1992 Presidential Address

The Winds of Change

JAY S. SKYLER

As the sun sets on my term as your president, I would like to express my gratitude to the membership of the American Diabetes Association for giving me the opportunity to serve you the last three years on the executive committee—as vice president, president-elect, and president. It has been an exciting and busy three years, the memories of which I shall cherish.

THE NEW AMERICAN DIABETES ASSOCIATION

Many of you may not be aware that during this period of time, the American Diabetes Association has undergone an internal restructuring that has unified our organization. The National Center and our 54 affiliates across the country now operate in harmony. We have introduced fund-raising into our culture, in such a way that in spite of a recession we have seen a dramatic growth in public support—over 20% last year and another 20% this year. The result is that our total public support for 1992 is approximately $52.5 million. We also have become united in our crusade to recognize that the enemy is diabetes and not each other. Therefore, we wish to bond together with anyone who recognizes diabetes as the enemy. As a result of this new attitude, at our central council meeting this Friday, something happened that would have been unthinkable just two years ago. The Wendell Mayes Lecture was delivered by Lee Ducat, the founder of the Juvenile Diabetes Foundation, and the leadership message also came from JDF. Likewise, Todd Leigh, our chairman of the board, delivered a leadership message two weeks ago at JDF's meeting. We also have joined together with our friends in industry to develop partnerships in which we can fight diabetes together. The enemy is diabetes. That's what we are fighting.

The mission of the American Diabetes Association is to prevent and cure diabetes and to improve the lives of all people affected by diabetes. That includes the 14 million Americans who have the disease, their 100–150 million family members, friends, coworkers, and colleagues who are affected by their diabetes, and the hundreds of millions of people around the world also affected by this disease.

PUBLIC POLICY INITIATIVES

Claude Bernard, the great French physiologist and diabetes investigator, said that "to conserve health and to cure disease, medicine is still pursuing a scientific solution to this problem that has confronted it from the first." As we pursue our mission and sail our ship, in changing winds, the issues I would like to raise relate to the stance taken in the last few years by the American Diabetes Association, in terms of our role as a public policy advocate. In our government relations activities, we have taken positions on many issues important to people with diabetes and those who are fighting diabetes. I would like to highlight three advocacy issues. One I will just mention—diabetes education. Two others I will detail—health care reform and the budget for the National Institutes of Health.

Outpatient diabetes education. As a direct result of testimony by the ADA in the House of Representatives, the Medicare Outpatient Diabetes Education Reimbursement Act was drafted (House Bill HR 3806 and Senate Bill S 2230). These bills are currently pending before Congress. They would expand the opportunities for diabetes

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ADA, American Diabetes Association; JDF, Juvenile Diabetes Foundation; NIH, National Institutes of Health; NIDDK, National Institute of Diabetes and Digestive and Kidney Diseases; BRDPI, biomedical research and development price index; CPI, consumer price index; AIDS, acquired immune deficiency syndrome; OBRA, Omnibus Budget Reconciliation Act.

education and provide reimbursement for education that patients with diabetes need to conduct their daily living. This bill formally recognizes that diabetes education is an essential component of diabetes management. With continued advocacy efforts, I trust that we will convince Congress to pass it, which clearly will improve the lives of people affected by diabetes.

Health care reform. In terms of health care reform, a storm has been brewing in this country. The public demand for it is great. Many of our public policy makers have offered various and sundry plans to try to address health care reform. But alas, as we look at each of these plans, we in the American Diabetes Association are concerned that uniformly they lack a chronic disease focus. Likewise, our current health care system lacks a chronic disease focus. This has resulted in a systematic exclusion of people with diabetes and other chronic diseases from our health care system. In my judgment, this has become a true national tragedy. The American Diabetes Association believes it is time for the nation to awaken to this deplorable condition and correct it. Our platform on health care reform has been reproduced in the registration packets you received for this meeting, and you may have noticed that our platform has been reproduced in both English and Spanish. This emphasizes the extra burden that diabetes has on minority populations. It does so here in this city of San Antonio, so rich in culture, where Spanish is such a prevalent language. You may or may not be aware that the theme of our central council and annual meeting was "Juntos Podemos—Together We Can." We provide emphasis to that theme by reproducing our health care reform platform in both languages.

