

April 22, 2013

The Honorable Jack Kingston  
Chair  
Subcommittee on Labor-HHS-Education  
Committee on Appropriations  
United States House of Representatives  
Washington, DC 20515

The Honorable Rosa DeLauro  
Ranking Member  
Subcommittee on Labor-HHS-Education  
Committee on Appropriations  
United States House of Representatives  
Washington, DC 20515

The Honorable Tom Harkin  
Chair  
Subcommittee on Labor-HHS-Education  
Committee on Appropriations  
United States Senate  
Washington, DC 20510

The Honorable Jerry Moran  
Ranking Member  
Subcommittee on Labor-HHS-Education  
Committee on Appropriations  
United States Senate  
Washington, DC 20510

Dear Chairman Kingston, Chairman Harkin, Representative DeLauro, and Senator Moran:

The undersigned organizations write to urge the House Appropriations Committee to include at least \$2 billion for the National Institutes of Diabetes, Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) as part of the Fiscal Year 2014 Labor, Health and Human Services, and Education Appropriations bill. Our organizations are dedicated to working with patients and health professionals to advance research, prevention, and treatment options for the more than 20 million adults, children, and adolescents with kidney disease in the United States today. We respect your leadership and commitment to both preventing illness and maintaining fiscal responsibility.

The mission of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is to support and conduct research to combat kidney, urologic, and hematologic diseases, diabetes and other endocrine and metabolic diseases, liver and other digestive diseases, nutritional disorders, and obesity. NIDDK's broad mission covers chronic, common, and costly diseases that have a devastating impact on our nation's citizens. We emphasize the importance of research into the nature and causes of kidney disease.

Sustained funding for NIDDK would continue the important work that is necessary to shift kidney care from a curative model—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. This shift would save taxpayer funds and create a better quality of life for Americans. Dialysis and kidney transplants—which nearly 600,000 Americans with kidney failure require to stay alive—are 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.

Examples of critical discoveries arising from NIDDK-funded research are numerous. For instance, investigative studies supported by NIDDK led to a groundbreaking discovery that helps explain racial/ethnic disparities that increase risks for kidney disease, which can lead to

earlier detection and treatment. Mutations in the APOL1 gene are associated with a significantly increased risk of focal segmental glomerulosclerosis, a rare but devastating kidney disease, especially amongst African American patients. The recent finding that African Americans with two variants of the APOL1 gene are likely to experience faster decline in kidney function, and earlier initiation of hemodialysis than their peers without the gene, is a crucial step in understanding differences in kidney disease progression across different populations and how early interventions may improve their outcomes.

NIDDK-funded research also led to treatments for children that prevent or delay the worst effects of hereditary diseases such as cystinosis—a metabolic disorder that affects the kidneys, eyes, thyroid, pancreas, and brain. 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.

Moreover, scientists supported by NIDDK identified mutations in two genes that help regulate blood pressure and salt balance in a rare, heritable disease that causes high blood pressure, or hypertension. Hypertension is a leading contributor to the development of kidney failure, so this finding may improve hypertension management in patients with kidney disease—possibly preventing kidney failure—and could lead to better therapies for controlling high blood pressure in the general patient population.

Funding from NIDDK has led to countless other cutting-edge basic, clinical, and translational research, and sustained, predictable investment in research is the only way that scientific investigations can be effective and lead to new discoveries. While we fully understand the difficult economic environment and intense pressure you are under as an elected leader to guide America forward during these tough times, we firmly believe that funding NIDDK at \$2 billion will continue to create jobs, support the next generation of investigators, and ultimately improve public health.

Should you have any questions or wish to discuss NIH, NIDDK, or kidney disease research in more detail, please contact: Katie Schubert with the American Society of Pediatric Nephrology at (202) 484-1100 or [kschubert@dc-crd.com](mailto:kschubert@dc-crd.com); or Rachel Shaffer with the American Society of Nephrology at (202) 640-4659 or [rshaffer@asn-online.org](mailto:rshaffer@asn-online.org).

Signed,

**American Association of Kidney Patients**  
**American Kidney Fund**  
**American Nephrology Nurses Association**  
**American Society of Diagnostic and Interventional Nephrology**  
**American Society of Nephrology**  
**American Society of Pediatric Nephrology**  
**American Society of Transplantation**  
**Baxter**  
**Centers for Dialysis Care**  
**DaVita**  
**DCI, Inc.**  
**Dialysis Patient Citizens**  
**IGA Nephropathy Foundation of America**  
**Kidney Care Partners**

***National Kidney Foundation***  
***NephCure***  
***Nephrology Nursing Certification Commission***  
***Northwest Kidney Centers***  
***NxStage***  
***Polycystic Kidney Disease Foundation***  
***Renal Support Network***  
***Satellite Healthcare***  
***US Renal Care***