

April 23, 2018

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

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, 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 2019, we respectfully request \$2.2 billion for the NIH over the enacted FY 2018 levels outlined in the Labor, Health and Human Services, and Education appropriations bill, including a robust funding increase for NIDDK that is at least proportional. In addition, we urge you to consider a Special Statutory Funding Program for Kidney Research at \$150 million per year over 10 years.

A January 2017 Government Accountability Office (GAO) report highlighted the pressing need for investment in kidney research; GAO found that the annual cost for care of the approximately 650,000 patients in the Medicare End-Stage Renal Disease (ESRD) program exceeds the budget allocation for the *entire* NIH (\$32.8 billion vs. \$31.1 billion). The equivalent of approximately just 1 percent of the annual total cost of care for kidney failure is allocated to kidney research at the NIH. Greater investment in kidney research should be an urgent priority to deliver better outcomes for patients and bring greater value to the Medicare program.

As the GAO highlighted, Congress made a commitment to treat all Americans with kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program—the only health condition for which Medicare automatically provides coverage regardless of age. This unique commitment underscores the imperative for Congress to foster innovation and discovery in kidney care.

Our organizations believe the Special Statutory Funding Program for Type 1 Diabetes Research provides an ideal model to foster breakthroughs in kidney therapies and cures. This Special Diabetes Program has generated remarkable progress for diabetes patients, including the development of the Artificial Pancreas. We urge your support for an additional \$150 million per year over 10 years to establish a similar program NIDDK focused kidney research—a Special Statutory Funding Program for Kidney Research—supplementing regularly appropriated funds that the NIDDK receives.

NIDDK funds the vast majority of federal research in kidney diseases, and despite the immense gap between the federal government's expenditures on kidney care and its investment in kidney research, NIDDK-funded scientists have produced several major breakthroughs in the past several years that require further investment to stimulate therapeutic advancements. For example, geneticists focused on

the kidney have made advances in understanding the genes that cause kidney failure, and other kidney scientists have developed an innovative method to determine if new drugs cause kidney injury before giving them to patients in clinical trials. NIDDK recently launched the Kidney Precision Medicine Project that will pinpoint targets for novel therapies—setting the stage for personalized medicine in kidney care. Additional, sustained funding is needed to accelerate these and other novel opportunities to improve the care of patients with kidney disease and bring better value to the Medicare ESRD program.

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 Erika Miller with the American Society of Pediatric Nephrology at (202) 484-1100 or emiller@dc-crd.com or Rachel Meyer with the American Society of Nephrology at (202) 640-4659 or rmeyer@asn-online.org.

Signed,

***Alliance for Home Dialysis
Alport Syndrome Foundation
American Association of Kidney Patients
American Kidney Fund
American Nephrology Nurses Association
American Society of Diagnostic and Interventional Nephrology
American Society of Transplant Surgeons
American Society of Transplantation
American Society of Nephrology
American Society of Pediatric Nephrology
Atypical HUS Foundation
Baxter
DaVita, Inc.
Dialysis Clinic, Inc.
Dialysis Patient Citizens
Halpin Foundation
Home Dialyzors United
IGA Nephropathy Foundation of America
Independent Dialysis Foundation
Kidney Care Council
Kidney Care Partners
Lowe Syndrome Association
National Kidney Foundation
National Renal Administrators Association
NephCure Kidney International
Nephrology Nursing Certification Commission
Northwest Kidney Centers
NxStage
Oxalosis & Hyperoxaluria Foundation
Polycystic Kidney Disease Foundation
Renal Pathology Society
Renal Physicians Association
Renal Support Network
Satellite Healthcare, Inc.
Society for Transplant Social Workers
The Rogosin Institute
U.S. Renal Care, Inc.***