I would like to review the five major planks of that health care reform platform. It emphasizes the need to have a chronic disease focus for health care reform.

The first is to prohibit exclusion from coverage of preexisting conditions, which discriminates against people with diabetes and other chronic diseases and prevents them, at a meaningful price, from getting the health care coverage that they need most dearly.

The second is to eliminate the problem of job lock. Those from abroad may not appreciate that in this country most of our health insurance is tied to employment and if one elects to change one's job, benefits may be lost, at least for a waiting period. To eliminate that, we need to guarantee portability of benefits—so that there is no interruption in coverage once it is obtained.

Third, we need to mandate community rating of insurance premiums instead of having experience rating, which discriminates against people with any preexisting disease, particularly a chronic disease such as diabetes. Community rating spreads the risk over the healthy as well as the ill. This is a basic principle of underwriting in insurance, which we need to advocate to effectively cover people with diabetes.

Fourth, we need to insist that any basic health coverage package cover the health management essentials necessary for people with diabetes, including prescription drugs, insulin, supplies (such as syringes and blood glucose equipment), and outpatient education.

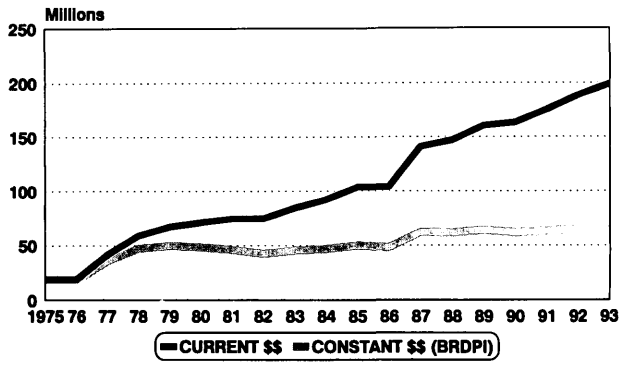

FIG. 1. Diabetes research and training budget of NIDDK (and its predecessor institutes) from fiscal year 1975 through fiscal year 1993, in both current dollars and constant dollars corrected by the BRDPI.

And finally, we need to ensure universal access to health care for all Americans. Some 37 million Americans at the current time are either uncovered or undercovered in terms of their insurance needs.

This then is our platform. We appreciate that the winds are blowing, that health care reform is coming, and that to be effective we need to be sure that the needs of people with diabetes and other chronic illnesses are included in whatever system evolves.

The NIH budget. Let me turn now to science and the NIH. Sir Francis Bacon said that, "The true and lawful goal of the sciences is none other than that human life can be endowed with new discoveries and powers." Seeking new solutions is the goal of research. In the fulfillment of that goal, in my judgment, the NIH is the crown jewel in our national treasure. I can cite many reasons for that. I will name but one. Through the 1980s, 84 individuals who had been supported by NIH have gone on to become Nobel Laureates. This national treasure—NIH—is important for the health of our nation. It provides one of our greatest scientific strengths. Moreover, I believe that biotechnology is critical for the future of this country and for all mankind. This is not only because of its scientific contributions, but because if the U.S. is to remain competitive in the world economic arena we can only succeed if we stimulate science and biotechnology as areas in which we can compete effectively. We have already ceded automotives, steel, electronics, soft goods, and clothing. Our future strength as a competitor in the world arena lies in biotechnology and science, and to carry that out, we need to develop appropriate scientists—the manpower and womanpower necessary to achieve that end.

