

Testimony Prepared by the American Society of Pediatric Nephrology
Submitted for the record to the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
April 9, 2025

The American Society of Pediatric Nephrology (ASPN) appreciates the opportunity to provide outside witness testimony to the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) for the Fiscal Year (FY) 2026 Labor-HHS appropriations bill. We appreciate your consideration of the following requests:

- Appropriate \$51.303 billion for the National Institutes of Health (NIH), including a proportionate increase for the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK):
- Appropriate \$67 million for the Health Resources and Services Administration's Organ Transplantation Program and include related language on supporting pediatric priorities during the OPTN modernization in the report accompanying the FY 2026 Labor-HHS appropriations bill;
- Appropriate \$30 million for the Pediatric Subspecialty Loan Repayment Program (PSLRP); and
- Include report language on the pediatric dually eligible population in the report accompanying the FY 2026 Labor-HHS appropriations bill.

Founded in 1969, ASPN is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 700 members, making it the primary representative of the pediatric nephrology community in North America.

Support for Pediatric Kidney Disease Research at the NIH

Robust, sustained, and predictable funding is important for all biomedical research, including that related to kidney disease. ASPN requests that Congress appropriate at least \$51.303 billion in funding to NIH and a proportional increase for NIDDK that allows for meaningful growth to support promising pediatric nephrology science. 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 pediatric kidney disease, which differs significantly from adult kidney disease in important respects. For example, recent studies funded by NIDDK have found that chronic kidney disease affects brain development and cognition in pediatric patients, and children with chronic kidney disease have unique risk factors for progressing to end-stage kidney disease.

ASPN urges members of the Labor-HHS subcommittee to ensure that NIH continues to use the funds appropriated for its work as intended and to reject grant cancellations that will undermine progress in pediatric kidney disease and the future biomedical research workforce. An ASPN member at Riley Children's Hospital in Indiana recently learned that the Pediatric Scientist Development Program (PSDP) funding that supported a fellow at his institution had been

canceled with no further justification other than the funding was no longer consistent with the administration's priorities. The Association of Medical School Pediatric Department Chairs, which was awarded the grant and allocated it to research fellows across the country, was not given a chance to appeal the cancellation or revise the program to make it consistent with this administration's priorities. At Riley Children's Hospital, the \$400,000 from the PSDP supported a single pediatric nephrology fellow who was conducting basic science research on why congenital kidney abnormalities lead to increased risk of urinary tract infections; after completing this fellowship year, the funding was earmarked to support his first two years on the faculty ensuring adequate time can be spent advancing his research. Because of the threat of cuts and uncertainty around federal research funding, Riley Children's Hospital has a freeze on hiring and the future of this pediatric physician-scientist is now in doubt. This is just one example of the grant cancellations that are being issued to researchers across the country. It exemplifies the challenges that physician-scientists are facing, particularly in pediatrics where there is already a shortage of researchers. It takes 10 years for a physician-scientist to complete training and become an early-stage investigator. If these policies are not reversed immediately, the research pipeline will run dry, delaying innovations and new therapies for the children who need them most.

Support for HRSA's OPTN Modernization Initiative

After Congress passed bipartisan legislation to modernize OPTN, HRSA's Division of Transplantation had been charged with implementing these changes. However, the future of this work is now in question as the Department of Health and Human Services' recently announced reorganization folds HRSA into the New Administration for a Healthy America (AHA), without mention of what happens to the Division of Transplantation.

For children with end-stage kidney disease (ESKD), dialysis is a life-sustaining treatment and serves as a bridge to kidney transplantation. In contrast to adults with ESKD, nearly all children with ESKD are transplant-eligible, and the benefits of transplant (vs dialysis) to growth, development, and meaningful long-term health outcomes are well-recognized and prioritized by pediatric nephrologists through early and timely transplant referral. Given the limited lifespan of living and deceased donor kidneys, most children undergo multiple kidney transplants in their lifetimes. Consequently, the selection of high-quality, low-risk compatible organs with a high probability of long-term success is paramount when allocating organs to children. The HRSA Division of Transplantation and OPTN plays a vital role in the functioning of the country's transplant system and ensuring that there are appropriate standards for the safety and effectiveness of organ transplantation for children and adults. Efforts to strengthen the accountability and transparency of the transplant system have the potential to improve the health of this vulnerable patient population. Cuts to HRSA, particularly to the Division of Transplantation overseeing the current modernization of OPTN, will undermine the country's transplant system and its ability to meet the unique health needs of children, and must be prevented.

