

NATIONAL INSTITUTES OF HEALTH

Diabetes (Dollars in Millions)

	FY 1993 (actual)	FY 1994 (actual)	FY 1995 (actual)	FY 1996 (actual)	FY 1997 (actual)	FY 1998 (actual)	FY 1999 (estimate)	FY 2000 (estimate)	Percent Increase
NIH Total*	285.6	293.6	295.1	298.9	319.5	387.3	449.0	462.3	61.9%

*Includes transfer of \$27 million for Type I diabetes research for FY 1998 through FY 2002 in accordance with the Balanced Budget Act

$$\begin{array}{r}
 \text{Increase} \rightarrow \frac{449.0 - 285.6}{285.6} = 163.4\%
 \end{array}$$

$$\begin{array}{r}
 \frac{163.4}{285.6} = \text{Increase} \\
 \text{Start} \\
 = 57\%
 \end{array}$$

FOR: SARAH BIANCHI
FROM: MIKI SILVERMAN

Subj: JDF Washington Report No. 28
Date: 11/17/99 5:12:45 PM Eastern Standard Time
From: jdfadvocates-owner@jdfcure.org (jdfadvocates-owner@jdfcure.org)
Sender: owner-jdfadvocates@lists.jdfcure.org
Reply-to: jdfadvocates-owner@lists.jdfcure.org
To: jdfadvocates@lists.jdfcure.org

Juvenile Diabetes Foundation—Government Relations

JDF Washington Report
November 17, 1999
Volume II, No. 28

1. Diabetes Research Resolution Passes on the House Floor Unanimously
2. Budget Negotiations Still Undecided in Congress
3. NIDDK Names New Institute Director

Diabetes Research Resolution Passes on the House Floor Unanimously

A resolution (H Res. 325) expressing the sense of the House of Representatives regarding the importance of increased funding to combat diabetes was approved by the House of Representatives by a 414-0 margin yesterday. Representative LaFalce originally introduced the legislation on October 7. The resolution supported JDF's funding recommendations of \$827 million for diabetes research, based on the recommendations of the Diabetes Research Working Group report. Many of the Members mentioned their JDF Children's Congress delegates and sponsor Rep. LaFalce discussed the JDF Islet Cell Transplantation Centers. There were 109 cosponsors for H. Res. 325. While the resolution is non-binding, passage expresses the support of the House for the National Institutes of Health to allocate increased funds for diabetes research.

H. Res. 325

Whereas diabetes is a devastating, lifelong condition that affects people of every age, race, income level, and nationality;
Whereas diabetes is a serious disease that has a devastating impact, in both human and economic terms, on Americans of all ages;

Whereas an estimated 16 million Americans suffer from diabetes, and millions more are at greater risk for diabetes;
Whereas the number of Americans with diabetes has increased nearly 700 percent in the last 40 years, leading the Centers for Disease Control and Prevention to call it the 'epidemic of our time';

Whereas approximately 800,000 people will be diagnosed with diabetes in 1999, and diabetes will contribute to an estimated 198,000 deaths this year, making diabetes the sixth leading cause of death;

Whereas diabetes costs our Nation an estimated \$105 billion each year;

Whereas more than 1 out of every 10 health care dollars in the United States and about 1 out of every 4 Medicare dollars is spent on the care of people with diabetes;

Whereas more than \$40 billion a year in tax dollars are spent treating people with diabetes through Medicare, Medicaid, veterans care, Federal employee health benefits, and other Federal health programs;

Whereas diabetes frequently goes undiagnosed and an estimated 5.4 million Americans have the disease but do not know it;

Whereas diabetes is the leading cause of kidney failure, blindness in adults, and amputations;

Whereas diabetes is a major risk factor for heart disease, stroke, and birth defects and shortens average life expectancy by up to 15 years;

Whereas 800,000 Americans have type one diabetes, formerly known as juvenile diabetes, and 15.2 million have type two diabetes, formerly known as adult onset diabetes;

Whereas 18.4 percent of Americans age 65 years or older have diabetes and 8.2 percent of Americans age 20 years or older have diabetes;

Whereas Hispanic, African, Asian, and Native Americans suffer from diabetes at rates much higher than the general population, including children as young as eight years old who are now being diagnosed with type two diabetes;

Whereas there is currently no method to prevent or cure diabetes and available treatments have only limited success in controlling its devastating consequences;

Whereas reducing the tremendous health and human burden of diabetes and its enormous economic toll depends on identifying the factors responsible for the disease and developing new methods for treatment and prevention;

Whereas improvements in technology and the general growth in scientific knowledge have created unprecedented opportunities for advances that might lead to better treatments, prevention, and ultimately a cure;

Whereas after extensive review and deliberations, the Diabetes Research Working Group—established by Congress and selected by the National Institutes of Health—has found that many scientific opportunities are not being pursued due to insufficient funding, lack of appropriate mechanisms, and a shortage of trained researchers;

Whereas the Diabetes Research Working Group has developed a comprehensive plan for diabetes research funded by the National Institutes of Health and has recommended a funding level of \$827 million for diabetes research at the National Institutes of Health in fiscal year 2000; and

Whereas the House of Representatives as an institution and Members of Congress as individuals are in unique positions to help raise public awareness about the need for increased funding for research and for early diagnosis and treatment: Now, therefore, be it Resolved, That it is the sense of the House of Representatives that

- (1) the Federal Government has a responsibility
 - (A) to continue to increase research funding, as recommended by the Diabetes Research Working Group, so that the causes of, and improved treatment and cure for, diabetes may be discovered;
 - (B) to endeavor to raise awareness about the importance of the early detection and proper treatment of diabetes; and

448 - 5000

- Kathy Ruffo
- Frank Vinas

November 16 Congressional Record, available at that same website.

Budget Negotiations Still Undecided in Congress

Congressional and Administration negotiators are continuing to work on finalizing a budget agreement for fiscal year 2000. JDF is working hard to convince the negotiators to support \$827 million for diabetes research as recommended by the Diabetes Research Working Group report as well as provide \$17.9 billion for medical research at the National Institutes of Health, a fifteen-percent increase over last year's level. We will let you know as soon as the agreement is finalized.

(C) to continue to consider ways to improve access to, and the quality of, health care services for diagnosing and treating diabetes;

(2) all Americans should take an active role in fighting diabetes by using all the means available to them, including watching for the symptoms of diabetes, such as frequent urination, unusual thirst, extreme hunger, unusual weight loss, extreme fatigue, and irritability; and

(3) national and community organizations and health care providers should endeavor to promote awareness of diabetes and its complications and should encourage early detection of diabetes through regular screenings, education, and by providing information, support, and access to services.

Members speaking on the floor in support of the resolution included:

Bilirakis	(R-FL)
DeGette	(D-CO) Diabetes Caucus CoChair
Bilbray	(R-CA)
LaFalce	(R-NY)
Nethercutt	(R-WA) Diabetes Caucus CoChair
Romero-Barcelo	(D-PR)
Sweeney	(R-NY)
Lantos	(D-CA)
Morella	(R-MD)
Hinojosa	(D-TX)
Rodriguez	(D-TX)
Cook	(R-UT)
McKeon	(R-CA)
Kilpatrick	(D-MI)
Waxman	(D-CA)
Larson	(D-CT)
Smith	(R-NJ)

If one of your representatives is either a cosponsor or made comments supporting H. Res. 325, be sure to send him/her a thank you note to your Representative(s) at the following address: US House of Representatives, Washington, DC 20515.

To find out if your member was an original cosponsor to H. Res 325, go to <http://thomas.loc.gov/> and plug in H. Res 325. Also, the entire debate is available in the House section of the November 16 Congressional Record, available at that same website.

Budget Negotiations Still Undecided in Congress

Congressional and Administration negotiators are continuing to work on finalizing a budget agreement for fiscal year 2000. JDF is working hard to convince the negotiators to support \$827 million for diabetes research as recommended by the Diabetes Research Working Group report as well as provide \$17.9 billion for medical research at the National Institutes of Health, a fifteen-percent increase over last year's level. We will let you know as soon as the agreement is finalized.

Subj: Gore's "big increase"
Date: 11/5/99 11:23:18 AM Eastern Standard Time
From: JLAMOUNTAIN@DIABETES.ORG (Joseph LaMountain)
Sender: ADVOCATE@LISTSERV.DIABETES.ORG (ADA Advocate)
Reply-to: ADVOCATE@LISTSERV.DIABETES.ORG (ADA Advocate)
To: ADVOCATE@LISTSERV.DIABETES.ORG

I am so angry I cannot see straight. And advocate Patti Wong is the reason why. That's because Patti sent me a transcript of last week's debate between Al Gore and Bill Bradley in NH.

In response to a question, asked by the mother of a child with diabetes, Gore said: "You know, we've just had a big increase in research for juvenile diabetes, and I'm hopeful we can find a cure for that and cancer and other diseases."

As Patti asked me, "What is the big increase he is talking about?" Good question. Obviously, the VP has no clue whatsoever about diabetes funding, despite everything we've done over the last month.

During that time, ADA staff met with Gore's chief policy aide to explain the dismal state of funding. On top of that, thousands of calls, letters, faxes, and emails were directed to the VP by advocates, and not just by the 3,000 people who receive these email messages.

Yet the VP is still under the mistaken assumption that everything is hunky dory. Someone must be telling the VP and his staff that people with diabetes are happy with the current situation. How else can you explain it? This is depressing, frustrating and annoying all at once.

A wise man once said that "desperate times call for desperate measures." I say that desperate times call for desperate calls - to VP Gore's campaign offices, of course.

And I'm not talking about just one call to his office today. We've tried that and it hasn't worked. What we need is a steady drumbeat of calls, every day, until he and his staff wake up.

Will you call his office every day until the message gets through? If yes, please send me a message at jlamountain@diabetes.org and make sure to include your name, city and state.

Once I have a list of callers compiled and organized, I'll send you a phone number to call daily. I'll also include talking points and send you a reminder email each day.

We are down to the last few days in this year's budget cycle. The process is almost over. And unlike all the other candidates running for President, VP Gore can still make a difference because of his position. But we have to convince him.

I hope to hear from you soon.

Leading the fight to cure diabetes.....