Having said that, let us examine some facts, facts that at times are sobering or depressing, or both. The upper line in Fig. 1 shows, as our policy makers might wish to look at it, the growth of the budget for diabetes research and training of the National Institute of Diabetes, Digestive and Kidney Diseases from 1976 to present (1). Please note, however, that this is in current dollars. So I would like to introduce a concept that may or may not be familiar, namely the Biomedical Research and Development Price Index, developed by our Department of Commerce to adjust these figures for inflation. The lower

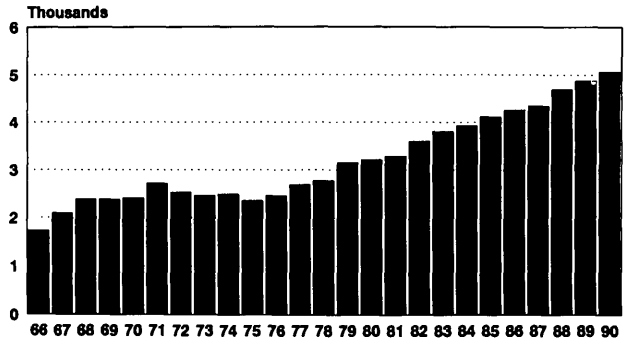

FIG. 2. Diabetes articles published in English, as retrieved via a Medline search, from 1966 to 1990.

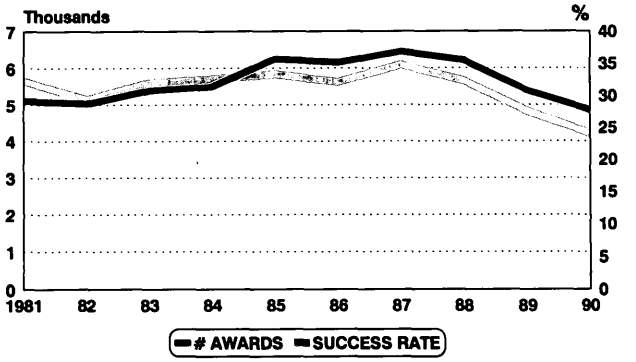

FIG. 4. Number of research grant awards by NIH and success rate (percentage of grants submitted actually funded) for fiscal year 1981 through fiscal year 1990.

line in Fig. 1 shows the figures for the NIDDK diabetes research and training budget corrected for the BRDPI. Rather than the dramatic increase that policy makers would point to, you see that the line is virtually flat. If we look at it carefully, we see two bumps in that line. One bump in 1976–1977 coincides with the passage of the National Diabetes Act of 1976 as recommended by the National Diabetes Commission of 1975, which so dramatically changed our support for diabetes research. In the 1970s, it was possible to do that kind of thing. We were waging a war on cancer, and it spilled off into other diseases and other initiatives. But, we must realize how that war on cancer began, because there may be some lessons in terms of the coalitions we need to develop. The war on cancer was initiated by three most unlikely allies: Mary Lasker, Richard Nixon, and Ted Kennedy. The second little bump in the BRDPI-corrected line occurred in 1986–1987. I call that the arthritis bonus. You may be aware that arthritis was once a part of this institute. It was spun off to have its own institute at that time, and there were some economies to be gained that gave diabetes the arthritis bonus.

Was there an impact from accelerating the support of science, such as was seen in 1976–1977? It is hard to measure, but I will show you one way I would like to measure it. Figure 2 tabulates a Medline search, suggested to me by Mike Pfeiffer, on the number of articles published in English on diabetes between 1966 and 1990. You can see a dramatic increase in the trajectory that occurs with the increased funding in 1976–1977, an increase sustained to this day. The question we face now as we attend these meetings and see that we are getting closer to solving many of the mysteries of diabetes is what the future direction of that trajectory will be. I would like to hope that we will have a far-reaching and new research kinetic that would make that trajectory go upward, but I am concerned that we may not.

Let's look at some additional data. Figure 3 tabulates extramural dollars expended by the entire NIH during the 1980s (2). Again, the uncorrected line looks like it is going up. This time, however, I have included recalculated data with two different inflators—the BRDPI and the usual Consumer Price Index—so that we can see the difference. Again, you will note that the line looks relatively flat when corrected for inflation. In fact, virtually all, if not all and maybe then some, of the increase can be accounted for by support for AIDS. If we look at the number of research grants that are awarded (Fig. 4), either the total number of research grants by all of NIH or the success rate (the number of approved grants that are actually funded), it is clear that in the last several years the line trends down, which is true for both NIDDK and NIH at large (2).

