



# American Society of Pediatric Nephrology

July ~ August 2020

## KIDney Notes

### *President's Corner*



Dear Colleagues,

I'd like to start off my first President's Corner by acknowledging and thanking Pat Brophy for his service as ASPN president over the last two years. Amidst myriad other responsibilities and through some unexpected bumps in the road, he showed unflagging attention to his role guiding ASPN. All of us are especially grateful to his insights on our workforce issue, and his ongoing determination to find solutions that are both achievable and sustainable.

In late June, we had our summer Council meeting where we take stock of what has been accomplished over the last year and what goals should take precedence over the next 12 months. In a true ZOOM extravaganza, we welcomed the new Council members who were elected last fall, and we had the opportunity to meet with the chairs of our committees.

A great deal of our discussions focused on the issues of racism, equity, diversity, and belonging, echoing many conversations that have been happening around the nation over the last 6 weeks. Council has determined that we need to maintain this dialogue and engage the membership broadly in hopes of understanding experiences and formulating approaches to the shortfalls that we all need to address. In July, a call will go out to membership asking those of you who would like to become more involved with a group to discuss initiatives around inclusion, and our ASPN president-elect, Jodi Smith, and our ASPN secretary, Meredith Atkinson, will be coordinating this group's efforts.

Over July, there will be four webinars to present content from the canceled spring ASPN meeting at PAS. As a member, there is no fee to register for this ASPN Summer Series, and MOC and CME credit will be offered. I would like to recognize Jennifer Charlton and the members of her Program Committee for their Herculean efforts essentially planning two meetings, and Jennifer's devotion to making sure that the transition to these virtual platforms is successful. I hope many of you will have the opportunity to join these sessions on upcoming Friday afternoons and make use of their educational potential.

Lastly, please find some time during the summer months to relax and enjoy family and friends. Although the COVID pandemic has made us face new realities in many realms, the importance of fostering our important social relationships in an era of physical distancing cannot be understated!

Sincerely,

Michael Somers, MD  
President, ASPN  
[michael.somers@childrens.harvard.edu](mailto:michael.somers@childrens.harvard.edu)

## ASPEN Corporate Liaison Board



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



## *From the Editor's Desk*

The year 2020 has so far been “transformative”- to put it mildly. While the Covid19 pandemic revealed deficiencies in our healthcare systems and the recent killings of African American citizens starkly exposed systemic racism, we also saw exceptional resilience and advocacy by a diverse population to address injustice. This is just the start and there is much work to be done.

Within academic settings, July has long been a period of change, when medical students of yesterday become interns of today, interns take the reins of teams as residents, and fellows cross the threshold to being independent practitioners.

In this spirit of growth and change, we at KIDney notes are introducing a new section- “Perspectives” where you- our members are invited, to share your thoughts and reflections on matters impacting your life and practice.

We will start off with this powerful ‘call to action’ by Dr. Ray Bignall and Dr. Whitney Bignall on ‘how to be an antiracist pediatric nephrologist’.

Please read, reflect and act on these brilliant thoughts.

Let us have the foresight to make the rest of 2020 count, with meaningful change personally, and within our spheres of influence, so in hindsight, 2020 will truly be a year of positive transformation.

Please email or message me your thoughts about the addition of this section in KIDney notes. You are also welcome to send ideas for this section, or your own “perspective” piece.

Take care all,  
Roshan

Roshan George, MD  
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**Roshan George, MD**  
*Editor, KIDneyNotes*

### Silence Is Not an Option: The Time Is Now to Become Antiracist Pediatric Nephrologists

O. N. Ray Bignall II, MD and Whitney J. Raglin Bignall, PhD



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There is perhaps no more challenging topic in academia than the topic of racism. Our default position is often to ignore racism and pretend it doesn't permeate every aspect of American life – including child health. However, in this moment of national awakening to the public health crisis racism poses to all of us, there is growing acknowledgement that staying silent about racial injustice only makes the problem worse.

Racism not only threatens the health and safety of our patients and our communities, but also the health and safety of our minority colleagues.

