

American Society of Pediatric Nephrology

November ~ December 2019

KIDNEY Notes

President's Corner



Dear Colleagues

I want to provide a heartfelt thank you to the IPNA Council and organizers of this year's IPNA meeting in Venice. By all accounts it was a resounding success and I am very pleased that the ASPN provided travel grants to our trainees to attend! As we gathered for this year's Annual American Society of Nephrology Meeting there were multiple events that occurred. Many of our committees have met and we had an advocacy group working to continue advancing our Pediatric Nephrology focused mission. I want to thank all of you who have participated in representing our society at the ASN program level and beyond.

While the focus of this meeting was networking and scientific engagement, I am very pleased that following our ASPN council meeting (Wed. Nov. 6th, 2019) we had a workforce summit with many important stake-holders present. The importance of this process is fundamental to the health of our sub-specialty. We have developed an agenda and will develop a white paper on future options for our sub-specialty. In addition, we will have sharable documents for any of our members to access in order to help their local efforts. The Summit also had representation from the American Board of Pediatrics and will be followed by a survey sent to our broad membership.

I wish you and your families a wonderful, safe and healthy Thanksgiving. Again, thank you all for what you do for our patients and their families.

Sincerely,

Patrick Brophy, MD, MHCDS
President, ASPN
Patrick_Brophy@urmc.rochester.edu

ASPEN Corporate Liaison Board



Please send us (info@aspneph.org) announcements and photos of pediatric nephrologists receiving awards, giving important lectures and news of other accomplishments so we can share them in *KidneyNotes*.



Committee Updates

Public Policy Committee Update

End Game for FY 2020 Appropriations Still Unsettled

The Federal Government's new Fiscal Year (FY) started on October 1, but Congress has not completed its work on the twelve appropriations bills to fund the government. To avert a government shutdown, the President signed into law a continuing resolution (CR) to keep the government open through November 21, giving lawmakers an additional eight weeks to pass their FY 2020 spending bills.

While the House finished its work on its FY 2020 spending bills, the Senate did not start on theirs until they returned from the August recess. They waited until the House and Senate reached a deal to raise the budget caps, which was needed to set the final spending levels for the Fiscal Year. The deal increases funding for domestic programs by \$24.5 billion over current levels, and provides an additional \$5 billion for these programs in FY 2021. Despite reaching a budget agreement, the Senate Appropriations Committee was not able to approve its Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) spending bill, which funds discretionary health programs, because of disagreement over policy riders related to Title X funding and funding for the President's border wall. House and Senate conferees will be forced to negotiate final spending levels without levels approved by the Senate Appropriations Committee.

Moving forward, Congressional leaders are taking steps to avert a government shutdown when the CR expires. Senate Appropriations Chairman Richard Shelby (R-AL) has been working with the Administration on a plan to complete the FY 2020 appropriations process, which will depend on the ability to reach consensus on spending allocation for each bill. Appropriators are now developing another CR that will run into December. However, it remains unclear if this will provide enough time to reach agreement on all of the FY 2020 spending bills. Some in Congress think it's possible all or parts of the government will be forced to operate under a full year CR.

ASPEN Report Language Included in Senate Labor-HHS Appropriations Report

The Senate Appropriations Committee may not have approved its FY 2020 Labor-HHS spending bill, but they have released their bill and the accompanying report. While the Labor-HHS report does not have the force of law, report language is an important way for Congress to send a message to administration regarding its priorities. ASPEN advocated for the inclusion of language urging the Department of Health and Human Services (HHS) to examine the costs of ESRD care and the following was included in the Senate Labor-HHS report:

Pediatric Kidney Disease - The Committee recognizes that children with end-stage renal disease [ESRD] have unique care needs and require services that are not typically required by adult ESRD patients. Additional costs associated with these needs may not be accurately reflected in the ESRD bundled payment and pediatric outlier. Therefore, the Committee encourages HHS to conduct a study of pediatric dialysis costs to ensure that the data being collected by CMS is accurate. The study should include an evaluation of whether existing payment systems accurately capture and reimburse these costs. The Committee requests the Secretary to report findings in the fiscal year 2021 CJ.