Figure 5 shows NIDDK's success rate superimposed on the NIH total success rate, and the little blip in 1987 is

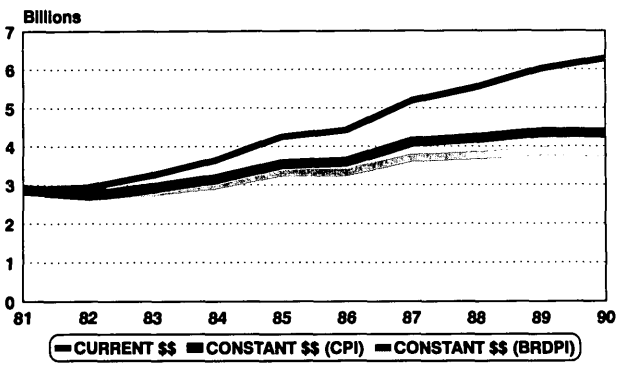

FIG. 3. Budget for NIH extramural awards for fiscal year 1981 through fiscal year 1990, in current dollars and constant dollars corrected by the CPI and BRDPI.

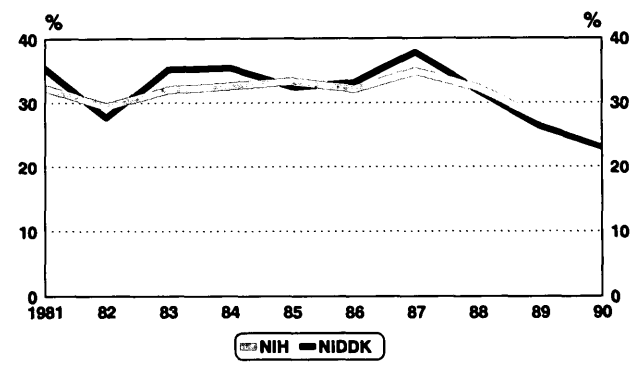

FIG. 5. Success rates (percentage of grants submitted actually funded) for fiscal year 1981 through fiscal year 1990 for NIH and for NIDDK.

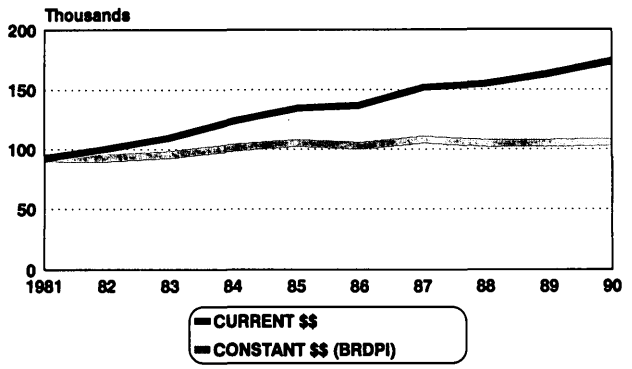

FIG. 6. Average size of total grant award for investigator-initiated individual research grants (R01s) for NIH for fiscal year 1981 through fiscal year 1990, in both current dollars and constant dollars corrected by the BRDPI.

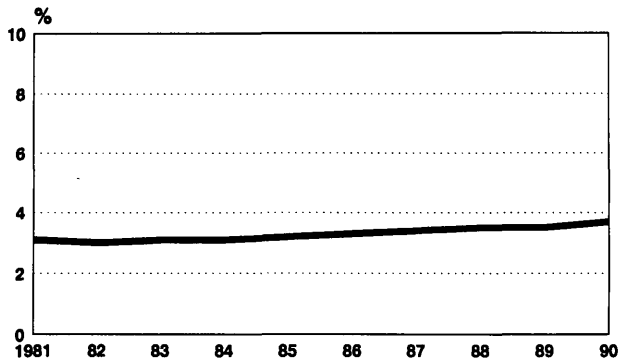

FIG. 8. Health research and development expenditures in the U.S. as a percentage of total health costs for fiscal year 1981 through fiscal year 1990.

again the arthritis bonus, which has long since evaporated (2). Our policy makers, when they look at this data, say "well you guys, you know you fund or you approve more grants than you can afford to fund, and that just makes the figures look distorted and you're getting bigger budgets now and that is what does it." Well, if you examine the question of bigger budgets, again correcting for the inflator, it is not true. Figure 6 shows total dollars awarded in R01s, the major research grant that NIH provides, during the 1980s, and again the inflation corrected line is flat (2). It is also flat for direct costs (Fig. 7) (2).

