



American Society of Pediatric Nephrology

November ~ December 2018

Kidney Notes



President's Corner

Dear Colleagues,

As we hurtle through autumn and the holiday season fast approaches, ASPN has just completed another cycle of Council and committee meetings during Kidney Week in San Diego. The projects ongoing in the society form an impressive list, and once more the enthusiasm and commitment of our membership was evident by the progress presented and the new plans outlined. Our committees are welcome to all, and I urge any of you not yet involved in a committee to reach out to a committee chair or the ASPN central office and express your interest. For us to be most effective as an organization, our committees and leadership need to reflect the breadth and depth of the ASPN membership as a whole – so if you are at all interested, please volunteer!

The most exciting update since the last Kidney Notes is the rollout of our new website. This website reflects untold hours of work by our Communications Committee, assisted by our ASPN Executive Director Connie Mackay. The website represents a huge step forward in our having a modern platform that can both facilitate exchange of information to and between members as well as to promote ASPN and its mission to optimize the care of children with kidney disease. We also now have greatly enhanced our capability of making changes or additions to the website, so please check it out and feel free to offer suggestions as to content you'd like to see included.

The website can also be used to learn about the benefits of ASPN membership as well as to apply for membership or to renew membership dues. Memberships can also learn about the ASPN Foundation and opportunities to make charitable contributions that are tax deductible and that can be earmarked for specific projects within ASPN. Membership renewal is due by the end of the calendar year, so while checking out the new website in the next few weeks, renew your membership and consider a Foundation contribution.

Mark your calendars now for the ASPN Spring meeting at the 2019 Pediatric Academic Societies meeting in Baltimore on April 27-30. We will be ending the celebration of ASPN's 50th year and details about the didactic program will be available in the next several weeks on the website, including augmented nephrology-specific sessions on the last day of the meeting. ASPN also plans to hold a Capitol Hill Day event in Washington, DC on May 1, and information about this opportunity for advocacy and how to sign up to participate will also be forthcoming. To echo my comments above, our public policy efforts like all of our ASPN endeavors will succeed best if we have participants that represent all facets of our pediatric nephrology community, so do not be shy to lend your voice to our cause!

A handwritten signature in black ink that reads "Michael Somers".

Michael Somers, MD
Acting President
michael.somers@childrens.harvard.edu

News and Announcements

Member of the Month (September and October 2018)

Congratulations to our Members of the Month for their service to ASPN. Send nominations for those who have gone above and beyond to Michelle Rheault (rheau002@umn.edu):

SEPTEMBER



Dr. Kartik Pillutla
Dell Children's Medical Center of Central Texas
Chair of the ASPN Workforce Committee

OCTOBER



Dr. Shamir Tuchman
Children's National Medical Center
Co-Chair of the Training Programs Directors Sub-Committee

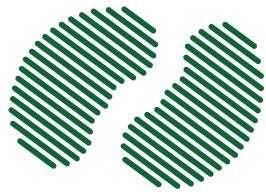
.....

Please send us (info@aspneph.org) photos of pediatric nephrologists receiving awards or giving important lectures so we can share them in *KidneyNotes*.



ASPN Corporate Liaison Board





American Society of Pediatric Nephrology FOUNDATION

ASPN Foundation End of Year Giving

As you are thinking about your end of year giving, the American Society of Pediatric Nephrology Foundation asks that you consider supporting the Foundation and its work to enhance the education, research, and advocacy programs of our society. Contributions may be made through the ASPN website, <https://www.aspneph.org/aspn-foundation/donate/>.

The ASPN Foundation provides travel grants to fellows both to national and international meetings, supports the American Society of Pediatric Nephrology Leadership Development Program and the affiliate program.

We wish you a happy holiday season as well as a peaceful and joyful 2019.

SUPPORT THE ASPN FOUNDATION
WHILE YOU SHOP!



We have recently joined Amazon Smile, which will donate 0.5% of what you spend on [Amazon.com](https://www.amazon.com) to the ASPN Foundation. This is a very easy way to support the ASPN while just going about your daily life.

AmazonSmile: You shop. Amazon gives.

Committee Updates

Research Committee Update

Update your NIH biosketch and eRA Common's personal profile

In an effort to help Program Officers (POs) to track the success of pediatric nephrologists and for Scientific Review Offices (SRO) to assign expertise in pediatric nephrology to study sections for grant review, check that both your eRA Common's personal profile and your NIH biosketch includes the words Pediatrics and Nephrology in the job titles.

