

Overview of ASPN's 2020/2021 Public Policy Agenda

At the beginning of each year, the ASPN Public Policy Committee (PPC) identifies and discusses various legislative and regulatory issues that may affect the pediatric kidney community. Depending on the Society's past progress on previous priorities, paired with identifying new and emerging health policy legislation, the Society settles on three to four priority issues that define ASPN's public policy agenda. 2020 was an eventful year, with the following activities:

Promoting and Increasing Funding for Biomedical Research

- ASPN joined forces throughout the year with the biomedical research community and patient advocacy groups to urge Congress to make National Institute of Health (NIH) funding a priority in the Fiscal Year (FY) 2021 budget. We succeeded, and NIH received a \$1.25 billion increase.
- For the eighth year in a row, ASPN, together with the American Society of Nephrology (ASN), organized an organizational sign-on letter directed specifically at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) funding for FY2021. ASPN and ASN garnered organizations' signatures on this letter.
- ASPN continues to participate in the Friends of NIDDK, Friends of the National Institute of Child Health and Human Development (NICHD), and Friends of the National Institute on Minority Health and Health Disparities (NIMHD) advocacy coalitions.
- For the 21st year, ASPN was successful in ensuring that language directed at pediatric nephrology issues was included in the House or Senate Labor-Health and Human Services (HHS) appropriations report. For FY 2021, we secured language requesting a report on the pediatric nephrology workforce from HRSA and NIDDK in the report accompanying the appropriations bill.

ESRD PPS

- With nine full years of living under the ESRD prospective payment system (PPS) for dialysis facilities, ASPN continues to work with its membership and the Centers for Medicare and Medicaid Services (CMS) to improve the formula used to pay pediatric facilities. We held a number of meetings with administration and CMS staff to discuss options to improve pediatric ESRD payment to reflect the resources required to deliver care to pediatric patients. All of the options we proposed were discussed by the ESRD PPS Technical Expert Panel (TEP) which met in December.
- ASPN convenes the Quality and Payment Subcommittee to address quality and payment issues, as well as develop strategies to advocate for pediatrics within CMS.
- ASPN continues to escalate its issues with PPS, both with CMS and Congress, holding several conference calls and scheduling desk-side briefings on Capitol Hill to ensure that key lawmakers are aware of ongoing issues with the pediatric facility bundle. We worked with Representatives Suzan DelBene (D-OR) and Larry Bucshon (R-IN) on a letter to CMS on the need for a pediatric-specific modifier to the ESRD PPS.

- ASPN continues to nominate its members to sit on relevant advisory panels and Eileen Brewer, Alicia Neu, and Joseph Flynn participated in the ESRD PPS TEP that specifically addressed the costs and issues associated with pediatric ESRD care.

QIP and Quality Measures

- ASPN remains in a key position as the expert with respect to pediatric quality measures.
- ASPN remains a member of the National Quality Forum (NQF) and recently nominated a member to serve on the Renal Standing Committee.

Affordable Care Act (ACA) Advocacy

- ASPN continues to support and monitor the implementation of the ACA by:
 - Continued monitoring and reporting on implementation of health insurance exchanges in states.
- ASPN continues to support efforts to protect the Medicaid expansion and patient protections included in the ACA.

Advocacy Scholars

- 2020 marked the tenth year for the John E Lewy Foundation for Children’s Health Advocacy Scholars Program. Scholars participated virtually in ASPN’s Spring and Fall Virtual Capitol Hill Days.
- The current scholars, along with those who have already graduated from the program, are active participants of ASPN’s PPC, and have taken on leadership roles within PPC and other ASPN committees.

Other Highlights

- ASPN held two successful virtual Capitol Hill Days in May and November.
- ASPN continued to support the Living Donor Protection Act that was reintroduced on a bipartisan basis in both the House and Senate. In addition, ASPN continued to support the development of immunosuppressive drug coverage legislation, which was passed by Congress as part of the end-of-year legislative package.
- ASPN commented on the 2021 Physician Fee Schedule, which included the evaluation and management documentation payment changes, increases to the ESRD Monthly Capitation Payment services, and outlined the requirements for year 5 of the Quality Payment Program.
- ASPN submitted a joint letter with ASN and the Renal Physicians Association on HHS’ final ESRD Treatment Choices model that was released as part of the Kidney Initiative. This model does not include patients under 18 years of age, but could inadvertently require participation by pediatric facilities which ASPN is attempting to fix.
- ASPN submitted joint comments with RPA opposing the administration’s changes to the visa program, which would negatively impact the ability of foreign-born graduates to participate in the nephrology workforce.

- ASPN submitted a joint letter with RPA on legislative action needed to address the COVID-19 pandemic in the spring. ASPN also submitted a separate letter to Congressional leaders with pediatric-specific requests for COVID relief.
- ASPN submitted comments to NIDDK in response to the Request for Information for NIDDK's Strategic Plan.
- ASPN submitted comments on HRSA's proposed rule to remove financial barriers to organ donation for living donors.
- ASPN submitted comments to Representative Blumenauer (D-OR) on the BETTER Kidney Care Act, which ultimately excluded pediatric patients, per our request.

Building on the 2020 agenda's successes, the 2021 agenda includes a number of legislative and regulatory issues that the Society will continue to tackle. ASPN's advocacy efforts are flexible, often changing to reflect current Washington debate and utilizing the membership's own advocacy expertise to appropriately match and most effectively communicate our message to the right people. With this in mind, the ASPN will focus on targeted legislative and regulatory work including appropriations and Medicare reimbursement as well as quality issues at the federal level. In 2021, ASPN will expand and strengthen its agenda to educate a new generation of society members to engage with the PPC and work with federal agencies, including CMS and the NIH, on a broader level.

