Dear Chairwoman DeLauro and Ranking Member Cole:

As you begin consideration of the FY 2023 Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill, we respectfully request the Subcommittee expand federal investment in kidney health by providing $15 million for the Centers for Disease Control and Prevention’s (CDC) Chronic Kidney Disease (CKD) Initiative as well as a substantial increase in funding to the National Institutes of Health (NIH) to support the work of the National Institute for Digestive, Diabetes, and Kidney Diseases (NIDDK). This funding increase is necessary to expand kidney disease research, awareness, detection, management, and monitoring.

An estimated 37 million Americans have kidney disease, and almost 800,000 have progressed to kidney failure. Unfortunately, because early-stage kidney disease can be asymptomatic, 90 percent of people with chronic kidney disease do not realize they have the condition. It is a disease of comorbidities, lack of access, and early intervention. As many as 80 million Americans are at risk of developing kidney disease due to common comorbidities like diabetes, hypertension, and cardiovascular disease.

Additionally, the Centers for Medicare and Medicaid Services (CMS) estimates that up to 35 percent of patients do not receive any nephrology care — or in some cases, even know they have kidney disease — before beginning dialysis. Rates of kidney failure, also known as End Stage Renal Disease, are increasing and from 2009 to 2019, the number of individuals living with ESRD increased 40.4%. It is clear that our current funding levels are insufficient to meet this growing challenge. Funding must be available for public awareness, outreach, education and early intervention in order to decrease CKD and mitigate its progression to kidney failure.

Kidney disease also disproportionately affects communities of color and persons living in areas of high social deprivation. African-Americans are more than four times more likely and Hispanics and Latinos and Native Americans are each twice as likely to have kidney failure compared to white Americans. Although they make up only 13.5 percent of the population, African-Americans make up more than 35 percent of dialysis patients. Although a kidney transplant is the optimal treatment for kidney failure, Black patients face barriers to access at every step of the process and on average wait a year longer than white patients to receive a kidney transplant. Many never make it on to the transplant waitlist at all due to eligibility requirements that disproportionately disqualify patients of color.
Medicare spends 24 percent of its annual budget — $130 billion— on care for existing kidney patients, and yet since 2008, investment in research into understanding and preventing kidney disease at NIH has barely outpaced inflation. According to the CDC, kidney disease was the 8th leading cause of death nationwide in 2019. However, NIH invests only $18 per CKD patient, a fraction of what it spends on other major diseases. Fiscal Year 2021 funding for NIDDK increased by less than 1%, the smallest percentage increase of any disease Institute under NIH. From FY 2015-2020, NIH monetary support for kidney research increased at half the rate of NIH funding increases overall. This current funding structure puts Medicare at risk: waiting until patients are ill to pay for their treatment instead of making early investments in research that could slow or stop the progression of CKD to ESRD is shortsighted.

Additionally, the CDC Chronic Kidney Disease Initiative comprehensive public health strategy was created at the urging of Congress and NKF fifteen years ago to support public awareness, outreach, and tracking of CKD. Annual funding has fluctuated between $1.6 million and $2.6 million. With a significant increase in funding, this program could accelerate and amplify its activities to educate the public about their risk for kidney disease, educate clinical professionals and spur innovation by entities serving the kidney disease community.

Finally, the ongoing COVID-19 pandemic has been devastating to those living with kidney disease, especially those who have irreversible kidney failure. According to the US Renal Data Services 2021 report, almost 18,000 more dialysis patients died in 2020 than would have been expected based on previous years. That is an increase of nearly 20% from 2019 deaths. Further, while COVID-19 wreaks havoc on existing kidney patients, it also causes kidney damage in patients who recover from COVID-19. In the same 2021 report, USRDS indicates that during the spring 2020 wave, more than 40% of hospitalizations involved Acute Kidney Injury. It is essential that those patients know and understand their kidney health status so they can make the right choices to protect their health.

For these reasons, we strongly urge the Committee to provide an increase in funding for NIDDK to be greater than or commensurate with the increase to NIH as a whole. We similarly request $15 million for the CDC’s Chronic Kidney Disease Initiative to accelerate and expand activities aimed at increasing kidney disease awareness, early detection, and access to care.

Thank you for your consideration of these important requests.

Sincerely,

Bobby L. Rush  
Member of Congress

Bill Posey  
Member of Congress

Marilyn Strickland  
Member of Congress
Jan Schakowsky
Member of Congress

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Jennifer González-Colón  
Member of Congress

Stacey E. Plaskett  
Member of Congress
1 https://adr.usrds.org/2021/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities