The Role of the American Society of Nephrology in Shaping Health Policy

Upon receipt of the Albert Lasker Medical Research Award in September, 1986, Dr. Lewis Thomas stated, "If you are looking about for examples of things that the government can do, and do beautifully well, rest your eyes on the NIH. The existence of this institution in its present form owes much to the political leaders in and out of Congress, whose wisdom and statecraft put it in place." Well, times have changed, and it is imperative that every member of ASN undertake an individual responsibility to ensure that time and fiscal constraints do not permanently alter the ability of the NIH to do its business.

These days, money for medical research is not so easily found. In the 1991 President's Budget Request, NIH received an inflationary increase of 4%, while NASA was slated to receive a 47% increase for space exploration to the moon and Mars. Fortunately, Congress decided medical research should be a high priority and provided an overall increase for the NIH of $730 million. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) received a $36 million increase, and report language accompanying the bill requires that a substantial portion of the increase be directed to kidney-related research programs.

An increase, yes; however, it falls far short of what is needed to stabilize our medical research efforts, train young scientists, and address the many research opportunities that exist. With this budget, NIDDK will fund 27% of the approved grants (up from 22% for fiscal year '90); funding for research training will go unchanged; and the number of centers will increase from 40 to 42, with "downward negotiations" of approximately 30%.

Funding trends over the past several years demonstrate that the long-term investment in maintaining and improving the health and welfare of Americans—namely medical research—is threatened and on the verge of irreparable harm. This fiscal constraint blatantly ignores the plight of at least 150 million Americans who suffer from chronic, fatal, or incapacitating diseases.

And yet, medical research is a proven winner. For every dollar invested in medical research, it is estimated that 13 dollars are returned in direct and indirect costs. We have seen an end to exploratory surgery because of magnetic resonance imaging (MRI) and CAT scans. We can pulverize kidney stones, perform surgery with lasers instead of scalpels, and give the gift of life through the miracle of organ transplantation.

Kidney diseases are among the nation's most critical health problems and account for the expenditure of substantial federal resources. Last year, approximately 13 million Americans suffered from kidney and related diseases and over 250,000 people died as a result.

Kidney disease also provides a classic case of spending priorities being out of balance. The federal government now spends about $84 billion annually (over 8% of the entire federal reimbursement budget) to treat end-stage renal disease, but only $156 million on research to cure and prevent kidney disease (2.3% of the federal research budget).

Experts now predict that health care costs will be out of sight by the end of the century, and public officials strain to develop creative solutions to contain these costs that approach $2 billion a day. As a nation, we spend more in 5 days for health care costs than is spent in an entire year for research, cures, and prevention programs. Clearly, learning how to prevent and cure disease offers the most effective approach to reducing these expenditures. With a relatively modest increase in research funds, we can significantly reduce the national health care costs and at the same time increase economic productivity and vitality.

The case for expanding medical research programs is a strong one. What is needed now are some "champions" in Congress to carry on the vision of their predecessors who conceived the NIH and a personal commitment of every ASN member to do their part. Results in the policy arena do not come overnight but require a sustained effort and a commensurate commitment of human and economic resources.

In a survey taken by ASN, 83% of the membership responded that ASN should undertake an active leadership role in the development of federal health policy and 84% endorsed efforts to increase research funding for the NIH and the Veteran's Administration (VA). To carry out this mandate, ASN has developed a long-term strategy that includes establishment of a Public Policy Committee; implementation of a State Network to provide grassroots support for federal efforts; development of a Public Policy Workshop to teach advocacy skills; and, a Washington Update column in JASN to provide information to the general membership.

The Public Policy Committee has met and recommended the following objectives to the ASN Council:
• increased funding for medical and nephrology research and research training;
• education of members of Congress and key agency officials regarding the merits of investing in kidney research and the potential to eradicate kidney disease;
• development of an educated grassroots network to respond to key policy issues; and,
• increased visibility in the policy arena for the public policy priorities of the ASN.

This strategic plan provides a beginning, but only a beginning. As ASN embarks on this strategy, we hope that you will become a key player in the process. In the business of science, as with any other business, you get what you pay for, and the promise of medical research will be realized only if support is provided. The federal government is the appropriate and only logical source of the level of support necessary. We challenge you, as researchers and physicians, to have a hand in shaping your future—and the future of your patients—by actively supporting the leadership of the ASN in their public policy efforts when you are asked.

Terry Lierman
ASN Washington Representative
Washington, D.C.