Legislative

- As the only representative of pediatric nephrology patients, it remains essential that ASPN representatives visit the Hill and engage with Members of Congress to continue current relationships and build new ones with Committee staff and key members of Congress. ASPN will hold a virtual Capitol Hill Day in the spring and will schedule meetings for ASPN members who wish to meet with their representatives outside of our advocacy day.
- ASPN will continue to advocate for a pediatric-specific modifier to be applied to the ESRD bundled payment.
- ASPN will explore legislative solutions to support and expand the pediatric nephrology workforce.
- If Congress introduces legislation to reform entitlement programs such as Medicare or Medicaid, ASPN will continue to advocate that pediatric kidney patients have continued access to necessary subspecialty care.

Promoting Biomedical Research Funding

- ASPN supports the highest attainable funding level for NIH and fight for increases for federal research programs in the FY 2022 budget, while identifying alternative funding streams of interest to members.
- ASPN will draft new appropriations report language in 2021 for FY2022. The Society will work to ensure that this appropriations report language is included in both the Senate and House Labor, Health and Human Services, Education Appropriations bills.

- ASPN will work with the NIDDK, the National Heart, Lung, and Blood Institute (NHLBI), NICHD, NIMHD and any other relevant Institutes within the NIH to elevate issues related to research and pediatric kidney disease, specifically the role social determinants of health and racial and ethnic inequities play in kidney disease.

Affordable Care Act (ACA) Repeal and Replacement

- Given the outcome of the 2020 election and the judicial challenge to the ACA, Congress and the Biden administration may take action to change provisions or modify implementation of the law. ASPN will advocate to ensure that patients maintain their access to necessary medical care, particularly young adults navigating the transition from pediatric to adult healthcare and those who received coverage as part of the Medicaid expansion.

Kidney Specific Legislation

- ASPN will continue to advocate for the Living Donor Protection Act and actively support its passage this Congress.

Drug Shortages and Pricing

- Drug pricing will remain on Congress' agenda this year. ASPN will advocate to ensure that the Society's concerns about pricing and shortages are considered during the development of any legislative solutions. ASPN will support policies that improve pediatric patient access to appropriate therapies.

Pediatric Nephrology Work Force

- In December 2020, Congress passed a historic increase to the Medicare graduate medical education (GME) program, funding 1,000 new Medicare-supported residency positions. ASPN will monitor distribution of these GME positions and advocate for support of pediatric nephrology where appropriate.
- ASPN will monitor closely and weigh in on workforce issues, including loan repayment, graduate medical education and any other relevant initiatives.

Advancing Health Equity

- ASPN recognizes the disproportionate impact of kidney disease on communities and children of color and advocates to enact policies that will advance health equity. ASPN will monitor for opportunities to raise awareness of inequalities in nephrology care access and funding for research to eliminate underlying drivers of unequal access to nephrology care.

Regulatory

MIPPA Implementation

- ASPN will continue to develop its relationship with CMS to ensure that the pediatric nephrology voice is heard.

- ASPN will continue to expand its leadership on pediatric issues within the ESRD and chronic kidney care community.
- ASPN will continue to provide guidance to and engage with CMS on pediatric issues related to the PPS and QIP, including the development of pediatric-specific modifier to the ESRD bundled payment.
- ASPN will collaborate with the National Renal Administrators Association (NRAA) on member education activities related to Medicare payment and dialysis.

Quality Issues

- The ASPN Quality and Payment Subcommittee of the Public Policy Committee will continue to offer guidance and expertise on quality measures as new issues arise.
- ASPN will continue to nominate members for CMS TEPs, which work to develop new ESRD quality measures prior to their inclusion in the QIP.
- ASPN members will work closely with RPA to maintain and improve physician-level renal quality measures.
- ASPN will continue to ensure that at least one member of the NQF's Renal Standing Committee is a pediatric nephrologist.

Medicare Physician Payment

- ASPN will continue to engage as appropriate on CMS' policy changes for evaluation and management documentation and payment and will work in coalition as appropriate.
- ASPN will monitor the implementation of MACRA, the legislation replacing the SGR, to ensure members have meaningful methods to participate and to provide guidance on new payment models, particularly for pediatric nephrology-related items.
- ASPN will continue to monitor and engage when appropriate on nephrology-specific alternative payment models.

Drug Shortages and Pricing

- ASPN will continue to engage with the FDA and CMS to promote access to necessary drugs and formulations of drugs for children with kidney disease.

Monitoring and Coalition Building

- ASPN will continue to monitor the implementation of the ACA and weigh in where appropriate on proposed rules and legislation.
- ASPN will monitor legislation and other federal initiatives, such as Healthy People 2030, taking advantage of opportunities to weigh in or provide public comment on such initiatives.
- ASPN will continue to work with CMS and kidney community groups such as the Kidney Care Partnership (KCP) to inform its membership about MIPPA Implementation, CROWNWeb and any other relevant issues should they arise.
- ASPN will continue to foster its relationship with other organizations, such as the Children's Hospital Association (CHA), American Academy of Pediatrics (AAP), American

Society of Nephrology (ASN), Renal Physicians Association (RPA) and National Renal Administrators Association (NRAA).

- The JELF Scholars will work with CRD Associates to develop content for ASPN's advocacy social media accounts.
- The Society will monitor and advocate for any other relevant issues as necessary.