STATEMENT OF THE NATIONAL KIDNEY FOUNDATION 30 EAST 33RD STREET NEW YORK, NY 10016 SUBMITTED TO THE SENATE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES IN SUPPORT OF FY 2023 FUNDING FOR CDC AND NIDDK SUBMITTED BY SHARON PEARCE SENIOR VICE PRESIDENT, GOVERNMENT RELATIONS

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The National Kidney Foundation (NKF) is pleased to submit testimony to highlight the significant burden that chronic kidney disease (CKD), including irreversible kidney failure, places on patients, families, society, and our nation's health care system. We urge the subcommittee to increase funding for programs and activities as a bold step to help transform CKD awareness, prevention, detection, and management. Specifically, NKF requests \$15 million for CKD activities at the Centers for Disease Control and Prevention and an increase for kidney research activities under the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that is at least proportional to the funding increase for NIH overall. We also request that appropriations for the Advanced Research Projects Agency for Health (ARPA-H) be in addition to a robust increase for NIH. Lastly, we urge greater collaboration between NIDDK and other Institutes studying related comorbidities and conditions that occur in kidney patients, such as hypertension, cardiovascular disease, immunology, disparities, and genomics.

About CKD

Chronic kidney disease impacts an estimated 37 million American adults and is the nation's 10th leading cause of death, and 1 in 3 Americans are at risk of developing it. Although it is detectable through simple blood and urine tests, an estimated 90% of patients are undiagnosed, often until advanced stages when it is too late for interventions to slow disease progression (up to 40% of people with advanced kidney disease have not seen a nephrologist prior to progressing to kidney failure). Alarmingly, some patients are not *diagnosed* until they have progressed to irreversible kidney failure (end stage kidney failure, or ESKD) and must undergo urgent start dialysis. Nearly 800,000 Americans have ESKD, requiring kidney dialysis at least 3 times per week at a dialysis center, daily home dialysis, or a kidney transplant to survive. The five-year survival rate for a dialysis patient is only 35%. The mortality rate for dialysis patients aged 66-74 is twice that of heart failure and 2.5 times that of cancer.

Medicare spends an estimated \$153 billion annually (fee-for-service and Medicare Advantage combined), nearly 25% of Medicare expenditures, on the care of people with a kidney disease diagnosis. Individuals with ESKD represent 1% of Medicare beneficiaries but comprise 7% of Medicare fee-for-service expenditures. *The need for an increased federal commitment to address the societal and economic burdens of CKD is undeniable*.

CKD is a disease multiplier, with patients often experiencing cardiovascular disease, bone disease, anemia and fatigue, and increased hospitalization. Quality of life is impacted by cognitive challenges, depression, infection, dietary restrictions, and other factors. CKD also is an

independent risk predictor for heart attack and stroke. Early-stage intervention can improve outcomes and lower costs, yet fewer than half of patients with high blood pressure or diabetes (which together are responsible for three-fourths of all cases of ESKD) receive CKD testing. To improve awareness, early identification, and early-stage intervention, NKF calls on Congress to invest in kidney health programs throughout HHS.

Disparities

CKD is characterized by stark racial, ethnic, and socioeconomic disparities. Blacks/African Americans, Hispanics/Latinos, Asian Americans and Pacific Islanders, and Native Americans and Alaska Natives are at higher risk for CKD and ESKD. Blacks/African Americans make up 13 percent of the U.S. population, but account for 35 percent of Americans with kidney failure. Kidney failure among Blacks/African Americans and Hispanics/Latinos are 4 times and 1.3 times more likely compared to Whites, respectively. Blacks/African Americans and Hispanics/Latinos experience more rapid decline of kidney function than Whites and are less likely to have had a visit with a nephrologist prior to starting dialysis. Blacks/African Americans and Hispanic/Latinos have less access to the kidney wait list, experience a longer wait once listed, and are less likely to receive a transplant from a living donor compared to Whites. The prevalent kidney transplant population with a functioning graft is 52% White, 20% Blacks/African Americans, and 16% Hispanics/Latinos. Among patients waitlisted in 2014, the median wait time for a transplant was 37 months for Whites, 64 months for Blacks/African Americans, Americans, and 57 months for Hispanics/Latinos.

COVID-19

COVID-19 has amplified the CKD and ESKD disparities discussed above, as kidney patients (including transplant recipients) are at risk for severe COVID-19 infection. This increased vulnerability is due to a series of factors, including compromised immune systems, multiple comorbidities, and exposure through the in-center dialysis care environment that necessitates close contact with others. COVID-19 hospitalizations in April 2021 were 8,617 per 100,000 Medicare ESKD beneficiaries, compared to 1,932 per 100,000 Medicare beneficiaries overall. Transplant recipients in particular face higher COVID-19 mortality risk. In addition, patients with severe COVID-19 are at an increased risk of developing acute kidney injury (AKI), often requiring the need for acute dialysis and sometimes resulting in CKD or irreversible kidney failure.