Predatory Publishing Resource

In a previous Kidney Notes, we brought attention to the practice of “predatory publishing” (a publishing model that deceives researchers into submitting their work and then charges them to publish it). We wanted to draw attention to a potential resource: there is a website to help authors assess whether a journal may be using predatory publishing practices: <https://thinkchecksubmit.org>.

PAS is Coming Soon

Pediatric Academic Societies abstracts are due by Jan 2. Don't forget the ASPN sponsors residents and selected other non-fellow trainees with interest in Pediatric Nephrology to travel to the ASPN. Nominations are due by Friday January 25.

Highlight Pediatric Nephrology successes!

As a reminder: The ASPN research committee is looking 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.

Submitted by Kim Reidy and Ulf Beier on behalf of the Research Committee

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 will close on December 31st, 2018 and we will move forward with the 2018-2019 Academic Year webinar series after that time. 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 Pathology Webinar

Date: Monday, November 5, 3PM (Eastern)!

Topic: 14yo with uveitis

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.

Washington Update

Congress Addresses FY 2019 Spending, Health Priorities

In late September, Congress passed and the President signed the FY 2019 Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) spending bill. This was the first time in 22 years the Labor-HHS spending bill was approved prior to the start of the new fiscal year!

Congress was able to address many of the annual appropriations bills, including Labor-HHS, before the start of the new fiscal year because they passed Bipartisan Budget Act in February. This legislation set this year's spending caps so appropriators knew how much funding was available for federal programs in FY 2019. The final Labor-HHS spending bill addresses many of ASPN's priorities, providing a \$2 billion increase for the National Institutes of Health (NIH) and a \$10 million increase for the Children's Graduate Medical Education funding. At this time, several pieces of important report language were also finalized. ASPN had requested language related to the National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK) pediatric kidney disease research, specifically requesting that the Institute report back on progress made towards additional pediatric focused clinical studies. There is also language related to removing impediments to living donation, requesting a study to look at the cost effectiveness of the Center for Medicare and Medicaid Services' (CMS) current policy on immunosuppressive drug coverage, and supporting the KidneyX initiative.

Living Donor Protection Act Update

We have good news that the Living Donor Protection Act, which reduces barriers to living organ donation, will be introduced in the Senate after the election recess. ASPN and other stakeholders have spent much of this Congress looking for a new Senate Republican champion without success, but finally identified a new lead Republican during ASN's Kidney Community Advocacy Day. Senator Tom Cotton (R-AR) agreed to work with Senator Kristen Gillibrand (D-NY) to introduce a Senate companion before the end of this Congress. While it is unlikely that the bill will pass before the 115th Congress ends, both Senators Cotton and Gillibrand will be willing to reintroduce the bill next year.

What's Next for the Affordable Care Act?

In early September a hearing was held in Texas v. United States, the lawsuit challenging the constitutionality of the individual mandate, and potentially, the entire Affordable Care Act (ACA). Texas was brought by 20 Republican state attorneys general and governors, and the hearing addressed the plaintiffs' request for a preliminary injunction against some or all of the ACA.

A preliminary injunction is an injunction entered by a court prior to a final determination of the merits of the case. Given the upcoming open enrollment period, the Department of Justice (DOJ) had asked that a decision beyond the constitutionality of the individual mandate be delayed until 2019.

The plaintiffs' case centers on the constitutionality of the individual mandate. Last year's tax bill did not repeal the individual mandate, but instead reduced the penalty to \$0. The plaintiffs have argued that it is unconstitutional to levy a tax of \$0 and continue that the mandate is not severable from the rest of the ACA, invalidating the entire law.

The Trump administration declined to defend the ACA against this challenge. Rather than arguing the entire law is unconstitutional, however, the DOJ has maintained that the ban on pre-existing conditions and community rating provisions should be invalidated. Both of these provisions are two of the very popular patient protections included in the ACA. Regardless of the ruling on the injunction, all the parties expect the ruling, regardless of the outcome, to be appealed immediately.

Much discussion inside and outside the court has focused on congressional intent. With the midterm election approaching, health care and protections for individuals with pre-existing conditions are very popular issues. Republican members of Congress have stated that they did not intend to repeal the ban on pre-existing conditions when they supported last year's tax law.

To demonstrate this, Senator Tillis (R-NC) introduced the Ensuring Coverage for Patients with Pre-Existing Conditions Act. However, this legislation is flawed. While this legislation will ensure that everyone has access to insurance coverage, it does not require plans to cover individuals' pre-existing conditions. It is in effect providing for guaranteed issue without ensuring the coverage that is issued is meaningful.

