American Society of Pediatric Nephrology
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January 13, 2025

President-Elect Donald J. Trump
Vice President-Elect James D. Vance
c/o John Brooks, Team Lead HHS Agency Review Team
President-elect Donald J. Trump's Transition Team
Washington, DC

Dear President-elect Trump and Vice President-elect Vance:

The American Society of Pediatric Nephrology (ASPN) congratulates you on your election and looks forward to working with your administration to advance care for children with kidney disease. 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.

An estimated 150,000 children and adolescents currently suffer from kidney disease; about 10,000 of them suffer from end-stage kidney disease where the kidneys can no longer function on their own, relying on either dialysis or a kidney transplant to survive. Children with end-stage kidney disease (ESKD) are the only children automatically eligible for Medicare, and approximately one-third are covered by the program with another third covered by Medicaid and the remaining third covered by private insurance. Children and adolescents undergoing dialysis or kidney transplants are unique, and very different from adults. While the most common causes for ESKD in adults are secondary to hypertension and diabetes, for children causes are predominantly congenital abnormalities, glomerular diseases and rare genetic disorders. Children with ESKD experience their condition during a vulnerable time and thus suffer from impaired growth and neurocognitive development as a result. They also have different drug metabolism, which changes over time as they grow to be adults. Managing and optimizing the health of these children requires different strategies and resources as well as other pediatric specialists.

For children, dialysis is typically a bridge to transplant. Kidney transplant is preferable for children with ESKD because it improves survival in adulthood, growth, and their health-related quality of life. The 10-year patient survival rate after transplantation is 90-95 percent.[1] Most children who receive a transplant will need dialysis again in their lifetime, since the life expectancy of a transplanted kidney is 15 to 20 years from a living donor and 8 to 12 years from

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6251502/

a deceased donor.[2] There were 5,519 children living with ESKD with 1,389 either on hemodialysis or peritoneal dialysis in 2020.[3] Children with kidney disease have extensive health care needs. According to the United States Renal Data System (USRDS), for children with commercial insurance, the cost of pre-dialysis care for CKD is estimated to be $20,764 per year, compared to $2,092 for children without CKD.[4] A recent analysis of children on dialysis showed that mean monthly costs were $3500, for a total of $87,000 for 40 months of treatment. For children who had a kidney transplant, mean monthly costs were $1,900, for a total of $48,000 in 50 months.[5]

ASPN appreciates that during your first administration, President Trump signed an Executive Order on Advancing America's Kidney Health. As you set your administration's priorities, we urge you to continue your commitment to improving the lives of Americans living with kidney disease, including children, and incorporate the following policy recommendations to improve outcomes for our pediatric patients with kidney disease.

Add-on Payment for Pediatric Dialysis Services

The Centers for Medicare & Medicaid Services (CMS) has recognized that the End-Stage Renal Disease Prospective Payment System (ESKD PPS) is inadequate to cover the cost of dialyzing children and adolescents. The current reimbursement does not account for the costs associated with the specially trained care team and supplies required to treat pediatric patients as young as several months old or the unique comorbidities and treatment goals in this special patient population. The reimbursement of pediatric dialysis care has been particularly problematic since the implementation of Medicare Improvements for Patients and Providers Act (MIPPA) in 2011 when the pediatric adjustment was eliminated. In the CY 2024 EKRD PPS final rule, CMS finalized the Transitional Pediatric ESKD Add-on Payment Adjustment (TPEAPA) for pediatric patients with ESKD receiving renal dialysis services, which is a 30 percent adjustment for dialysis treatments delivered to patients under 18 years of age for three calendar years effective January 1, 2024. Although this add-on payment is necessary to accurately reimburse for this specialized care, it is only temporary and there needs to be a more permanent solution.

CMS is collecting data on pediatric ESKD on its cost reports and has updated the freestanding dialysis facility form to allow pediatric supplies and staff to be itemized. However, the hospital-based form has not been updated, and the majority of children are dialyzed in children's hospitals. We have worked closely with our members to ensure that they are accurately reporting the cost to provide care to pediatric ESKD patients. However, there are significant challenges for children's hospitals to report this information accurately. Since we recognize that the amount of the add-on payment after TPEAPA expires will depend on this data, we are working closely with CMS to identify a solution. We look forward to continuing to work with your administration to ensure that this process continues and that the correct add-on payment is finalized after the TPEAPA ends.

Improving Care for Dually Eligible Children

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[2] https://www.kidney.org/kidney-topics/kidney-transplant

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

[4] National Institute of Diabetes and Digestive and Kidney Diseases (U.S.). *USRDS Coordinating Center. U.S. Renal Data System … Annual Data Report, Researcher's Guide, Reference Tables, ADR Slides*. Ann Arbor MI: National Institute of Diabetes and Digestive and Kidney Diseases U.S. Renal Data System Coordinating Center.