HHS typically responds to report language in the next year's budget documents so we will look for the agency's response next spring.

ASPEN Working with HHS to Address Pediatric Specific ESRD Issues

This summer HHS launched its [Advancing American Kidney Health Initiative](#) which includes policy solutions to achieve the following three goals: fewer patients developing kidney failure, fewer Americans receiving dialysis in dialysis centers, and more kidneys available for transplant. This initiative is striving to transform kidney care, but does not specifically address the issues faced by pediatric patients.

ASPEN has been working closely with HHS to ensure that the agency does address the unique needs of pediatric patients. We have raised our concerns related to pediatric ESRD reimbursement, the pediatric nephrology workforce shortage, and research on pediatric specific therapies. At this point, we do not know what pediatric specific policies HHS will advance, but we will keep membership updated on our work.

ASPEN Submitted Three Comment Letters to CMS in September

September was a busy month on the regulatory front with the Public Policy Committee working on comments to three rules proposed by the Centers for Medicare and Medicaid Services (CMS): the [ESRD Treatment Choices \(ETC\) model](#), which is the first of five models to come out of the Administration's Kidney Initiative, the [CY 2020 End-Stage Renal Disease \(ESRD\) Prospective Payment System \(PPS\)](#) and the [ESRD Quality Incentive Program \(QIP\)](#), and the [CY 2020 Physician Fee Schedule \(PFS\)](#).

CMS proposed that the ETC model be mandatory, but excluded patients younger than 18 from the model based on the unique medical needs of this population. ASPEN's comments agreed with this proposal, and urged CMS to work with the Society to improve reimbursement for pediatric ESRD care and develop new metrics that apply to the children treated by our member pediatric nephrologists. The comments also encouraged the agency to include long-term coverage of immunosuppressive drugs as part of any initiative aimed at improving kidney transplant rates.

In response to the proposed changes to the ESRD PPS and QIP, we shared our concerns with the agency about the undervaluation of pediatric ESRD services and supplies, which impacts reimbursement. ASPEN continues to work with CMS to ensure adequate reimbursement for pediatric

Committee Updates

nephrologists. Our comments also requested that the agency ensure that new products and therapies for ESRD patients include innovations that pertain to the pediatric population.

CMS revised its policy on evaluation and management (E/M) services set to be implemented in CY 2021 in the proposed PFS. In response, ASPN supported the agency's proposal to implement the revised E/M services and values as developed by the CPT Editorial Panel and valued by the American Medical Association Relative Value Scale Update Committee respectively. The Society also commented on CMS' proposal to recognize ESRD monthly services as being closely tied to the outpatient E/M services that were used as building blocks in the valuation of these services and provided input on how to value these services. CMS had proposed eliminating the Pediatric Kidney Disease: ESRD Patients Receiving Dialysis: Hemoglobin level <10 g/dl measure from the Quality Payment Program (QPP), and ASPN urged the agency to change course and not eliminate this or any other pediatric nephrology-specific measures.

ASPN Issues Statement on Proposals that Impact Immigrants Access to Health Care

ASPN and the American Society of Nephrology (ASN) released a joint statement on September 10th opposing two recent Administration policies that would negatively impact children's access to medical care: 1) [the Department of Homeland Security's final rule on public charge considerations](#); and 2) [U.S. Citizenship and Immigration Services \(USCIS\) decision to end the Medical Deferral Program](#). The statement was submitted for the record to the House of Representatives Civil Rights and Civil Liberties Subcommittee of the House Oversight and Reform Committee's hearing on September 11th on "The Administration's Apparent Revocation of Medical Deferred Action for Critically Ill Children."

Since this statement was submitted, three federal courts blocked the implementation of the public charge rule and the Administration backtracked on its position on the Medical Deferral Program. ASPN will continue to advocate for policies to protect access to medical care for children and their families.