Then the policy makers say, "well, we give you enough, just figure out how to spend it better." The hard question to answer is what is enough? We scientists are always accused of wanting more. So how can we look at it and decide and get a relative feel for what is enough? Figure 8 shows that, in the 1980s, if we look at health research and development expenditures in the U.S. as a whole, as a percentage of the total U.S. expenditures on health costs, it ranges between 3 and 3.7% (3). As a basis for comparison, Table 1 notes research and development as a percentage of sales by major U.S. industries in 1991 (4). If we look at the successful industries—electronics, computers, medical equipment, and pharmaceuticals—we see that the range is from 5 to 16%. In science-based industries, a heavy investment is needed in research and development.

Worse still, if we look in terms of the billions of dollars expended in health research and development during the 1980s, where is it coming from? Figure 9 depicts the growth in NIH dollars over that time, what other federal agencies have expended, what voluntary health agencies (e.g., ADA and JDF) spend, and that the biggest single increase is coming from private industry (3). That's where the growth has been, if we have grown at all, in health research expenditures in the last decade. Some would argue that that is right—that industry is going to benefit from scientific advances, thus industry should foot the bill. However, I would argue that it is also the responsibility of our government to support the science effort.

Science education. Emil Fischer said that, "Science is not abstract, but rather as the product of human work, its development is linked with the individual characteristics and fate of those who devote themselves to science." That refers to the manpower and womanpower pool, the people we need to populate our scientific arena.

Are we attracting young people into the field of science? Let us look at some data that reflect on that (5). In 1977, 4 million high school sophomores were exposed to biology in their schools, and at that point fully 20% expressed an interest in science as a career. But, by the time they graduated high school, the figure had been reduced by a quarter, so that only 15% were still interested in science. Annother third of those, or more, were lost by the time they entered college the next year,

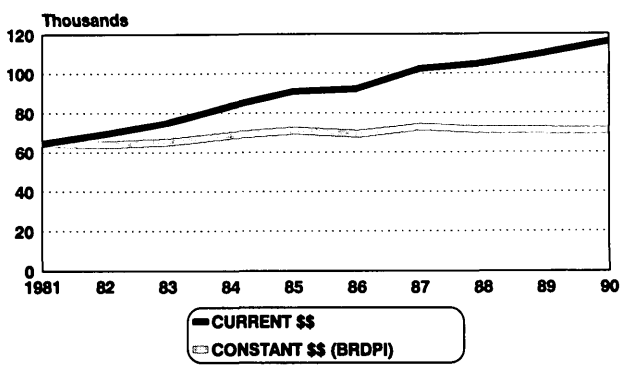

FIG. 7. Average direct costs awarded for investigator-initiated individual research grants (R01s) for NIH for fiscal year 1981 through fiscal year 1990, in both current dollars and constant dollars corrected by the BRDPI.

TABLE 1
Research and development costs as a percentage of sales for selected U.S. industries in 1991

Industry	Percentage (%)
All manufacturing	2.9
Aerospace	3.4
Electronics	5.5
Computers	7.9
Medical equipment	8.8
Pharmaceuticals	16.1

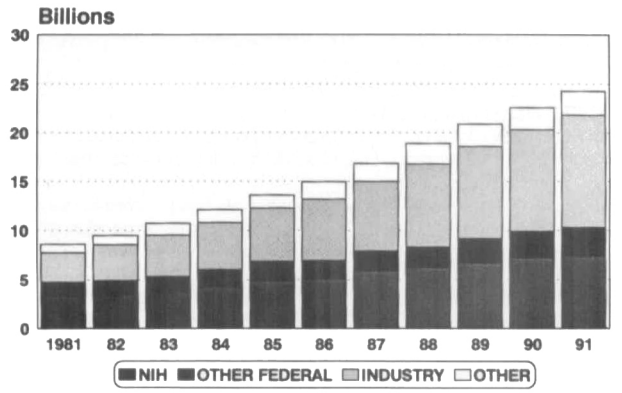

FIG. 9. Overall national support for health research and development expenditures, by source, for fiscal year 1981 through fiscal year 1990.

because only 9% of that original pool expressed an interest in having a science major on entering college. And by the time they graduated, only 1.5% of that initial group had baccalaureate degrees in science. Only 1.1% of the initial group went on to earn masters degrees in sciences. And, alas, by this year (1992), only 0.2% of that initial group had earned science PhDs and were pursuing scientific research as a career.