[5] Iorembar, Franca and Bamgbola, Oluwatoyin; Structural Inequities and Barriers to Accessing Kidney Healthcare Services in the United States: A Focus on Uninsured and Undocumented Children and Young Adults. Front. Pediatric., April 4, 2022. Volume 10 – 2022. https://doi.org/10.3389/fped.2022.833611.

Children with ESKD are the only pediatric population with guaranteed access to Medicare benefits. 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 three years post-transplant, when their transplanted kidney fails, if and until they receive a second transplant, etc. Often these children are dually eligible with Medicare as their primary payer and Medicaid as their secondary payer. Children with Medicare as the primary payer have issues accessing other pediatric specialists who do not accept Medicare, such as pediatric pulmonologists, speech and occupational therapists, and pediatric nursing. In this case, Medicaid should provide coverage and reimbursement as the secondary insurer, but in many cases, states simply follow the lead of Medicare and do not offer payment. Furthermore, Medicare coverage policies are written to assess what services, devices, and therapies are medically necessary for individuals 65 years of age and older. Since children fall outside of the typical demographic, ASPN requests that services, supplies, and equipment be evaluated specifically for pediatric patients given the federal commitment to ESKD care. Despite the challenges faced by dually eligible beneficiaries, it is important to maintain Medicare coverage as the higher reimbursement more adequately covers the higher cost of ESKD care, and provides greater access to care for pediatric ESKD patients. We look forward to working with your administration to ease the regulatory burden on pediatric patients and their families and facilities, and ensure that our patients have access to appropriate and medically necessary care.

Access to Telehealth Services

ASPN appreciates the work that the first Trump administration did to expand access to telehealth services, which has been vital for continued access to nephrology services for our pediatric patients. There is a workforce shortage of pediatric nephrologists across the country, and this has led to difficulties accessing these specialists in many areas. Telehealth has benefitted our pediatric patients who are on dialysis, as well as transplant patients, by connecting them with the care they need, and we look forward to continuing to work with your administration to continue and expand Medicare telehealth services within the statutory constraints.

Continue to Strengthen the Transplant System

ASPN supported the bipartisan legislation that directed the effort to improve the accountability and transparency of the Organ Procurement and Transplant Network (OPTN) Modernization Initiative. Due to the significant advantages of transplantation over dialysis in a child, dialysis is a bridge to transplant for the majority of children with ESKD, and transplant referral is critical for optimal pediatric ESKD care. Ongoing efforts to strengthen the accountability and transparency of the transplant system have the potential to improve the health of this vulnerable patient population. ASPN has asked that HRSA ensure the needs of pediatric patients, their families, pediatric nephrologists, and pediatric centers are considered in the modernization effort. It is critical that pediatric transplant patients and pediatric nephrologists have a voice in any changes made to OPTN.

The existing multidisciplinary committees are a strength of the OPTN; these committees are key to weighing in on allocation priorities and setting policy. ASPN has requested that HRSA maintain this committee structure, and require a pediatric representative on each organ-specific committee. This will allow pediatric specialists to have input on allocation changes and ensure that policies protect pediatric patients. The families of children who are eligible for transplants should also be included in these discussions.

ASPN has also requested that HRSA's publicly available data include pediatric data for organ transplantation and waitlists by organ. Transplant requirements and considerations differ between children and adults. Without pediatric data, it is impossible to have a complete picture of how the transplant system is functioning for children with ESKD. We look forward to continuing to work with your administration to ensure that the policies considered reflect the needs of children.

Innovation in Pediatric Nephrology Care

ASPN strongly supports the American Society of Nephrology's partnership with the Department of Health and Human Services on KidneyX. The Society believes it is critical to support innovation in kidney care, and there must also be a specific focus on innovating in the pediatric space. New products and therapies that come to market are not always tested in the pediatric population or are even appropriate for these patients because of the differences in kidney disease in children and adults. Policies must be put in place to change this moving forward.

Due to the small size of the pediatric population, there has been a lack of high-quality clinical trials in pediatric nephrology. Most studies that are done have been observational and not interventional. There needs to be more focus on the disease types that disproportionately cause childhood kidney disease. Examples include, but are not limited to pediatric hypertension, congenital abnormalities, autoimmune disorders, nephrotic syndrome, C3 glomerulopathy, IgA nephropathy, FSGS and minimal change nephrotic syndrome. ASPN suggests the following policy recommendations:

- Prioritize clinical trials that focus on these diseases and coordinate collaboration between investigators to increase the numbers of patients included (NIDDK).
- Focus on renal priorities under the Best Pharmaceuticals for Children Act needs to be continued (NICHD).

Thank you for your consideration of these recommendations as your administration develops your priorities. ASPN stands ready to work with you to improve children's health. Please contact Erika Miller, ASPN's Washington representative, at emiller@dc-crd.com should we be able to provide you with any assistance advancing these goals or if you have any questions.

Sincerely,

Meredith Atkinson
President, American Society of Pediatric Nephrology