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# 1997 Presidential Address

## We Are What We Repeatedly Do

Philip E. Cryer

We are what we repeatedly do. Excellence, then, is not an act, but a habit.

—Aristotle

**E**xcellence is an elusive goal for us as individuals and for our American Diabetes Association. Our Association has not reached that goal, but in my view, it is moving in that direction.

The 1996–1997 organizational year was an eventful one for the American Diabetes Association. We continued to accelerate our commitment to diabetes research; strengthened the roles of clinicians, educators, and scientists; established new diagnostic criteria and, for the first time, recommended regular diagnostic testing of those at risk for diabetes; introduced our new provider recognition program; spread the message that diabetes is serious and advocated widely for people with diabetes; and reorganized to increase our efficiency in fund-raising and programs. We should be pleased. But we cannot be satisfied.

### CORE MESSAGES

As your president, I have stressed three points over the past year. First, diabetes is serious. Second, our mission—to prevent and cure diabetes and to improve the lives of all people affected by diabetes—must continue to drive all of our decisions. Third, increased support of research is the right thing to do.

**Diabetes is serious.** Diabetes is an increasingly common, potentially devastating, extraordinarily expensive, treatable—but incurable—lifelong disease. It affects an estimated 5% of the U.S. population, as many as 20% of our Medicare population over 65 years of age, and more than 100 million people worldwide.

Diabetes is potentially devastating. It is the leading cause of blindness, with its onset in working-age adults; the leading cause of end-stage renal disease, requiring dialysis and transplantation; and the leading cause of nontraumatic amputations. People with diabetes are at a two- to fourfold increased risk for a myocardial infarction, the most common cause of premature death among people with diabetes, and for a cerebrovascular accident.

Diabetes is extraordinarily expensive. In 1992 medical care of people with diabetes consumed about 15% of all health care

expenditures in the U.S. and about 25% of the Medicare expenditures. The direct cost of medical care for people with diabetes was about \$90 billion that year. When one adds the indirect costs, such as lost productivity, the figure rose to nearly \$140 billion. Hopefully, these costs are coming down, but diabetes will likely continue to be our most expensive single disease until we reduce the complications substantially or eliminate the disease.

Diabetes is treatable, and current treatments are demonstrably effective. They have been proven to prevent or delay the long-term retinal, renal, and neural complications of diabetes and, in the setting of comprehensive medical care, likely reduce the atherosclerotic disease that leads to myocardial and cerebral infarctions. These long-term complications are responsible for much of the human costs and most of the dollar costs of diabetes, and they are at least in part preventable. One of the many challenges to our Association and to the diabetes community around the world is to extend those demonstrably effective treatments to all people with diabetes.

But current treatments are far from ideal. Diet and exercise are difficult for many people. Oral hypoglycemic agents often become ineffective and sometimes have side effects, as do antihypertensive and lipid-lowering drugs. Furthermore, all insulin replacement regimens are grossly imperfect. Thus, albeit perhaps at reduced rates, complications still occur, despite current therapies. Most importantly, diabetes cannot yet be prevented or cured.

Diabetes *is* serious. I know that. You know that. The public and our political leaders need to know that through the continued information and advocacy programs of our Association. **Our mission must continue to drive our decisions.** The volunteers and staff of any organization, particularly an organization such as the American Diabetes Association that raises and spends more than \$100 million (from revenue, including both public support and fees from exchange transactions) each year, must make innumerable operational and policy decisions. Those decisions are best made by asking which option best serves our mission to prevent and cure diabetes and to improve the lives of all people affected by diabetes? The principle that our mission must continue to drive all of our decisions might seem simple and obvious. But, it is fundamentally important. In some instances, a decision that best serves all people affected by diabetes does not best serve some individuals in the diabetes community.

**Increased support of research is the right thing to do.** You and I, and our Association as a whole, know that increased support of diabetes research is the right thing to do. Only research will prevent and cure diabetes. Research has improved the lives of all people affected by diabetes. It will continue to do so.

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To these three core messages—diabetes is serious, our mission must continue to drive our decisions, and increased support of diabetes research is the right thing to do—I will add a fourth: Our American Diabetes Association needs *you*.

**Our Association needs you.** There are many members of our professional section who have worked tirelessly in our Association; in its chapter and affiliate programs, fund-raising, and leadership; in its medical and scientific committees and its professional activities; and in its governance. I thank you for those efforts and hope you will continue to contribute. But there are many more who are not involved in the work of our Association. We need your input and help to continue to move our Association in the direction of excellence. I urge you to get involved, not only in our research, information, and advocacy programs, but also in our fund-raising and in our leadership. The future of our Association and its professional section is up to you.