Joseph LaMountain
National Director of Advocacy
American Diabetes Association
1701 N. Beauregard Street
Alexandria, VA 22311
fax: 703-549-8748

----- Headers -----

Return-Path: <owner-advocate@LISTSERV.DIABETES.ORG>

Received: from rly-yd02.mx.aol.com (rly-yd02.mail.aol.com [172.16.150.2]) by air-yd03.mail.aol.com (v62.15) with ESMTP; Fri, 05 Nov 1999 11:23:18 -0500

Received: from Wilma.Diabetes.ORG (wilma.diabetes.org [207.78.21.3]) by rly-yd02.mx.aol.com (v62.10) with ESMTP; Fri, 05 Nov 1999 11:23:06 -0500



Mission
to prevent and cure diabetes
and to improve the lives of all
people affected by diabetes.

THE DIABETES PLEDGE:

Since 1981, the share of NIH's budget dedicated to diabetes has fallen 30% while the diabetes death rate has risen 30%.

If elected President, will you triple NIH funding for diabetes research by 2004?

This amount was recommended by the Diabetes Research Working Group, a panel of experts appointed by NIH.

_____ Yes _____ No

Signature: _____

New Hampshire Office

249 Canal Street Tel: (603) 627-9579
Manchester, NH 03101 Fax: (603) 669-1477

For Information Call 1-800-DIABETES • <http://www.diabetes.org>

The Association gratefully accepts gifts through your will.

- * "...among killer diseases, breast cancer and AIDS aren't even near the top of the list. Breast cancer is eighth, AIDS seventeenth. Yet AIDS, with its 1.8 billion-dollar NIH budget, gets the most money. The number one killer, heart disease, last year got half a billion dollars less." [John Stossel, 20/20]
- * Legislation in the House "includes a \$2.3 billion increase- or 15 percent- in funding for the National Institutes of Health, increasing the NIH budget from \$15.6 billion to \$17.9 billion." [JDF-Oct. 28, 1999]

The Diabetes Research Working Group was established by Congress to make recommendations for future diabetes research and provide budget estimates for this research. The group is comprised of 12 scientific experts in diabetes and 4 diabetes lay representatives. Their report was presented in 1999, after a year long study. The report is entitled, Conquering Diabetes: A Strategic Plan for the 21st Century.

JDF....The Juvenile Diabetes Foundation

ADA..The American Diabetes Association

DIABETES FACTS

HOW MANY?

- * 16 million Americans have diabetes [DRWG-p.2]
- * "about 800,000 new cases are diagnosed each year." [DRWG-p.2]
- * A new case of diabetes is diagnosed every 40 seconds [JDF]
- * There are 62,000 diabetics in NH [ADA]
- * In greater Manchester alone, there are 14,608 diabetics [ADA]

HEALTH IMPACT

- * "Diabetes is the 6th leading cause of death due to disease in the US." [DRWG-p.2]
- * It "contributes to the deaths of over 179,000 Americans every year." [JDF]
- * It "reduces average life expectancy by up to 30%." [JDF]
- * "shortens average life expectancy by up to 15 years." [DRWG-p.1]

- * "Diabetes affects virtually every tissue of the body with long term and severe damage." [DRWG-p.2]

- * "Diabetes is the leading cause of kidney failure, blindness in adults, and amputations." [DRWG-p.1]

- * "Diabetes is the number one cause of new blindness." [JDF]

- * "Diabetic kidney disease (nephropathy) accounts for 42% of new cases of end-stage renal disease, and is the fastest growing cause of kidney dialysis and transplantation (over 100,000 cases per year)." [DRWG-p.2]

- * "Nervous system damage (neuropathy) affects over 60 percent of diabetics, causing impaired sensation or pain in the feet or hands, slowed digestion of food in the stomach, impotence and other problems." [DRWG-p.2]

- * "More than half of lower limb amputations in the United States occur among people with diabetes." [DRWG-p.2]

- * "Heart disease death rates in adults with diabetes are about 2 to 4 times those of people without diabetes." [DRWG-p.2]

- * "High blood pressure affects over 60 percent of people with diabetes. As a result of the combination of hypertension and diabetes the risk of stroke is increased 2 to 4 times." [DRWG-p.2]

- * "The prevalence of diabetes is increasing at alarming rates in all age groups..."
[DRWG-p.15]

ECONOMIC IMPACT

- * "The cost of diabetes to the nation is over \$105 billion annually." [DRWG-p.2]
- * "More than one of every ten U.S. health care dollars is spent for diabetes." [DRWG-p.2]
- * "One of about four Medicare dollars pays for health care of people with diabetes."
[DRWG-p.2]
- * The annual direct economic cost in greater Manchester alone is \$101,503,392. [ADA]

FUNDING PROBLEM

- * NIH will spend about \$443 million in FY 1999 on diabetes research. [DRWG-p.3]
- * "The federal investment in diabetes research represents about 3 cents out of each dollar, that is about 3 percent of the NIH research budget.....this is clearly a small investment for a disease that affects 6 to 7 percent of the population and accounts for more than 10 percent of all health care dollars." [DRWG-p.3]
- * "The proportion devoted to diabetes research, relative to the whole NIH budget, has decreased by more than 30 percent since 1981, at a time when the death rate due to diabetes has increased by 30 percent." [DRWG-p.3]
- * "The DRWG report calls for NIH to spend \$827 million in fiscal year 2000 on diabetes research..."
[JDF-10/28/99]
- * "Last year AIDS got twenty-four hundred dollars per patient from NIH, breast cancer two hundred and thirty dollars, heart disease just one hundred and eight dollars. Parkinson's: seventy-eight dollars. And diabetes, which last year killed more people than AIDS and breast cancer combined, just twenty-eight dollars."
[John Stossel, ABC-TV, 20/20, Oct. 11, 1999]
- * "Sixteen million people suffer from diabetes in America, five times more than AIDS and breast cancer combined."
[Stossel., 20/20]

Diabetes Research Working Group News

This Strategic Research Plan for diabetes research funded by the National Institutes of Health has been developed by an independent, congressionally-established Diabetes Research Working Group, with input from diabetes investigators, diabetes patients, and other members of the broad diabetes research community. The Working Group is composed of scientific and lay experts external to the National Institutes of Health, as well as leaders of major diabetes voluntary organizations. The views, conclusions, and recommendations expressed in this document are solely those of the members of the Diabetes Research Working Group and do not necessarily reflect the positions or judgments of the National Institutes of Health, the Department of Health and Human Services, or the Administration, which must weigh the competing requirements of multiple programs and activities. (NIH Publication No. 99-4398)

Summary of the Report and Recommendations of the Congressionally-Established Diabetes Research Working Group

A Strategic Plan for the 21st Century

Transmittal to the Congress

In accordance with directives from the House and Senate Appropriations Committees, I am pleased to transmit to the Congress the summary of the Strategic Plan for NIH-funded diabetes research developed by the congressionally-established Diabetes Research Working Group.* As specified by the Congress, this Research Plan includes recommendations for future diabetes research directions and corresponding overall budget estimates for implementing the proposed new research initiatives.

The Diabetes Research Working Group is an independent panel composed of twelve scientific experts in diabetes and four representatives from the lay diabetes community. In developing its Strategic Research Plan, the Working Group held plenary meetings and subcommittee discussions, analyzed the existing NIH diabetes research portfolio, sought the expertise of *ad hoc* scientists, and enlisted public commentary. The Diabetes Research Working Group believes that the culmination of this year-long, in-depth planning process is a set of recommendations that will be of value to the Congress and to the NIH.

Clearly, the congressional action calling for the establishment of the Diabetes Research Working Group and the development of its Research Plan reflects the strong and continuing commitment of the Congress to conquering diabetes. The implementation of the research initiatives recommended in this Strategic Research Plan is the next vital step toward attaining that objective.

C. Ronald Kahn, M.D.
Chairman
Diabetes Research Working Group

*Note: The congressional directives calling for the establishment of the Diabetes Research Working Group and the development of its Strategic Research Plan can be found in Senate

Report 105-58 (1998, p. 76, p. 110), House Report 105-205 (1998, p. 69, p. 98) and House Report 105-635 (1999, p. 69). The charge to the Diabetes Research Working Group called for the development of a comprehensive plan for all NIH-funded diabetes research efforts, including the recommendation of future diabetes research initiatives and directions. Congressional language specifically asked the Working Group to include overall cost estimates to accomplish its recommendations in the final research plan.

The Challenge

Sixteen million people in the United States have diabetes mellitus. In both human and economic terms, it is one of our nation's most costly diseases. Diabetes is the leading cause of kidney failure, blindness in adults, and amputations. It is a major risk factor for heart disease, stroke, and birth defects, shortens average life expectancy by up to 15 years, and costs the nation in excess of \$100 billion annually in health-related expenditures. At present, more than one of every ten health-care dollars and about one of every four Medicare dollars are spent on people with diabetes. Over the next decade these numbers will grow as the number of people afflicted by diabetes continues to increase at an accelerating rate. At present, there is no method to prevent or cure diabetes, and available treatments have only limited success in controlling its devastating consequences.

This problem is made more complex by the fact that diabetes mellitus is not a single disease, but occurs in several forms, and has complications that affect virtually every system of the body. The most common forms are Type 1 (insulin-dependent) diabetes, which usually starts in childhood or adolescence, and Type 2 (non-insulin dependent) diabetes, which typically affects adults and increases dramatically with age and obesity.

Congress has clearly recognized the gravity of diabetes through the establishment of a bipartisan Diabetes Caucus and has concluded that the only way to reduce the tremendous burden of this disease is through intensified biomedical research. Over the past three years, Congress has emphasized diabetes research in funding increases provided to the NIH and through other special initiatives. Realizing the critical need to build upon these important steps, the Congress directed the establishment of the Diabetes Research Working Group (DRWG) and charged it with developing a comprehensive plan for diabetes research. This plan is intended to help increase the effectiveness of NIH-funded diabetes research and find solutions to the extremely serious problems posed by this disease. During 1998, the DRWG and its subcommittees held a series of meetings, consulted with a wide range of experts in the field, and heard public commentary. It evaluated all aspects of the diabetes problem in an effort to develop a comprehensive plan for submission to the Congress. This document provides the Strategic Research Plan of the Diabetes Research Working Group.