Only 0.2% of young Americans are going into careers in science. If my tenant is accepted that biotechnology and science is the future of the United States and the future of our economy, I would argue that this is not enough. It is far less than in other countries around the world, such as Singapore, Japan, and most European countries.

A CIVICS LESSON

A dark storm appears to be brewing over science, such that we feel entrapped, more so when we face our critics in the policy arenas of government. We feel entrapped because the civics books are wrong. What we learned in elementary civics is no longer true. The rules have been rewritten. When we, your leadership of the American Diabetes Association, faced Congress, we discovered, to our horror, that they were almost powerless. We learned that it was no longer true that if we went before an appropriations subcommittee on health that they could actually appropriate. We did that in April and May—Ken Quickel, Lee Ducat, Mary Tyler Moore, and I—to speak the diabetes message. We found that we were talking to friends on the health and education appropriations subcommittee. Representative William Natcher (of Kentucky) has chaired that subcommittee for 15 years. He's been on it for 39 years—the entire NIH budget was only $73 million when he started. But he sits there and throws up his hands, because with the new rules they cannot add money, they cannot take money from nonhealth and education programs; all they can do is allocate a piece of pie they have already been given, between one or another health or education programs. They cannot add to the pie and they cannot take from other arenas. So when we go pitch the diabetes message and our friends are there pitching the cancer message or the heart message or the need for basic education message, we are all talking about the same piece of pie.

How did that happen? How did the rules change and the American people not appreciate it? I would submit to you that in my analysis, it began with the Reagan tax cut of 1981, which created an unmanageable federal deficit, which has driven the federal budget ever since. The first attempt to gain some control over that was initiated by Senators Gramm, Rudman, and Hollings when they passed a feeble and somewhat inaccurately directed attempt to control the deficit. When that did not work, a budget summit was held that resulted in something even more onerous, the Omnibus Budget Reconciliation Act, which I believe is the reason the entire Congress is now paralyzed. To follow the rules that they adopted with OBRA, they cannot initiate any new program unless they find new dollars—that is, raise taxes—which they are not inclined to do, or cancel other programs and transfer those dollars. But alas, it is even worse. Although we have a growing peace in the world, although we have taken down the walls between East and West, between communism and capitalism, OBRA erected a fire-wall and that fire-wall, by law, prevents any domestic program from having a peace dividend. All of the dollars in defense must remain in defense in perpetuity, unless we change the law. How many of you are aware of the serious limitations that OBRA has placed on us? I certainly was not. I submit that we need to break out of this rut, change the rules, and build the strength that has made our country great. And I would submit that this is an obligation for all of us.

ADVOCACY

The winds are changing. How do we address the situation when the winds change? The pessimist looks astern, laments for the past, or drops anchor and waits. The optimist looks upward, awaiting a miracle, hoping that Pegasus will swoop down and provide that miracle and deliver it. But alas, that does not happen. And the realist, the realist adjusts the tiller, trims the sails, and tries to navigate a new course and set a new national agenda. New priorities need to be a commitment to science, science education, and the NIH budget, which I believe is the critical element that drives our advances in science. And the action plan needs to be involvement by scientists and those interested in science in the political process. With all of our commitment and all of our energy, we as individuals, we as organizations like the American Diabetes Association, we must take this as our charge and move ahead.

At the end of World War II, Vannevar Bush said "It has been the basic policy of the U.S. that government should," and I would submit must, "foster the opening of new frontiers." I would also submit that it is our obligation as a country to support science, and that we need to take that obligation seriously. If we do, we can build a strong country, we can safely sail our ship through these changing winds, and we can reach numerous goals in terms of both strengthening the country and hopefully also achieving our goal of the American Diabetes Association: a world without diabetes.

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