I am a practicing pediatrician at St. Louis Park Medical Center and director of the Diabetes Education Center. And I take care of, personally, close to 400 juvenile diabetics. I am also serving as president-elect of the American Diabetes Association, and have been one of the six nongovernmental physician-scientists of the National Commission.

The recent report of the President's Biomedical Research Panel very firmly approved the structure of the NIH and its efforts at the present time.

One area of concern, the panel's concern, was that there were frequent and substantial delays between the first medical application of the discovery and the widespread use by practicing physicians, to be followed only by delays in acceptance by the patient population.

One of the areas of need that we see in the area of diabetes is certainly the concept of developing a cure. It appeals to all of us. It would be very nice if every diabetic could go into a physician's office tomorrow and receive an injection of a substance similar to penicillin which would cure diabetes.

NIH is certainly coming up and looking for sure cures. The rarely discussed problem is how do we deliver that cure once it is obtained, or how do we pass on to the consumers of health care any improvements in treatment.

We have seen this very dramatically in the case of hypertension; where some 22 million people are thought to have hypertension, only half are detected, half are under treatment, and only half of those are appropriately treated when they essentially have the cure. That means about 1 person in 10 is really receiving the "cure" developed by investigation and medical research available today.

These are the problems that we see, again, in the national diabetes bill.

The very character of the bill when it was initially designed included seven representatives of heads of the NIH. And while this is important, to have that input, we did not have the input from the Health Resources Administration or Health Services Administration.

That has been corrected in the Commission's report, and it has also been adhered to in the National Diabetes Advisory Board Act. The other vital Federal agencies now have representation on the Board.

There are many parts of the Government which are not coordinated. The CDC program, the efforts that we mentioned in the Health Services and Health Resources Administration need to be brought together and coordinated along with those of NIH and other groups. That will be the responsibility of the National Advisory Board, to pull these groups together along with the private sector's efforts so that there are communications not just within the Federal Government but also from the consumers.

As was pointed out, the voluntary health agencies in this country need to have some input into national programs. They support research; they provide educational programs; and they represent the consumer.

One of the major areas of health care that we have been very concerned about is the role of the consumer. They are assuming advisory responsibilities on hospital boards and other medical policy.

We as health professionals need to know to work with them toward common goals. In the present legislation there is a significant part of the diabetes centers that include not just basic research, but also education of health professionals and training related to how to deliver treatment.

We repeatedly see problems where there is appropriate treatment but it is not able to be delivered at the present time.

The education of the patient and his involvement and participation in health care is a concept that must be brought before the medical profession at the present time, and appropriate needs and facilities to develop those concepts are included in S. 2910.

In summary, I appreciate your input into this bill. We see that basic research is important, but also research in the areas of education and treatment are equally important if we are going to conquer diabetes, the third leading cause of death by disease in this country.

Senator SCHWEIKER. Certainly, Dr. Etzwiler, we appreciate your leadership, too, as a member of the National Commission. I appreciate the constructive role that you play as a member of that Commission.

Dr. Cahill, do you think there is enough research capability in the country to absorb more money?

As you probably know, we have a package amendment that will go before my Appropriations Committee, which will substantially increase diabetes research across the board, regardless of whether this bill that we are dealing with here passes or not. And it is a significant increase from what we have been spending.

If we increase the funding of diabetes research substantially, will we have enough qualified researchers available for this capability or not?

Dr. CAHILL. I think with the funds, in reading your recommendation, yes; the answer is yes, at the moment.

We are also recommending, as you know only too well, the application of some of those funds for the developing of further manpower. So, if there be an incremental build-up, then the manpower can be satisfied where the funds will meet the incremental build-up of personnel.

The sums that you have recommended, the answer would be yes, they could be well used.

One thing I did not state, Senator, is that the past year—and this is really putting on the scientist's hat for just a few seconds—we have seen so many changes in our knowledge of the fundamental problem of the juvenile diabetic, the etiology, that now, today, it is a guess—but it is probably a very good guess—that it is any one of a number of common household viruses setting up shop inside the insulin-producing mechanism. And then the body may turn against both the virus and its own Beta cells making insulin.

This we did not even think of 2 years ago. But there is reasonable data to suggest that this may very well be true.

And this means that we have the foot in the door, literally, for the cure. And I am very optimistic here, that if ever there would be a time to pour funds in rapidly to expand all of the areas of diabetes, it couldn't be more favorable than to be today, literally.

Because I am willing to place a bet—and this is sticking my head way out—that juvenile diabetes may be a disease of the past. And this is what we are all here for, Senator.

Senator SCHWEIKER. Do you have any thoughts on what we might do in terms of health education relating to recent advances of diabetes knowledge?

Maybe Dr. Etzwiler wants to comment on this, too—what we ought to be thinking of doing or what we are not doing.

Dr. CAHILL. Well, we know today—again, this is also a spin-off of the past 2 or 3 years—it used to be anecdotal, more or less, that “Billy, the lower you bring your sugar down, the better you will be for a long life.”

And now, today, I think the facts are pretty solid to strongly suggest that the better the diabetic takes care of himself, the lesser blindness, the lesser kidney problems.

And the question, as Dr. Etzwiler knows better than anyone else in the world—

Senator SCHWEIKER. Let me say, before he does, that I spoke with Monell Chemical Senses Center in Philadelphia, at the University of Pennsylvania last night. And, of course, they have done a lot of research in the area of taste and sugar.

One of the more interesting products that they have come up with, strictly in an experimental form, is a new sugar that is made out of protein. And, to me, this protein sugar—and I believe it is a thousand times as sweet as sugar in the body—I think we will have tremendous, tremendous impact on our diabetic population if we can bring it to an economically viable option.

And it just shows, I think, the kind of unscratched surfaces we have if we can supply for that sweet taste or whatever it is the diabetic feels the need for chemically in this area.

That is a little unrelated, I know, to what you were saying, but I was impressed with the fact that we do have some protein sugars on the horizon. And I cannot but stand in awe of what potential this would have to our diabetic program.

Dr. Etzwiler, go ahead and respond.

Dr. ETZWILER. In terms of the education, as Dr. Cahill mentioned, there is evidence that the microangiopathy or small blood vessel disease that occurs in the young diabetic may be minimized or, hopefully, eliminated by long term control of this disease.

One of the problems that we frequently encountered in the National Commission public hearings were complaints or comments from the consumers of health care that they really did not know where they could find someone in their locale who was competent to work in the field of diabetes and provide them with expert care.

One professor of a school of pediatrics in this area said that he felt that there were probably only about 50 trained pediatricians in the country capable of really managing the juvenile diabetic. We are

talking about somewhere around 86,000 to 100,000 juvenile diabetics who are threatened by very, very severe complications, limited life expectancy—probably a mean life expectancy of 27 years after the onset of their disease. And the question is, “How do we get this information to the health professionals?”

In the Committee on Education of the National Commission they tried to solicit information from the various medical schools as to what portions of their curriculum was devoted to diabetes, they really could not come up with a figure. There was not a designed educational experience in this at many of the medical schools.

Dr. CAHILL. Senator Schweiker, I feel very strongly with the Bio-medical Panel, too, that this—what Dr. Etzwiler said—should not fall under the purview of the NIH. The NIH, as the Panel has recommended, should stay strictly in research.

And I agree, as a research scientist, this is their area. And this is another reason why the Advisory Board, with a much broader scope and problems, has to keep a continuing eye on diabetes and not place this in the purview of the NIH, because I hate to see the moneys going for what Dr. Etzwiler is talking about and being taken away from the basic research. In other words, “Robbing Peter to pay Paul” would be a poor thing to do for the long haul.

Senator SCHWEIKER. Well, I want to thank you very much, Dr. Cahill and Dr. Etzwiler, for your contributions to the Commission, your attention here today, and your overall help to this committee. Thank you very much, sirs.

[The prepared statement of Dr. Etzwiler follows:]



American
Diabetes

STATEMENT OF

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UNITED STATES SENATE

94th Congress

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Subject: S. 2910

May 11, 1976

Mr. Chairman and distinguished members of the Subcommittee:

I am Donnell Etzwiler, a pediatrician with the St. Louis Park Medical Center and Director of the Diabetes Education Center in Minneapolis. I am also Clinical Associate Professor in the Department of Pediatrics at the University of Minnesota School of Medicine, and I serve as President-Elect of the American Diabetes Association. I was one of six nongovernment physician-scientist members of the National Commission on Diabetes, and I appreciate the opportunity to appear before you today.

Almost ten million Americans have diabetes. Diabetes and its associated complications are considered the third leading cause of death in the United States. It is estimated that diabetes costs this nation over \$5.2 billion per year and its impact upon the citizens in terms of emotional stress and premature loss of friends and relatives is impossible to measure.

The Congress of the United States and the President recognized the seriousness of this disease when in 1974 they passed the National Diabetes Act. This Act established a National Commission on Diabetes to survey the nation's needs and report their recommendations to Congress. I can assure you the National Commission worked very hard in the limited period of time available. Public hearings were held throughout the country and over 300 national and international consultants participated in numerous workshops and conferences.