Our Association was founded as a professional society, with a focus on physician education and physician-directed patient education, in 1940. It remained strictly a professional society for 30 years. We made a fundamental change in 1970. At that time, the American Diabetes Association became a voluntary health agency that embraced nonmedical volunteers. Through the work of those volunteers, we raise public funds to support our research, information, and advocacy programs.

As a voluntary health agency that includes a professional section, ours is a unique organization. It is fundamentally different from the strictly professional societies to which many of us belong—the Endocrine Society, the American Association of Diabetes Educators, the American Dietetic Association, etc. Those professional societies do not have substantial research budgets and advocate for their individual professional constituencies. In contrast, the American Diabetes Association has a growing research budget, is the authoritative source of information about diabetes in the U.S. and increasingly around the world, and advocates for people with diabetes.

The fact that the American Diabetes Association is a voluntary health agency has important pragmatic implications for its professional section. If we wish to move our Association in the direction of excellence as we see it, we must provide compelling evidence that the changes we favor are in the best interests of *people with diabetes*. While our interests as clinicians, educators, or scientists often coincide with those of people with diabetes, our interests *per se* are the purview of our other professional societies, not our voluntary health agency.

#### THE PROFESSIONAL SECTION PERSPECTIVE

Despite our successes, some members of our professional section believe the pendulum has swung too far in the direction of the voluntary health agency. Accordingly, the views of our professional section were surveyed in some detail and then debated and discussed by our Task Force on the Role of Health Professionals in the American Diabetes Association during late 1995 and throughout 1996. The Task Force then issued its recommendations, which were accepted by the board of directors in March of 1997. In my view, these are fundamentally important to the future of our professional section. I will, therefore, mention each of them.

As agreed unanimously by the executive committee in August of 1996 and the board of directors in November of

1996, the Task Force recommended that the Association should continue as both a voluntary health organization and a professional society. Clearly, there is consensus on that fundamental point.

Based on the perception that there is diminishing participation in chapter and affiliate activities by clinicians, educators, and scientists, the Task Force recommended that the Association should develop clear roles for health professionals at the community level. Again, I urge each of you, including the scientists, to get involved in the work of our Association. If we are not involved, we are not in a strong position to shape the future of the American Diabetes Association.

At the governance level, the Task Force recommended that the Association should replace the current Professional Section Advisory Panel, composed of the chairs of its scientific and medical committees and of its councils, with a Professional Section Steering Committee composed of two working groups: a scientific and medical advisory group, chaired by the president-elect, and a health care and education advisory group, chaired by the health care and education president-elect. A central premise of this recommendation is that professional section input will be most effective if it comes from individuals who actually practice the diverse clinical, educational, or scientific disciplines represented in our professional section. Another is that the chairs of the groups, both being members of the executive committee, will be able to move the recommendations of the Steering Committee directly to the executive committee and board of directors. A third is that the Steering Committee will both provide strategic direction and identify highly qualified candidates for leadership of the Association. Obviously, the success of the Steering Committee structure will be a function of the willingness of a cross section of our professional section to commit to active participation in its deliberations. Again, the American Diabetes Association needs *you*.

At the clinical level, the Task Force recommended that the Association should ensure that all people with diabetes have access to the special health professionals and physicians with expertise in the care of people with diabetes and with materials and procedures that have been demonstrated to facilitate implementation of the Association's clinical practice recommendations so as to improve the health, quality of life, and long-term prognosis of people with diabetes. One challenge to us, implicit in this recommendation, is the need for us to provide systematic documentation of the logical premise that, on balance, the elements of subspecialty care that we espouse provide superior care. The program of the 57th Annual Scientific Sessions includes an impressive number of systematic studies that provide further support for this premise.

The Task Force also recommended that the Association should organize the annual scientific sessions to allow continuity within a given area of interest and use a broad range of individuals in determining the themes of the meeting, increase the number of abstracts presented to 70% of those submitted, and publish all abstracts. Your scientific sessions committee initiated several of these recommendations at this year's meeting, the largest in the history of our Association, with more than 6,000 registrants and more than 1,100 abstracts of original data presented. Despite the growth and diversity of our professional membership, our primary objective remains to present the results of novel critical research,

ranging from fundamental biology through systematic clinical science to evidence-based health care outcomes research relevant to people with diabetes.