Based on its extensive review and deliberations, the DRWG recognizes both great urgency and unprecedented opportunities in diabetes research. The seriousness of the disease and the widespread problems associated with it demand accelerated and expanded research programs, not only to discover the means to prevent and cure diabetes, but also to develop better and more effective treatment strategies. Meeting these challenges requires a well-thought-out and continuously updated research plan; a cadre of talented researchers and physician-scientists; a supportive infrastructure; and appropriate budgetary resources. The DRWG is convinced that taking action now to increase significantly NIH support of diabetes research will save many thousands of men, women and children from the severe consequences of a dangerous, often disabling and potentially even fatal illness, and will also save the nation many billions of dollars in medical care and lost productivity. From both human and scientific perspectives, now is the time for the United States to move swiftly and decisively to begin to ensure a future for America without diabetes.

Magnitude of the Problem

The magnitude of the problem created by diabetes is clearly defined by a few simple facts:

- **Diabetes currently affects an estimated 16 million Americans, and about 800,000 new cases are diagnosed each year.**
- **Diabetes spares no group—attacking men, women, children, the elderly and people from every racial background.**
 - African, Hispanic, Native and Asian Americans, some of the fastest growing segments of the U.S. population, are particularly vulnerable to diabetes and its most severe complications.
 - Diabetes strikes both ends of the age continuum. Children and young adults with Type 1 diabetes face a lifetime of daily insulin injections and the possibility of early complications whose severity will likely increase with duration. Elderly diabetics are frequently debilitated by multiple complications.
- **Diabetes affects virtually every tissue of the body with long term and severe damage.**
 - Diabetic eye disease (retinopathy) is the most common cause of blindness in working age adults.
 - Diabetic kidney disease (nephropathy) accounts for 42 percent of new cases of end-stage renal disease, and is the fastest growing cause of kidney dialysis and transplantation (over 100,000 cases per year).
 - Nervous system damage (neuropathy) affects over 60 percent of diabetics, causing impaired sensation or pain in the feet or hands, slowed digestion of food in the stomach, impotence, and other problems.
 - More than half of lower limb amputations in the United States occur among people with diabetes. From 1993 to 1995, about 80,000 amputations were performed each year on people with diabetes.
 - Heart disease death rates in adults with diabetes are about 2 to 4 times those of people without diabetes. Premenopausal women lose their protection from heart disease and have even more markedly increased risk.
 - High blood pressure affects over 60 percent of people with diabetes. As a result of the combination of hypertension and diabetes the risk of stroke is increased 2 to 4 times.
 - Pregnancy related problems confront diabetic women. The rate of major congenital malformations and death of the fetus and newborn are increased 3 to 4 times.
 - Higher rates of infection, periodontal disease, and many other problems occur in people with diabetes.
- **Diabetes is the sixth leading cause of death due to disease in the U.S., and the third leading cause in some minority groups.**
 - Since 1980, the age-adjusted death rate due to diabetes has increased by 30 percent while the death rate has fallen for other common multifactorial diseases, such as cardiovascular disease and stroke.
 - Life expectancy of people with diabetes averages 10 to 15 years less than that in the general population.
- **The economic impact of diabetes is staggering.**
 - The cost of diabetes to the nation is over \$105 billion annually.
 - More than one of every ten U.S. healthcare dollars is spent for diabetes.
 - One of about four Medicare dollars pays for health care of people with diabetes.

The Federal Investment in Diabetes Research

Reducing the tremendous health and human burden of diabetes and its enormous economic toll depends upon identifying the factors responsible for the disease and developing new methods for treatment and prevention. These advances can only occur through increased biomedical research. Although Federal support for diabetes research has produced a number of major advances in the past two decades, many scientific opportunities are not being pursued due to insufficient funding, lack of appropriate mechanisms, and a shortage of trained researchers. Improvements in technology and the general growth in scientific knowledge offer unprecedented opportunities for advances that might lead to better treatments, prevention and possibly cure. Unfortunately, the current funding, level of effort, and scope of diabetes research fall far short of what is needed to capitalize on these opportunities.

The U.S. Government, through the National Institutes of Health (NIH), will spend an estimated \$443 million in FY 1999 on diabetes-related research. While this amount has steadily increased since 1981, there is unanimous agreement in the DRWG that this funding level is far short of what is required to make progress on this complex and difficult problem. In fact, the current federal budget for diabetes research represents less than one-half of one percent (0.5 percent) of the annual cost of diabetes to the U.S. economy. When compared with the 5 to 15 percent budgets for research and development in other high-technology sectors, the investment in diabetes research is trivial.

Meeting the challenges posed by diabetes requires investment of additional resources to conduct the needed research and a well-conceived, comprehensive research plan for its effective use. This Plan by the DRWG is the first step in this direction.

The Federal Investment in Diabetes Research

- **Represents about 3 cents out of each dollar, that is about 3 percent of the NIH research budget. Although there is no accepted method for determining appropriate levels of research funding, this is clearly a small investment for a disease that affects 6 to 7 percent of the population and accounts for more than 10 percent of all health care dollars.**
- **The proportion devoted to diabetes research, relative to the whole NIH budget, has decreased by more than 30 percent since 1981, at a time when the death rate due to diabetes has increased by 30 percent.**
- **Represents only about \$30 per person affected with diabetes per year--less than two people might spend for a movie and a pizza.**

The Research Plan

The Diabetes Research Working Group is convinced that a significant investment in research today will greatly speed progress in understanding and conquering this disease and its complications. The Strategic Research Plan set forth has two overarching goals:

- **Understand the causes and define approaches to prevent the development of Type 1 and Type 2 diabetes and their complications.**
- **Develop methods for optimal management, treatment and ultimate cure of diabetes and its complications.**

The DRWG has divided this Research Plan into the following three major components, and provided specific recommendations concerning the types of efforts, budgetary requirements and program mechanisms that should be pursued to realize compelling research goals:

- **Extraordinary Opportunities:** Rapidly expanding, crosscutting areas in which increased investment or development of new mechanisms will significantly speed research.
- **Special Needs for Special Problems:** Equally important, but more focused research areas targeted to specific populations, complications, and methodological approaches.
- **Resource and Infrastructural Needs:** A bold plan for increasing research manpower, technology and other infrastructure elements for diabetes-related research.

Extraordinary Opportunities

Exciting and rapid research advances in recent years have opened the door to a new understanding of diabetes. The next decade offers important research opportunities that, if seized now, can vastly improve the lives of people with or at risk for diabetes. The Diabetes Research Working Group has identified five areas that offer extraordinary opportunities for making genuine and significant progress toward understanding, more effectively treating, and ultimately preventing and curing diabetes. They are: the genetics of diabetes and its complications; autoimmunity and the beta cell; cell signaling and cell regulation; obesity; and clinical research and clinical trials of critical importance.

Genetics of Diabetes

Because Type 1 and Type 2 diabetes and their complications have strong genetic determinants, defining the specific genes involved is essential to prevention and could lead to new and better therapies. Defining the genes for diabetes and its complications will also help isolate the environmental factors involved in the disease and may identify genetic factors that contribute to variations in response to medications. Thus, a major goal for the coming decade must be to identify these predisposing genes.

Although most of the basic tools for genetic studies are in place and much progress has been made, current approaches are inadequate to tackle the vital genetics questions in a reasonable time frame. Three major impediments are inadequate resources; the lack of an appropriate mechanism to bring together the groups of researchers and patient samples to conduct the necessary studies; and fragmented genetic repositories.

Recommendations:

- **Establish a National Consortium for the Study of the Genetics of Diabetes to create a strong, coordinated effort for analysis of the role of genetics in diabetes and its complications.**
- **Enhance research in laboratory animals and humans to discover the biochemical mechanisms by which diabetes genes function to create susceptibility to diabetes and its complications.**

Autoimmunity and the Beta Cell

Type 1 diabetes is an "autoimmune" disease in which the body's own defense system mistakenly attacks and destroys insulin-producing beta cells of the pancreas. Important discoveries and concepts have emerged during the past decade from research in basic immunology, cell biology, and autoimmune diseases, including Type 1 diabetes. Based on this solid research foundation, the DRWG believes that aggressive pursuit of three scientific areas over the next decade could lead to dramatic improvements in diabetes therapy and prevention.

Recommendations:

- **Define the immunological basis of Type 1 diabetes and develop methods for prevention of the disease.**
 - Intensify research to understand the immunological basis of Type 1 diabetes.
 - Complete mapping of T cell specificity of autoimmune responses to major pancreatic islet cell proteins and identify optimal strategies for immunotherapy.
 - Expand the scope of efforts to identify immune response markers that reliably detect individuals predisposed to Type 1 diabetes in the population at large.
 - Conduct additional clinical trials of immunoprevention of Type 1 diabetes using antigen-specific, cytokine- or antibody-based immunotherapy.
- **Advance research on islet cell transplantation for treatment of diabetes.**
 - Establish Centers for Islet Transplantation with appropriate funding to undertake immediate clinical trials of islet transplantation in patients with Type 1 diabetes and to evaluate various methods of immune intervention.
 - Support an expanded system for national collection of human pancreas for isolation and distribution of islets for clinical studies, trials, and basic research, and establish a Task Force to make recommendations on approaches to enhance this process.
- **Develop methods to stimulate beta cell growth and regeneration.**
 - Increase basic research on the control and regulation of islet cell differentiation, growth and development, and devise methods for stimulating growth or regeneration of islet cells.
 - Create Interdisciplinary Centers for Beta Cell Biology to expand current efforts and bring new investigators into the field. These Centers should be applicable to research efforts on both Type 1 and Type 2 diabetes.

Cell Signaling and Cell Regulation

Intracellular and intercellular communication is the basic mechanism for the regulation of all cells. Disturbances in cell signaling are central to disturbances in insulin secretion and action, which lead to diabetes and to both micro- and macrovascular complications. Basic research in this area is not only essential to understanding diabetes, but is also critical to understanding many diabetes-related complications. Most importantly, this type of "discovery" research can identify important targets for new treatments. It would also complement the important new information about the genetic underpinnings of disease.

Recent progress in research on signaling systems and in the ability to use genetic methods to study these pathways has created an extraordinary opportunity to determine the exact mechanisms of signal communication and its alterations in diabetes. A parallel opportunity exists to identify the molecular events responsible for the insulin resistance characteristic of Type 2 diabetes.

The DRWG has identified five areas of opportunity in cell signaling and regulation that warrant increased research. These are: dissection of insulin and hormone signaling pathways; understanding and countering insulin resistance; defining mechanisms regulating beta cell function; metabolic staging of diabetes; and defining alterations in signaling pathways that lead to development of diabetes complications.

