

The Mission of the American Diabetes Association

1993 Presidential Address

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The mission of the American Diabetes Association is "to prevent and cure diabetes, and to improve the lives of all people affected with diabetes."

The importance of this mission is borne out by the fact that, in the U.S., some 13 million people have diabetes. Almost 700,000 people will be diagnosed this year and 160,000 will die from the disease, making it the sixth leading cause of death (fourth by disease) in the U.S. Diabetes also causes enormous disability, as you are all well aware: blindness, kidney and heart disease, stroke, and amputations.

We estimate that more than \$90 billion is spent annually for diabetes health care, constituting some 5% of total health costs.

The American Diabetes Association, in keeping with its mission, was instrumental in 1974 in persuading Congress to instruct the Director of NIH to establish a National Commission on Diabetes.

The recommendations of the Commission led to the National Diabetes Long-Range Program, which increased federal NIH funding for diabetes research and education from \$39 million in 1975 to \$126 million in 1979 to \$279 million today.

With the internal restructuring of our Association in 1989 and the appointment of new national staff officers, we have experienced a marked improvement in the morale of the American Diabetes Association. The trust that now exists between the local state Affiliates and the National Center has allowed us to move forward aggressively in two vital areas: fund raising and volunteer development.

FUND-RAISING, RESOURCE ALLOCATION, AND RESEARCH FUNDING

— Fund-raising is growing by leaps and bounds. In Table 1, you can see that the results are impressive. Our total income has gone from \$31 million to \$71 million from 1985 to 1992, just 7 years! Total public support is what we raise, revenue is our store, what we sell to people: journals, educational materials, scientific meetings, etc. Revenue is generally a wash, we try to break even in this category, and generally do. Thus, the important item in fund-raising is public support income. And, despite a dramatically slowed economy, we have done extremely well in this category, going from \$20 million in 1985 to \$51 million in 1992.

Table 1—American Diabetes Association nationwide public support and revenue for fiscal years 1985–1993

	Public Support	Revenue	Total
1985	\$20.1	\$11.2	\$31.3
1986	\$24.2	\$11.9	\$36.2
1987	\$27.0	\$13.6	\$40.6
1988	\$30.8	\$15.2	\$45.9
1989	\$35.4	\$18.4	\$53.8
1990	\$37.6	\$18.7	\$56.3
1991	\$43.5	\$21.5	\$65.0
1992	\$51.2	\$19.7	\$70.9
1993 (Est)	\$59.6	\$20.0	\$79.6

Dollar amounts are in millions.

One of the reasons for our success in fund-raising has been volunteer development. We are attracting an expanding group of outstanding individuals who devote their valuable time and talents to this organization.

How are these funds we raise being allocated nationwide by the American Diabetes Association? The pie graph in Fig. 1 shows you this: resources go 8% for management services, 26% for patient activities, 7% for community activities, 21% for public activities, 10% for professional activities, and 12% for research.

Over the years, there has been disquiet by many in the professional section, including myself, about the commitment to research by an organization that publicly solicits money from donors to find a cure.

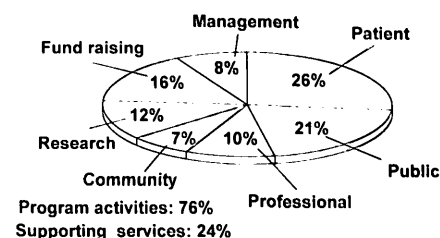


Figure 1—Combined results; expenses by type for fiscal year 1992.

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NIH, National Institutes of Health; NIDDM, non-insulin-dependent diabetes mellitus; GDP, gross domestic product; DCCT, Diabetes Control and Complications Trial; NIDDK, National Institute of Diabetes and Digestive and Kidney Diseases; CDC, Centers for Disease Control.

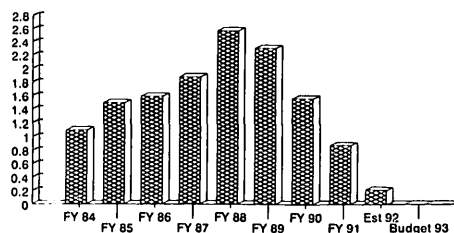


Figure 2—American Diabetes Association Affiliates local research awards and grants in millions of dollars.

To understand the present level of support for research, we need to take an historical context. Our Association phased out research awards at the local state Affiliate level in 1988. This was done for two reasons: central research peer-review ensured even-handed evaluation of all proposals throughout the organization, allowing support for the best possible research, and it allowed the best investigators to be funded irrespective of their geographical location.

The result of the phase-out of these local Affiliate programs is shown in Fig. 2. By 1993, these disappeared. The assumption by the Board of Directors was that those monies, previously used locally for research, would come nationally for research by voluntary contribution from the Affiliates. This has not occurred.

