

STATEMENT OF THE NATIONAL KIDNEY FOUNDATION
30 EAST 33RD STREET NEW YORK, NY 10016
SUBMITTED TO THE HOUSE COMMITTEE ON ENERGY AND COMMERCE
SUBCOMMITTEE ON HEALTH
HEARING ON "ARPA-H: THE NEXT FRONTIER OF BIOMEDICAL RESEARCH"
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The National Kidney Foundation (NKF) is pleased to offer the following comments and recommendations on the Advanced Research Projects Agency for Health (ARPA-H). The National Kidney Foundation is largest, most comprehensive and longstanding, patient-centric organization dedicated to the awareness, prevention, and treatment of kidney disease in the U.S. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation, since 1997 through the Kidney Disease Outcomes Quality Initiative (KDOQI).

As it creates the policy and authority of ARPA-H, we encourage Congress to prioritize chronic kidney disease as an area for significant focus and investment. Despite the toll of chronic kidney disease (CKD) on patients, families, and society (including a disproportionate share of Medicare expenditures for individuals with end stage kidney disease), innovation in kidney disease research lags far behind that of other major diseases. The federal government's current support of kidney research funding is insufficient to meet this growing burden. An estimated 37 million Americans have CKD, but insufficient funding results in lost opportunities to slow disease progression, improve patient quality of life and potentially reduce expenditures by Medicare, Medicaid, and other public and private payers. Even treatment options for ESKD are identical to what they were 40 years ago: dialysis, transplant, or palliative care and hospice care.

CKD is a comorbid condition with other diseases such as diabetes, hypertension, and heart disease. Approximately 40% of individuals with CKD have diabetes, 32% have hypertension, and 40% have self-reported cardiovascular disease. ARPA-H can provide avenues for interdisciplinary research on devastating comorbidities.

Diagnosis, disease progression, home dialysis utilization, access to kidney transplantation, and kidney transplant outcomes differ greatly by race and ethnicity. Differences in CKD outcomes—

whether due to genetic factors, economic and social factors, or systemic racism—are unconscionable. African Americans, Hispanics, Asian Americans, Pacific Islanders, Native Americans, or Alaska Natives are at higher risk of CKD and ESKD than White Americans. African American and Hispanic populations experience more rapid decline of kidney function than non-Hispanic Whites. African Americans make up about 13 percent of the general population, but account for 35 percent of Americans with kidney failure, and Hispanics or Latinos are 1.3 times more likely than non-Hispanic or non-Latino people to have kidney failure. African Americans and Hispanics are also less likely to receive a kidney transplant. African Americans made up one-third of patients on the kidney wait list in 2019, but they received only 21% of transplants.

To address the dire need for additional kidney research and capitalize on scientific opportunities, NKF convened two Research Roundtables in December 2020 comprised of nephrology leaders from prominent academic institutions, the pharmaceutical industry, and other experts, to identify and prioritize opportunities for pre-clinical and clinical kidney-related research. An Advisory Group consisting of patients, transplant recipients, family members, caregivers, and living donors also shared their perspectives on areas in need of further study.

The resulting Roundtables Roadmap consists of more than twenty recommendations in pre-clinical and clinical research (including implementation science) where additional funding could help bridge existing deficits in CKD management and treatments, reduce incidence and progression, reduce health disparities, improve patients' quality of life, and potentially reduce Medicare expenditures. While the Roundtables focus was on NIH, we believe unique opportunities will be present under ARPA-H that can speed the identification and delivery of unique solutions that are not possible under the traditional NIH framework. We urge the leadership of ARPA-H to consider many of the priorities identified in this roadmap, including:

- Research focused on racial and ethnically diverse populations to better understand genetic determinants of health in a broad range of chronic diseases, including CKD.
- Grants for targeted systems for the delivery of therapeutic compounds to specific cell types.
- The development of new biomarkers that more accurately assess kidney function, disease progression, and disease management efficacy.
- Creation of a nationwide, integrated informatics infrastructure platform for kidney research in which datasets can be shared across institutions to facilitate new research opportunities and treatment advances.
- Development of clinical trial consortiums to recruit CKD patients to test potential high-reward research for assessment of kidney outcomes and increase the enrollment of underrepresented populations.
- Demonstration projects that focus on underrepresented populations, including individuals who are marginalized because of social determinants of health. Clinical interventions

with primary care teams, nephrology care teams, and community organizations can identify at-risk individuals and implement culturally appropriate cost-effective interventions to prevent CKD incidence, slow CKD progression, and reduce incidence of kidney failure.

- Testing and implementing strategies to increase utilization of known therapies, especially in areas where cultural, community and other barriers inhibit access to treatment breakthroughs for marginalized populations.
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Conclusion

We strongly encourage Congress to prioritize chronic kidney disease as an area for significant focus and investment as it builds out the structure and priorities of ARPA-H. Chronic kidney disease places a tremendous toll on patients, families, and our health care system, yet the level of kidney disease research in the U.S. remains inadequate. We have identified key areas in which additional funding could help bridge deficits in kidney disease detection and treatments and improve patients' quality of life while potentially reducing kidney-related health care costs. The Administration's ARPA-H initiative will provide the opportunity to test solutions for many of the priorities contained in our research roadmap.

Thank you for your consideration.