HHS Proposes Changes to the Anti-kickback Statute for Home Dialysis

On October 9, the Office of Inspector General (OIG) for HHS released a proposed rule that makes revisions to the Safe Harbors under the Anti-Kickback Statute and Civil Monetary Penalty (CMP) rules. This proposed rule is part of HHS' [Regulatory Sprint to Coordinated Care](#), and HHS Deputy Secretary Eric Hargan held a call with the representatives of the kidney community to discuss how the proposed rule aligns with the [Advancing America's Kidney Health Initiative](#).

The proposed rule implements a provision in the Bipartisan Budget Act of 2018 that allowed patients receiving home dialysis to receive telehealth services. The goal of the proposal is to reduce barriers to the use of in-home dialysis and encourage its increased use, which will lead to improved quality of care for beneficiaries with end-stage renal disease (ESRD) and overall cost savings to federal health care programs. The proposed rule will also reduce burden by eliminating unnecessary travel time and costs for patients who are medically-appropriate to receive in-home dialysis.



Research Committee Update

Interested in starting a research career but not sure where to begin? Wondering about how to best connect with others with similar research interests? Have a research question but need robust data? The ASPN Research Committee is proud to announce its newly launched [Collaborative Research Resources](#) available on the members-only section of the website (<https://www.aspneph.org/committees/research-committee/>).

This resource lists active pediatric nephrology research collaborative groups with descriptions of each collaborative, the PI contact information, number of participants, availability of data and biospecimens and more. This resource is meant to be a "living document", so as changes come along (PI contact, etc.), new collaboratives are developed, and new information is provided this resource will be updated. Please contact one of the research committee co-chairs if you would like your research consortium listed or wish to update anything about your consortium.

The ASPN also supports research efforts via its [Longitudinal Research Mentoring Program](#). This successful program pairs junior investigators with senior mentors to help them achieve their research and career goals. If you are interested, please reach out to the ASPN Research Committee leadership with the following information: 1) Contact Information; 2) Research Interest; 3) Mentorship needs (grant writing/development; career guidance; work-life intersection; other)

And, please don't forget to tell us about any/all [Pediatric Nephrology successes](#)! The ASPN research committee loves to celebrate and acknowledge the accomplishments of the members of our community. Did a colleague receive a grant or a major publication? Let us know so we can celebrate their achievements in the next edition of Kidney Notes.

Tammy Brady, Brad Dixon, Michelle Denburg, ASPN Research Committee Co-Chairs
ResearchCommChair@aspneph.org | ResearchMentoring@aspneph.org

Committee Updates

Therapeutics Development Committee Update

As part one of "The ASPN Year of Clinical Trial Site Readiness," the Therapeutics Development Committee (TDC) has developed a Toolkit to help sites improve their readiness for participation in pediatric clinical trials in nephrology. This Toolkit is available online in the members-only section of the ASPN website. Just go to the committee page for the TDC. Thanks to Katherine Twombly and her team who developed this great resource. Members can refer to this Toolkit in preparation for feasibility meetings or when answering solicitations for sponsored research studies at their institutions.

The ASPN is interested in improving access to clinical research trials for all of our patients, and the TDC and the Research Committees have together made it part of their educational mission to improve trial readiness at our institutions. ASPN Council fully supports this mission, and has approved part two, which is a survey that was designed by content experts in the Research Committee and TDC. The goal of this survey is to assess the interest and the needs of the Pediatric Nephrology community for involvement in prospective clinical research. We are counting on your Center's responses to this survey to improve our nephrology community. For part three, there will be a workshop at the next PAS meeting on this topic. We hope the toolkit will continue to be a good reference for completion of the survey and for review after participation in the workshop.

[Click here](#) for the Toolkit.

ASPN Webinars

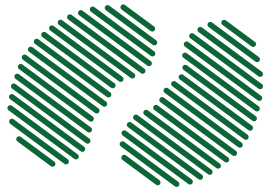
We are continuing the Nephrology Part II pathology and imaging webinar series, which allows members to have the opportunity to claim MOC 20 Part II points. Please note, claiming credit for the 2017 webinar series has closed and we will move forward with the 2018-2019 Academic Year webinar series. ASPN members will continue to have access to the content through the ASPN website.