You are now being asked to take action upon the recommendations of that Commission which you, the members of Congress, previously approved and funded to provide you with expertise in the field of diabetes. If indeed the Congress and the Administration were sincere in their concern for diabetes in 1974 when they established the Commission, then it is imperative that they take action upon the recommendations being brought before Congress at this time. We ask that this not be done blindly or as an isolated action, ignoring other national issues, but that the recommendations of the Commission be seriously considered and diabetes recognized as a major national health problem whose magnitude has been verified by the National Commission after

thoughtful, honest and scientific evaluation of the country's needs and resources.

A major effort to conquer this disease cannot realistically be put into motion overnight. The Commission has designed a modest but realistic stepwise approach to mobilizing a national effort which will benefit ten million of this country's citizenry.

The National Commission identified that in the fiscal year 1975 approximately \$45,703,000 was being expended on research in the area of diabetes. This means that while the nation is spending \$5.2 billion to care for its 10 million diabetics, less than \$4.50 per patient per year is being spent to find a solution to the problem. To put it more succinctly, about one out of every thousand dollars is being directed toward funding and delivering a cure for the disease.

The need for increasing support in those areas of research have already been attested to by others before this Senate Subcommittee. The largest source of that funding in the past has come through the federal government who, in turn, derives its funding from the citizenry. There are other important sources of funding for diabetes, such as private industry and voluntary health agencies. The major research efforts are funded through the National Institutes of Health, but much of this work is carried out in numerous universities and private investigational programs throughout the entire United States.

Diabetes is a very complex disease entity which affects and is affected by many facets of our society -- health professionals, patients, families, friends, voluntary health agencies, private foundations and institutions as well as numerous branches of the federal government. All of these groups are concerned with discovering a cure and making it available to everyone who manifests the disease. The magnitude of the problems of diabetes is so vast that it cannot be carried out by the private sector or the governmental sector alone. This indeed must be a combined and cooperative effort and should be identified and treated as such.

The National Commission has attempted to bridge these gaps between the "Feds", the citizenry, national voluntary health agencies, private foundations, etc., by the establishment of a National Diabetes Advisory Board. The lack of communications and joint efforts among the various branches of the federal government has astounded those of us on the National Commission and embarrassingly reflects the lack seen in similar areas in the private sector. The immense gap and sometimes suspicion which exists between those who represent the federal government and those who don't is real. I've been impressed by sincere concern expressed over the matter by nongovernmental persons and governmental employees. In today's society, where big government does exist, fears and problems arise because of a lack of communications, a lack of sharing ideas, and misunderstanding of concepts. Citizens frequently feel they are not represented, communications are frequently poor and this leads to dissatisfaction. In our country in the last 40 years we have seen a significant rise in consumerism where people want to express their concerns and have their input recognized not just in local and big business enterprises but also in local and national governmental actions. Rejection of the concept of authoritarianism pervades our news media at the present time.

In the field of diabetes nonfederal people are concerned about what kinds of activities are going on in the field of diabetes, what kind of programs are being supported and carried out, and whether they meet the needs. In the early 1940's scientists interested in diabetes banded together to form the American Diabetes Association so they might exchange scientific information and knowledge. In the early 1960's these scientists recognized the need for cooperative programs with the nation's diabetics themselves and other interested citizens, and so the American Diabetes Association became a voluntary health agency. This consortium has grown and the increased interest and activities of the American Diabetes Association and other voluntary health agencies has been notable. This has indeed been a healthy

relationship between the health professionals and the consumers of health. Communications have been enhanced and understanding and management of the disease improved. Support for research has been increased by the efforts of those who would benefit most from a cure.

The National Commission on Diabetes recognized the need for such a pooling of all the essential resources in this country to meet the challenge of diabetes. Accordingly the National Diabetes Advisory Board was recommended. The National Advisory Board brings together representatives from the various branches of the federal government, representatives of the scientific and academic world, voluntary health agencies, and "consumer" representation. While this would be supported Federally the financial expenditure is minimal and would add few people to the federal government. It would increased the overall efforts in the field of diabetes by pooling and uniting efforts. There is little need or excuse for duplicating thousands of dollars of research because of lack of coordination and communications. We are not asking for another federal governing board. We are asking for opportunities for consumers and nonfederal people to work together with the employees of the United States government in a common effort which would promote understanding and efficient cooperation among all groups interested in diabetes. The representation of the advisory board has been identified to fulfill those concepts and I urge acceptance and understanding of this concept and implementation of this legislation.

The Commission has recommended two programs of the utmost importance, initially to be under the purview of the National Diabetes Advisory Board; an examination of these programs clearly illustrates the need for a coordinating body.

The Commission believes that the cornerstone of good treatment practice is the acceptance by all members of the health care team that patient education is treatment. While other parts of the Commission's recommendations address education programs on a very small scale, mainly in reference to evaluation studies and the teaching

of the health care professional, it was obvious that a comprehensive program addressed to a variety of federal and nonfederal organizations had to be established to reach the majority of the diabetes community.

We therefore recommend the establishment of a National Diabetes Information and Education Clearinghouse to meet the essential need of a central resource for patient, professional and public educational materials and information. The Clearinghouse's functions would include the identification and collection of informational and educational materials available on diabetes and an assessment of their effectiveness; the development of vehicles for disseminating information and effective materials and their sources in cooperation with the Center for Disease Control, the Diabetes Research and Training Centers, and nonfederal organizations; the recommendation to federal and nonfederal organizations, publishers, pharmaceutical companies, etc., that needed materials be developed; the promotion of improved standards of diabetes education and care through such vehicles as Professional Standards Review Organizations, Certification Boards, Continuing Medical Education, and third party reimbursement guidelines; and the evaluation of the effectiveness of the Clearinghouse programs.

The Clearinghouse would work closely with the National Diabetes Advisory Board to promote the rapid flow of research data to the Clearinghouse from the Diabetes Research Training Centers, NIH, and the Center for Disease Control, thereby accelerating the immediate translation of research data into education materials for health professionals. The Clearinghouse would also be in a position to respond immediately to the communication needs of the National Diabetes Advisory Board and the diabetes community.

The Commission also strongly recommends the establishment of a National Diabetes Data Group, supported by Federal funds, to foster the collection from multiple sources, the analyses, and the dissemination of diabetes data related to public health policy. There is a significant need for a systematic approach for a data base

to support a public health policy for diabetes; the public health impact of diabetes mellitus has not been generally known because of the inadequate definition of the disease and its measurement, the resultant underreporting of its incidence and prevalence, and the failure of mortality statistics to recognize diabetes as a cause of death due to complications in mortality statistics. The Data Group would be composed of representatives of appropriate federal agencies, such as the National Center for Health Statistics, the National Institute of Arthritis, Metabolism, and Digestive Diseases, the Center for Disease Control, the Social Security Administration, and representatives from nonfederal organizations such as voluntary health agencies and diabetes service agencies.

The President's Biomedical Research Panel recently criticized the Office of Management and Budget for making too many science policy decisions without strong scientific guidance. The Panel also noted there were frequent and substantial delays between the first medical application of a discovery and the widespread use by practicing physicians to be followed only by delays in acceptance by the patient population.

The National Diabetes Advisory Board, and its adjunct groups -- the Clearinghouse and the Data Group -- could and should be highly influential in minimizing and eliminating these problems between agencies, institutions and people.

The second portion of the National Diabetes Advisory Board Act deals with the establishment of Distinguished Scientist Grants, and previous testimony on this has indicated the importance of this support for senior investigators.

The final portion of the National Diabetes Advisory Board Act deals with funds for Diabetes Research and Training Centers. Congress recognized the concept and validity of such Centers in passing its National Diabetes Act of 1974; in accord with the Act, the National Commission has recommended a plan for the establishment of these Centers. In the Commission's report details of the Centers, their goals,

objectives, and responsibilities are outlined. However, the dates of the authorizing section have to be amended because of the length of time involved in its passage. The Commission agreed with Congress concerning the initial amounts of funding that should be provided, and has asked only that these monies be extended for an additional two years at the same third-year level.

These Centers would not only carry out basic laboratory research, but would strike at other deficits in our present system. The Centers would also be concerned with research into the delivery of treatment and the education of health professionals and patients intent upon the prevention, management and control of this disease. The importance of research for a cure has already been described and is indeed valid. Even after a cure is discovered, however, its use and effectiveness must be longitudinally evaluated. The treatment for those with diabetes will continue to be a vital part of our health care system for generations to come.

There is new significant evidence that proper management of diabetes can result in the minimization and hopefully elimination of many of the serious long-term problems associated with the disease. Within the past three months in both the Journal DIABETES and The New England Journal of Medicine there were papers concerning the importance of proper treatment of diabetes and its effect on long-term control. Despite the availability of many effective medicines and therapeutic regimens, most of the ten million diabetics in this country are not receiving optimal care. The mean life expectancy of the child with diabetes is still less than 30 years and many of the 300,000 deaths from diabetes and its complications each year are unnecessary and premature.