Figure 3 gives data on voluntary contributions from Affiliates, which dropped and then remained constant at the \$0.9 to \$1 million mark for 4 years. They did not rise.

Why? Because, at the same time,

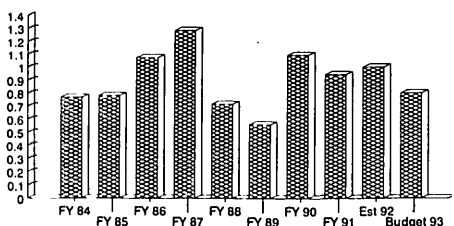


Figure 3—American Diabetes Association Affiliates voluntary research contributions in millions of dollars.

the divisibility formula between state Affiliates and the National Center was changed so that the National Center received 25% instead of 20% of divisible income, with the extra 5% coming centrally from the state Affiliates targeted specifically for research. Most state Affiliates interpreted this as their only requirement for research funding and therefore did not voluntarily give additional monies for research, even though their total fund-raising grew, and as previously mentioned, local research outlays disappeared.

As a result, the amount available for research actually fell between 1985 and 1992. The Executive Committee and Board of Directors of the Association have grappled with this problem this year. We have just approved a long-range plan of resource allocation that changes this course and moves to gradually increasing the funding for research to the \$20 million per year mark and beyond. This plan is shown in Table 2. Doing this will change our split of resource allocation from the present 14% for research versus 65% for other pro-

grams versus 21% for supporting services to a 22/57/21% split.

Is this enough? Are we keeping faith with our donors? Many people in this audience are dissatisfied with the figures. For an answer, we must look at the present culture of the American Diabetes Association.

Look again at the pie chart of how we spend our money in Fig. 1. You must realize that 75% of the money is spent locally by Affiliates, who also raise most of the public support money locally. They use this money for camps and other youth services, patient education, professional education, community programs, and state government relations. Also, some of the money goes for fund-raising activities.

But we, you and I, members of the Professional Section, have not done a good job of educating the volunteer fund-raisers and the Affiliates about the research we are doing and why we are doing it. We have not informed them adequately of the advances we are making with the research dollars and how this will affect the person with diabetes.

Table 2—Research and other uses of divisible public support

Fiscal year	Divisible public support	Research awards and grants		Other programs and services	
		Amount	% of DPS	Amount	% of DPS
1985 Actual	\$16.7	\$ 4.6	28	\$12.1	72
1986	\$20.9	\$ 4.1	20	\$16.8	80
1987	\$22.3	\$ 5.2	23	\$17.1	77
1988	\$25.0	\$ 7.2	29	\$17.8	71
1989	\$24.8	\$ 6.2	25	\$18.6	75
1990	\$28.5	\$ 6.3	22	\$22.2	78
1991	\$33.6	\$ 5.6	17	\$28.0	83
1992	\$40.0	\$ 5.4	14	\$34.6	87
1993 Budget	\$48.6	\$ 6.8	14	\$41.8	86
1994 Projected	\$54.4	\$ 8.2	15	\$46.2	85
1995	\$60.5	\$ 9.4	16	\$51.0	84
1996	\$67.2	\$11.5	17	\$55.7	83
1997	\$74.8	\$13.9	19	\$60.9	81
1998	\$83.3	\$16.8	20	\$66.5	80
1999	\$92.8	\$20.1	22	\$72.6	78

Dollar amounts are in millions. DPS, divisible public support.

As a result, many of our fund-raisers unfortunately view research as a dark hole where money disappears, money that they feel they can use more productively for their other programs.

All of us here in this room need to reverse that culture. The Association Board of Directors has instructed the Research Policy Committee this year to make its first priority the publicizing of our research program to the Association. But the publicity effort also requires the involvement of all of you in this audience. How many of you are active in your Affiliates? How many of you actually donate money to the American Diabetes Association? How many of you have ever helped to raise funds for the Association? I will tell you, very few.

I will also tell you that you can make a great difference. You must be a participant in your Affiliate. You cannot just sit back, say you want the money to go to research, and do nothing to help raise it. If you don't help raise the funds, you will have little impact on their allocation. At present, what the Task Force on Resource Allocation has recommended is, frankly, the most that the current American Diabetes Association culture will accept. It is, I believe, a major step forward in that we have formally committed to research and to expanding the funding for research in the years ahead. To get an even bigger slice of the pie for research than is now proposed to be allocated, members of the Professional Section need to become stronger participants and stronger advocates at the local level.