Pediatric nephrologists are well-acquainted with the profound impact of racial health disparities on pediatric kidney disease outcomes. Many of these outcomes find their roots in the centuries of racial injustice perpetrated on Black Americans: disparities in prematurity and low-birth weight, access to kidney transplant, progressive chronic kidney disease, and allograft outcomes are all touched by the long shadow of racism in America.

Racism is also reflected in the policies of our government and institutions. Explicitly racist policies in housing, education, employment, and industry have existed at every level of public and private life, and pre-date the founding of America. Discriminatory policies at the federal level – including the recent presidential executive order suspending work visas for international medical professionals – disproportionately impact ethnic minority colleagues in nephrology, one of the most diverse specialties in academic medicine.

In a healthy and just society, dismantling racism is everyone's responsibility. How can we approach this task in academic pediatrics?

The first step we must take is to educate ourselves about racism and racist systems, and how they affect our daily lives. There are many books and websites that are helpful resources for understanding racism. We have included a couple of our favorite links here so that you can share them with your family and colleagues: the [21 Day Challenge](#) helps us to develop habits of racial equity, and the [American Academy of Pediatrics has compiled a list of articles](#) detailing the impact of racism on child health.

Next, we must commit ourselves to being antiracist. It is not enough to simply say "I am not racist," because we all have a duty to speak out against injustice, and speak up for our patients, neighbors, and colleagues who suffer injustice. Antiracism is a standard of actively opposing inequality and injustice as we encounter it in our lives. We must learn to develop radical empathy for those who are struggling to be heard and helped. We must listen intently to minority voices, whose experiences are different from our own. Antiracism also requires that we cease to be "bystanders," and become "upstanders" instead: individuals who do not hesitate to confront racist or intolerant language or behavior in our institutions, our communities, and our homes.

Once we are personally committed to antiracism, we can begin to inspire a commitment to antiracism amongst our colleagues and within our institutions. For instance, pediatric nephrologists can use clinical encounters with Black patients to inquire regarding their mental and emotional health as they grapple with the disturbing news of acts of racial violence. We can screen for social determinants of health – including personal experiences with racism – during clinical encounters. Physician-scientists can be intentional about recruiting diverse research teams, and working with diverse

talent to determine how best to foster a culture of inclusion amongst all its members. Nephrology divisions can incorporate implicit bias training into their continuing education curricula. Academic institutions must learn how to establish dynamic, community-led partnerships within minority populations. This includes encouraging our institutions to develop the leadership capacity of members from communities that we serve, and investing our time, talents, and funds to build these partnerships.

The fight against racism is a marathon, not a sprint. It is not the responsibility of people of color to fight this fight alone. Building a truly antiracist society requires us all – pediatric nephrologists included – to be committed to equity and justice each and every day.



**Whitney J. Raglin Bignall, PhD**  
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# Committee Updates

## Certification Committee Update

### MOCA-Peds Has Arrived in Pediatric Nephrology!!

This month's update is regarding the new options available in Pediatric Nephrology for Maintenance of Certification (MOC) Part 3 (the exam!- that's how it's referenced on the ABP website, just without the !). Starting this past January, the MOCA Peds option became available in Pediatric Nephrology, starting with those individuals who enrolled in a five-year cycle in 2019.

What is MOCA Peds, you may ask! This testing option was pilot tested among general pediatricians in 2017 and 2018 and then, after being well-received, went live with General Pediatrics (along with a few pediatric subspecialties) in 2019, so you may already be familiar with it. It is an alternative on-line option in which you will receive a set of questions to complete each quarter, but you can choose how and when to do the testing. You may receive up to 20 multiple-choice, timed questions to complete each quarter. However, you may choose to do anywhere from one question a given day to completing all 20 at once, from the comforts of your office, your kitchen (which may now be the home office for some of us), or anywhere you may comfortably get on-line. Each question, though, is timed individually with 5 minutes per question. You have the option of using references (books, on-line searches,...) to answer the questions, as long as the references are not other individuals, but still needing to respond to the given question within that five-minute time limit.