Recommendations:

- **Complete the dissection of hormone signaling pathways, particularly the pathways of insulin action, and define their alterations in diabetes, including insulin resistance.**
 - Significantly increase research in the fundamental science of cellular signaling as it relates to diabetes and its complications.
 - Remove the limits currently present on research project (RO1) and program

project (PO1) grants, such as budget caps, limitations on growth of programs, and considerations of average grant size, to maximize the opportunity for effective research teams to be formed.

- Establish research centers to focus on development of methods to study cellular signaling at the molecular and genetic level in humans with diabetes to allow correlation between the physiological defects and the molecular alterations.
- Expand research to identify the underlying genetic and biochemical basis of insulin resistance, and to develop interventions to prevent, reverse and ameliorate it in Type 2 diabetes and obesity.
- **Define mechanisms regulating beta cell function and their alterations in Type 2 diabetes.**
 - Increase research on signaling pathways involved in the regulation of normal beta cell function and their derangements in diabetes.
 - Use the proposed Interdisciplinary Centers for Beta-Cell Biology to study the alterations in signaling in Type 2 diabetes.
- **Allow metabolic staging of diabetes and identify the mechanisms of complications.**
 - Develop a program of research to allow metabolic staging of Type 2 diabetes, and to detect individuals at high risk for this form of the disease and its complications.
 - Expand support of interdisciplinary research to identify the mechanisms of the complications of diabetes, including interactive mechanisms and program project grants, which bring together investigators with different areas of expertise.

Obesity-Critical in Diabetes and a Major Problem of Its Own

Obesity is a major risk factor for the development of Type 2 diabetes and insulin resistance, as well as a major cause of morbidity and mortality in the U.S. One of every two Americans is overweight, and the prevalence has increased 30 percent in the past decade alone. Obesity disproportionately affects minorities. Over 60 percent of African American, Mexican American, and Native American women meet the criteria of being overweight and between 33 and 37 percent are obese. Moreover, obesity in children and adolescents is increasing at alarming rates, leading to occurrence of Type 2 diabetes in these groups.

Obesity results from an imbalance between energy intake and energy expenditure. The recent discovery of the fat cell hormone, leptin, and other appetite-regulating hormones has demonstrated that certain types of obesity are not simply due to overeating, but are the result of misregulated pathways that control the balance between appetite and energy expenditure. These new discoveries have provided a revolutionary understanding of obesity at the molecular level, thus leading to extraordinary opportunities in biomedical and behavioral research.

Recommendations:

- **Increase the size, scope, number and funding level of NIH sponsored Obesity Research Centers to meet appropriately the severity of this problem in the U.S.**
- **Significantly increase research in the basic sciences underlying obesity to capitalize on recent advances in hormonal control of appetite, energy regulation, metabolism, and adipocyte development.**
- **Develop stronger industry-NIH relationships to support obesity-related research.**
- **Enhance behavioral research in obesity.**

Clinical Research and Clinical Trials of Critical Importance

Translation of basic research into human therapies depends on an active and vigorous clinical research program. Studies in test tubes, cells and animals can answer questions of fundamental importance, and often provide the basis for development and initial testing of potential interventions. However, it is clinical studies in patients with diabetes that are essential for validating these observations and their relevance to human disease. In addition, clinical studies give key insights into the genetic, immune, hormonal, metabolic and environmental factors involved in the disease, and allow true testing of therapeutic strategies. Several prevailing forces, however, have significantly hampered clinical research and clinical trials in diabetes. Investigator-initiated clinical research is decreasing as a result of decreasing numbers of clinical investigators, limitations on funding of clinical research, the high cost of clinical research, and the complexity of clinical challenges. A major factor hampering clinical trials is the lack of infrastructure to organize and support them.

For diabetes, the long-term nature of the complications adds to the complexity of clinical trials. In most clinical studies, it is difficult to have adequate representation of high-risk minority groups due to the *ad hoc* nature of the organization of clinical trials. For robust and effective clinical research, additional well-trained clinical investigators and increased funding of meritorious clinical studies are required. Also needed are efficient systems for clinical research to provide the necessary numbers of patients and the stability of operations for long-term studies, and opportunities to include sufficient numbers of appropriate minority groups.

A comprehensive program for tackling a major public health problem such as diabetes requires a major investment, not only in basic research, but also in clinical research and clinical trials. The latter are particularly needed to document the safety and efficacy of various therapeutic strategies and generate the knowledge base for "evidence based medicine" that will lead to better treatment of diseases. There are two major needs to achieve these goals. The first is creation of an infrastructure to facilitate clinical trials-both improving efficiency and lowering cost. This need is especially apparent in diabetes where clinical trials to "hard endpoints" may take many years and even decades. The second need is a commitment to using clinical trials as a mechanism to develop the proper base of knowledge and to assure steady improvement in the care of people with diabetes.

Recommendations:

- **Establish a national diabetes trial network (Diabetes TrialNet) of cooperative clinical research groups to create the stable, high-quality infrastructure necessary for the conduct of effective and efficient clinical trials in diabetes.**

In addition, the Diabetes Research Working Group recommends that NIH:

- Increase funding of meritorious clinical trials of emerging new therapies for diabetes and its complications.
 - Support critical trials on how to most effectively apply the current methods of therapy and identify new, more generally applicable methods for achieving tight blood glucose control without hypoglycemia.
 - Support clinical trials on the prevention of microvascular and macrovascular disease, the major causes of morbidity and death in people with diabetes.
 - Develop effective partnerships among the NIH, academia and industry for collaboration and co-funding of clinical trials in diabetes and to provide training in the science of clinical trials.
- **Increase funding of meritorious clinical research for physiological studies and development of new technologies for metabolic assessment. These should include efforts to:**
 - Initiate clinical studies of promising new therapies for diabetes, such as gene

- therapy, or tissue-specific approaches to microvascular complications.
- Initiate studies to determine the reasons that women and some minority populations with diabetes have higher risks for diabetic complications.
- Increase opportunities for and support of clinical research training in diabetes.
- Perform clinical studies to establish and validate surrogate endpoints for the complications of diabetes to be used in clinical research and clinical trials.

Special Needs for Special Problems

Micro - and Macrovascular Complications

The different types of diabetes and the array of complications they present offer a wide range of specific research needs unique to each. The micro- and macrovascular complications of diabetes are responsible for most of the morbidity and mortality in both Type 1 and Type 2 diabetes. Their prevention and reversal will greatly reduce the burden of this disease on individuals and on the nation. Understanding and combating the complications of diabetes will require significantly expanded research in mechanisms involved in the development and progression of the complications of diabetes. Several promising research avenues must be pursued through intensified basic and clinical research. This will require an increased effort from the existing community of scientists working in diabetes, as well as important new input from scientists in immunology, genetics, neurology, atherosclerosis, obesity and maternal and child health.

Recommendations for Microvascular Complications:

- **Expand support of research to identify the mechanisms of the microvascular complications of diabetes.**
- **Enhance clinical research and clinical trials.**
- **Develop valid surrogate markers for disease staging.**
- **Establish centers dedicated to the study of microvascular complications.**
- **Recruit scientists from outside the field to enrich research on diabetic complications.**

Recommendations on Diabetic Kidney Disease:

- **Increase the study of the basic mechanisms involved in diabetic nephropathy, including studies of extracellular matrix, growth factors, cytokines and genetic factors, and develop strategies to prevent and reverse this process.**
- **Initiate clinical studies to establish and validate additional markers for staging of disease and use in clinical trials on diabetic nephropathy, including functional imaging and other minimally invasive approaches.**
- **Establish multidisciplinary centers for the study of diabetic nephropathy in order to expand basic and clinical research studies and identify leads for prevention and treatment.**

Recommendations on Diabetic Eye Disease:

- **Increase basic and clinical research on the role of hormones, growth factors and other molecules in the development and progression of diabetic retinopathy.**
- **Increase research into the potential for tissue-specific gene therapy and drug delivery, including approaches for regeneration and rescue of retinal function.**
- **Increase basic and clinical research to develop and improve prosthetics and transplantation technology for diabetic retinopathy.**

Recommendations on Diabetic Nerve Disease:

- **Significantly increase the investment in fundamental research to determine the mechanisms of the nerve damage in diabetes, to expand research on nerve regeneration and rescue, and to evaluate methods to enhance peripheral and autonomic function.**
- **Initiate clinical studies to establish and validate surrogate markers for use in clinical trials on diabetic neuropathy, including new technologies that will aid in the measurement and evaluation of nerve function in people with diabetes.**
- **Establish new multidisciplinary centers for the study of metabolic nerve diseases, with an emphasis on diabetic neuropathy, to develop leads for prevention and treatment.**

Recommendations on Macrovascular Complications:

- **Increase research on the mechanisms by which diabetes and insulin resistance enhance the atherosclerotic process and on the mechanisms of angiogenesis and its use in the treatment and prevention of macrovascular disease.**
- **Increase research to determine the mechanisms responsible for the loss of the vascular-protective effect in premenopausal women.**
- **Increase basic and clinical research to study myocardial function and the cardiac and micrometabolic environment in diabetic heart disease in order to identify the mechanisms that lead to the high mortality in the peri-infarction period and in patients undergoing surgery, and to develop effective preventive interventions.**
- **Support research to develop appropriate animal models of diabetes and atherosclerosis.**
- **Support further analysis of existing studies and new clinical research to identify the presence, predict the progression, and assess the response to therapy of macrovascular complications in patients with diabetes.**
- **Create multidisciplinary Centers for Diabetes and Vascular Disease.**

Methods to Optimize Glucose Control

Despite the findings of clinical trials and other studies that have demonstrated the importance of tight glucose control to minimize the risk of long-term complications, many patients continue to have far less than optimal control. This is due in part to the risk of hypoglycemia, which increases with intensified therapy, and in part to the difficulty of obtaining optimal control in a general clinical setting. The Diabetes Research Working Group believes that identification of methods that promote implementation of these standards of treatment should be a high priority of current clinical research.

Recommendations:

- **Increase basic and clinical research to discover novel approaches for controlling hyperglycemia in diabetes. These approaches should include designing small, orally bioavailable molecules mimicking insulin action; overcoming insulin resistance or stimulating insulin secretion in a physiologic manner; and developing technologies that enable administration of insulin by routes other than injection. This research could involve enhanced collaboration with the pharmaceutical and biotechnology industry.**
- **Develop a focused, multi-disciplinary research program on hypoglycemia and hypoglycemic unawareness. This research should include the neuroendocrine and neuroscience mechanisms that underlie these problems, and increased clinical research to find simple, reliable techniques to identify patients at greatest risk for severe hypoglycemia.**
- **Initiate immediate review of the research program to develop mechanical**

approaches to insulin replacement by the Diabetes Technology Taskforce (see "Resource and Infrastructural Needs").

