Overview of ASPN’s 2016/2017 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 approximately three to four front-burner issues that define ASPN’s public policy agenda. 2016 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 NIH funding a priority in the FY2017 budget. While the government is operating under a continuing resolution through April 28, the 21st Century Cures legislation establishes an innovations fund at NIH to support specified projects.
- For the fourth year in a row, ASPN with ASN organized a sign-on letter directed specifically at NIDDK funding for FY2017. ASPN, together with ASN, garnered several organizations’ signatures on this letter.
- ASPN continues to participate in the Friends of NIDDK, Friends of NICHD, and Friends of NIMHD advocacy coalitions.
- For the seventeenth year, ASPN was successful in ensuring that language directed at the National Institutes of Health related to pediatric chronic kidney disease research was included in the report accompanying the appropriations bill.
- For the fifth year in a row, ASPN met with the leadership of the NIDDK to discuss research issues, and for the second time, ASPN met with representatives from the National Institute for Minority Health and Health Disparities, and looks forward to continuing these relationships.
- ASPN held a Capitol Hill Day in conjunction with the annual meeting and advocated for increased NIH funding in FY 2017.

ESRD PPS

- With five full years of living under the end-stage renal disease prospective payment system (ESRD PPS) for dialysis facilities, ASPN continues to work with its membership and CMS to improve the formula used to pay pediatric facilities.
- ASPN regularly convenes the Quality and Payment Subcommittee to address quality, payment and Medicaid issues coming out of meetings with CMS to ensure a louder pediatric voice from the nephrology community.
- ASPN once again successfully positioned itself as the expert on pediatric ESRD matters, coordinating groups such as the Kidney Care Partners (KCP), American Society of Nephrology (ASN), Renal Physicians Association (RPA), Children’s Hospital Association (CHA) American Academy of Pediatrics, National Renal Administrators Association (NRAA) among others.
• ASPN continues to elevate 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.

QIP and Quality Measures
• ASPN remains in a key position as the expert with respect to pediatric quality measures.
• Regarding the Quality Incentive Program (QIP), the Society:
  o Provided comments to CMS on its latest proposed rule;
  o Met with the nephrology team at CMS to discuss pediatric implications of the most recent rule; and
  o Provided expert opinion and advice to the kidney community on the QIP.
• ASPN continues to nominate its members to sit on relevant measure development entities, such as the latest CMS technical expert panel (TEP), with appointments to the ESRD TEP on emergency department visits in 2016.
• ASPN worked with RPA to ensure that existing pediatric measures are endorsed by the National Quality Forum (NQF).
• ASPN remained a member of the National Quality Forum (NQF).

Affordable Care Act Implementation
• ASPN continued to support and monitor the implementation of the Affordable Care Act by supporting:
  o Appropriations requests for the pediatric subspecialty loan repayment program; and
  o Continued monitoring and reporting on implementation of health insurance exchanges in states.

Advocacy Scholars
• 2016 marked the sixth year for the John E Lewy Foundation for Children’s Health Advocacy Scholars Program, bringing ASPN’s four current scholars to DC for legislative training via the ASPN Capitol Hill Day and visits to NIH specific to ASPN.
• ASPN held multiple training sessions for the scholars and met with members of Congress, patient advocacy organizations, RPA, NIDDK, and NIMHD to continue ASPN’s Advocacy efforts.
• The four 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 has conducted meetings with those relevant in the kidney community, including: the Children’s Hospital Association, the Alliance on Home Dialysis, staff for Congressmen Jim McDermott and Tom Marino, co-chairs of the Congressional Kidney Caucus, Baxter and Dialysis Patient Citizens, National Kidney Foundation, and the American Association of Kidney Patients among others.
• ASPN continued to support Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act and the Living Donor Protection Act in both the House and Senate, as well as work on the development of a pediatric specific immunosuppressive drug coverage bill.
• ASPN commented on the implementation of the Medicare Access and CHIP Reauthorization Act (MACRA), which repealed the sustainable growth rate and replaced it with the new Quality Payment Program (QPP).
• ASPN commented on the 2017 Physician Fee Schedule proposed rule.

Building on the 2016 agenda’s progress, the 2017 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 the current Washington debates and utilizing the membership’s own advocacy expertise to appropriately match and most effectively get our message to the right people. In this changing advocacy world, ASPN will focus on targeted legislative and regulatory work, as ASPN continues to expand its agenda from appropriations and Medicare reimbursement and quality issues at the federal level to include grooming a new generation of Society members to play a strong role on the PPC and working with the NIH on a broader level.