The questions will mostly come from the list of 45 learning objectives listed on the ABP website, however starting with your second quarter of MOCA Peds, a few questions may also come from featured peer-reviewed journal articles (up to 2 questions per article) also listed on the ABP website. Because of this feature, you will also earn 1.25 MOC Part 2 points per quarter (or 5 points per year) by participating in MOCA-Peds, thus simultaneously satisfying a portion of your Part 2 requirements (up to half) over a full five-year cycle. Additionally, your four lowest scored quarters in any five-year cycle will be dropped, so if you have a bad session or quarter, it won't count against your final scoring. And if your remaining scored quarters do not satisfy the requirements to pass, then you simply need to enroll and pass the traditional, proctored re-certification examination before the end of your five-year cycle, which is what you would have had to do previously. The traditional re-certification examination option remains- just without the flexibility of timing on your own, the use of references, the ability to drop lower sections, or the additional awarding of Part 2 points.

Also, as no Certification Committee update is complete without some mention of MOC Parts 2 and 4, the ABP has announced that they will award 25 points in both Part 2 and Part 4 to all pediatricians maintaining certification in June 2020 to recognize their commitment to lifelong learning and improvement during the COVID-19 pandemic. So, if you have requirements due in 2020 and have not yet satisfied them, you will receive **any remaining** MOC points needed in early June. Also, if you have activity requirements due in any other year will receive 25 Part 2 and 25 Part 4 points in **June**. However, physicians who have already satisfied their activity requirements for 2020 will receive 25 Part 2 and 25 Part 4 points in **January 2021** to ensure they are applied to their next MOC cycle. These points will be awarded without any documentation necessary and will count towards any open cycles at that time. So, please log in to the website and review your portfolio to see that those points have been awarded.

Rene VanDeVoorde, MD for the Certification Committee



## Planning Committee Update

The Program Planning Committee met in small working groups virtually throughout April, leading up to a half day meeting on Zoom with everyone present. The Committee received 42 proposals for symposia, excluding 4 sessions from the 2020 PAS that were up for consideration to reschedule. After much organizing and strategizing, a program proposal was constructed for 3 workshops and 8 symposia (7 of which will likely go ahead, one as a backup). The proposal was presented to Council May 8 and approved in principle. New this year, we are excited to announce to ASPN Foundation funded lectureships: The Adrian Spitzer lectureship, which will target speakers with a background in developmental nephrology and physiology; and the H. William Schnaper Lectureship, which will target speakers in numerous areas paralleling the accomplishments of Dr. Schnaper. For 2021, this will reflect Dr. Schnaper's work with ESPN, and invite a colleague from Europe. Formal terms of reference for the lectureships are currently under consideration by the Council. The Program Planning Committee is currently working with the PAS organizing Committee, awaiting direction on timelines and whether the meeting will have a virtual component or not, should travel still be restricted at the time of the meeting in April 2021. Speaker confirmations will likely be available over the summer. Many thanks to the hard working members of the Committee for getting the work done under virtual circumstances!

Maury Pinsk, MD FRCPC  
Chair, PAS 2021 Planning Committee (Vancouver)



# Committee Updates

## Public Policy Committee Update

### **Congress Begins to Turn Its Attention to Other Issues Despite Ongoing COVID-19 Needs**

The House passed the HEROES Act, its version of the fourth COVID-19 relief bill, on May 15, but Congress has not taken additional action to enact legislation to address a number of outstanding COVID-19 needs facing providers, health systems, states, and ordinary Americans. Unfortunately, the time line for action continues to grow. Buoyed by the recent jobs report, Senate Majority Leader McConnell does not plan to begin negotiating the next relief package until late July, preferring to wait for the next jobs report and for the administration to disburse more of the aid already appropriated.

ASPN is continuing to advocate for our priority issues – additional aid for children's hospitals and providers, funding for the National Institute of Diabetes and Digestive and Kidney Diseases to perform COVID-19 related research and to support restarting National Institute of Health (NIH)-funded research, and expanded liability protections for providers. We anticipate that when Congress negotiates the next relief package it will include liability provisions, aid to state and local governments which can be used to support public hospitals and universities, additional Medicaid FMAP adjustments, and funding for NIH.