Diabetes and the Environment

The environment appears to play important roles in Type 1 diabetes as a trigger for the autoimmune response and in Type 2 diabetes as a modifier of pre-existing genetic risk. While the latter influence is partly understood, but difficult to control, the former influence has been difficult to define in any specific way. Identification of these environmental factors would provide important information for any preventive strategies for either form of diabetes.

Recommendations:

- **Hold a series of conferences and workshops to explore new methods to search for the environmental triggers of Type 1 diabetes and other autoimmune diseases.**
- **Perform epidemiologic analysis of suspected triggering factors, such as latent or endogenous viruses (including retroviruses) or other substances, whose activation may initiate the autoimmune process.**
- **Explore with the Centers for Disease Control and Prevention the possibility of a national registry for Type 1 diabetes as a mechanism to enhance epidemiologic research.**
- **Support research to develop and apply new technologies to provide accurate, affordable, quantitative measures in normal, living humans of individual-specific energy expenditure, energy intake and macronutrient composition, which contribute to obesity and Type 2 diabetes.**
- **Initiate new epidemiological studies taking into account genetic susceptibility to help identify additional environmental risk factors for Type 2 diabetes, such as stress levels and bacterial/viral infectious agents.**
- **Study environmental factors responsible for the increase in Type 2 diabetes in children and ways to modify them.**

Diabetes in Women, Children and the Elderly

Diabetes mellitus presents additional problems to women with its impact on reproductive health and vascular complications. Children and the elderly present special problems in management and may have additional physiological variables that must be addressed through specific research.

Recommendations:

- **Increase basic and clinical research to identify the mechanisms by which the intrauterine environment, including the diabetic environment, affects the immediate and long-term health outcomes for children and their risks of diabetes and obesity.**
- **Support research to determine the impact of Type 1 and Type 2 diabetes on women, including their reproductive health; risk of cardiovascular disease; the relationship of insulin resistance syndrome and polycystic ovarian disease; and the risk of diabetes following gestational diabetes mellitus.**
- **Increase studies about specific psychosocial issues that face women, children and the elderly with diabetes, including eating disorders, impact of school settings on diabetes, and the management of diabetes in assisted-living situations.**
- **Increase studies of how to implement effectively the principles of the Diabetes**

Control and Complications Trial (DCCT) in children with Type 1 diabetes in an effort to improve glucose control and reduce the complications of disease.

- **Increase studies on age-related changes in the development of Type 2 diabetes, and the effects of these changes on responses to treatment and prevention strategies in older persons.**

Diabetes in Minority Populations

Minority populations, including African Americans, Hispanics, Native Americans, and Asians, have the highest incidence of diabetes and the highest rates of complications of the disease. Current research has only begun to address the reasons for this in a very limited way. These groups are rapidly growing segments of the population and specific research must address the reasons for the disproportionate impact of diabetes they bear.

Recommendations:

- **Increase efforts in genetic studies in minority populations as part of the proposed National Consortium for the Study of Genetics of Diabetes.**
- **Support research to identify physiologic and environmental determinants for development of Type 2 diabetes and its complications in minority populations, including in children and adolescents.**
- **Support research to identify risk factors, co-morbidities, and primary and secondary prevention strategies for micro- and macrovascular complications of diabetes in minority populations.**
- **Initiate research to develop culturally sensitive, preventive and therapeutic approaches utilizing appropriate, innovative communication and education techniques applicable in relevant, "real world" settings, for example, rural clinics, county clinics, and urban health centers.**
- **Design and conduct studies in partnership with minority communities to understand more fully the cultural, familial, and other factors that influence adoption of health-promotion, and to change high risk behaviors in those with or at risk for Type 2 diabetes.**

Genetic Engineering

The ability to modify the function of cells through genetic engineering opens up tremendous opportunities for new therapeutic approaches to diabetes and its complications. The Diabetes Research Working Group recommends that several applications of this technology be explored.

Recommendations:

- **Increase research to explore the possible use of genetic engineering as a strategy for beta-cell replacement and immunomodulation of transplanted cell lines.**
- **Expand research to explore the potential for gene therapy for Type 2 diabetes.**
- **Bolster research to explore unique applications of gene therapy for tissue-specific approaches to micro- and macrovascular complications.**

Behavioral and Health Services Research

Lifestyle variables, such as dietary intake and physical activity, represent important risk factors for Type 2 diabetes. Type 1 diabetes management can also be influenced by behavioral patterns and can greatly influence personal, family and social dynamics.

Recommendations:

- **Intensify clinical behavioral research to develop interventions to improve patients' adherence to diabetes treatment and their quality of life, and promote sustained improvements in lifestyle behaviors, particularly diet and exercise, which will effectively prevent and reduce the risk for diabetes.**
- **Extend research and development of valid methodologies to measure psychosocial and behavioral factors in diabetes.**
- **Integrate behavioral and pharmacological approaches to reduction of risk factors for diabetes and its complications.**
- **Develop interdisciplinary research teams and training programs to bring together individuals who have training in behavioral sciences with those who have training in diabetes, nutrition, and exercise physiology.**
- **Study the effectiveness of different clinical practices, interventions and technologies; and identify deficiencies in access to care for diabetic patients.**
- **Support research to address lifestyle risk factors and behavioral modification/counseling programs, including obesity, unhealthy dietary preferences, and smoking cessation.**

Oral Complications of Diabetes

Oral complications of diabetes include periodontal diseases, mucosal infections, salivary gland dysfunction, and neurological disorders. These complications are extremely common, as well as problematic. In addition, they are difficult to treat and greatly interfere with essential daily tasks such as eating and speaking.

Recommendations:

- **Establish multidisciplinary Centers for Oral Complications of Diabetes and identify means for prevention and treatment.**
- **Increase studies of the oral complications of diabetes, particularly with respect to the chronic destruction of gingival tissues, the immune response to oral bacteria, salivary dysfunction, healing of oral wounds, and oral neuropathies.**

Resource and Infrastructural Needs

An effective program of diabetes research can exist only if there is a supportive infrastructure. New and expanded initiatives are required to address issues of human resources, clinical research, special needs for animal research, high-cost technology, and other components of infrastructure. Also essential are mechanisms for ongoing review, evaluation, and advice regarding implementation of all of the recommendations in the Strategic Research Plan set forth by the Diabetes Research Working Group.

Recommendations:**For Strengthening Human Resources for Research**

- **Create new mechanisms and significantly modify existing programs to maximize recruitment, research training, and research career development of diabetes investigators, including special initiatives to promote clinical research and to attract investigators from other disciplines.**

For Enhancement of the Diabetes Research Centers

- **Create new Comprehensive Diabetes Research Centers (CDRCs) to provide enhanced infrastructure support, and enhance the effectiveness**

of existing Diabetes Centers (DERCs and DRTCs) by significantly increasing their funding levels and expanding their mission.

For Developing and Harnessing New Technologies

- **Create a National Diabetes Technology Task Force.**
- **Create new regional centers with advanced technologies required for metabolic and functional imaging studies, such as nuclear magnetic resonance (NMR), positron emission tomography (PET), and related technologies, which are required for contemporary diabetes research, and provide ongoing support for their operation.**

For Animal Models for Study of Diabetes

- **Establish regional Centers for Animal Models of Diabetes and Related Disorders.**
- **Support mechanisms to develop and characterize larger animal models of Types 1 and 2 diabetes and their complications, and distribute these models for enhanced approaches to genetic and metabolic studies and the full range of diabetes complications.**

For Human Materials for Diabetes Research

- **Expand support of programs for procurement of human tissues and organs in order to serve cutting-edge diabetes research; to provide adequate numbers of pancreases for islet cell clinical trials and research; to obtain appropriate tissues for study of diabetes complications and genetic research; and to ensure availability of a range of human tissues required to establish DNA and RNA libraries.**

For NIH-Pharmaceutical and Biotechnology Interactions

- **Establish an NIH-Industry-Academia Task Force to foster interactive research initiatives.**

For the Intramural Programs of the NIH

- **Create an advisory panel, established by the Director of the National Institutes of Health, to review and make recommendations concerning intramural NIH diabetes research efforts in all Institutes and Centers.**

For Extramural Research and Ongoing Strategic Planning

- **Create a Task Force on Strategic Planning in Diabetes Research that would report biennially to the Congress and the Directors of NIH and NIDDK.**

SUMMARY OF BUDGET RECOMMENDATIONS

The Diabetes Research Working Group has conducted a careful review of NIH-funded diabetes research and believes that this enterprise is a strong and valuable component of U.S. biomedical research efforts. However, the nation is far from achieving its maximal potential with this difficult problem. Limitations are created in part by under-funding of diabetes research, and by the design of existing research mechanisms and infrastructure. The Diabetes Research Working Group believes that progress over the past decade, coupled with the explosion of information in science, makes this an appropriate time to increase significantly the nation's investment to conquer this disease. To implement its recommendations, the Diabetes Research Working Group calls upon the Congress and the American people to increase research funding through new appropriations to NIDDK and other Institutes and Centers of NIH.

The table on the following page summarizes these budgetary recommendations. They call for stepwise expansion of funding for diabetes research providing an increment of \$384.5

million for FY2000 rising to an increment of \$1.166 billion by FY2004. Built on a base of diabetes research funding for FY1999 of \$442.8 million, this proposed budget increment would result in an approximate four-fold increase in overall NIH funding for diabetes research over the coming five-year period. The Diabetes Research Working Group believes that such a budget increase is necessary for implementation of the programs presented in this Research Plan, consistent with the rising impact of diabetes on the U.S. in both human and economic terms, and that the proposed budget is more in line with the levels of research funding for other major disease areas. Most importantly, the Diabetes Research Working Group believes that such an investment has the potential to reduce dramatically the personal, societal and economic burden of diabetes for the American people in the 21st century.