Regardless of the outcome of the election, the lawsuit has guaranteed that the ACA, and its patient protections in particular, will remain an issue in the lame duck and most likely in the 116th Congress. ASPN will continue to keep members updated on the latest developments and issue calls to action when appropriate.

Submitted by Erika Miller

John E. Lewy Foundation (JELF) Scholars Update

Kidney Community Advocacy Day (KCAD) 2018 by the numbers...

75 kidney community advocates from 13 organizations, of which there were:

16 pediatric nephrologists (approximately 2% of all US pediatric nephrologists, and 21% of all KCAD participants!)

9 JELF scholars and JELF alumni

2 pediatric kidney patients (and 1 parent, because, of course, they are kids)

We educated lawmakers and their staff on the importance of:

- Increased funding for the National Institutes of Health
- Sponsorship of the Living Donor Protection Act, HR 1270
- Support of the KidneyX innovation accelerator, a public-private partnership designed to inspire and accelerate breakthroughs in kidney care

Tweet

Patty Seo-Mayer
@PSeoMayer

Pediatric nephrologists representing
at #KidneyCommunityAdvocacyDay
@DrRayMD @zjmodi @ASPNe
@AdvocacyAspn @ASNKidney
@ASNAAdvocacy #JELFing

Translate from Catalan

9/27/18, 8:52 AM

ASN Advocacy @ASNAdvocacy · 9/27/18 ·
Off to great start for Kidney
Community Advocacy Day! Thank
you @SenToddYoung for your
commitment to kidney patients and y...

ASN Advocacy @ASNAdvocacy · 9/27/18 ·
Thank you @sendavidperdue and staff
for your support of living donors and
funding for innovations to treat #kidney
diseases! ...

JELF Scholars meet with Baxter Director of Government Policy and Reimbursement and Alliance Development

Current JELF scholars (with the guidance of Erika Miller and Zara Day) met with a member of the Baxter leadership team to discuss promising dialysis innovations, and to learn about the challenges of introducing technical advancements within the bundled payment dialysis reimbursement model.

Help keep our voices heard! SUPPORT ASPN ADVOCACY through your annual dues renewal

The JELF program is 100% funded by the generosity of the ASPN membership and we are so grateful for your support. More than ever, our patients need our voices to be heard, and your contributions help ensure our visibility where it matters. You can contribute to the Perlman Program for Perpetual Participation and the John E. Lewy Fund through your ASPN annual dues renewal. To donate directly, click here: <https://www.aspneph.org/aspn-foundation/donate/>. Learn more about the JELF program by contacting David Hains at dhains@iu.edu or visiting <https://www.aspneph.org/jelf-advocacy-scholars-program/>

Patty Seo-Mayer, MD, FAAP, JELF Scholar 2017-2019
Inova Children's Hospital and Pediatric Specialists of Virginia

Transplantation Update

OPTN/UNOS NEWS:

I had previously reported that a joint working group (representing the UNOS Pediatric and Kidney Committees as well as other stakeholders) was analyzing the data and specifically the effects of KAS on children. Unfortunately, a lot is happening at UNOS/OPTN that has led to a "tabling" of this effort, at least temporarily.

Because of legal challenges to the use of DSA (donor service areas) and Regions as units of deceased donor organ allocation, HRSA has directed the UNOS/OPTN to **completely eliminate the use of DSA or regions in allocation policy** in order to be compliant with The Final Rule <https://optn.transplant.hrsa.gov/governance/about-the-optn/final-rule/>

The Final Rule requires that organ allocation policies "shall not be based on the candidate's place of residence or place of listing, except to the extent required" by other requirements of The Rule. Those "other requirements" are for allocation policies to include *sound medical judgement, best use of organs, the ability for centers to decide whether to accept an organ offer, to avoid wasting organs and to promote efficiency.*

To move forward with new allocation policies (for all organs including pediatric recipients) that do not rely on the DSA or Regions the ad hoc Geography Committee of UNOS/OPTN has put forth 3 potential organ distribution frameworks that are felt to legally fulfill the requirements set forth by The Final Rule. <https://optn.transplant.hrsa.gov/governance/public-comment/frameworks-for-organ-distribution/>.

These 3 frameworks of distribution 1) Fixed distance from the donor hospital, 2) Mathematically optimized boundaries and 3) Continuous distribution are presently being modeled by the organ specific committees of UNOS/OPTN and have been out for public comment this fall cycle. Public comment closed in early October. The UNOS/OPTN BOD will vote in early December on a framework to move forward with. The choice of framework will depend on how a new framework affects access for adults as well as vulnerable populations such as the highly sensitized and children, cost and travel requirements and the effect on marginal organs and potential organ utilization.