Legislative

• Given the current political environment and budgetary outlook, 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 host a Capitol Hill Day in April 2017 to educate the new Congress on the Society’s high priority issues and on the mission of the Society.
• In conjunction with the JELF Advocacy Scholars program, the ASPN will provide advocacy training and schedule Hill visits for the scholars and their mentors with the goal of educating Members of Congress on pediatric chronic kidney disease, reimbursement, quality and access, workforce and biomedical research funding.

Pediatric Case Mix Adjustor
• ASPN will work to educate Congress about the pediatric case mix adjustor to the Medicare ESRD PPS, and to explore potential legislative solutions to improve the formula and ensure patients have access to needed care.

Promoting biomedical research funding
• ASPN supports the highest attainable funding level for NIH and will continue to fight additional cuts to discretionary spending, while identifying additional funding streams of interest to members.
• ASPN will draft new appropriations report language in 2017 for FY2018 with patient input. 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, NHLBI, NICHD, NIMHD and any other relevant Institutes to elevate issues related to research and pediatric kidney disease.

**Affordable Care Act Repeal and Replacement**
- As Congress develops legislation to repeal and replace the Affordable Care Act, ASPN will advocate to ensure that patients maintain their access to necessary care, particularly as related to young adults navigating the transition from pediatric to adult healthcare.
- ASPN will develop principles to inform the development of replacement legislation.

**Medicare Physician Payment**
- 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. The Society will educate its members on the reporting requirements being imposed under MACRA.

**Immunosuppressive Drug Coverage and Living Donor Protection Act**
- ASPN will continue to advocate for these two pieces of legislation, should they be reintroduced, and participate in the Transplant Roundtable coalition.
- ASPN supports the introduction of legislation that provides immunosuppressive drug coverage for the pediatric transplant population.

**Drug Shortages and Pricing**
- Drug pricing is likely to be on the agenda for the new Congress. ASPN will advocate to ensure that the Society’s concerns about pricing and shortages are considered during the development of any legislative solutions.

**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 grow its voice as the expert on pediatric issues within the ESRD and chronic kidney care community.
- ASPN is working to update its existing webinars aimed at quality issues and other areas of interest to Society members.
- ASPN PPC will continue to hold regular phone calls and webinars with dialysis facility medical directors to discuss Medicare ESRD PPS, QIP, and any other relevant issues.
- ASPN will continue to provide guidance to and engage with CMS on pediatric issues related to the PPS and QIP.
• The ASPN PPC and Clinical Affairs Committee will update, when necessary, its MIPPA “tool kit” for members.
• ASPN will collaborate with 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 in the policy area of quality measures as new issues arise.
• ASPN will continue to nominate members for CMS technical expert panels (TEPs), which will work to develop new ESRD quality measures prior to their inclusion in the QIP.
• ASPN members will work closely with RPA as they work to maintain 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.
• The Society will educate members on MACRA’s new quality reporting requirements through a variety of methods, including a webinar and updates in Kidney Notes.

Drug Shortages
• In 2013, ASPN began exploring the issue of drug shortages. In 2014, off the heels of a shortage in Baxter’s dialysis solution, ASPN reached out to FDA to conduct a conference call on the broader issue of drug shortages.
• In 2015, ASPN continued to hold conversations with FDA and Congress on the matter.
• In 2016, the Public Policy Committee began implementing the ASPN’s Washington Representative’s drug shortages advocacy plan.
• In 2017, the ASPN will continue to engage with the FDA and Congress to promote access to necessary drugs and necessary formulations of drugs for children with kidney disease.

Monitoring and Coalition Building
• ASPN will continue to monitor the implementation of the Affordable Care Act and weigh in where appropriate on proposed rules and legislation.
• ASPN will monitor legislation and other federal initiatives, like NIH’s strategic planning process and others, taking advantage of opportunities to weigh in or provide public comment on such initiatives.
• ASPN will monitor closely and weigh in on workforce issues, including loan repayment, graduate medical education and any other relevant initiatives.
• ASPN will continue to work with CMS and kidney community groups such as the 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, American Academy of Pediatrics, American Society of Nephrology, Renal Physicians Association and National Renal Administrators Association, and in particular the patient advocacy organizations in the kidney space.

• The Society will monitor and advocate for any other relevant issues as they arise.