Summary of Budget Recommendations

	Year 1	Year 2	Year 3	Year 4	Year 5
	2000	2001	2002	2003	2004
	<i>(in millions of dollars)</i>				
Extraordinary Opportunities					
Genetics of Diabetes	40.5	72.0	85.0	99.0	101.0
Autoimmunity and the Beta Cell	30.0	45.0	58.0	66.0	79.0
Cell Signaling and Cell Regulation	38.0	57.0	73.0	86.0	94.0
Obesity	15.0	25.0	37.0	46.0	52.0
Clinical Research and Clinical Trials	87.0	139.0	191.0	252.0	280.0
Subtotal	210.5	338.0	444.0	549.0	606.0
Special Needs for Special Problems					
Microvascular Complications	51.0	80.0	106.5	124.0	129.5
Macrovascular Complications	34.0	58.0	79.0	95.0	102.0
Optimization of Glucose Control	9.5	16.0	24.0	29.0	36.0
Diabetes and the Environment	3.0	4.0	6.0	8.0	10.0
Special Needs in Women, Children, and the Elderly	20.0	40.0	60.0	80.0	80.0
Special Needs in Minority Populations	9.0	15.0	22.5	30.0	32.0
Genetic Engineering	8.0	15.0	22.0	28.0	35.0
Behavioral and Health Services Research	8.0	13.5	20.0	27.0	40.0
Oral Complications of Diabetes	1.0	1.5	2.0	2.5	3.0
Subtotal	143.5	243.0	342.0	423.5	467.5
Resource and Infrastructural Needs					

Research Training and Manpower Development	3.0	5.0	8.0	10.0	10.0
Diabetes Research Centers Program	6.0	15.0	25.0	40.0	40.0
Technology Taskforce	13.0	17.0	21.0	13.0	13.0
Regional Centers for Animal Models	5.0	10.0	16.0	26.0	26.0
Human Materials for Diabetes Research	2.0	2.0	2.0	2.0	2.0
NIH-Pharmaceutical and Biotechnology Interactions	0.5	0.5	0.5	0.5	0.5
Review of Intramural Programs of NIH	0.5	0.5	0.5	0.5	0.5
Taskforce for Strategic Planning	0.5	0.5	0.5	0.5	0.5
Subtotal	30.5	50.5	73.5	92.5	92.5
Increment over FY99 Base to Implement Recommendations in DRWG Strategic Research Plan	384.5	631.5	859.5	1065.0	1166.0
FY99 Base for Diabetes Research	442.8	442.8	442.8	442.8	442.8
Grand Total for Diabetes Research	827.3	1074.3	1302.3	1507.8	1608.8
<i>More detailed budgetary information presented in terms of the specific scientific recommendations and the corresponding additional funds proposed for individual Institutes and Centers of the National Institutes of Health will be found in the full Strategic Plan of the Diabetes Research Working Group.</i>					

DIABETES RESEARCH WORKING GROUP

C. Ronald Kahn, M.D., Chairman
Director, Joslin Diabetes Center
Mary K. Iacocca Professor of Medicine
Harvard Medical School

Jose Caro, M.D.
Lilly Research Laboratories

Nancy Cox, Ph.D.
University of Chicago

Lee Ducat
National Disease Research
Interchange/
Human Biological Data Interchange

Joyce C. Dugan
Eastern Band of Cherokee Indians

Robert N. Frank, M.D.
Wayne State University School of
Medicine

James R. Gavin III, M.D., Ph.D.
Howard Hughes Medical Institute

Willa Ann Hsueh, M.D.
University of California, Los Angeles

Hugh O. McDevitt, M.D.
Stanford University

Douglas Melton, Ph.D.
Harvard University

Christopher B. Newgard, Ph.D.
UT Southwestern Medical Center at Dallas

Daniel Porte, Jr., M.D.
University of Washington and
Seattle Veterans Affairs Medical Center

Stephen Smith
American Diabetes Association

Emily Spitzer
Juvenile Diabetes Foundation International

Michael P. Stern, M.D.
University of Texas Health Science Center at
San Antonio

Rena Wing, Ph.D.
University of Pittsburgh School of Medicine and
Brown University

Lester B. Salans, M.D., LBS Advisors, Inc., New York, New York, served as Senior Medical Advisor.

AD HOC CONSULTANTS TO THE CONGRESSIONALLY-ESTABLISHED DIABETES RESEARCH WORKING GROUP

Kelly J. Acton, M.D., M.P.H., F.A.C.P. Indian Health Service	Daryl K. Granner, M.D. Vanderbilt University School of Medicine	Jerrold M. Olefsky, M.D. University of California, San Diego
Michael A. Brownlee, M.D. Albert Einstein College of Medicine	Thomas C. Hohman, Ph.D. Wyeth-Ayerst Research	Jeffrey E. Pessin, Ph.D. University of Iowa
Thomas A. Buchanan, M.D. University of Southern California School of Medicine	George L. King, M.D. Harvard University	Kenneth S. Polonsky, M.D. The University of Chicago
Patrick Concannon, Ph.D. University of Washington	John Kitzmiller, M.D. Good Samaritan Hospital	E. Albert Reece, M.D. Temple University School of Medicine
Donald Coustan, M.D. Brown University School of Medicine	S. Robert Levine, M.D. Juvenile Diabetes Foundation International	Douglas L. Rothman, M.D., Ph.D. Yale University School of Medicine
George S. Eisenbarth, M.D., Ph.D. University of Colorado Health Sciences Center	Michael Mauer, M.D. University of Minnesota Medical School	Christopher D. Saudek, M.D. Johns Hopkins University
Edwin Fisher, Ph.D. Washington University	Boyd E. Metzger, M.D. Northwestern University	Gerald I. Shulman, M.D., Ph.D. Yale University School of Medicine
Michael S. German, M.D. University of California - San Francisco	Richard Nesto, M.D. Beth Israel Deaconess Medical Center	Anders A.F. Sima, M.D., Ph.D. Wayne State University School of Medicine
Marvin C. Gershengorn, M.D. Cornell University Medical College		Lorraine Valdez Indian Health Service Diabetes Program

Diabetes Research Working Group News

FOR: SARAH BIANCHI

FROM: MIMI SILVERMAN

THE DIABETES PLEDGE:

Since 1981, the share of NIH's budget dedicated to diabetes has fallen 30% while the diabetes death rate has risen 30%.

If elected President, will you triple NIH funding for diabetes research by 2004?

This amount was recommended by the Diabetes Research Working Group, a panel of experts appointed by NIH.

_____ Yes _____ No

Signature: _____



FOR: SARAH BIANCHI
FROM: MIMI SILVERMAN

DIABETES FACT SHEET

THE NEXT PRESIDENT MUST TRIPLE DIABETES RESEARCH FUNDING!

HERE'S WHY

- Diabetes currently affects about 16 million people in the United States, between 6 and 7 percent of the total population. 800,000 new cases of diabetes will be diagnosed this year.
- Death rates for cancer, cardiovascular disease, and stroke have all decreased during the last twenty years, largely due to increased research dollars and better treatments. For diabetes, however, death rates have **increased** by 30 percent over the same time period.
- The economic cost of diabetes is staggering – annually, over \$105 billion in the United States alone. One of every four Medicare dollars pays for health care for people with diabetes.
- While diabetes accounts for over 10 percent of all health care dollars, federal funding for diabetes research is only about 3 percent of federal health-related research.
- Since 1981, the death rate due to diabetes has increased by 30 percent. But at the National Institutes of Health, where the majority of disease-related research takes place, the proportion of the overall budget devoted to diabetes research has **decreased** by 30 percent during that same time.
- Directed to do so by Congress, the NIH appointed a Diabetes Research Working Group (DRWG), charging it with developing a comprehensive plan for diabetes research. In 1999, the DRWG reported to Congress. It found that the amount being spent by NIH in 1999 for diabetes research (approximately \$443 million) was inadequate, stating "...many scientific opportunities are not being pursued due to insufficient funding."
- The DRWG specifically recommended that funding be substantially increased during each of the next five years – spending \$827 million in the year 2000 and culminating in over \$1.6 billion to be spent in the year 2005. The DRWG reported to Congress: "[We are] convinced that a significant investment in research today will greatly speed progress in understanding and conquering this disease and its complications."

Subj: Gore's "big increase"
Date: 11/5/99 11:23:16 AM Eastern Standard Time
From: JLAMOUNTAIN@DIABETES.ORG (Joseph LaMountain)
Sender: ADVOCATE@LISTSERV.DIABETES.ORG (ADA Advocate)
Reply-to: ADVOCATE@LISTSERV.DIABETES.ORG (ADA Advocate)
To: ADVOCATE@LISTSERV.DIABETES.ORG

I am so angry I cannot see straight. And advocate Patti Wong is the reason why. That's because Patti sent me a transcript of last week's debate between Al Gore and Bill Bradley in NH.

In response to a question, asked by the mother of a child with diabetes, Gore said: "You know, we've just had a big increase in research for juvenile diabetes, and I'm hopeful we can find a cure for that and cancer and other diseases."

As Patti asked me, "What is the big increase he is talking about?" Good question. Obviously, the VP has no clue whatsoever about diabetes funding, despite everything we've done over the last month.

During that time, ADA staff met with Gore's chief policy aide to explain the dismal state of funding. On top of that, thousands of calls, letters, faxes, and emails were directed to the VP by advocates, and not just by the 3,000 people who receive these email messages.

Yet the VP is still under the mistaken assumption that everything is hunky dory. Someone must be telling the VP and his staff that people with diabetes are happy with the current situation. How else can you explain it? This is depressing, frustrating and annoying all at once.

A wise man once said that "desperate times call for desperate measures." I say that desperate times call for desperate calls - to VP Gore's campaign offices, of course.

And I'm not talking about just one call to his office today. We've tried that and it hasn't worked. What we need is a steady drumbeat of calls, every day, until he and his staff wake up.

Will you call his office every day until the message gets through? If yes, please send me a message at jlamountain@diabetes.org and make sure to include your name, city and state.

Once I have a list of callers compiled and organized, I'll send you a phone number to call daily. I'll also include talking points and send you a reminder email each day.

We are down to the last few days in this year's budget cycle. The process is almost over. And unlike all the other candidates running for President, VP Gore can still make a difference because of his position. But we have to convince him.

I hope to hear from you soon.

Leading the fight to cure diabetes.....

Joseph LaMountain
National Director of Advocacy
American Diabetes Association
1701 N. Beauregard Street
Alexandria, VA 22311
fax: 703-549-8748

----- Headers -----

Return-Path: <owner-advocate@LISTSERV.DIABETES.ORG>

Received: from rly-yd02.mx.aol.com (rly-yd02.mail.aol.com [172.18.150.2]) by air-yd03.mail.aol.com (v62.15) with ESMTP; Fri, 05 Nov 1999 11:23:16 -0500

Received: from Wilma.Diabetes.ORG (wilma.diabetes.org [207.78.21.3]) by rly-yd02.mx.aol.com (v62.10) with ESMTP; Fri, 05 Nov 1999 11:23:06 -0500

DIABETES FACTS

HOW MANY?

