September 6, 2024

The Honorable Patty Murray Chair Committee on Appropriations U.S. Senate Washington, DC 20510

The Honorable Tom Cole Chair Committee on Appropriations U.S. House of Representatives Washington, DC 20515 The Honorable Susan Collins Ranking Member Committee on Appropriations U.S. Senate Washington, DC 20510

The Honorable Rosa DeLauro Ranking Member Committee on Appropriations & Labor, Health and Human Services, Education and Related Agencies Subcommittee U.S. House of Representatives Washington, DC 20515

Dear Chair Murray, Ranking Member Collins, Chair Cole and Ranking Member DeLauro:

On behalf of the undersigned organizations representing kidney patients and health professionals dedicated to improving patient care, thank you for your continued commitment to funding medical research and the health workforce. The House and Senate Fiscal Year (FY) 2025 Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) appropriations bills and accompanying reports provide an unprecedented level of attention to the needs of the 37 million Americans with kidney diseases, from disease surveillance at the Centers for Disease Control and Prevention, to models of care delivery at the Centers for Medicare and Medicaid Services. We are grateful for the bipartisan and bicameral support of kidney health and urge the finalization of the FY 25 LHHS appropriations process so that these important funding increases and instructions can take effect.

To ensure a continued focus on research and innovation, we ask that you include at least the \$48.811 billion in funding to the National Institutes of Health (NIH), which is what was included in the FY 2025 Senate Labor-HHS bill, and a proportionate increase to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). This would build on Congress' recent investments in NIH that have allowed for advances in discoveries toward promising therapies and diagnostics, supported current and new scientists nationwide, and advanced the potential of medical research. It will also allow NIH to support meritorious research in kidney disease, including pediatric kidney disease, which differs significantly from adult kidney disease in important respects, including its causes. We commend the focus on innovation for people with kidney diseases, demonstrated by the Advanced Research Projects Agency for Health's exploration of the bioartificial kidney noted in the House report, and ask that the \$5 million in funding for KidneyX included in both the House and Senate is finalized.

Consistent, reliable funding is necessary to stem the tide of increasing federal costs for treating late-state kidney disease, and expand kidney disease research, awareness, detection, management, and monitoring. The Chronic Kidney Disease (CKD) Initiative at the CDC provides public health strategies for promoting kidney health, including surveillance, screening, and early detection. Early detection and intervention can make a big difference for patients and reduce Medicare spending, but because early-stage CKD is typically asymptomatic, 90 percent of people with CKD do not realize they have the condition. Support for the CKD Initiative makes a substantive difference in patient lives, and decreases Medicare expenditures by getting more patients screened, diagnosed, and on a treatment plan before they reach expensive kidney failure. We ask that you please continue supporting the CKD Initiative and finalize the \$4.5 million allocated to this essential program.

As Health Resources and Services Administration (HRSA) implements the Organ Procurement and Transplantation Network Modernization Initiative ("Initiative"), additional funding is needed to support this investment. The Initiative is a comprehensive effort to address the current challenges in the organ transplant system by increasing transparency and accountability and improving overall system performance. While the Initiative is being implemented, it is critical that the system continue to function and serve transplant patients with minimal impact on patient care. We are asking that Congress appropriate at least \$67 million for the Organ Transplantation Program at HRSA, as was included in the Senate FY 2025 Labor-HHS report. This funding will be used to support the "Next-Generation" improvements to the transplant system, including upgrading the technology and data systems that will drive future increases in performance of the transplant system. Further, we ask that the additional \$1 million in funding for the National Living Donor Assistance Center included in the House report is finalized. This program provides financial support to low-income organ donors, enabling transplantation as a choice for more families.

Finally, we request that you support funding for the pediatric nephrology workforce. There is a shortage of all nephrologists, but particularly pediatric nephrologists who are specially trained to treat children with kidney disease. American Board of Pediatrics' data indicate that in 2022, that two states that had no pediatric nephrologists and a significant number of states had fewer than one pediatric nephrologist for every 100,000 children.¹ Recruitment into the specialty is a problem. Between 2016 and 2018, only 53% of pediatric nephrology fellowship openings were filled in the U.S. National Resident Matching Program (NRMP). Compensation is a concern for many residents making the decision to specialize given large medical school debts. Data show that career earnings for pediatric nephrologists are potentially \$750,000 less than those of a general pediatrician, despite three additional years of specialized training.² Based on results from the Association of American Medical Colleges (AAMC) Faculty Salary Survey (2016-2017), decreased subspecialty compensation is correlated with decreased enrollment in fellowship positions. with nephrologists receiving less compensation compared to other pediatric subspecialists. If these trends continue, there will not be enough pediatric nephrologists to deliver the specialized care children with kidney disease require. Both the House and Senate recommended flat funding of \$10 million for this program. However, without action, this workforce shortage will only grow, and we request that you act now by including \$30 million for the Pediatric Subspecialty Loan Repayment Program (PSLRP) in FY 2025 to reduce disincentives to pediatric trainees considering subspecialty careers.

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 emiller@dc-crd.com, Zach Kribs with the American Society of Nephrology at zkribs@asn-online.org or Lauren Drew with the National Kidney Foundation at lauren.drew@kidney.org.

Sincerely,

American Society of Nephrology American Society of Pediatric Nephrology National Kidney Foundation Renal Physicians Association

¹<u>https://www.abp.org/dashboards/pediatric-subspecialty-us-state-and-county-maps</u>

² Primack, William A. et al. The US Pediatric Nephrology Workforce: A Report Commissioned by the American Academy of Pediatrics. American Journal of Kidney Diseases, Volume 66 (2015), Issue 1, 33 – 39