The activities of the Advisory Board components would concern themselves with patient education. The role of the patient who is participating in the management of a chronic disease is obvious in diabetes. About 98% of the care is actually carried out by the patients themselves under the supervision of health professionals.

The day to day administration of insulin, the monitoring of diet and exercise, urine testing etc., are all patient responsibilities and failure of compliance with recommended regimens undoubtedly is a major contributor to inappropriate care and the development of chronic complications. This means that new methods of teaching, educating and training patients to take an active participation in their program is imperative. It is necessary that we initiate and encourage the concept of patient participation and that qualified members of the health care team be able to accept the responsibility for training and development of a communications and support system.

The Diabetes Research and Training Centers are in no sense intended to be a means of providing massive health care delivery systems for the diabetic population in America, either in the immediate or remote future. But the Centers will, in conjunction with the activities of the rest of the components of the Commission's recommendations, translate advances in research into excellent continuing care. We were indeed impressed in the hearings of the National Commission by patients stating that while their hope for a cure was great, it was important that emphasis be given to providing the best possible care for those who already suffer from diabetes.

The reason for some of the current therapeutic failures include a lack of understanding of the nature of the disease and its treatment among patients and health professionals alike; the inability of patients and health professional to develop and carry out effective treatment programs; lack of availability and accessibility of diabetes education and treatment services for large segments of our population; failure to provide health professionals with effective training in the delivery of health services, and a significant lack of appreciation, resources, and support necessary for conducting clinical and evaluative research in the health care delivery system. It is clearly evident at the present time that effective

health care for those with diabetes can be achieved only by informed patients cooperating with knowledgeable and interested health professionals in an organized plan of treatment.

One professor of pediatrics testified before the Commission "...only a handful of pediatricians have the training to care for children with diabetes. As a result children who need and deserve the best care and management to safeguard normal growth, development and maturation...in fact are getting the worse medical care." The lack of knowledge of health professionals in the field of diabetes was verified and it was reported that existing advances in research and knowledge generated by our medical schools simply are not reaching those who are caring for the patient. The professional education activities of the Clearinghouse, along with the Centers' program to generate the most competent professional personnel both for research in diabetes and for management of the diabetic, can do much to make that quotation obsolete.

Health care needs in the United States are changing rapidly and new diagnostic procedures and therapeutic agents are being discovered almost daily. It would be expected that the system to delivery these services would also change rapidly. Unfortunately this has not been true and health care in this nation is still delivered in an antiquated method which is episodic in nature and responsible primarily to the acute needs of patients. We are currently concerned about the quality, quantity, and cost of such health care. However, very few efforts have been made to plan the delivery of health care. Investigation into modes and systems are virtually absent. Planned delivery of care does require the development of health care teams and systems which function with knowledgeable leadership. Planning, training, and investigation into these areas are indeed rare and efforts to significantly meld together the health care team consisting of health professionals and consumers are minimal. The National Commission on Diabetes has presented an organized program,

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carefully constructed to overcome the lack of coordination of research and health care delivery apparent in our system today.

In summary I can state that the National Diabetes Advisory Board Act, as suggested by the National Commission on Diabetes, came after extensive investigation, deliberation and consultation with leading authorities in the health and consumer populations. It attempts to bring together federal and nonfederal health professionals and scientists and integrates them with the consumer population of the United States and voluntary health agencies, thus developing a national comprehensive long range plan for diabetes as requested by the Congress.

The need for Distinguished Scientist Grants is apparent. The importance of establishing and supporting national Diabetes Research and Training Centers, not only for basic research in diabetes, but also research into the delivery of effective care to patients and training of health professionals, is a valid concept which I would implore you to understand, accept and support. The coordination of a national comprehensive long range plan for diabetes under the National Diabetes Advisory Board Act is essential for the Commission's recommendations.

Thank you.

Senator SCHWEIKER. We will now call our last panel. We will call Mrs. Lee Ducat, national president of the Juvenile Diabetes Foundation; its president-elect, Mrs. Carol Lurie, Juvenile Diabetes Foundation, and Dina Merrill Robertson, who is going to also testify on behalf of the diabetes constituency.

I want to say to Mrs. Ducat that she was one of those who educated me in the constituent-senatorial relationship about what was not being done for diabetics. I know that she came into the picture with her own experience, feeling that the status quo was totally inadequate and unresponsive, both in the diabetic constituency and in government.

She certainly convinced me that the government was unresponsive. I would like to give her a lot of credit for stimulating the kind of work that legislators probably should be doing in this area, and for educating me about what was not being done.

So we have found out a lot about diabetes and diabetics, and you can certainly take some of the credit for that educational process.

STATEMENT OF LEATRICE DUCAT, NATIONAL PRESIDENT, JUVENILE DIABETES FOUNDATION, ACCOMPANIED BY CAROLINE S. LURIE, PRESIDENT-ELECT, JUVENILE DIABETES FOUNDATION AND DINA MERRILL ROBERTSON, PARENT OF A JUVENILE DIABETIC

Mrs. DUCAT. Thank you, Senator Schweiker.

And, of course, I appreciate what you have said to me and I guess I could say double to you, because we are tremendously grateful for everything that you have done for us and for the diabetics that we represent. Maybe "eternally grateful" is saying too much, but tremendously grateful for your understanding of the disease. So thank you.

Mr. Chairman, I am Lee Ducat, and I am national president of the Juvenile Diabetes Foundation. And as you know, we are a national voluntary health organization, just ready to celebrate its third birthday.

And I am here with the president-elect, who is Carol Lurie, and a member of our board of directors, Dina Merrill Robertson, who is here to testify here today, too.

We appear here on behalf of the board and directors and members of the 70 chapters of the Juvenile Diabetes Foundation, representing 200,000 diabetics and their families in 40 States.

And I have prepared a statement, which I would like to submit for the record, but I just would like to skim through it for you today, Senator Schweiker.

Senator SCHWEIKER. It will be received without objection.

Mrs. DUCAT. Two years ago I testified to this very committee, urging the adoption of the diabetes legislation introduced by you, Senator Schweiker, and Senator McGee.

My testimony at that time 2 years ago included a description of the tremendous problems faced daily by the diabetic dependent on an alcohol swab, an insulin bottle, and a syringe for life.

I discussed the bleak forecast of a shortened life expectancy and a grabbag of many dreadful complications. I noted the tremendously accelerating incidence of diabetes in our population.

We are very grateful to you, Senator Schweiker, as I said, for the enactment of the original diabetes legislation in 1974 which established the National Diabetes Commission to investigate the problems that diabetes creates and to formulate a plan to combat these problems.

Now, for the first time in history, we are able to document the staggering statistics and dimensions of the diabetes problem. And we have already gone through some of those statistics.

We believe the Commission report fulfills the intention of Congress, as set forth in the Diabetes Act. And we commend the Congress for the enactment of the legislation which established the Commission and we commend the Commission for a superb job done in a relatively short period of time. Congress can feel justly proud of the Commission report and its recommendations.

And I am happy to say that I was a member of that Commission.

The first step in the battle to combat diabetes was taken with the passage of Public Law 93-354 in 1974. The next step forward was the completion and submission of the Commission report to Congress in December 1975.

In May 1976, we are here to urge you to take the next step, the third step, the giant step on the road to defeat diabetes. The next step must bridge the gap from carefully-drawn plan to actual implementation of the elements of the long-range plan.

Diabetes is a unique disease and, therefore, requires a unique plan. Diabetes is unique in that it affects the whole body and all body systems. Diabetes is unique in that it is a long-term chronic ailment which must be managed for a lifetime by a team, including the patient, his family, his physician, and the whole community.

Diabetes is unique in that it is dramatically accelerating in incidence. There is no preventative. There is no cure. There are no measures, as yet, to stop the tide of the incidence of diabetes and its complications.

We who are parents of diabetics must live and think in the short range. The long range plan, a 5-year plan may be too long for some of us. There is already a lag period of one year built into the plan because its design included fiscal 1976.

Fiscal 1976 has come and gone. The Congress has completed its fiscal 1977 recommendations, and even if the diabetes legislation were passed today, there is a built-in lag period of 1 year which will need adjusting.

Therefore, we recommend the establishment of the Diabetes Advisory Board in the position of authority, so that it can begin to advise the agencies of HEW, NIH, start to move the 5-year plan, make the adjustments necessary to a plan already hampered by a 1-year delay.

The short range step of the long range plan is the immediate enactment of bill S. 2910 and the establishment of the Diabetes Advisory Board.

We support the section entitled "Distinguished Scientist Award." This part of the legislation is an attempt to focus on a serious problem of catchup. Research expansion must depend on the expansion of research manpower. Without competent researchers, you cannot have quality research.

The Distinguished Scientist Award would help the recruitment of researchers to a long neglected and undernourished field. The need

to develop research manpower is great. The Distinguished Scientist Award is a barebones beginning and, in that context, we support the authorization for fiscal support to men of proven ability and accomplishment in diabetes research.