THE RESEARCH AGENDA — Moving to our actual research agenda, I want to tell you that in addition to our ongoing programs, which are very successful, we have taken a major step this year into targeted research with our Genetics of NIDDM Project. Its purpose is to establish a national data base to coordinate efforts of investigators to locate the susceptibility genes for NIDDM. It will include eight family acquisition centers,

one central data center, one cell repository, and one central assay center. This is a project jointly sponsored by us and by the NIDDK and is a promising model for future endeavors. It allows us to identify an important area of investigation that needs funding, and then lets us collaborate with government to get it off the ground.

HEALTH-CARE REFORM — Now, I wish to address an item of great present interest. We are, in our country today, in the midst of a polemic about health-care reform. Sometime this summer or fall, the Clinton Administration will present a plan, which will then be extensively debated by Congress, the press, and the American people.

Three issues are basic to this debate: cost, universality, and quality of care. With regard to the first, the problem has been an inability to stem costs, which have risen at a much higher rate than the standard of living. The cost of care today is 13% of the GDP, and by the end of the decade, if the rate of increase is not slowed, it will reach 20% of GDP. Economists who see such a rise react with horror. So do industrial leaders who watch helplessly as they see these costs increase their expenses and sabotage their efforts to remain competitive in an increasingly difficult world market.

The second item is our present inability to provide care for everyone. Even though some apologists for the present system state that many of the 30% of Americans without health insurance are only between jobs, or get it anyway somehow, we physicians and nurses know it isn't true. Many a poor, or not so poor, person falls through the holes of the safety net to land unattended and uncared for in a dark corner of our common house.

Third, and crucial, is quality of care, which has proven difficult to evaluate. This country, and certainly its politicians, will get into deep trouble if we gravitate everyone to the lowest cost al-

Table 3—Statement of principles on health-care reform

1. Ensure universal access to quality diabetes treatment
2. Prohibit pre-existing condition exclusions
3. Provide coverage for prescription drugs and insulin, diabetes-related supplies, equipment, and education
4. Mandate community rating

ternative without maintaining or improving the quality of care they receive.

On all three of these issues, the American Diabetes Association has a major interest. Our statement of Principles on Health Care Reform has four headings (Table 3).

Ensuring universal access to quality diabetes treatment will be the issue we will need to fight particularly hard for. You have heard the results of the DCCT. Better blood glucose control today can lead to less disability later. Thus, appropriate diabetes control defines treatment for the prevention of disability. We need to make clear, at a time when the clamor and competition will be for cheaper medical care, that adequate standards of care for diabetic individuals today can lead to large savings of disability dollars in the future. This will be a difficult case to make in a rather hysterical time. We must convince politicians and providers that our standards of care make sense: that care by well-informed health professionals to patients educated about their disease with resources to control it will actually cost less money to the country and the taxpayer in the long run.

OTHER GOVERNMENT RELATIONS INITIATIVES

With regard to other government relations initiatives, the Association is actively engaged in resurrecting the Medicare Outpatient Diabetes Education Act, which failed to move in the 102nd Congress. This legislation would provide greater access to outpatient diabetes education for the Medicare population and correct

Table 4—NIH appropriations

	1992	1993	1994
NIH appropriations	\$10,006,390	\$10,339,196	\$10,667,984
NIH grants	6795	5652	5594

inconsistencies in current reimbursement practices for such services. It would be a great step forward in our efforts to gain recognition and reimbursement for diabetes education, which we know is so crucial for attaining diabetes control.

Also, the Association was encouraged by the overturning of the ban on fetal tissue research by President Clinton on 22 January 1993 (NIH Reauthorization Act—H.R. 2507). Although it is unclear at this point whether the use of fetal tissue for transplantation purposes in human diabetes will be effective, it is important to press ahead with the experiments that will tell us whether such an approach is feasible.

GOVERNMENT RESEARCH FUNDING

In 1990, the House and Senate Appropriations Committees ordered NIH to adopt a financial management plan that included 1) 6000 new and competing grants each year, 2) a stable pool of 24,000 active grants, 3) abandonment of downward negotiation of grants to prevent a large fraction of each grant award from being cut, 4) an increase in research training support, 5) the development of an NIH long-range

plan, and 6) stability and predictability to federal biomedical research funding.

Today we find this congressional order in total disarray. Of the six rather simple requests, only one has been carried out: the recently unveiled NIH Strategic Plan, which does not really speak to the other points and whose future is in doubt because the NIH Director changes with the new U.S. Administration.

With regard to NIH appropriations, these have been essentially flat from 1992 to those proposed for 1994. In constant dollars, they have actually dropped.

With regard to the number of new and competing grants, NIH has taken a zig-zag course since 1989, but the present trend is clearly down again (Table 4), from 6795 in 1992 to 5652 in 1993 to 5594 grants projected in 1994.