We (pediatricians) have been participants in the process but the true extent of the effect these changes will have on access for children is a bit of an unknown since modeling does not predict future changes in behavior/acceptance practices. In general, larger sharing areas for children are being proposed so in theory this may be to the overall benefit of the pediatric candidates. Stay tuned.....

UNOS/OPTN call for nominations

UNOS/OPTN is seeking nominations to fill available at-large positions on OPTN/UNOS committees. Committee members are all volunteers, representing a variety of professional disciplines and personal experience and expertise in organ transplantation. The organization values diversity and strives for a committee system that represents the community we serve. Committee members may be donation or transplant professionals, transplant candidates or recipients, living donors, donor families, and/or members of the general public. The

overall composition of the committee should reflect diversity in opinions as well as race, ethnicity, and gender. All candidates must submit a bio form online by November 19 to be considered for a committee vacancy. <https://optn.transplant.hrsa.gov/members/get-involved/>

Pediatric Program Requirements

Due to the massive nature of this project, applications will not be required until sometime in 2019. It is anticipated that late Spring/early Summer 2019 the 90 day application period will open. All applications for pediatric transplant programs will be reviewed by the MPSC (Membership and Professional Standards Committee) of UNOS/OPTN. At this point, the likely timeline for decisions to be made will be Summer/Fall 2019 with BOD approval anticipated at either the June 2020 or December 2020 BOD meeting. Will keep you updated as more regarding the timeline becomes available.

AST Call for Nominations

AST is now accepting nominations for 2019 AST Board of Directors. Detailed information and the nomination criteria can be found on the AST Website. Your role in the board nomination process is important. If you are interested in submitting an application, or if you know of an AST member who matches the nomination criteria, click here. The AST depends on its members to submit recommendations for qualified and deserving candidates. For more information on the process, click here. All nominations must be received by Friday, November 30, 2018 at 5 pm EST. If you have further questions you can contact the AST office at info@myAST.org or (856) 439-9986.

Pediatric Transplant Training Opportunity

The IPTA sponsored meeting dedicated to the training of clinical and research fellows, trainees, residents and post-docs in pediatric solid organ transplantation will be held in Costa Rica, November 12-13, 2018. Visit WWW.tts.org/ipta for more details.

SAVE THE DATE

The next **IPTA meeting** will be held May 3-7, 2019 in Vancouver! Call for abstracts has gone out. https://d19cgyi5s8w5eh.cloudfront.net/empl/OddS-RoTQu0lx8laY_MgQ?e=tom.blydhansen%40cw.bc.ca&a=2QOkQbvSSGK76ltLwk3dLA&f=1b2b026c&t=1

Respectfully submitted, Sharon M. Bartosh, MD
November, 2018

**Please see call for
Transplant Interest
Group on page 9.**

Announcements

NephCure Announcement



Dear Nephrology Friends –

We need your help to identify **Nephrotic Syndrome Specialists**.

NephCure is a research focused, patient advocacy group with the mission of expediting treatments for **Primary Nephrotic Syndrome**. It has been recognized that there is a significant connection between a patient's timely and effective care and their resulting prognosis. This realization inspired us to launch a 'Specialists' program.

The goal of this initiative is to provide patients with earlier access to those clinicians who are specialists in and routinely treat Nephrotic Syndrome.

As you know, patients receiving expert care early on in their diagnoses with Primary Nephrotic Syndrome are more likely to access a broader array of appropriate treatments (including clinical trials) and experience better outcomes. Conversely, patients who experience a delay in finding expert care are at risk for irreversible kidney and podocyte damage.

Please accept this invitation to nominate one or more 'Specialist' pediatric and/or adult nephrologist for this special recognition. As you consider qualified individuals, please note that we are evaluating candidates who exhibit excellence in clinical care as opposed to scientific achievement. Those who choose to participate are encouraged to nominate more than one person but must complete one form per nominee. Additionally, self-nominations are welcomed.

Nomination forms can be found by [clicking here](#).

In closing, please know that this list, while simple in format, will be an invaluable resource for patients and their loved ones impacted by Nephrotic Syndrome. Your participation will help families find a comprehensive list of specialists in diverse care settings and various geographic regions. Please feel free to reach out to us with questions and/or comments at any time. I look forward to hearing from you.

Thank you for your time.

Sincerely,

Irv Smokler, Board Chairman

Josh Tarnoff, Chief Executive Officer



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Email: info@nephcure.org

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Announcements

Call for Transplant Interest Group (TIG)

- Do you take care of children who are pre or post kidney transplant?
- Do you wonder how to stay current on transplant related regulations, standard of care, new developments, etc when your transplant practice is not the major focus of your clinical work?
- Do you have an interest in connecting with others who feel similarly?