We support and urge the authorization of the diabetes research and training centers. This section is an extension of the authorization of Public Law 93-354. The centering of diabetes research in universities and academically based institutions where multidisciplinary cross-fertilization of research can take place must be encouraged by funding to institutions of excellence in order to establish centers of specialization in diabetes research and training of health professionals.

We have evidence already of centers of diabetes research excellence emerging, nurtured by seed grants from our own foundation. The centers proposed by the diabetes legislation will function as core areas for research initiation and development, multidisciplinary conferences, demonstration of proper treatment, and development of research into better methods of treatment.

It is important to note, however, that the Diabetes Center program was authorized in 1974; the congressional appropriations committee has already acted for fiscal year 1977 to fulfill the authorization made in 1974.

We are grateful for the appropriation of funds for centers in fiscal year 1977, but we want to underscore that the delay from authorization to fiscal appropriation is a total of 3 years.

We support the section of the Diabetes Advisory Board bill which extends the authorization of the diabetes centers to year 1981, and we urge immediate action on fiscal support for those centers authorized in Public Law 93-354.

We enthusiastically support the establishment of diabetes centers as a necessary step toward stimulation and expansion of the diabetes research effort.

Mr. Chairman, distinguished members of the committee, in dealing with the disease, the proportions of which are approaching the crisis level, we are faced with an administration which insists that in vital matters of health, research and training must be curtailed.

We, the people living daily with the problems of diabetes, look to you, the Congress, for leadership.

Parents of the Juvenile Diabetes Foundation are people in a hurry. It doesn't seem so very long ago that I testified to this committee on the Diabetes Act of 1974. But 2 years have passed.

Two years ago, David, of Allentown, Pa., was what we called "a normal diabetic." Two years later, David is legally blind. Little, blond Andrew, of Philadelphia, was 3 years old when the Diabetes Act of 1974 was passed. He is now 5, in kindergarten, and has been injected 1,530 times since the bill was passed.

Don, who lives in Detroit, 2 years ago was in his third year of medical school. Today, he is in his first year of pediatric residency, and he has discovered development of a severe case of diabetic retinopathy at age 23. Jody, from Philadelphia, was 16 years old and a normal diabetic 2 years ago. Today, she would have been 18 years old. She is dead of cardiovascular degeneration.

Who of the tens of thousands of blond and black children injected each day by their parents will suffer dreadful incapacity and short-

ened life because of our lack of attention and support in the spring of 1976.

Nineteen hundred seventy-six—our Bicentennial Year—must be the year we have another revolution. A diabetes revolution, hopefully. There is no other choice than to support this revolution, or we will suffer the consequences of the lag, delay and inability to catch up from a 50-year “Rip-VanWinkle” sleep.

Our goals must be to secure a truly coordinated diabetes program across all the institutes of NIH and all the other agencies of Government involved in education, treatment, training and research.

Our goals must be to pass the Diabetes Advisory Board legislation in a hurry, to take that third giant step, the implementation of the long range plan to construct an accelerated program to find the cause, methods to arrest the complications, preventatives and, someday we pray, a cure for diabetes.

On behalf of the Juvenile Diabetes Foundation, all of our children, and parents, and young people with diabetes, I would like to say how grateful we are to have this opportunity to share our deepest feelings with you today.

And Carol Lurie will continue our testimony, specifically on the Diabetes Advisory Board section of the act.

Senator SCHWEIKER. All right. Thank you very much, Lee. It was a very eloquent and very meaningful presentation. I think the committee will certainly take it seriously.

Mrs. LURIE. Mr. Chairman and distinguished members of this committee my name is Caroline Lurie, and I speak to you as president-elect of the Juvenile Diabetes Foundation and as a parent of a 19-year-old son who has had diabetes for almost 10 years.

I appear here today as a representative of a very determined and vital organization that will never be deterred from their original and binding goal: the prevention and cure of diabetes and its devastating complications.

This is truly a day of firsts. It is the first time I have ever had the honor to testify before a Senate committee and if I appear nervous it is because I truly am.

It is the first hearings on behalf of Senate bill 2910, the Diabetes Advisory Board bill. But above all, it is the first time a projected new attack on an old disease is coming to fruition through innovative measures.

The immensity of our problem is staggering. Thanks to the leadership of you, Senator Schweiker, and others like Senator Harrison Williams and Senator Gale McGee, and so many who have listened so intently, the seeds have finally been planted for a full scale attack on diabetes, and we are now on the brink of a truly escalating program.

Within the proposals of the National Diabetes Advisory Board bill lay the foundation of a constructive support system for diabetes research and treatment.

The National Diabetes Commission, which was created by and has recently reported to Congress, has documented for us the magnitude and complexity of this disease, but diabetes has yet to receive recognition as a major public health problem. We have been living for too long with inadequate data, inadequate treatment, inadequate research

and grossly inadequate funding in all areas related to work on this problem.

S. 2910 presents for the first time the need for broadening the base of research, education and treatment of the diabetic. The cure for diabetes requires the input of all NIH facilities, monitoring and analyzing efforts of the Center for Disease Control, the establishment of a national diabetes information and education clearinghouse, and a national diabetes data group.

Since these efforts must involve the full resources of the Federal Government, and not merely those of NIH, we agree completely with the National Commission on Diabetes that the Advisory Board called for in Senate bill 2910, should be organizationally located in the Office of the Assistant Secretary for Health, HEW.

The Juvenile Diabetes Foundation sincerely believes in and supports the establishment of the National Diabetes Advisory Board as a coordinating and advising body, and as a strong link of communication.

Through this board, the left hand will finally know what the right hand is doing, and the board will act as a highly effective helping agent for all of the bodies that must be part of a coordinated attack on this disease.

And I think it is important to remember here that specified within the bill itself is a 5-year limitation on the life of the National Diabetes Advisory Board. This coincides with the National Commission on Diabetes' 5-year plan. Hopefully, the Diabetes Advisory Board will have outlived its usefulness by the end of its 5-year term.

Diabetes crosses the lines of demarcation between the various National Institutes of Health. There is also the immense job of monitoring the progress of services rendered to diabetics, the education of them, their families and their physicians.

In addition, there is an important function of advising with respect to the implementation of the long-range plan to combat diabetes, as spelled out by the National Commission for Diabetes.

The mechanism for this has been created in S. 2910, and is called the National Diabetes Advisory Board.

Not only will the board oversee the blueprint established by the National Commission, but through its review and evaluation it will be able to bring together and annually present to the Congress a comprehensive picture of the progress of all of Government's efforts in the battle against this national health problem.

The Juvenile Diabetes Foundation sees the terrifying and desperate need to bring together the many specialized scientific disciplines in the health field, and to coordinate the many fragmented research and scientific endeavors into a broader collaborative plan of attack under the vital mechanism of the National Diabetes Advisory Board.

The composition of this board, as outlined in S. 2910, attempts to create the broad approach necessary for an all-encompassing diabetes program. However, there is a dire need for congressional implementation. And I believe that it requires your direct participation.

The Juvenile Diabetes Foundation therefore strongly recommends that the National Diabetes Advisory Board be enlarged to include two Members from the Senate, two Members from the House of Repre-

sentatives, with equal representation from both political parties. Direct congressional representation will not only increase the prestige of the program, but will materially benefit the national diabetes program by the advice and counsel of the distinguished Members from the Congress.

One additional recommendation of the Juvenile Diabetes Foundation is that the composition of the National Diabetes Advisory Board be amended to include two parents of diabetic children rather than only one, as now specified in S. 2910.

Our experience with the National Commission on Diabetes, which included two parents in its makeup, has convinced us of the absolute need for this amendment to S. 2910. And we strongly urge its adoption.

Senator Schweiker, we who are involved daily with the lives of the juvenile diabetic live with this disease not knowing any of the time answers. The diabetic is treated by methods that have no definitive solutions. We are given information and treatment that conflict in methodology and advice. Their futures are frighteningly uncertain, and we live with that every day.

The time for further congressional action is now at hand. And we have come this far in a long and hard fight, and we greatly appreciate all the efforts of every Member of Congress, but we have only taken the first step.

There is a young man 27 years old from our Detroit chapter who had a kidney transplant and is having great difficulty at this moment, or he would have been with us here in Washington today. He wrote to me last Friday that he had read his fortune in a Chinese fortune cookie, and it said, "He who has hope, has everything."

Distinguished members of this committee, fulfillment of our hopes now lie in your hands, and only through the passage of Senate bill 2910, the National Diabetes Advisory Board Act, can that hope be taken one step further.

On behalf of the Juvenile Diabetes Foundation and our tens of thousands of members, I thank you.

Mrs. DUCAT. Thank you, Carol.

And now we would like the presentation of Dina Merrill Robertson, who also is a parent of a diabetic.

Mrs. ROBERTSON. Senator Schweiker and distinguished members of the committee, I am Dina Merrill Robertson and I thank you sincerely for the opportunity to share my thoughts with you on this very exciting and important day.