If you are interested in claiming MOC 20 Part II credit in the upcoming 2018-2019 academic year series, you must complete 10 webinars and answer a total of 50 question/answers (5 per webinar) via REDCap. For this series, unlike the previous one, you will be required to remit payment of \$50 (credit card or cash) to the Children's Hospital of Philadelphia (to cover the cost of managing the MOC points). The REDCap link will be available on the webinars as well as the ASPN website in the Members Only version of the Member Education Committee page. Please address any questions to Rebecca Ruebner, and Ben Laskin, emails: ruebne1@jhmi.edu and LaskinB@email.chop.edu.

ASPN Renal Imaging Webinar

Date: December 9, 2019 at 3pm ET
Topic: TBD

The ASPN Member Education Committee invites all members to attend our monthly renal pathology interactive webinars/discussions. These will feature a new case each month with pathology presented by Dr. Patrick Walker of Nephropath and a content expert from the ASPN membership. The sessions will typically be the 1st Monday of each month at 3PM Eastern. Watch for an email from ASPN with call-in details.



American Society of Pediatric Nephrology FOUNDATION

John E. Lewy Foundation Advocacy Scholars Program



In Celebration Of Dr. Lewy

We enjoyed celebrating at the **10th Anniversary Celebration of the JELF Advocacy Scholars Program!!** Thank you to those who were able to join in the fun!!

JELF was created in 2009 by the Lewy family in remembrance of Dr. John E. Lewy's dedication to pediatric nephrology, advocacy, science, and education. (Schnaper et al) We honor Dr. Lewy today.

JELF Scholar Highlight Dr. Kiri Bagley

As a pediatric nephrology fellow, I have become particularly interested in the effects of disaster events on pediatric dialysis patients. Physical displacement and loss of resources, including electricity and clean water, represent not only an inconvenience, but also a potential danger for this vulnerable population. I was awarded a grant, which has allowed me to develop Disaster Preparation Backpacks and enhance disaster readiness educational material for our institution's pediatric dialysis patients, as a quality improvement project. Each Disaster Preparation Backpack will include necessities for the emergency setting such as a flashlight, radio, batteries, sterilizing solutions, and other items to reduce infection risk; waterproof bags to hold medications, medication lists, and emergency contacts; and information concerning patient demographics and medical history. We are grateful for funding assistance from an institutional grant, Carolina for the Kids.

Applications to the JELF Advocacy Scholars Program are Open!! Due November 30th!!

The **JELF Advocacy Scholars Program** serves to develop a pipeline of leaders in pediatric nephrology with an interest in and commitment to public policy and advocacy. It provides a 2-year immersive experience to develop leadership skills, particularly with expertise in governmental and regulatory processes. With close mentorship we facilitate the success of pediatricians committed to advocate for important issues regarding child health in nephrology. <https://www.aspneph.org/event/jelf-advocacy-scholars-application-deadline/>

JELF Scholar Testimonial Dr. Ray Bignall

As a John E Lewy Fund Advocacy (JELF) Scholar I have been privileged to amplify my voice as a pediatric nephrologist on behalf of my colleagues, my



patients and their families. This includes interacting with key staff at the NIH to promote the prioritization of funding for pediatric kidney disease research, and speaking with members of Congress and White House staff to advance the policies



that achieve the goals of our society. Children with kidney disease and their families often exist on the frontlines of social disadvantage, where they face adverse health outcomes from poverty, housing instability, food insecurity, and systemic discrimination: these adversities often make their clinical conditions much worse. The JELF program has equipped me with the tools I need to challenge these forces at both a regional and national level, and to make an even greater and longer-lasting impact.