In direct response to some organizational difficulties relating to two of our journals, the Task Force recommended that the Association should provide sufficient financial support to produce high-quality professional journals and affirm that their editorial content should be the purview of the editors and journal policy the purview of Association volunteers, as in the past.

Finally, the Task Force recommended that the Association should advocate for substantially increased federal support of diabetes research, to a level commensurate with the high prevalence and extraordinary human and economic costs of the disease, and that the Association should commit a sum equivalent to at least 40% of its sharable public support to research awards and grants. I will spend the rest of my time developing the rationale for, and some of the potential approaches to, the issue of our research funding.

### SUPPORT OF DIABETES RESEARCH

There is compelling evidence that diabetes research is underfunded in the U.S. In dollars per afflicted individual, the National Institutes of Health (NIH) spends four times as much on heart disease research as it does on diabetes research, fourteen times as much on cancer research as it does on diabetes research, and fifty times as much on AIDS/HIV research as it does on diabetes research. In dollars per \$100 in direct costs of medical care for people with AIDS (1992), cancer (1990), heart disease (1991), or diabetes (1992), in fiscal year 1994, NIH spent \$12 on AIDS research, \$5 on cancer research, \$2 on heart disease research, and 25 cents on diabetes research. The U.S. federal expenditure for diabetes research is less than one-half of one percent of the direct costs of medical care for people with diabetes. As yet another example of the underfunding of diabetes research, while the support of NIH grew by 114% over the past decade, that of the National Institute of Diabetes and Digestive and Kidney Diseases grew by only 38%. Over that time frame, diabetes research fell from 3.9 to 2.5% of all NIH research. Clearly, diabetes research is underfunded and losing ground. The recent dramatic progress in the treatment of AIDS illustrates the success of well-funded biomedical research. We should not spend less on AIDS, cancer, or heart disease. We should spend *more* on diabetes.

These data underscore the critical need for our Association to continue to advocate for substantially increased federal support of diabetes research. They also underscore the critical importance of our research program. Our American Diabetes Association research program is unique and makes a difference to the diabetes community. It supports the training of the next generation of diabetes investigators through mentor-based postdoctoral fellowships and faculty career development awards, the testing of innovative ideas through research awards and clinical research grants, and our areas of special research interest.

No one knows precisely how diabetes will be prevented or cured or even the next as-yet unseen major advance in the treatment of diabetes. But we know that better treatments will come and that diabetes will ultimately be prevented and cured through research. Thus, it is appropriate for our Association to support fundamental, as well as applied, research.

Our areas of special research interest are more tangible. They include our Genetics of Noninsulin Dependent Diabetes (GENNID) program, designed to facilitate the discovery of the genes responsible for susceptibility to type 2 diabetes, and our support of the Diabetes Prevention Trial-1 and of the Diabetes Prevention Program, designed to test the hypotheses that type 1 and type 2 diabetes, respectively, can be prevented. They also include our requests for proposals relevant to cardiovascular risk reduction and to perfected insulin replacement.

Clearly, our research program is not a mini-version of the NIH program. Rather, it is tailored to the specific needs of the diabetes community. In a very real sense, our research program nurtures the human and conceptual infrastructure of future diabetes research. How do we fund our research program?

Our research awards and grants expenditures, the dollars actually sent out to investigators through our research program (i.e., direct costs), totaled \$11.2 million last year; \$11.2 million is not a trivial sum. I am sure we all appreciate the hard work of the volunteers who raised that money and recognize the importance of that money to the diabetes community. Nearly two-thirds of our research awards and grants dollars come from a share of affiliate public support (after its adjustment to sharable public support) and the remainder from affiliate voluntary research contributions and from research-restricted bequests and gifts, including those to our Research Foundation. In the aggregate, our fiscal year 1996 awards and grants expenditure of \$11.2 million (the total derived from a share of public support, voluntary contributions, bequests, and gifts) was a sum equivalent to approximately 20% of our sharable public support. You and I, and our Association as a whole, know the latter is not the right thing to do. Rather, we have agreed that increased support of research, the first outcome envisioned in our 1995–1998 strategic plan, is the right thing to do.