Exciting and important because when, just over a year ago on April 23, 1975, I had the privilege of testifying before the National Commission on Diabetes. It would have been labeled a "mother's fantasy" to seriously believe then that some 13 months later I would be back before a prestigious and powerful committee of the U.S. Senate, seeking to implement the beginnings of a dream I have long shared with the entire diabetic community.

In this year of our Nation's Bicentennial celebration, pride in its achievements is an integral part of almost every American who understands the greatness of our country and who allow that problems, however serious, are an integral part of history.

Your responsiveness to the Commission's superb work, reflecting the problems and needs of millions of diabetic Americans, is for all of

us yet another proud moment in the best tradition of the men and women who we, as citizens, elect and expect to serve us.

I cannot thank you enough for listening, understanding and acting in such a prompt and positive manner.

As many of you know, the diabetes problem was suddenly and dramatically thrust upon my family some 11 years ago when my son David, age 14, became a juvenile diabetic. David died in an accident three summers ago, but in the 10 years that he and we fought diabetes—grappling each day with the strictures, the uncertainties, the fears for his future, and the emotional chaos and hurt caused by this complex and destructive disease—I became ever more determined that I would do all in my power to help hasten the day in which medical science will understand the cause, alleviate the terrible complications and ultimately find the cure for diabetes.

Today, we move one step closer to the fulfillment of that dream. I know that had David lived, he would have wanted to be here with me to share the warm sense of accomplishment and hope we now feel.

My efforts, through these many years, have been spread amongst all of the many fine institutions and organizations working in the field of diabetes. I am here today, however, as a member of the board of directors of the Juvenile Diabetes Foundation, a very unique agency, founded a few short years ago by Lee Ducat and a handful of other parents of diabetic children.

I have little doubt that the growth, impact and relentless determination of the JDF is known to each of you, and that you will agree with me that through its efforts, an accelerated momentum is underway toward the realization of a major national effort to overcome a catastrophic health disaster, draining the manpower and economic resources of this great country.

Thus, my purpose here is to lend my strongest support to the legislation pending before this committee and to urge the enactment of S. 2910—with the amendments proposed and supported by the Juvenile Diabetes Foundation—at the soonest possible moment. I am deeply aware of the time, consideration and effort put forth by Senator Schweiker, other members of the committee and their respective staffs in discussing, studying and drafting this constructive and urgently needed legislation.

Failure to assure its passage into law would be a severe and tragic setback to the threshold of progress on which we are standing at this moment.

As a Nation, we cannot now afford that setback and, as the most concerned citizens affected by the problem, our combined and unanimous voices are represented here to command your actions—to help your colleagues recognize the wisdom of what has been proposed and to urge their support, in response to the need and the will of more than 10 million Americans—sizable numbers of whom are amongst their own respective constituents.

To each of you here who has been so responsive in the giving of your precious time and your invaluable help, my personal appreciation and that of the vast diabetic community is boundless. You will not be forgotten by us—and, again, I thank you.

Senator SCHWEIKER. I want to say, Mrs. Robertson, we know you have been active in a number of different diabetes activities, fundrais-

ing as well as leadership. And we certainly appreciate taking the time from your schedule today to help us dramatize the need and the urgency of this very important problem.

So, we greatly appreciate you being here today and participating on the panel.

Mrs. ROBERTSON. Thank you, Senator.

And may I also say that I am delighted to be here with all the various members of the diabetic community, with the ADA, with Don Etzwiler—of whose Youth on Diabetes Committee I am a very proud member—of George Cahill. I am a member of the board of directors of the Joslin Research Laboratory, and a member of the board of the Juvenile Diabetes Foundation.

And I am particularly happy that we are all here together to speak with one voice from the community of diabetics to support what you are doing and to urge your help on all our efforts.

Senator SCHWEIKER. Thank you.

Lee, I would like to ask if you could tell us a little bit about the activities of your group and also the membership of your foundation. I think it would help the record if you would just elaborate on a little bit of that.

Mrs. DUCAT. Well, we have many activities geared mostly to support of the diabetic, the young diabetic and the family situation, the parents of the diabetic. We have a membership of just about 98.5 percent volunteers across the country.

And our activities, besides supporting the diabetic, are mostly aimed at being a catalyst to the research community and trying to raise funds for diabetes research which, as you know, has been on the bottom of the list, you know, for years.

So we found that that was going to be our most important job. And that has been one of our key activities.

In fact, we are very proud, in the latest National Information Bureau survey which has just been published, to have been named as the top voluntary health organization in amount of funds, amount of total funds given to research. And our latest annual report notes 88 percent of our total funds collected go directly into diabetes research projects.

Senator SCHWEIKER. Eighty-eight percent go into research?

Mrs. DUCAT. Right.

And we are hoping in June, on our third birthday, to raise over \$1 million for diabetes research projects.

Senator SCHWEIKER. Maybe just one other question would be of interest.

I know that you were the founder of the Juvenile Diabetes Foundation. How did it start?

Mrs. DUCAT. Well, I guess it started out in desperation and frustration.

A young mother, at the time, of a diabetic son who had no one to turn to. And I know all of us have experienced the same problem—there was no one to turn to for help, besides our practicing physician. Even at that, we didn't know whether we had the right physician or not for our children.

So, we desperately came together, trying to find other parents of diabetics to ask questions, for support, for hope. And that was really

the beginning, Senator Schweiker, a realizing that the services were not available for us as parents of diabetics and for our kids, who would have to make it for a very long time on their own with a chronic illness.

And, of course, now you know we have 70 chapters across the United States and in Canada, and there are other organizations like ours developing all over the world. And we kind of like to think maybe it is because what we started here in the United States.

Senator SCHWEIKER. If the space does not become a problem, we would be glad to include the annual report of your group into the record.

Mrs. DUCAT. Well thank you, Senator. I appreciate that.

Senator SCHWEIKER. And we will extend, of course, the same opportunity to the ADA also, so that we can get an across-the-board view of just exactly what the health constituencies of diabetes are doing.

[The prepared statements of Mrs. Ducat, Mrs. Lurie, and Mrs. Robertson follow:]

PREPARED STATEMENT OF LEATRICE DUCAT, NATIONAL PRESIDENT, JUVENILE DIABETES FOUNDATION

Mr. Chairman, distinguished members of the Committee. I am Lee Ducat, National President of the Juvenile Diabetes Foundation. J.D.F. is a National Voluntary Health Organization, just ready to celebrate its third birthday, dedicated to furthering education and research in the field of Diabetes. I would like to introduce to you our President-Elect Carol Lurie who will give specific testimony relating to the Diabetes Advisory Board proposal of the Diabetes Advisory Board Act. Carol and I appear today on behalf of the Board of Directors and members of the 70 chapters of the Juvenile Diabetes Foundation, representing 200,000 Diabetics and their families in 40 states.

Two years ago I testified to this Committee urging the adoption of the Diabetes Legislation introduced by Senator Schweiker and Senator McGee which became Public Law 93-354. My testimony included a description of the tremendous problems faced daily by the Diabetic dependent on an alcohol swab, an insulin bottle and a syringe for life. I discussed the bleak forecast of a shortened life expectancy and a grab bag of many dreadful complications. I noted the tremendously accelerating incidence of Diabetes in our population. We are grateful to the Congress for the enactment of the National Diabetes Mellitus Research and Education Act of 1974 which established the National Diabetes Commission to investigate the problems of Diabetes and to formulate a plan to combat those problems. The Commission report documents outstandingly the state of the arts as regards Diabetes' scope, impact, education, treatment and research.

Now, for the first time in history we are able to document the staggering dimensions of the Diabetes problem. Among other things, the Commission Report documents the following facts:

- * 10 Million Americans have Diabetes
- * There are 600,000 new cases a year, about 2,000 new cases each day
- * Diabetes is the leading cause of blindness, heart disease, kidney disease and gangrene
- * Diabetes is the 3rd leading cause of death in the United States, with some 300,000 deaths attributed to it
- * Diabetes is accelerating in incidence in the Black population

- * Diabetes is accelerating in incidence in the female population
- * Diabetes affects all stratas of our population equally, knowing no racial, ethnic, class or geographic barriers.

We believe the Commission Report fulfills the intention of Congress as set forth in the National Diabetes Mellitus Research and Education Act. We commend the Congress for the enactment of the legislation which established the Commission and we commend the Commission for a superb job, done in a relatively short period of time. Congress can feel justly proud of the Commission Report and its recommendations. I am happy to say that I am a member of that Commission.

The first step in the battle to combat Diabetes was taken with the passage of P.L. 93-354 in 1974. The next step forward was the completion and submission of the Commission Report to Congress in December, 1975. In May of 1976 we are here to urge you to take the next step, the 3rd step, the Giant step on the road to defeat Diabetes. The next step must bridge the gap from carefully drawn plan, to actual implementation of the elements of the Long Range Plan.