*Credits to Kiri Bagley MD & Ray Bignall MD
Kaye Brathwaite, MD*

JELF Advocacy Scholars Program Call for Applications

Colleagues,

The John E. Lewy Fund for Children's Health and the American Society of Pediatric Nephrology Foundation are pleased to announce the **10th Advocacy Scholar's Program**. The purpose of this program is to develop a pipeline for the next generation of leaders in pediatric nephrology with specific expertise in governmental and regulatory processes affecting children's health care and advocacy for pediatric nephrology, and to educate future leaders in the conduct and application of advocacy. To achieve this mission, we currently offer a two-year immersive experience for leadership and advocacy skills development.

Please take a few minutes to peruse the information and application form. We look forward to receiving numerous applications and the continued growth of this program in the future. The deadline for the simple application is **November 30, 2019**.

Click below for program information:
[Information and Application](#)



Recognize your colleagues

In 2018, the ASPN Foundation initiated a named trainee travel grant program. This fall, we have received three named travel awards: The George Schwartz Research Travel Award donated by Pat Brophy, MD and The Kevin and Shiralee Meyers Family Travel Award donated by the Meyer's family and the Jose Strauss Pathway travel award. This brings the total number of travel awards to seven. Providing a three or five year named travel award pledge in honor of a colleague or colleagues is a great way to recognize others and to contribute to the development of our pediatric nephrology trainees. Others also have made significant gifts to support trainee travel. See the ASPN website for opportunities to make a tax deductible contribution to the Foundation for the ASPN's education and research programs. We hope you will include a donation as you consider any year-end philanthropic gifts.



Grant Award: Congratulations!

Chia-shi Wang, MD, MSc, Assistant Professor of Pediatrics at Emory University, Division of Pediatric Nephrology, has been awarded a K23 Career Development Award by the NIH-NIDDK (1K23DK118189-01A1). Her project, "A Novel Mobile Application for Childhood Nephrotic Syndrome Management", aims to examine the preliminary efficacy and perform a process evaluation of the implementation of an innovative mobile app designed to assist families and caregivers in managing nephrotic syndrome (ClinicalTrials.gov Identifier: NCT04075656). The mobile app, UrApp, is jointly developed by clinicians, caregivers, and engineers, (at Children's Healthcare of Atlanta and Georgia Institute of Technology) and is available for free download on the Apple App Store. Contact Dr. Wang at: chia-shi.wang@emory.edu for more information.

Noteworthy Presentations from ASN Kidney Week!

Two of our own Pediatric Nephrologists presented at ASN Kidney Week this year! The two are:

- Michael Mauer of the University of Minnesota presented the Barry M. Brenner Endowed Lecture. Topic: Diabetic Kidney Disease: Structural–Functional Relationships and the Possibilities of Cure
- Rasheed Gbadegesin of Duke University presented the Michelle Winn Endowed Lecture. Topic: GWAS-Derived Targets for Glomerular Diseases

ASPN Online Board Review Course Registration Now Open!

Please register online at: <https://apps.aspneph.org/brconline2019/>

Online Course Includes:

- ◆ Videotaped lectures, case-based discussion, panel Question and Answer sessions and board-style question sessions led by expert faculty
- ◆ Study material formatted to the content specifications
- ◆ Question bank
- ◆ These items can be downloaded, but not printed and will expire October 31, 2021.

Course Fee:

- ◆ ASPN Fellow-in-Training Member*: \$325
- ◆ ASPN Member*: \$745
- ◆ Non-member: \$955

*ASPN membership must be current in order to register for the member price. Fellows must also be registered as a member to receive the fellow member price. Fellows who are graduating and will be attending physicians at the time of the course are eligible to register at the fellow rate. Early registration is encouraged. Fellows will be required to provide the name and contact information for their Training Program Director.

Questions: Contact Sarah Duran (sarah@aspneph.org).

