March 23, 2012

The Honorable Dennis Rehberg
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 Richard Shelby
Ranking Member
Subcommittee on Labor-HHS-Education
Committee on Appropriations
United States Senate
Washington, DC 20510

Dear Chairman Rehberg, Chairman Harkin, Rep. DeLauro, and Senator Shelby:

The undersigned organizations write to urge the House Appropriations Committee to include $2 billion for the National Institutes of Diabetes, Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) as part of the FY2013 Labor, Health and Human Services and Education Appropriations bill. Our organizations are dedicated to working with patients and medical professionals to advance research, prevention and treatment options for those who suffer from kidney disease and 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. The 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. Estimates of chronic kidney disease (CKD) in the United States suggest that it affects more than 23 million adults, children and adolescents, and more than 550,000 Americans have irreversible kidney failure.

Without research funded by the 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 the 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 the 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 4.5% increase in funding for the 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 the 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 NIDDK, scientists have been able to pursue cutting-edge basic, clinical and translational research. While we fully understand the difficult economic environment and the intense pressure you are under as an elected official to guide America forward during these tough times, we firmly believe that funding the NIH and 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; or Rachel Shaffer with the American Society of Nephrology at (202) 640-4659 or 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 Transplant Surgeons***
- ***American Society of Transplantation***
- ***Amgen***
- ***Baxter***
- ***Centers for Dialysis Care***
- ***DaVita***
- ***DCI, Inc.***
- ***Dialysis Patient Citizens***
- ***Independent Dialysis Foundation, Inc.***
- ***Kidney Care Partners***
- ***National Kidney Foundation***
- ***Northwest Kidney Centers***
- ***Renal Physicians Association***
- ***Renal Support Network***
- ***Vascular Access Society of America***