Diabetes is a unique disease and therefore requires a unique plan. The long range plan to combat Diabetes developed by the National Commission is a masterful design involving government participation spanning the executive branch. Diabetes is unique in that it affects all body systems. Therefore commission research recommendations span most of the institutes of NIH and VA and other agencies. Diabetes is unique in that it is a long term chronic ailment which must be managed for a lifetime by a team, including the patient, his family, his physician and the whole community. Therefore the Commission's plan includes those agencies which are best equipped to carry out supportive educational and training programs for Diabetes and Health Professionals. Diabetes is unique in that it is dramatically accelerating in incidence. There is no preventative, there is no cure! There are no measures as yet to stem the tide of the incidence of Diabetes and its complications.

We submit that there is an urgency to take the third "giant step" now, as quickly as possible. We urge that the Diabetes Advisory Board legislation be enacted in 1976 to guarantee implementation of the steps

necessary to lead to the goals of prevention and cure of Diabetes and its complications and to improve the care and quality of life of those individuals who have Diabetes. As President of the Juvenile Diabetes Foundation may I express my gratitude to Senator Schweiker and Congressman Dr. Tim Lee Carter and the many co-sponsors for the submission of bill S2910 and H.R.11626 to the Senate and the House of Representatives. We fully support the Diabetes Advisory Board and urge its prompt enactment.

We, who are Parents of Diabetics must live and think in the short range. The long range plan - a five year plan, may be too long for some of us. If we are to be perfectly honest, there is already a lag period of 1 year built into the plan because its design included fiscal '76. FY'76 has come and gone. The Congress has completed its fiscal '77 recommendations. Even if the Diabetes Advisory Board Legislation were passed today, there is a built in "lag period" of 1 year which will need adjusting. Therefore we recommend the establishment of the Diabetes Advisory Board in a position of authority so that it can advise and coordinate the agencies of HEW and NIH and start to move the five year plan and to make the adjustments necessary to a plan already hampered by a one year delay. The short range step of the long range plan is the immediate enactment of bill S2910 and the establishment of the Diabetes Advisory Board.

We support the section of bill S2910 entitled "Distinguished Scientist Award". This part of the legislation is an attempt to focus on a serious problem of "catch up". Research expansion must depend on the expansion of research manpower. Without competent researchers, you cannot have quality research. The Distinguished Scientist Award would help the recruitment of researchers to a long neglected and undernourished field. The needs to develop research manpower are great. The Distinguished Scientist Award is a "barebones" beginning and in that context we support the authorization for fiscal support to men of proven ability and accomplishment in Diabetes Research.

We support and urge the authorization of the Diabetes Research and Training Centers Section of Bill S2910. This section is an extension

of the authorization of Public Law 93-354 which originally authorized the Diabetes Centers. The Centering of Diabetes Research in Universities and academically based institutions where multidisciplinary, crossfertilization of research can take place must be encouraged by funding to institutions of excellence in order to establish centers of specialization in Diabetes Research and training of Health Professionals. We have evidence already of centers of Diabetes Research excellence emerging, nurtured by seed grants from our own foundation. The centers proposed by the Diabetes Legislation will function as core areas for research initiation and development, multidisciplinary conferences, demonstration of proper treatment, and development of research into better methods of treatment.

It is important to note, however, that the Diabetes Center Program was authorized in 1974, the Congressional appropriations committee has already acted for FY'77 to fulfill the authorization made in 1974. We are grateful for the appropriation of funds for centers in FY'77 but we want to underscore that the delay from authorization to fiscal appropriations is a total of 3 years. We support the section of the Diabetes Advisory Board bill which extends the authorization of the Diabetes Centers to year 1981, and we urge immediate action on fiscal support for these Diabetes Centers authorized in P.L. 93-354. We are happy to note that the National Institute of Arthritis and Metabolic and Digestive Diseases has appointed the Associate Director for Diabetes as authorized by P.L. 93-354. We enthusiastically support the establishment of the Diabetes Centers as a Giant Step toward stimulation and expansion of the Diabetes Research effort.

Mr. Chairman, distinguished members of the Committee, in dealing with a disease, the proportions of which are approaching a crisis level, we are faced with an administration which insists that in vital matters of health, research and training must be curtailed. We the people living daily with the problems of Diabetes look to the Congress for leadership. We are requesting prompt passage of the Diabetes Advisory Board legislation.

Parents of the Juvenile Diabetes Foundation are people in a "hurry".

It doesn't seem so very long ago that I testified to this Committee on the Diabetes Act of 1974. Two years have passed. Two years ago a Philadelphia boy was what we called a "Normal Diabetic". Two years later, today, he is legally blind. Two years ago, a Detroit Michigan boy was waiting for his first kidney transplant. Today he is ill waiting for his second kidney transplant. A little, blond Philadelphia boy was 3 years old when the Diabetes Act of 1974 was passed. He is now five, in kindergarten, and has been injected 1,530 times since the bill was passed. A young man two years ago was in his third year of Medical School. Today he is in his first year of Pediatric residency and he has discovered development of a severe case of Diabetic Retinopathy at age 23. A 16 year old girl was a "normal diabetic" two years ago. Today she would have been 18 years old. She is dead of cardiovascular degeneration.

Who of the tens of thousands of blond and black children injected each day by their parents will suffer dreadful incapacity and shortened life because of our lack of attention and support in the Spring of 1976?

1976, our Bicentennial Year, must be the year we have another revolution. A Diabetes Revolution. There is no other choice than to support this revolution or we will suffer the consequences of the "lag", "delay" and inability to "catch up" from a 50 year Rip Van Winkle sleep. Our goals must be to secure a truly coordinated Diabetes program across all of the institutes of the National Institutes of Health and the other agencies of government involved in education, training, and research. Our goals must be to pass the Diabetes Advisory Board Legislation in a "Hurry" to take that 3rd Giant Step, the implementation of the long range plan to construct an accelerated program to find the cause, methods to arrest the complications, preventatives and someday, we pray, a cure for Diabetes.

On behalf of the J.D.F. and our 200,000 members in 40 states, may I say that we are grateful to have this opportunity to share our thoughts and feelings with you today.

STATEMENT FOR PRESENTATION BEFORE THE HEALTH SUBCOMMITTEE
OF THE SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE

MAY 11, 1976

BY CAROLINE S. LURIE

MR. CHAIRMAN AND DISTINGUISHED MEMBERS OF THIS COMMITTEE, MY NAME IS CAROLINE LURIE AND I SPEAK TO YOU AS PRESIDENT ELECT OF THE JUVENILE DIABETES FOUNDATION AND AS A PARENT OF A 19 YEAR OLD SON WHO HAS HAD DIABETES FOR ALMOST 10 YEARS.

I APPEAR HERE TODAY AS A REPRESENTATIVE OF A VERY DETERMINED AND VITAL ORGANIZATION THAT WILL NEVER BE DETERRED FROM THEIR ORIGINAL AND BINDING GOAL, THE PREVENTION AND CURE OF DIABETES AND ITS DEVASTATING COMPLICATIONS.

THIS IS TRULY A DAY OF FIRSTS. IT IS THE FIRST TIME I HAVE EVER HAD THE HONOR TO TESTIFY BEFORE A SENATE COMMITTEE AND IF I APPEAR NERVOUS IT IS BECAUSE I TRULY AM.

IT IS THE FIRST HEARINGS ON BEHALF OF SENATE BILL 2910, THE DIABETES ADVISORY BOARD BILL. BUT ABOVE ALL, IT IS THE FIRST TIME A PROJECTED NEW ATTACK ON AN OLD DISEASE IS COMING TO FRUITION THROUGH INNOVATIVE MEASURES.

THE IMMENSITY OF OUR PROBLEM IS STAGGERING. THANKS TO THE LEADERSHIP OF SENATOR RICHARD SCHWEIKER AND OTHERS LIKE SENATOR HARRISON WILLIAMS AND SENATOR GALE MCGEE AND SO MANY WHO HAVE LISTENED SO INTENTLY, THE SEEDS HAVE BEEN PLANTED FOR A FULL SCALE ATTACK ON DIABETES AND WE ARE NOW ON THE BRINK OF A TRULY ESCALATING PROGRAM.

WITHIN THE PROPOSALS OF THE NATIONAL DIABETES ADVISORY BOARD BILL LAY THE FOUNDATION OF A CONSTRUCTIVE SUPPORT SYSTEM FOR DIABETES RESEARCH AND TREATMENT.

THE NATIONAL DIABETES COMMISSION WHICH WAS CREATED BY AND HAS RECENTLY REPORTED TO CONGRESS HAS DOCUMENTED FOR US THE MAGNITUDE AND COMPLEXITY OF THIS DISEASE. YET, IT REMAINS FOR DIABETES TO RECEIVE RECOGNITION AS A MAJOR PUBLIC HEALTH PROBLEM IN THIS COUNTRY. WE HAVE BEEN LIVING FOR TOO LONG WITH INADEQUATE DATA, INADEQUATE TREATMENT, INADEQUATE RESEARCH AND GROSSLY INADEQUATE FUNDING IN ALL AREAS RELATED TO WORK ON THIS PROBLEM.

