

March 28, 2019

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

The Honorable Tom Cole, 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 DeLauro, Chairman Blunt, Representative Cole, 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 2020, we respectfully request \$2.5 billion for NIH over FY 2019 levels, 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 exceeded the budget allocation for the *entire* NIH. While NIH's budget allocation has grown since that time, we still dedicate equivalent of approximately just 2 percent of the annual total cost of care for kidney failure to kidney research at the NIH.

Since the GAO study was published, the number of patients with kidney diseases and associated costs to the taxpayer have also risen. There are now 720,000 Americans living with kidney failure, and Medicare spends \$35 billion managing kidney failure and \$114 billion managing kidney diseases, 23% of all Medicare spending. 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 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
American Association of Kidney Patients
American Kidney Fund
American Nephrology Nurses Association
American Society of Nephrology
American Society of Pediatric Nephrology
American Society of Transplantation
American Society of Transplant Surgeons
Baxter
Children's Organ Transplant Association
Chinese American Society of Nephrology
Fresenius Medical Care
Home Dialyzors United
IGA Nephropathy Foundation of America
Kidney Care Council
Kidney Care Partners
National Kidney Foundation
Nephrology Nurses Certification Commission
Northwest Kidney Centers
Oxalosis and Hyperoxaluria Foundation
PKD Foundation
Renal Physicians Association
Renal Support Network
Rogosin Institute
Satellite Healthcare
Society for Transplant Social Workers
U.S. Renal Care***