- * 16 million Americans have diabetes [DRWG-p.2]
- * "about 800,000 new cases are diagnosed each year." [DRWG-p.2]
- * A new case of diabetes is diagnosed every 40 seconds [JDF]
- * There are 62,000 diabetics in NH [ADA]
- * In greater Manchester alone, there are 14,608 diabetics [ADA]

HEALTH IMPACT

- * "Diabetes is the 6th leading cause of death due to disease in the US." [DRWG-p.2]
- * It "contributes to the deaths of over 179,000 Americans every year." [JDF]
- * It "reduces average life expectancy by up to 30%." [JDF]
- * "shortens average life expectancy by up to 15 years." [DRWG-p.1]

- * "Diabetes affects virtually every tissue of the body with long term and severe damage." [DRWG-p.2]

- * "Diabetes is the leading cause of kidney failure, blindness in adults, and amputations." [DRWG-p.1]

- * "Diabetes is the number one cause of new blindness." [JDF]

- * "Diabetic kidney disease (nephropathy) accounts for 42% of new cases of end-stage renal disease, and is the fastest growing cause of kidney dialysis and transplantation (over 100,000 cases per year)." [DRWG-p.2]

- * "Nervous system damage (neuropathy) affects over 60 percent of diabetics, causing impaired sensation or pain in the feet or hands, slowed digestion of food in the stomach, impotence and other problems." [DRWG-p.2]

- * "More than half of lower limb amputations in the United States occur among people with diabetes." [DRWG-p.2]

- * "Heart disease death rates in adults with diabetes are about 2 to 4 times those of people without diabetes." [DRWG-p.2]

- * "High blood pressure affects over 60 percent of people with diabetes. As a result of the combination of hypertension and diabetes the risk of stroke is increased 2 to 4 times." [DRWG-p.2]

- * "The prevalence of diabetes is increasing at alarming rates in all age groups..."
[DRWG-p.15]

ECONOMIC IMPACT

- * "The cost of diabetes to the nation is over \$105 billion annually." [DRWG-p.2]
- * "More than one of every ten U.S. health care dollars is spent for diabetes." [DRWG-p.2]
- * "One of about four Medicare dollars pays for health care of people with diabetes."
[DRWG-p.2]
- * The annual direct economic cost in greater Manchester alone is \$101,503,392. [ADA]

FUNDING PROBLEM

- * NIH will spend about \$443 million in FY 1999 on diabetes research. [DRWG-p.3]
- * "The federal investment in diabetes research represents about 3 cents out of each dollar, that is about 3 percent of the NIH research budget.....this is clearly a small investment for a disease that affects 6 to 7 percent of the population and accounts for more than 10 percent of all health care dollars." [DRWG-p.3]
- * "The proportion devoted to diabetes research, relative to the whole NIH budget, has decreased by more than 30 percent since 1981, at a time when the death rate due to diabetes has increased by 30 percent." [DRWG-p.3]
- * "The DRWG report calls for NIH to spend \$827 million in fiscal year 2000 on diabetes research..." [JDF-10/28/99]
- * "Last year AIDS got twenty-four hundred dollars per patient from NIH, breast cancer two hundred and thirty dollars, heart disease just one hundred and eight dollars. Parkinson's: seventy-eight dollars. And diabetes, which last year killed more people than AIDS and breast cancer combined, just twenty-eight dollars."
[John Stossel, ABC-TV, 20/20, Oct. 11, 1999]
- * "Sixteen million people suffer from diabetes in America, five times more than AIDS and breast cancer combined." [Stossel., 20/20]

- * "...among killer diseases, breast cancer and AIDS aren't even near the top of the list. Breast cancer is eighth, AIDS seventeenth. Yet AIDS, with its 1.8 billion-dollar NIH budget, gets the most money. The number one killer, heart disease, last year got half a billion dollars less." [John Stossel, 20/20]
- * Legislation in the House "includes a \$2.3 billion increase- or 15 percent- in funding for the National Institutes of Health, increasing the NIH budget from \$15.6 billion to \$17.9 billion." [JDF-Oct. 28, 1999]

The Diabetes Research Working Group was established by Congress to make recommendations for future diabetes research and provide budget estimates for this research. The group is comprised of 12 scientific experts in diabetes and 4 diabetes lay representatives. Their report was presented in 1999, after a year long study. The report is entitled, Conquering Diabetes: A Strategic Plan for the 21st Century.

JDF....The Juvenile Diabetes Foundation

ADA..The American Diabetes Association



Mission
to prevent and cure diabetes
and to improve the lives of all
people affected by diabetes.

THE DIABETES PLEDGE:

Since 1981, the share of NIH's budget dedicated to diabetes has fallen 30% while the diabetes death rate has risen 30%.

If elected President, will you triple NIH funding for diabetes research by 2004?

This amount was recommended by the Diabetes Research Working Group, a panel of experts appointed by NIH.

_____ Yes _____ No

Signature: _____

New Hampshire Office

249 Canal Street Tel: (603) 627-9579
Manchester, NH 03101 Fax: (603) 669-1477

For Information Call 1-800-DIABETES • <http://www.diabetes.org>

The Association gratefully accepts gifts through your will.

October 9, 1999

Dear ____:

Thank you for taking the time to share with Vice President Gore your personal concerns about the devastating impact that Diabetes has on your son and millions of people across America. The Vice President and I share your concern about this disease and I would like to respond on his behalf.

The Vice president is working diligently with all federal departments and agencies to address the challenges that face Americans with diabetes. The issues you raised related to treatment and funding of Diabetes are of key concern to this Administration. We are working hard to bring about legislation that would expand coverage, improve quality of care, and foster an environment of compassion and tolerance for people with diabetes.

I wish the very best to you and your family and hope to soon see the day when a cure for Diabetes will be found.

Sincerely,

Sarah A. Bianchi
Senior Health Care Advisor to the Vice President
Associate Director, Domestic Policy Council

Subj: 20/20 transcript
Date: 10/21/1999 9:41:25 AM Eastern Standard Time
From: JLAMOUNTAIN@diabetes.org (Joseph LaMountain)
To: Dchret1600@aol.com

File: 2020 transcript.doc (56832 bytes)
DL Time (26400 bps): < 1 minute

Here it is. Also included as an attachment

To: SARAH BIANCHI
From: MIMI SILVERMAN
BEDFORD, NH
(603-472-5814)
6 pages total

Unidentified Announcer: Next, star power and politics. When it comes to money for medical research, it's a potent combination that could mean the difference between life and death.

John Stossel reporting:

If you have an actor come to Congress, does that make a difference?

Announcer: John Stossel and the business of lobbying for lives, when 20/20 continues.

...

Connie Chung, co-host:

If anything in Washington could be above politics, you'd think it might be the way Congress spends your tax dollars to battle diseases. Every year the government puts billions into finding cures. But how is that pie cut up? Is it fair? John Stossel wanted to find out who gets the biggest slice and why. His story starts with a woman whose life or death may depend on how those questions are answered.

Stossel: It is nine in the morning, and Joan Samuelson is trying to get up. Some days she can't get up. Twelve years ago, Joan learned she had Parkinson's disease. Since then, she's been gradually losing control of her body. Mornings, she is almost completely frozen, unable to make her muscles obey or stop the shaking.

Joan Samuelson (Parkinson's Patient): It's like being a prisoner, and the jail cell is my body. And I'm locked in, and I can see out, and I can think and I can know what I want to do with my day, but I can't move.

Stossel: She says it takes all her strength to slowly reach the pills that control some of her symptoms. Joan's doctors tell her eventually the pills won't work anymore and Parkinson's will take her life.

Samuelson: I will slowly slide away. I will lose my capacity to take care of myself, and for some period of time I will disappear, at some point or another, unable to move and speak, before I die.

Stossel: Yet, even more devastating than her disease, she says, is that scientists tell her they could cure her Parkinson's if they just had more research money. But they don't, they say, because the money goes elsewhere. That means that even when her pills get her moving, as they did today, Joan says her own life is slipping away needlessly.

Samuelson: Parkinson's is going to be treated effectively, cured, whatever you want to call it, probably—I mean, probably easily within twenty years.

Stossel: In time for you?

Samuelson: Twenty years won't be in time for me. Ten years probably won't be in time for me.

Stossel: If they just gave more research money, it could be in time for you?

Samuelson: Oh, absolutely.

Stossel: Samuelson's now given up her career as a lawyer to devote what time she has left to asking Congress to set aside more money for Parkinson's. Here she got to meet with Senator Arlen Specter, who explains to her that often it's he and other senators, rather than research scientists who know best how the money should be spent.

Senator Arlen Specter (Republican, Pennsylvania): We have contacts with America much more so than the people in the confines of NIH.

Stossel: NIH means National Institutes of Health. Scientists here decide which researchers around the country have the most promising ideas. And then they distribute grant money to those scientists. Now, NIH isn't the only source of research money. Your charitable contributions help, too—all of those charity balls and walk-a-thons. But the millions these campaigns raise amount to little compared to the billions government spends.

* Now, given that these billions are your tax money, you would think they would be sure to spend it on the research scientists think will save the most lives or relieve the most suffering. But amazingly they don't, because Congress makes sure that they spent the lion's share of the money on the people who have the most political clout.

If you want to know how to make money and influence the government, look no further than the AIDS lobby. Fifteen years ago, as AIDS was killing more and more people, NIH spent little on AIDS research. So, desperate to be heard, AIDS activists rewrote the book on medical research lobbying. They heckled President Reagan, stopped traffic, marched on Congress and accused politicians who ignored their demands of discrimination against homosexuals.

Unidentified Activists: Shame, shame, shame, shame.

Stossel: The result? AIDS research now gets more money per patient than any other disease. The remarkable success of the AIDS lobby then became a model for people who wanted more money for breast cancer.

Group: (In unison) Show us the money. Show us the money.

Stossel: They were even specific about how many billions they should have.

Group: (In unison) 2.6 billion dollars. 2.6 billion dollars.

Fran Visco (President, National Breast Cancer Coalition): The Republican leadership was unable to walk five minutes from inside the Capitol to be out here with us today.