We are considering initiating a Transplant Interest Group (TIG) with the intent of providing a mechanism for like-minded pediatric nephrologists who care for children both pre and post transplant but who do not have the ability to attend the annual transplant meetings or be active members of the transplant societies to fill that need. We also encourage the participation of those of our members who are heavily involved in transplant as part of their practice.

To assess interest in this new initiative, I would appreciate if you could reach out to me at smbartosh@wisc.edu and copy info@aspneph.org.

More details to follow!!!

Sharon M. Bartosh, MD

ASPN Marketplace

ASPN Marketplace is the place to advertise employment opportunities in Pediatric Nephrology. To place an advertisement, go to <https://www.aspneph.org/employment-ads/>.



Funded Grant Announcement

Jyothsna Gattineni, UT Southwestern Medical Center
R01: Consequences of Elevated FGF23 in the Presence and Absence of Kidney Disease

Looking for content experts

The member education committee is looking for help for their monthly webinars. During each webinar, there is a content expert who delivers a 10-15min powerpoint presentation on the topic with a few multiple choice questions. This webinar is for physician learners at all levels of experience from fellows to experienced full professor faculty so we are looking for innovative and updated information on the topics. These conferences are typically held on the first Monday of every month at 3PM EST. There is usually one practice session one week before the conference. Below are the next few topics for both pathology and radiology. If you are interested in being a content expert, please email me at Joann.Carlson@rutgers.edu.

Next Pathology webinars will cover HSP, transplant, and obesity related glomerulopathy.

Next Radiology webinars will cover ADPKD/tuberous sclerosis, nephrocalcinosis and renal tumors.

Meeting & Lecture Announcements

SAVE THE DATE

MARCH 8 - 10, 2019 46TH MIAMI PEDIATRIC NEPHROLOGY SEMINAR

We are happy to invite you to our **46th Pediatric Nephrology Seminar** which will take place at the Miami Beach Resort in beautiful Miami Beach from **March 8-10, 2019**. The Seminar will have another exciting scientific program covering a wide range of topics, including **Genetic/Developmental and Rare Disorders of the Kidney, New Frontiers in Pediatric Nephrology, Practical Nephrology for the Clinician, Recent Advances in Glomerular Disorders, CKD and Hypertension, Bone Disease, FGF23 and the Kidney, Growth and Nutrition in CKD (Workshop), Progressive CKD, Dialysis and Transplant Challenges**. In addition, at the end of the Seminar we will offer a workshop for **Pediatric Critical Care Nephrology** with live CRRT procedures conducted at Holtz Children's Hospital for selected participants. We hope you will enjoy attending this unique, international, interactive scientific meeting. For details regarding the full program, speakers, registration, grant applications for fellows and pediatric residents and hotel reservations contact our Web page at <http://pediatrics.med.miami.edu/nephrology/seminar>.



MIAMI BEACH RESORT

4833 Collins Avenue, Miami Beach, FL 33140



ISN
WORLD
CONGRESS OF
NEPHROLOGY

April 12-15, 2019
Melbourne (VIC), Australia



Including the joint session "Medical complications of pediatric-onset chronic kidney disease" in partnership with the International Pediatric Nephrology Association.

Upcoming Meeting Dates*

Meeting	Place	Meeting Dates	Abstract deadline	Online registration opens	Early bird registration ends
IPTA 2019	Vancouver, Canada	May 4-7	Extended - November 15, 2018, 23:59 EST	November 15, 2018	Feb 1, 2019
ATC 2019	Boston, Massachusetts	June 1-5	November 30, 2018, 11:59 PM PST	January 2019	Member rates if member dues for 2019 paid by May 24 th , 2019
ASPN 2019	Baltimore, Maryland	April 27 - 30	January 2, 2019	November 15, 2018	March 14 th , 2019 (PAS)

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

Meeting & Lecture Announcements



program@ipna2019.org
www.ipna2019.org



November 12-13, 2018
IPTA 2018 Symposium in Organ Transplantation in Children
San José, Costa Rica

Meeting & Lecture Announcements



SAVE THE DATE

**46th MIAMI
PEDIATRIC
NEPHROLOGY
SEMINAR
MARCH 8-10
2019**

MIAMI BEACH RESORT
MIAMI BEACH,
FLORIDA

<http://pediatrics.med.miami.edu/nephrology/seminar>



American Society of
Pediatric Nephrology

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.

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KIDney NOTES
The Bi-Monthly Newsletter of the
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