THE AMERICAN SOCIETY OF NEPHROLOGY

WRITTEN TESTIMONY IN SUPPORT OF INCREASED FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK)

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

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EXECUTIVE SUMMARY

The American Society of Nephrology (ASN) requests \$32 billion in funding for the National Institutes of Health (NIH) and \$2.03 billion in funding for NIH's National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in the Fiscal Year (FY) 2013 Labor-HHS-Education Appropriations bill.

ASN is dedicated to the study, prevention, and treatment of kidney disease, and the society respects your leadership and commitment to both preventing illness and maintaining fiscal responsibility. Estimates of chronic kidney disease (CKD) in the United States suggest that it affects more than 26 million, or 1 in 9, Americans, and more than 550,000 of them have irreversible kidney failure.

Without research funded by NIH broadly and NIDDK specifically, research leading to advances in the care and treatment of adults and children afflicted with kidney disease would not be conducted.

For instance, hereditary diseases such as cystinosis—a metabolic disorder that affects the kidneys, eyes, thyroid, pancreas, and brain—can now be treated to prevent or delay its worst effects on children. Although cystinosis is a relatively rare disease, this achievement highlights that advancing understanding of the genetics of kidney diseases in children enables us to address a previously untreatable condition as well as gain significant insight into the mechanisms of other kidney conditions.

In addition, investigative studies supported by NIH and NIDDK generated a groundbreaking discovery that helps explain racial/ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and treatment. The recent finding that African Americans with variant APOL1 genes are at increased risk of kidney disease is a crucial step in understanding why this sector of our population is four times more likely to have kidney failure than non-Hispanic whites.

Funding from NIH and NIDDK also enabled research that could improve ESRD patients' heart health and physical wellness: patients receiving daily in-center dialysis had better outcomes compared to conventional thrice-weekly dialysis. The discovery of these advantages has significant implications for the future of dialysis care for patients with end-stage renal disease (ESRD).

A funding increase of 4 percent for NIH and 4.5 percent for NIDDK would continue the important work that is necessary to move the model from curative health care, where interventions occur late in the natural history of a disease, to a preemptive model in which the onset of disease is significantly delayed or even prevented—saving taxpayer funds and creating a better quality of life for Americans.

ESRD is covered by Medicare regardless of a patient's age or disability status. Consequently, preventing kidney disease and advancing the effectiveness of therapies for kidney failure— starting with innovative research at NIDDK—would have a greater impact at the highest level of costs within the Centers for Medicare and Medicaid Services. Perhaps most importantly, in human terms, the applied research will help prevent greater suffering among those who would otherwise progress to an even greater level of illness.

Sustained, predictable investment in research is the only way that scientific investigations can be effective and lead to new discoveries. With funding from NIH and NIDDK, scientists have been able to pursue cutting-edge basic, clinical and translational research. While ASN fully understands the difficult economic environment and the intense pressure you are under as an elected official to guide America forward during these tough times, the society firmly believes that funding NIH at \$32 billion and NIDDK at \$2.03 billion will continue to create jobs, support the next generation of investigators, and ultimately improve public health.

Several recent studies have concluded that federal support for medical research is a major force in the economic health of communities across the nation.

It is critically important that the nation continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global innovation economy—particularly as other countries increase their investments in scientific research.

Most important, a failure to maintain and strengthen NIH and NIDDK's ability to support the groundbreaking work of researchers across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN strongly recommends that the FY 2013 Labor-HHS-Education Appropriations bill uphold its longstanding legacy of bipartisan support for biomedical research by providing funding of no less than \$32 billion for NIH and \$2.03 billion for NIDDK.

Should you have any questions or wish to discuss NIH, NIDDK, or kidney disease research in more detail, please contact ASN Manager of Policy and Government Affairs Rachel Shaffer at (202) 640-4659 or <u>rhaffer@asn-online.org</u>.

ABOUT ASN

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's 13,500 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's website at www.asn-online.org.