March 11, 2016

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

The Honorable Roy Blunt, Chair Subcommittee on Labor-HHS-Education Committee on Appropriations United States Senate Washington, DC 20510 The Honorable Rosa DeLauro, Ranking Member Subcommittee on Labor-HHS-Education Committee on Appropriations United States House of Representatives Washington, DC 20515

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

Dear Chairman Cole, Chairman Blunt, Representative DeLauro, and Senator Murray:

On behalf of the undersigned organizations, representing kidney patient advocates and health professionals dedicated to improving patient care, thank you for your steadfast commitment to the National Institutes of Health (NIH) and leadership in securing an increase in FY 2016 for the agency, including the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). As you draft the Labor, Health and Human Services, Education and Related Agencies appropriations legislation for FY 2017, we respectfully request \$2.165 billion for NIDDK.

We continue to urge your support for an additional \$150 million per year over 10 years for NIDDK kidney research above the current funding level. Because kidney research has consistently been underfunded in the past, we believe this is a crucial and necessary investment that would bolster your commitment to preventing illness and maintaining fiscal responsibility. Investing in research to slow or halt the progression of kidney disease and improve therapies for patients would yield significant savings to Medicare and taxpayers in the long run.

In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program—the only health condition Medicare automatically provides coverage for regardless of age or income. The ESRD Program represents nearly 7% of Medicare's budget even though patients with kidney failure represent approximately 1% of the Medicare population. Despite the burden of kidney disease, NIH investments in kidney research are less than 1% of total Medicare costs for patients with kidney disease.

The vast majority of federal research leading to advances in the care and treatment of patients with kidney disease is funded by NIDDK, and there have been several major breakthroughs in the past several years thanks to NIDDK-funded research. For example, geneticists focused on the kidney have shaped our understanding of the pathogenesis of nephrotic syndrome and chronic kidney disease. Just last year, scientists announced a method for growing new kidneys in a laboratory as well as a rapid method for screening new prescription medications using kidney cells that would spare the expense and time of conducting human clinical trials.

Change is on the way because of advances made through NIDDK-funded kidney research. Additional, sustained funding is needed to accelerate these and other novel therapies that could improve the care of patients with kidney disease and result in significant savings to Medicare. A failure to maintain and strengthen 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.

Thank you again for your leadership, and for your consideration of our request. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact Katie Schubert with the American Society of Pediatric Nephrology at (202) 484-1100 or <a href="mailto:kschubert@dc-crd.com">kschubert@dc-crd.com</a> or Grant Olan with the American Society of Nephrology at (202) 640-4657 or <a href="mailto:golan@asn-online.org">golan@asn-online.org</a>.

## Signed,

Alliance for Home Dialysis

Alport Syndrome Foundation

American Association of Kidney Patients

American Kidney Fund

American Nephrology Nurses Association

American Renal Associates

American Society of Diagnostic and Interventional Nephrology

American Society of Nephrology

American Society of Pediatric Nephrology

Baxter

Centers for Dialysis Care

DaVita Healthcare Partners, Inc.

Dialysis Clinic, Inc. -- see Nonprofit Kidney Care Alliance

**Dialysis Patient Citizens** 

Fresenius Medical Care North America

Halpin Foundation

Home Dialyzors United

IGA Nephropathy Foundation of America

Independent Dialysis Foundation

Kidney Care Council

Kidney Care Partners

National Kidney Foundation

National Renal Administrators Association

NephCure Kidney International

**Nephrology Nursing Certification Commission** 

Nonprofit Kidney Care Alliance -- see Dialysis Clinic, Inc.

Northwest Kidney Centers

NxStage

Oxalosis & Hyperoxaluria Foundation

Renal Physicians Association

Renal Support Network

Renal Ventures Management LLC

The Rogosin Institute

U.S. Renal Care, Inc.

Vasculitis Foundation