Our decision that increased support of research is the right thing to do actually antedated our current strategic

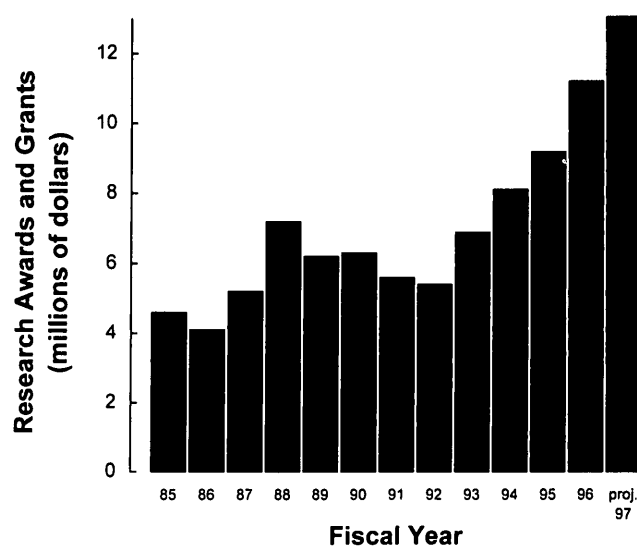


FIG. 1. American Diabetes Association research awards and grant expenditures (direct costs) from fiscal years 1985–1996 and projected for fiscal year 1997.

plan. Our research awards and grants expenditures have increased steadily over the past 4 years and doubled from \$5.4 million in fiscal year 1992 to \$11.2 million in fiscal year 1996. We now project research awards and grants of more than \$13.0 million in fiscal year 1997. This more than doubling of our direct research expenditures (Fig. 1) is tangible evidence of our commitment to research. We should be pleased. But we cannot be satisfied. Despite this growth, our awards and grants budget is still a sum equivalent to only 20% of our sharable public support.

The proportion of sharable public support allocated to research awards and grants will itself increase progressively to 20% by fiscal year 2000. (It was 6.25% in fiscal year 1990.) Thus, public support allocation policies currently in place plus voluntary contributions, bequests, and gifts can be expected to increase our aggregate research awards and grants budget to a sum equivalent to about 25% of our sharable public support by fiscal year 2000.

Our 1995–1998 strategic plan envisions a research awards and grants expenditure of \$16 million by fiscal year 1998. Our leadership goal is \$20 million by fiscal year 2000. As I mentioned earlier, our professional section believes that a sum equivalent to 40% of our sharable public support is an appropriate long-term goal. Some volunteers, including some thoughtful volunteers committed to the concept of research, doubt that we can reach the 40% figure. This volunteer believes we can, if we decide to do so and then develop a systematic long-term plan to reach that goal. Given our mission to prevent and cure diabetes and to improve the lives of all people affected by diabetes, a distribution of 40% of public support to research, 40% to information and advocacy, and 20% to fund-raising and management would seem a reasonable, fair, and attainable goal. But *your* input is critical if we are to agree to incorporate that goal into our new 1999–2001 strategic plan that will be developed in our 1997–1998 organizational year.

How, in addition to a generalized increase in fund-raising, will we reach these goals? One option, which has not been discussed seriously but might well be the topic of a future debate, would be for our Association to decide to increase the percentage allocation of sharable public sup-

port to research, expand the base from sharable to total public support, or both. Alternatively, and preferably, at least in the short-term, in my view, we can raise additional funds specifically for research—our Research Foundation is designed to do just that—and decide to increase our grassroots voluntary contributions to the research program.

Why have our voluntary research contributions not increased substantially, despite growth in public support, for several years? That approach was successful in my own affiliate and has been one of my core messages to volunteers and staff throughout our Association as your president-elect and president. Substantially increased voluntary research contributions would be the *ideal* solution, would it not? Why have I failed to convince more of our affiliates to increase their voluntary research contributions?

One of my favorite quotations, from a novel that was popular many years ago, is: “Contradictions do not exist. Whenever you are facing a contradiction, check your premises. You will find that one of them is wrong” (1). Perhaps one of my premises is wrong. Is a research expenditure of a sum equivalent to 20%, or even 25%, of our sharable public support *not* a contradiction for our Association and its mission to prevent and cure diabetes and to improve the lives of all people affected by diabetes? Will research *not* continue to improve the lives of all people affected by diabetes? Will something *other* than research prevent and cure diabetes? I don’t think my premises are wrong. Clearly, the American Diabetes Association needs your guidance and committed efforts if our goals are to be achieved—if excellence is to be achieved.

“We are what we repeatedly do. Excellence, then, is not an act, but a habit.” With that habit, we will move relentlessly toward a world in which diabetes becomes progressively less common, less devastating, and less expensive because of the widespread application of the current demonstrably effective therapies, new therapies, and, ultimately, prevention and cure—a world without diabetes.

#### REFERENCES

1. Rand A: *Atlas Shrugged*. New York: Dutton, 1992 (first published in 1957)