S2910 PRESENTS FOR THE FIRST TIME A MEANS OF BROADENING THE BASE OF RESEARCH, TREATMENT AND EDUCATION OF THE DIABETIC. THE CURE FOR DIABETES REQUIRES THE INPUT OF ALL THE NIH FACILITIES, MONITORING AND ANALYZING EFFORTS OF THE CENTER FOR DISEASE CONTROL, THE ESTABLISHMENT OF A NATIONAL DIABETES INFORMATION AND EDUCATION CLEARING HOUSE, AND A NATIONAL DIABETES DATA GROUP. SINCE THESE EFFORTS MUST INVOLVE THE FULL RESOURCES OF THE FEDERAL GOVERNMENT -- AND NOT MERELY THOSE OF NIH -- WE AGREE COMPLETELY WITH THE NATIONAL COMMISSION ON DIABETES THAT THE ADVISORY BOARD CALLED FOR IN S2910 SHOULD BE ORGANIZATIONALLY LOCATED IN THE OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH, HEW.

THE JUVENILE DIABETES FOUNDATION SINCERELY BELIEVES IN AND SUPPORTS THE ESTABLISHMENT OF THE NATIONAL DIABETES ADVISORY BOARD AS A COORDINATING AND ADVISING BODY, AND AS A STRONG LINK OF COMMUNICATION. THROUGH THIS BOARD THE LEFT HAND WILL FINALLY KNOW WHAT THE RIGHT HAND IS DOING AND THE BOARD WILL ACT AS A HIGHLY EFFECTIVE HELPING AGENT FOR ALL OF THE BODIES THAT MUST BE PART OF A COORDINATED ATTACK ON THIS DISEASE.

AND, I THINK IT IS IMPORTANT TO REMEMBER HERE, THAT SPECIFIED WITHIN THE BILL ITSELF, IS A FIVE-YEAR LIMITATION ON THE LIFE OF THE NATIONAL DIABETES ADVISORY BOARD. THIS COINCIDES WITH THE NATIONAL COMMISSION ON DIABETES' FIVE YEAR PLAN. HOPEFULLY, THE DIABETES ADVISORY BOARD WILL HAVE OUTLINED ITS USEFULNESS BY THE END OF ITS FIVE YEAR TERM.

DIABETES CROSSES THE LINES OF DEMARCATION BETWEEN THE VARIOUS NATIONAL INSTITUTES OF HEALTH. THERE ALSO IS THE IMMENSE JOB OF MONITORING THE PROGRESS OF SERVICES RENDERED TO DIABETICS AND THE EDUCATION OF THEM, THEIR FAMILIES AND THEIR PHYSICIANS. IN ADDITION, THERE IS THE IMPORTANT FUNCTION OF ADVISING WITH RESPECT TO THE IMPLEMENTATION OF THE LONG RANGE PLAN TO COMBAT DIABETES AS SPELLED OUT BY THE NATIONAL COMMISSION ON DIABETES.

THE MECHANISM FOR THIS HAS BEEN CREATED IN S2910 AND IS CALLED THE NATIONAL DIABETES ADVISORY BOARD.

NOT ONLY WILL THE BOARD OVERSEE THE BLUEPRINT ESTABLISHED BY THE NATIONAL COMMISSION BUT THROUGH ITS REVIEW AND EVALUATION IT WILL BE ABLE TO BRING TOGETHER AND ANNUALLY PRESENT TO THE CONGRESS A COMPREHENSIVE PICTURE OF THE PROGRESS OF ALL THE GOVERNMENT'S EFFORTS IN THE BATTLE AGAINST THIS NATIONAL HEALTH PROBLEM.

THE JUVENILE DIABETES FOUNDATION SEES THE TERRIFYING AND DESPERATE NEED TO BRING TOGETHER THE MANY SPECIALIZED SCIENTIFIC DISCIPLINES IN THE HEALTH FIELD, AND TO COORDINATE THE MANY FRAGMENTED SCIENTIFIC ENDEAVORS INTO A BROADER COLLABORATIVE PLAN OF ATTACK UNDER THE VITAL MECHANISM OF A NATIONAL BOARD OF DIRECTORS.

THE COMPOSITION OF THIS BOARD AS OUTLINED IN SENATE BILL 2910 ATTEMPTS TO CREATE THE BROAD APPROACH NECESSARY FOR AN ALL ENCOMPASSING DIABETES PROGRAM. HOWEVER, THERE IS A DIRE NEED FOR CONGRESSIONAL IMPLEMENTATION OF THIS ENTIRE PROGRAM, AND I BELIEVE THAT IT REQUIRES YOUR DIRECT PARTICIPATION. THE JUVENILE DIABETES FOUNDATION, THEREFORE STRONGLY RECOMMENDS THAT THE NATIONAL DIABETES ADVISORY BOARD BE ENLARGED TO INCLUDE TWO MEMBERS FROM THE SENATE AND TWO MEMBERS FROM THE HOUSE OF REPRESENTATIVES, WITH EQUAL REPRESENTATION FROM BOTH POLITICAL PARTIES.

DIRECT CONGRESSIONAL REPRESENTATION WILL NOT ONLY INCREASE PRESTIGE, BUT WILL MATERIALLY BENEFIT THE NATIONAL DIABETES PROGRAM BY THE ADVICE AND COUNSEL OF THE DISTINGUISHED MEMBERS FROM CONGRESS.

ONE ADDITIONAL RECOMMENDATION OF THE JUVENILE DIABETES FOUNDATION IS THAT THE COMPOSITION OF THE NATIONAL DIABETES ADVISORY BOARD BE AMENDED TO INCLUDE TWO PARENTS OF DIABETIC CHILDREN, RATHER THAN ONLY ONE, AS NOW SPECIFIED IN S2910. OUR EXPERIENCE WITH THE NATIONAL COMMISSION ON DIABETES, WHICH INCLUDED TWO PARENTS IN ITS MAKEUP, HAS CONVINCED US OF THE ABSOLUTE NEED FOR THIS AMENDMENT TO S2910. WE STRONGLY URGE ITS ADOPTION.

WE, WHO ARE INVOLVED DAILY WITH THE LIVES OF THE JUVENILE DIABETIC LIVE WITH THIS DISEASE NOT KNOWING ANY TRUE ANSWERS. THE DIABETIC IS TREATED BY METHODS THAT HAVE NO DEFINITIVE SOLUTIONS. WE ARE GIVEN INFORMATION AND TREATMENT THAT CONFLICT IN METHODOLOGY AND ADVICE. THE DIABETICS FUTURE IS SO FRIGHTENLY UNCERTAIN.

THE TIME FOR FURTHER CONGRESSIONAL ACTION IS NOW AT HAND. WE'VE COME THIS FAR IN A LONG AND HARD FIGHT AND WE GREATLY APPRECIATE THE EFFORTS OF EVERY MEMBER OF CONGRESS BUT WE HAVE TAKEN ONLY THE FIRST STEP.

THERE IS A YOUNG 27 YEAR OLD MEMBER OF OUR JDF CHAPTER IN DETROIT WHO HAS HAD A KIDNEY TRANSPLANT AND IS HAVING GREAT DIFFICULTY AT THIS MOMENT OR HE WOULD HAVE BEEN HERE WITH US TODAY. HE WROTE ME SAYING THAT HE HAD JUST READ HIS FORTUNE IN A CHINESE FORTUNE COOKIE. IT READ -- "HE WHO HAS HOPE, HAS EVERYTHING."

DISTINGUISHED MEMBERS OF THIS COMMITTEE, FULFILLMENT OF OUR HOPE NOW RESTS IN YOUR HANDS, FIRST, - AND ONLY THROUGH THE PASSAGE OF SENATE BILL 2910, THE NATIONAL DIABETES ADVISORY BOARD ACT, CAN THAT HOPE BE TAKEN ONE STEP FURTHER.

ON BEHALF OF THE JUVENILE DIABETES FOUNDATION, AND OUR TENS OF THOUSANDS OF MEMBERS THROUGHOUT THIS GREAT COUNTRY, I THANK YOU, SENATOR SCHWEIKER, FOR ALLOWING ME TO EXPRESS MY VIEWS.

STATEMENT FOR PRESENTATION BEFORE THE HEALTH SUBCOMMITTEE
OF THE SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE

May 11, 1976

BY DINA MERRILL ROBERTSON

SENATOR SCHWEIKER, DISTINGUISHED MEMBERS OF THE COMMITTEE, I'M DINA MERRILL ROBERTSON -- AND I THANK YOU SINCERELY FOR THE OPPORTUNITY TO SHARE MY THOUGHTS WITH YOU ON THIS VERY EXCITING AND IMPORTANT DAY. EXCITING AND IMPORTANT, BECAUSE WHEN JUST OVER A YEAR AGO, ON APRIL 23, 1975, I HAD THE PRIVILEGE OF TESTIFYING BEFORE THE NATIONAL COMMISSION ON DIABETES, IT WOULD HAVE BEEN LABELED A MOTHER'S FANTASY TO SERIOUSLY BELIEVE THEN, THAT SOME 13 MONTHS LATER, I WOULD BE BACK BEFORE A PRESTIGIOUS AND POWERFUL COMMITTEE OF THE UNITED STATES SENATE, SEEKING TO IMPLEMENT THE BEGINNINGS OF A DREAM I HAVE LONG SHARED WITH THE ENTIRE DIABETIC COMMUNITY.