Meeting & Lecture Announcements

Upcoming Meeting Dates*

Meeting	Place	Meeting Dates	Abstract deadline	Online registration opens	Early bird registration ends
Annual Dialysis Conference, 2020	Kansas City, Missouri	February 8-11, 2020	Oct 7, 2019	Open now	January 25, midnight, CST
PAS 2020 meeting	Philadelphia, PA	April 29-May 6, 2020	Jan 6, 2020	Nov 5, 2019	March 5, 2020
American Transplant Congress (ATC) 2020	Philadelphia, PA	May 30- June 03, 2020	Dec 6, 2019, 11:59 PST	Jan 2020	April 29, 2020

*Please verify dates on the individual meeting websites as they are subject to change.

52nd ANNUAL SCIENTIFIC MEETING OF THE EUROPEAN SOCIETY FOR PAEDIATRIC NEPHROLOGY

16-19 September 2020
Ljubljana, Slovenia



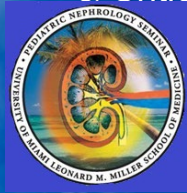
ASPEN members are warmly invited to the ESPN Congress in 2020 in Ljubljana, Slovenia, September 16-20, with Keynote Speakers, Pierre Ronco and Arvind Bagga. ASPEN Speakers will be announced shortly.

-submitted by Priya Verghese (ASPEN Liaison to the ESPN)

Meeting & Lecture Announcements

Save the Date!
November 12-15, 2020

Pediatric Nephrology Seminar XLVII
& Critical Care Workshop VII



Royal Palm South Beach
Miami Beach, Florida

22ND INTERNATIONAL CONFERENCE ON
**DIALYSIS ADVANCES
IN KIDNEY DISEASE**
2020



January 21-24, 2020
Los Angeles, CA

CALLING ALL ABSTRACTS!!!!



*We are excited to announce that the abstract submission **site is now open**. Submit your abstract for the **22nd International Conference on Dialysis - Advances in Kidney Disease Week 2020**. This conference will take place January 21-24, 2020 at the Loews Hollywood Hotel in Los Angeles, CA.*

Start your submission now

Meeting & Lecture Announcements

Fellows can
join RPA for
FREE!



When you become a member, you will have access to a special section on our website giving you access to useful and valuable resources and tools:

- Employment Center
- Practice Management resources
- Legislation, Regulation and Compliance information
- Patient Care resources and education



To join, visit www.renalmd.org.

ASPEN Central Office

Connie Mackay, Executive Director

6728 Old McLean Village Drive ~ McLean, VA 22101

Ph. 703-556-9222 ~ Fax 703-556-8729 ~ info@asneph.org ~ www.asneph.org

ASPEN is managed by Degnon Associates, an accredited professional association management company.

ASPEN Leadership

OFFICERS

President

Patrick Brophy, MD (2020)

University of Rochester

Patrick_Brophy@urmc.rochester.edu

President Elect

Michael Somers, MD (2020)

Boston Children's Hospital

michael.somers@childrens.harvard.edu

Secretary

Jodi Smith, MD (2020)

Seattle Children's Hospital

jodi.smith@seattlechildrens.org

Treasurer

Adam Weinstein, MD (2022)

Dartmouth Hitchcock Medical Center

adam.r.weinstein@hitchcock.org

COUNCILORS

Sandra Amaral, MD (2022)

The Children's Hospital of Philadelphia

amarals@email.chop.edu

Meredith Atkinson, MD (2022)

Johns Hopkins University School of Medicine

matkins3@jhmi.edu

Blanche Chavers, MD (2020)

University of Minnesota Medical School

chave001@umn.edu

Ewa Elenberg MD, MEd (2020)

Baylor College of Medicine

elenberg@bcm.edu

Rasheed Gbadegesin, MD (2020)

Duke University Medical Center

rasheed.gbadegesin@duke.edu

David Hains, MD (2020)

Riley Hospital for Children

dhains@iu.edu

Washington Representative

Erika Miller, JD

Cavarocchi Ruscio Dennis Assoc, L.L.C.

emiller@dc-crd.com

Newsletter Editor

Roshan George, MD

Emory University School of Medicine

roshan.punnoose.george@emory.edu

KIDney NOTES

The Bi-Monthly Newsletter of the
American Society of Pediatric Nephrology