ASPN encourages this subcommittee to ensure that the function and expertise of the Division of Transplantation are preserved and to appropriate additional funding to support this modernization aimed at addressing system challenges by increasing transparency, accountability, and system performance. While the modernization is being implemented, it is critical that the

system continues 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 for FY 2026.

To ensure that pediatric kidney transplant patients and their families are prioritized in the modernization, we ask you to include the following language in the report accompanying the Labor-HHS bill:

HRSA Modernization Initiative – The Committee applauds the work that HRSA has done to implement the Organ Procurement and Transplantation Network (OPTN) Modernization Initiative. As HRSA continues this work, it is critical that the needs of pediatric transplant patients and their families be prioritized. Specifically, the Committee urges HRSA to maintain the multidisciplinary committees in the OPTN system, and to require pediatric representation on each organ-specific committee.

Support Funding for the Pediatric Nephrology Workforce

There is a shortage of pediatric nephrologists 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 – \$1.2 million 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. Therefore, we request that you include \$30 million for the PSLRP in FY 2026 and ensure that this program retains a home within HHS during the reorganization.

Report Language to Support Dually Eligible Pediatric Beneficiaries

Despite the small population of children with ESKD—there were 5,519 children living with ESKD with 1,389 either on hemodialysis or peritoneal dialysis in 2020³—a significant number are dually eligible for Medicare & Medicaid. Children with ESKD are the only pediatric population with access to Medicare benefits based on their medical status. Given the treatments available for ESKD, it is typical for children with kidney failure to be eligible for Medicare at multiple points in their life: at the initial diagnosis of ESKD until 36-months post-transplant, when their transplanted kidney fails, and until, and if, they receive a second transplant.

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

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

³ <https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/8-esrd-among-children-and-adolescents>

Pediatric patients with ESKD often face challenges accessing pediatric care as Medicare coverage policies are tailored to adults. Children have specific needs and require different medicines, devices, and staff that differ from those used to treat adults with ESKD. Since children are not usually eligible for Medicare, the formulary does not include all necessary medications, nutritional formulas, and devices required for children, which may force them to switch or stop their medications, equipment, or care routines. This is both costly and time consuming. Some pediatric patients with ESKD even lose access to their long-term family pediatricians, or their home care services for infusions as the pediatrician or home nurse does not accept Medicare. Additionally, pediatric patients with ESKD require specialized nutrition services such as the use of formula independent of a feeding tube to aid in the growth and development of the child. Medicare, however, does not cover formula in patients that do not have a feeding tube, and Medicaid is often hesitant to cover services and supplies that are not covered by Medicare.

Coordination of benefits over state lines can be challenging for dually eligible beneficiaries, especially those who live on the border of a state. In some states, patients who are on Medicaid must wait until they start dialysis to be covered by Medicare to receive out of state care; this impedes care coordination prior to dialysis. Medicare may also not provide families with any support for travelling to out of state or distant care centers, therefore limiting the care of these patients who lack the resources to travel. CMS must work to address these issues related to access and continuity of care for pediatric patients with ESKD.

This report language would direct CMS to communicate with state Medicaid programs and MACs on ways to reduce barriers to pediatric care, including facilitating care across state lines. It would also request an update from the agency on progress:

Pediatric Dually Eligible Beneficiaries – Children with end-stage kidney disease (ESKD) are the only children automatically eligible for Medicare based on their disease status. Despite the small size of this ESKD patient population of between 1,000 to 2,000 children, a significant number of those children are dually eligible for Medicare and Medicaid. Children with ESKD differ from adults in both in the root causes of their condition and the most effective care plans to support their health. Those who are dually eligible experience challenges accessing pediatric specialty care as Medicare's ESKD coverage policies are generally tailored to adults and some Medicaid programs will not cover care Medicare has already declined to cover. The Committee urges CMS to address these coverage challenges systematically and communicate ways to reduce barriers to pediatric appropriate ESKD care to the Medicare MACs and state Medicaid programs, including how to facilitate care across state lines. The Committee requests an update on the actions CMS has taken in 120 days.