Stossel: Politicians who were not quick enough to show their support for this cause were labeled anti-woman.

Visco: But they will hear from us.

Stossel: This campaign worked, too. In seven years, NIH breast cancer research funds increased tenfold. And today, what politician doesn't want to be seen supporting this cause?

Vice President Al Gore (United States): We all want to win the real race to find a cure.

* Stossel: We all do. But what surprised us, and what the AIDS and breast cancer lobbies may not want you to know, is that among killer diseases, breast cancer and AIDS aren't even near the top of the list. Breast cancer is eighth, AIDS seventeenth. Yet AIDS, with its 1.8-billion-dollar NIH budget, gets the most money. The number-one killer, heart disease, last year got half a billion dollars less. Per patient, the disparities are even greater. Last year AIDS got twenty-four hundred dollars per patient from NIH, breast cancer two hundred and thirty dollars, heart disease just one hundred and eight dollars. Parkinson's: seventy-eight dollars. And diabetes, which last year killed more people than AIDS and breast cancer combined, just twenty-eight dollars. Congressman Ernest Istook has been trying to even out the research grants, without success.

Representative Ernest Istook (Republican, Oklahoma): If you have the politically correct disease, the prospects of getting federal funding to help find the cure are a hundred times greater than if you have some other disease, even though it may be a much more common disease.

Stossel: Isn't this unfair? Daniel Zingale is executive director of the most powerful AIDS lobby.

When you're getting ten times as much money as other diseases, isn't there something wrong?

Daniel Zingale (AIDS Action): This is a deadly communicable disease. It's striking young people. It even threatens to bring down entire nations in some parts of the world. So the scientists take those factors into consideration, and they should.

Stossel: Though Zingale admits the politicians take other factors into consideration.

Rosie Perez (AIDS Advocate): (From TV commercial) And I called up all my fabulous friends and said, I'm going to be at the AIDS dance-a-thon.

Stossel: Rosie Perez is just one of the star-studded fraternity of AIDS advocates.

If you have an actor come to Congress, does that make a difference? Will that help people?

Zingale: It does. When Elizabeth Taylor came and talked about AIDS, it draws 20/20.

Stossel: And lots of other cameras and senators. It was a packed committee hearing.

Elizabeth Taylor (Actress): (From committee hearing) I will not be silenced, and I will not give up, and I will not be ignored.

Stossel: And she was not ignored. Compare this with the hearing where Joan Samuelson testified.

Samuelson: (From hearing) My testimony...

Stossel: Most of the legislators' chairs were empty.

What was your hope?

Samuelson: That the seats would be full, of course.

Stossel: They weren't.

Samuelson: And that they'd cry and gnash their teeth and say, We're going to do it.

Stossel: Didn't happen.

Samuelson: No, it didn't happen, no.

Stossel: If only she were Miss America.

Zingale: Hello.

Nicole Johnson (Miss America): Hello.

Zingale: How are you?

Stossel: Daniel Zingale's group, AIDS Action, pays a former Miss America to visit congressmen with him.

Specter: So you're carrying on your crusade to fight AIDS after giving up Miss America's crown?

Stossel: Senator Specter seemed very interested in talking to her about AIDS and other things.

Specter: That's why I came out. I thought you would be wearing a crown.

Johnson: Oh, no. Well, actually...

Specter: How long did you wear the crown?

Johnson: I wore it three times.

Stossel: When Samuelson visits the Congress, she's constantly reminded that without star power she has little influence. Congresswoman Carol Maloney tells her, if only she could bring some celebrities with her.

Representative Carol Maloney (Democrat, New York): If Mohammad Ali would come, Michael J. Fox would come...

Stossel: Recently she got Michael J. Fox to come to Washington. And sure enough, he got a special hearing before Senator Specter's committee.

Michael J. Fox (Actor, Director): (From hearing) I was shocked and frustrated to learn the amount of funding for Parkinson's research is so meager.

Stossel: There was lots of news coverage and lots of moving testimony.

Fox: (From hearing) With the help of daily medication and selective exertion, I can still perform my job, in my case, in a very public arena. I can still help out with the daily tasks and rituals involved in home life, but I don't kid myself, that will change. Physical and mental exhaustion will become more and more of a factor, as will increased rigidity, tremor and dyskinesia. I can expect in my forties to face challenges most won't expect until their seventies or eighties, if ever. But with your help, in my fifties I'll be dancing at my children's weddings.

Stossel: Suddenly, senators were talking about putting more money into Parkinson's research. Now, if celebrities want to lend their names and faces to support a charity, great, but since we're talking about deadly diseases and your tax money, shouldn't we expect Congress to focus less on glamour and more on allocating the money fairly? Daniel Zingale of AIDS Action says Congress should just give everyone more money.

Zingale: I—I reject the idea that we have to pit the dying against the dying, or the suffering against the suffering.

Stossel: But we do.

Zingale: We shouldn't.

Stossel: For years, AIDS lobbyists urged advocates for other diseases not to complain about who gets more or less, and most don't. But this winter the American Diabetes Association broke ranks and openly cried foul.

Unidentified Woman: Congress should just stop shortchanging diabetes and fully fund diabetes research.

Mike Malby (Diabetes Association): Why do other diseases seem to be getting so much more than we do?

Stossel: Mike Malby of the Diabetes Association says it was a shock to discover that diabetes was getting only twenty-eight dollars per patient when AIDS gets a hundred times more.

Malby: We were flabbergasted at the numbers. The numbers were horrendous.

Group of Demonstrators: (In unison) Cure diabetes

Cure diabetes

* Stossel: Sixteen million people suffer from diabetes in America, five times more than AIDS and breast cancer combined. Researchers say diabetes, like Parkinson's, could be cured sooner if only there were more money available. So what has the Diabetes Association done?

Johnson: Hi, good morning.

Unidentified Congressman: Hi. Nice to see you.

Johnson: Good to see you, too.

Stossel: AIDS was last year's Miss America, so diabetes brought in the current Miss America.

Congressman: Congratulations.

Johnson: Well, thank you. You, too.

Malby: People find time on their schedules to meet with her. We met with the speaker of the House. We met with the majority leader.

Stossel: Other diabetes groups use their celebrities. The Juvenile Diabetes Foundation brought sick children to Congress, accompanied by Tony Bennett and Mary Tyler Moore.

Specter: Probably best known for her television roles in "The Dick Van Dyke Show" and "The Mary Tyler Moore Show."

Stossel: Committee Chairman Specter admits that fame and photo opportunities sell.

Specter: Christopher Reeve made a trip to the White House and came back with a promise of ten million dollars from the president.

Stossel: Is that how it should work?

Specter: It--how should it work? Yes, I think that's a fair--a fair way.

Stossel: So whoever panders most to you gets the most money?

Specter: Whoever panders the most...

Stossel: ...gets the most money.

When I began my interview with Senator Specter, he made it clear that he and other politicians greatly influence NIH funds.

Specter: Well, the subcommittee took the lead in establishing a separate unit for women, and the National Institutes of Health followed that. We are having a special hearing on prostate cancer because the chairman of the full committee has had prostate cancer and we're having a hearing on it.

Stossel: But because the chairman has prostate cancer you have a hearing, I mean--

But when he realized our story is not about how great it is that he gets money for this or that disease, but that we're questioning why some diseases get so much more than others, he changed his tune.

Two thousand dollars per AIDS patient versus twenty dollars per diabetes patient. Isn't something off?

Specter: Well, the--the--the decision as to how much money is spent is made by the National Institute of Health. It is not made by the Senate or the House or the Congress.

Stossel: But under your control, you oversee them.

Specter: The decisions are made by the National Institute of Health.

Stossel: If that's true, why are so many politicians so eager to take credit for getting people money? Here's the president being heckled by AIDS activists.

President Bill Clinton (United States): Protecting the civil rights of all Americans--

Unidentified Man #1: People with AIDS are dying

Clinton: Wait, wait, wait, wait, wait. I would have been disappointed if you hadn't been here tonight. I'm getting kind of used to this. People with AIDS are dying, but since I've become president, we're spending ten times as much per fatality on people with AIDS as people with breast cancer or prostate cancer.

Stossel: Am I missing something? Why is it a good thing to spend ten times more on AIDS than on breast cancer or prostate cancer? Or, for that matter, twenty-five times more than on Parkinson's, which kills more people? Everyone supports trying to cure AIDS and breast cancer, but Joan Samuelson wonders, why are those lives are so much more important than the people who have diseases like hers. Isn't it important, she says, to help us, too?

Samuelson: What higher national priority could there be?

We go and rescue people in foreign countries because their lives matter, because it's the moral thing to do. Well, this is a moral thing to do, too.

Jack Ford, co-host:

After Michael J. Fox went before Congress, he made another appeal for Parkinson's research on "Good Morning America." Those appearances generated thousands of messages of support to Senator Arlen Specter's office. And as a result, there's now a push in Congress for more Parkinson's research money in the next budget. We'll be right back.

###

Leading the fight to cure diabetes.....

Joseph LaMountain
National Director of Advocacy
American Diabetes Association
1701 N. Beauregard Street
Alexandria, VA 22311
fax: 703-549-8748

----- Headers -----

Return-Path: <JLAMOUNTAIN@diabetes.org>

Received: from rly-yb01.mx.aol.com (rly-yb01.mail.aol.com [172.18.146.1]) by air-yb05.mail.aol.com (v62.10) with ESMTTP; Thu, 21 Oct 1999 10:41:25 -0400

Received: from Mail.Diabetes.ORG (wilma.diabetes.org [207.78.21.3]) by rly-yb01.mx.aol.com (vx) with ESMTTP; Thu, 21 Oct 1999 10:40:49 -0400

Received: from diabetes.org ([207.78.20.9])
by Mail.Diabetes.ORG (8.9.3/8.9.3) with SMTP id KAA25032
for <Ochret1600@aol.com>; Thu, 21 Oct 1999 10:40:45 -0400

Received: from ADA-Message_Server by diabetes.org
with Novell_GroupWise; Thu, 21 Oct 1999 10:40:41 -0400

Message-Id: <s80eeda9.041@diabetes.org>

X-Mailer: Novell GroupWise 5.2

Date: Thu, 21 Oct 1999 10:40:30 -0400

From: "Joseph LaMountain" <JLAMOUNTAIN@diabetes.org>

2



4

$$200 \overline{) 8,240}$$

□

$$\begin{array}{r} 50 \\ 40 \\ \hline 200 \end{array}$$