IN THIS YEAR OF OUR NATION'S BICENTENNIAL CELEBRATION, PRIDE IN ITS ACHIEVEMENTS IS AN INTEGRAL PART OF ALMOST EVERY AMERICAN WHO UNDERSTANDS THE GREATNESS OF OUR COUNTRY AND WHO ALLOWS THAT PROBLEMS, HOWEVER SERIOUS, ARE AN INTEGRAL PART OF HISTORY. YOUR RESPONSIVENESS TO THE COMMISSION'S SUPERB WORK, REFLECTING THE PROBLEMS AND NEEDS OF MILLIONS OF DIABETIC AMERICANS, IS FOR ALL OF US YET ANOTHER PROUD MOMENT, IN THE BEST TRADITION OF THE MEN AND WOMEN WHO WE, AS CITIZENS, ELECT AND EXPECT TO SERVE US. I CANNOT THANK YOU ENOUGH FOR LISTENING, UNDERSTANDING AND ACTING IN SUCH A PROMPT AND POSITIVE MANNER.

AS MANY OF YOU MAY KNOW, THE DIABETES PROBLEM WAS SUDDENLY AND DRAMATICALLY THRUST UPON MY FAMILY SOME ELEVEN YEARS AGO WHEN MY SON DAVID, AT AGE 14, BECAME A JUVENILE DIABETIC. DAVID DIED

IN AN ACCIDENT THREE SUMMERS AGO, BUT IN THE TEN YEARS HE AND WE FOUGHT DIABETES -- GRAPPLING EACH DAY WITH THE STRICTURES, THE UNCERTAINTIES, THE FEARS FOR HIS FUTURE AND THE EMOTIONAL CHAOS AND HURT CAUSED BY THIS COMPLEX AND DESTRUCTIVE DISEASE -- I BECAME EVER-MORE DETERMINED THAT I WOULD DO ALL IN MY POWER TO HELP HASTEN THE DAY IN WHICH MEDICAL SCIENCE WILL UNDERSTAND THE CAUSE, ALLEVIATE THE TERRIBLE COMPLICATIONS AND ULTIMATELY FIND THE CURE FOR DIABETES. TODAY, AS WE MOVE ONE STEP CLOSER TO THE FULFILLMENT OF THAT DREAM, I KNOW THAT HAD DAVID LIVED, HE WOULD HAVE WANTED TO BE HERE WITH ME TO SHARE THE WARM SENSE OF ACCOMPLISHMENT AND HOPE WE NOW FEEL.

MY EFFORTS, THROUGH THESE MANY YEARS, HAVE BEEN SPREAD AMONGST ALL OF THE MANY FINE INSTITUTIONS AND ORGANIZATIONS WORKING IN THE FIELD OF DIABETES. I AM HERE TODAY, HOWEVER, AS A MEMBER OF THE BOARD OF DIRECTORS OF THE JUVENILE DIABETES FOUNDATION, A VERY UNIQUE AGENCY, FOUNDED A FEW SHORT YEARS AGO BY LEE DUCAT AND A HANDFUL OF OTHER PARENTS OF DIABETIC CHILDREN. I HAVE LITTLE DOUBT THAT THE GROWTH, IMPACT AND RELENTLESS DETERMINATION OF THE JDF IS KNOWN TO EACH OF YOU, AND THAT YOU WILL AGREE WITH ME THAT THROUGH ITS EFFORTS, AN ACCELERATED MOMENTUM IS UNDERWAY TOWARD THE REALIZATION OF A MAJOR NATIONAL EFFORT TO OVERCOME A CATASTROPHIC HEALTH DISASTER, DRAINING THE MANPOWER AND ECONOMIC RESOURCES OF THIS GREAT COUNTRY.

THUS, MY PURPOSE HERE IS TO LEND MY STRONGEST SUPPORT TO THE LEGISLATION PENDING BEFORE THIS COMMITTEE AND TO URGE THE ENACTMENT OF S2910 -- WITH THE AMENDMENTS PROPOSED AND SUPPORTED BY THE JUVENILE DIABETES FOUNDATION -- AT THE SOONEST POSSIBLE MOMENT. I AM DEEPLY AWARE OF THE TIME, CONSIDERATION AND EFFORT PUT FORTH BY SENATOR SCHWEIKER, OTHER MEMBERS OF THE COMMITTEE AND

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THEIR RESPECTIVE STAFFS, IN DISCUSSING, STUDYING AND DRAFTING THIS CONSTRUCTIVE AND URGENTLY NEEDED LEGISLATION. FAILURE TO ASSURE ITS PASSAGE INTO LAW WOULD BE A SEVERE AND TRAGIC SETBACK TO THE THRESHOLD OF PROGRESS ON WHICH WE ARE STANDING AT THIS MOMENT. AS A NATION, WE CANNOT NOW AFFORD THAT SETBACK AND, AS THE MOST CONCERNED CITIZENS AFFECTED BY THE PROBLEM, OUR COMBINED AND UNANIMOUS VOICES ARE REPRESENTED HERE TO COMMEND YOUR ACTIONS -- TO HELP YOUR COLLEAGUES RECOGNIZE THE WISDOM OF WHAT HAS BEEN PROPOSED AND TO URGE THEIR SUPPORT, IN RESPONSE TO THE NEED AND THE WILL OF MORE THAN 10 MILLION AMERICANS -- SIZEABLE NUMBERS OF WHOM ARE AMONGST THEIR OWN RESPECTIVE CONSTITUENTS. TO EACH OF YOU HERE WHO HAS BEEN SO RESPONSIVE IN THE GIVING OF YOUR PRECIOUS TIME AND YOUR INVALUABLE HELP, MY PERSONAL APPRECIATION AND THAT OF THE VAST DIABETIC COMMUNITY, IS BOUNDLESS. YOU WILL NOT BE FORGOTTEN BY US -- AND AGAIN, I THANK YOU.

STATEMENT OF THE AMERICAN OPTOMETRIC ASSOCIATION, ON S. 2910, "THE NATIONAL DIABETES ADVISORY BOARD" SUBMITTED TO THE SUBCOMMITTEE ON HEALTH, COMMITTEE ON LABOR AND PUBLIC WELFARE, UNITED STATES SENATE

Mr. CHAIRMAN. The American Optometric Association appreciates the opportunity to present written testimony on S. 2910, a bill to establish the National Diabetes Advisory Board and to take other actions to insure the implementation of a long range plan to combat diabetes.

Because of optometry's inherent interest in providing vision care for all Americans, it has long been a source of serious concern for this profession to note the increasing numbers of Americans who have diabetes and its accompanying complications.

The main concern of the optometrist is usually not with the general condition itself but with the ocular symptoms and manifestations which may occur.

Today diabetes has become the primary cause of blindness in the United States and has therefore become a pathology of particular concern to vision specialists. The chances of acquiring blindness vary with the age at diagnosis, the severity of the disease, the degree of metabolic control and the duration of the disease.

The most frequently described involvements include retinopathy, arteriosclerosis, lens opacities, iris changes, extra-ocular muscle paresis, changes in the intra-ocular pressure, amblyopia, reduction in the amplitude of accommodation in the two eyes and changes in the refractive state.

All of these manifestations can be symptoms of unsuspected diabetes as well as side effects of the already diagnosed disease.

As optometrists provide two-thirds of the nation with their primary eye care, it is the optometrist who often recognizes the unsuspected diabetic in a routine yearly eye examination. When diabetes is suspected in a patient, he is then referred to a medical doctor for further conclusive tests.

Thus, the referral role of the optometrist becomes a necessary link to the detection of this disease and in obtaining prompt medical attention.

Because of the vital role optometry plays in diabetes detection, the American Optometric Association applauds the intent of S. 2910. Formation of such a board with primary responsibility for reviewing, evaluating and advising implementation of a long-range plan to combat diabetes will result in a necessary public awareness to this disease and its implications. This awareness is long overdue.

We offer the full support of our profession toward the creation of such a Board and wish to express here our deep interest in providing professional input into the prompt establishment of such a body.

Mrs. DUCAT. Thank you very much for that and for everything else, Senator.

Senator SCHWEIKER. All right.

Well, this concludes our hearings this morning. And I want to say that I think it was conducted not only in reviewing the progress that we have made and reviewing the work of the Commission and the report of the Commission, and taking the third step—as has been said here today—but also I think they gave us a basis for working out some of our problems and coming up with an approach that we can agree on that might get all the way through the legislative process.

So, I think it is a very, very constructive morning and thank everybody for participating. The Health Subcommittee will stand adjourned.

[Whereupon, the subcommittee adjourned at 11:55 a.m.]