CDC Chronic Kidney Disease Initiative

The CDC Chronic Kidney Disease Initiative comprehensive public health strategy was created at the urging of Congress and NKF more than 15 years ago. Annual funding fluctuated between \$1.6 million and \$2.6 million until Congress provided \$3.5 million for FY 2022, for which we are most appreciative. The CKD Initiative supports a web site, surveillance and epidemiology activities, and assistance to the National Center for Health Statistics for CKD data collection. However, in order to address the roughly 90% of patients who are unaware they have CKD, and the 40% who receive no kidney-specific care before crashing into dialysis in full kidney failure, we must improve awareness of CKD among the public and health care practitioners to improve early detection, provide early intervention and improve outcomes. Early intervention can slow

CKD progression and, in some instances, prevent kidney failure, reduce the impact of comorbidities, and reduce hospitalizations and readmissions. A sustained public awareness initiative under the guidance of CDC will educate at-risk individuals to enhance awareness of the causes, consequences, and comorbidities of kidney disease, and educate clinical professionals on early detection and opportunities for intervention. Especially in light of the connection between surviving COVID-19 and increased risk of developing kidney disease, the time is right for a major nationwide program to improve awareness and early detection of kidney disease.

To expedite activities to improve early detection and intervention measures, NKF requests \$15 million for the CKD Initiative to increase public awareness, educate clinical professionals and expand health system capacity to diagnose and manage CKD, implement systemic changes to reduce disparities, and spur innovation by entities that serve the kidney disease community. Additional funding also would expand capacity for national CKD prevalence surveillance to allow for repeated laboratory measures in the National Health and Nutrition Examination Survey (NHANES). Current national estimates of CKD prevalence using NHANES rely on single measurements of both serum creatinine and urinary albumin, preventing researchers from estimating CKD persistence.

<u>NIDDK</u>

Despite CKD's impact on patients and Medicare, NIH funding for kidney disease research is only about \$700 million annually, or about \$19 per CKD patient, a fraction of what is provided on other major diseases. Fiscal Year 2021 funding for NIDDK increased by less than 1%, the smallest percentage increase of any disease Institute, and the FY 2022 increase was 3.4%. From FY 2015-2020, NIH monetary support for kidney research increased at half the rate of NIH funding increases overall. As a result, innovation in kidney research and treatment has lagged that of other diseases. Scientists however are at the cusp of potential breakthroughs in improving our understanding of CKD. Further advances can lead to new therapies to delay and treat kidney diseases, which has the potential to provide cost savings to the government like that of no other chronic disease given its unique Medicare coverage.

In October 2021, NKF released a Research Roadmap containing recommendations for opportunities in pre-clinical and clinical research in which additional funding could help bridge existing deficits in kidney disease detection and management, reduce incidence and disparities, improve outcomes, and lower healthcare costs. Key recommendations include increasing the number of and access to clinical trials related to kidney disease (including increased participation by under-represented populations) and identifying and implementing strategies to improve the delivery of evidenced-base care in under-represented populations. Our roadmap was the culmination of input from nephrology leaders and from kidney patients, family members and care givers, and living kidney donors. NKF leadership and staff presented the final recommendations to NIDDK staff and to representatives from other Institutes and participated in a briefing that was available to congressional staff and the public.

As the first step towards expanding kidney research opportunities, NKF requests a substantial funding increase for NIDDK that is commensurate with the percentage increase to NIH as a whole. Within that increase, we respectfully request a percentage increase for kidney research

proportional to if not greater than that of NIH overall. NKF applauds recent clinical practice changes in the diagnosis of kidney disease and requests priority consideration of new markers to estimate kidney function. NIDDK should prioritize research into the adoption of new equations for estimating the Glomerular Filtration Rate (eGFR) that do not include race as a modifier. We also request NIDDK give priority consideration to additional investments in CKD clinical trials, including diversity of participants, and initiatives to improve evidence-based care in under-represented populations.

Lastly, we request Congress encourage related Institutes to consider additional funding of kidney activities. Opportunities include NHLBI support for cardiorenal syndromes in CKD patients; NIAID initiatives to study CKD effects on the immune system; and NCI activities to study decreased kidney function in cancer patients.

Thank you for your consideration of the National Kidney Foundation's requests for Fiscal Year 2023.