

March 24, 2023

The Honorable Robert Aderholt, 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 Tammy Baldwin, Chair
Subcommittee on Labor-HHS-Education
Committee on Appropriations
United States Senate
Washington, DC 20510

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

Dear Chairman Aderholt, Chairwoman Baldwin, Representative DeLauro, and Senator Capito:

On behalf of the undersigned organizations, representing kidney patients, caregivers and health professionals dedicated to improving patient care, thank you for your steadfast commitment to the National Institutes of Health (NIH), 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 2024, we respectfully request \$3.465 billion for NIH over FY 2023 levels, including a proportional robust funding increase for NIDDK of no less than \$168 million. In addition, we urge you to consider a Special Statutory Funding Program for Kidney Research at \$150 million per year over 10 years.

Health disparities challenge every aspect of U.S. health care, but kidney diseases are particularly prone to impact the nation's most vulnerable populations. Unfortunately, kidney diseases and kidney failure are more common among Americans who have been historically underserved in the U.S. health care system, including racial and ethnic minorities; the elderly; and people with lower socioeconomic status or in rural communities further from sites of care. For instance, Black Americans are more than 4 times as likely than White Americans to have kidney failure and Hispanic Americans 1.3 times as likely to have kidney failure than White Americans. All these communities continue to be disproportionately affected by the COVID-19 pandemic.

An estimated 90 percent of people with kidney diseases are undiagnosed, even though kidney diseases are the tenth leading cause of death in the United States and kidney patients are at a significantly higher risk of cardiovascular hospitalization and death.

People who progress to kidney failure require either dialysis or a kidney transplant to live. Dialysis, the most common therapy for kidney failure, has a five-year survival rate of less than 40 percent—worse than nearly all forms of cancer. Patients seeking a kidney transplant, the optimal therapy for most people with kidney failure, face a nearly 90,000 person-long waitlist, and the wait can be as long as 10 years in some areas of the country. As a result, 12 Americans die every day waiting for a kidney.

These statistics underscore why it is imperative for the federal government to invest in kidney disease research. Despite this, the NIH consistently underfunds and undervalues kidney research, spending an estimated \$18.13 for each American with kidney diseases while spending \$305.57 per cancer patient. Further, from FY 2017-2021 NIH support for kidney research increased at half the rate of NIH funding increases overall.

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 then enrolled in the Medicare End-Stage Renal Disease (ESRD) program exceeded the budget allocation for the *entire* NIH. While NIH's budget allocation and number of Americans living with kidney failure has grown since that time, we still dedicate approximately the equivalent of just 1.3 percent of the annual total cost of Medicare expenditures 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 risen. There are nearly 808,000 Americans living with kidney failure, and Medicare spends \$50.8 billion managing kidney failure and \$85.4 billion managing kidney diseases, 16.4% 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, Zach Kribs with the American Society of Nephrology at (202) 618-6991 or zkribs@asn-online.org, Sharon Pearce with the National Kidney Foundation at (703) 593-7143 or sharon.pearce@kidney.org.

Signed,

Akebia Therapeutics
Alport Syndrome Foundation
American Kidney Fund
American Nephrologists of Indian Origin
American Nephrology Nurses Association
American Society of Diagnostic and Interventional Nephrology
American Society of Nephrology
American Society of Pediatric Nephrology
Baxter
Centers for Dialysis Care
DaVita
Dialysis Patient Citizens
Fresenius Medical Care
Home Dialyzors United
IgA Nephrology Foundation
Kidney Care Partners
Kidney Care Council
Lowe Syndrome Association
National Kidney Foundation
NephCure Kidney International
Nonprofit Kidney Care Alliance
Northwest Kidney Centers
PKD Foundation
Renal Healthcare Association
Renal Pathology Society
Renal Physicians Association
Renal Support Network
Satellite Healthcare
The Rogosin Institute
The Oxalosis and Hyperoxaluria Foundation
U.S. Renal Care, Inc.
Vasculitis Foundation
Veterans Transplantation Association