With regard to the NIDDK, the picture is grim. Total funding went from \$662 million to \$680 million to \$677 million from 1992 to projected 1994. In constant dollars, funding has gone down since 1992 (Fig. 4). New and competing grants (Table 5), from 1987 to 1990, fell from 686 to 425, reversed to 628 in 1992, and now promise to dip to 443 in 1993 and 419 in 1994. This last figure is by far the lowest since 1980. Grant funding is now going backwards.

In addition (Table 6), the award success rate has dropped precipitously to a projected low of 19% in 1994, and the payline to the 16th percentile. On top of this, however, have been the extraordinarily hurtful negotiated cuts on the awarded grants that have steadily taken away funds, and now are slated to cut the enormous sum of 30% from each grant by 1994.

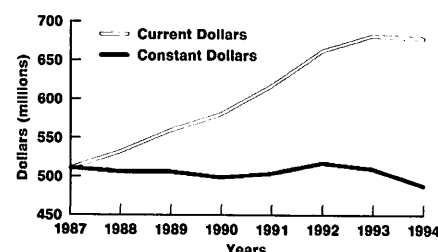


Figure 4—NIDDK appropriations.

This is indeed bad news. Bad news for older investigators. Terrible news for young investigators. In addition, all training programs have also taken cuts. Thus, at a time when we are closing in on answers relating to prevention and cure of diabetes, when the country has an outstanding cadre of scientists, government support for research is waning. The Association is doing all it can to turn this around through the lobbying of its Government Relations Committee, but each of you must also become advocates for adequate NIDDK funding. In addition, funding for CDC diabetes translation efforts and for Veterans Administration research has also stayed flat or been cut, when we clearly need an increase at the very least to keep pace with inflation. You can be effective by contacting your members of Congress, raising your voices for adequate government funding for diabetes research.

Table 6—The success rate—payline gap of NIDDK

	Success rate (%)	Payline percentile	Negotiated reduction (%)
1987	40	35	—7
1988	34	31	—10
1989	29	24	—11
1990	24	17	—12
1991	27	23	—17
1992	33	26	—25
1993	21	19	—25
1994	19	16	—30

Table 5—NIDDK grants

Year	Total	Competing
1987	2069	686
1988	2083	579
1989	2073	504
1990	2018	425
1991	2036	564
1992	2123	628
1993	2085	443
1994	2051	419

MINORITY INITIATIVES— As you know, diabetes disproportionately affects the minority populations in our country: black Americans, Latinos, and Native Americans. These groups also tend to manifest more frequent and more severe complications. The Association has moved this year to initiate programs to target these groups more effectively. We have particularly focused on the Latino population and have forged alliances with other organizations seeking better health care for them. We plan to proceed with a similar initiative for black Americans in the year to come.

PROFESSIONAL SECTION

ADVISORY PANEL— With regard to the governance of the Medical and Scientific Section, we have made significant strides this year. Much as the Affiliate Assembly acts for the voluntary health side of the organization, the Professional Section Advisory Panel will act for the Medical and Scientific Section (Fig. 5). The Professional Section Advisory Panel will be the body in which initiatives and problems of the Profes-

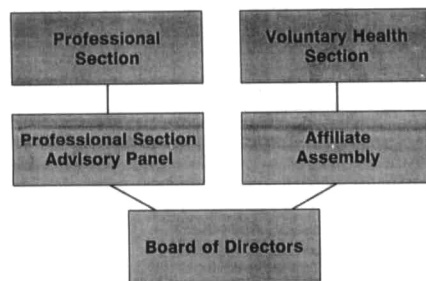


Figure 5—Table of the American Diabetes Association's organization.

sional Section will be discussed. Recommendations for action will come to the Board of Directors, paralleling those from the lay side, which come from the Affiliate Assembly. This will ensure that a knowledgeable and responsible group will look after the interests and needs of the members of the Medical and Scientific Section.

OTHER ENDOCRINE-

METABOLISM SOCIETIES— I want to make you aware of our recent meetings with other endocrine-metabolism

societies. I have initiated meetings this year among the officers of the American Diabetes Association, the Endocrine Society, the American Thyroid Association, the American Association of Clinical Endocrinologists, and the Lawson Wilkins Society. We have agreed to meet regularly and to work and speak out in areas of common concern. Our first initiative together will be to develop recommendations for a training curriculum for endocrine fellowship programs. We also hope to work together on government relations in the areas of health-care reform, research, and training, so as to have a greater impact. I am encouraged by our progress thus far, which bodes well for enhanced and fruitful collaboration in the future.

CONCLUSION— Let me say in conclusion that I was deeply honored to have been elected to serve as your president this past year, and I want to express my gratitude to all of you. I also wish to extend my best wishes to my successor, Dr. James Gavin, for what I know will be a most successful year.