Congress is turning its attention to FY 2021 appropriations, which have been delayed as they have been focused on the pandemic and members have been away from Washington for much of the spring. In a break with tradition, the Senate will mark up its appropriations bills first, including the bill that funds the Department of Health and Human Services. The House will follow. No formal announcement has been made, but the delay will almost guarantee that Congress needs to pass a continuing resolution to fund the government when the new fiscal year begins on October 1. Already, some members have expressed concern about a potential government shutdown if negotiations go poorly between President Trump and Speaker Pelosi. Stay tuned...

Other items on the agenda for the summer include police reform legislation in both chambers and Affordable Care Act (ACA) reforms in the House. Plans to pass legislation to bolster the ACA in late March to coincide with the anniversary of its passage were scuttled by COVID-19.

### **ASPN Holds Virtual Capitol Hill Day**

ASPN held a virtual Capitol Hill Day on May 13 to make sure that the voice of pediatric nephrology was included in the next COVID response legislation. Fourteen members of the Public Policy Committee participated by making calls and nine members participated by sending emails to their Senators and Representatives. Participants discussed the following asks during their meetings:

- Include funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and that funding is included to re-start NIH-funded research that had to pause due to the pandemic. This is particularly important due to the limited funding available for pediatric nephrology, which would be exacerbated without additional funds.
- Provide additional funding for provider relief, and designate funds from the Public Health Emergency Fund to children's hospitals to protect the pediatric workforce and maintain the pediatric health care infrastructure; and
- Expand federal liability protections so that volunteer health care providers do not face liability for offering services during the crisis. For pediatric nephrologists, extended liability protection could be necessary for those who are providing non-dialysis care, or providing care without proper personal protective equipment, for example.

There have been no formal announcements regarding when in-person meetings on Capitol Hill will resume, but we anticipate that it will be some time before they do. ASPN intends to hold future virtual advocacy days on our priority issues. Please contact the Public Policy Committee if you would be interested in participating.

### **ASPN Comments on High Blood Pressure Screening Draft Recommendations**

ASPN submitted comments to the United States Preventive Services Task Force (USPSTF) on its [draft recommendation](#) on screening for high blood pressure in children and adolescents. In particular, ASPN expressed concern about how the Task Force's conclusions might inadvertently harm the progress that has been made in identifying high blood pressure in the pediatric population. The letter also highlighted the link between childhood hypertension (HTN) and chronic kidney disease, which further strengthens the importance of screening children for high blood pressure. ASPN is also concerned that USPSTF is incorrect to focus on the research question of if screening for HTN in children leads to decreased cardiovascular mortality in adults. In the longer term, the Society will focus on developing the research necessary to provide USPSTF to change its recommendation moving forward.

### **Update on the Advancing American Kidney Health Initiative**

The Department of Health and Human Services (HHS) is planning to finalize the participants in the [Kidney Care First \(KFC\) model](#) from last year's Advancing America's Kidney Health Initiative as the administration begins to resume work on non-COVID related policies. HHS expects to re-engage the stakeholder community on the Initiative this summer with an event to focus on the progress made since last summer's kick-off event.

# Committee Updates

## Research Committee Update

Back by popular demand – the ASPN Research Committee will be hosting its annual **Grant Review Workshop** this October 2020 by ZOOM! We aim to time the virtual workshop to coincide with ASN to allow maximal participation by those who may not otherwise have dedicated time from clinical responsibilities. This is a great opportunity for anyone, particularly junior faculty and fellows, to get an expert review of grant materials prior to submission. So, if you are working on a mentored grant award for the NIH, a foundation grant, an institutional grant, the NIH Loan Repayment Award Program –any grant –and would like content experts and seasoned, funded clinician scientists to review and critique your proposal, we want to hear from you! To participate, we request at a minimum a Specific Aims page and a Career Development Plan, but the more grant materials the better (draft of Research Strategy is also encouraged). To provide the most thorough, thoughtful review the sooner we receive your materials the better. This gives us time to identify appropriate reviewers and gives the reviewers time to review your materials. *Please let the ASPN research committee co-chairs know of your interest in participating, your research topic/field, and any preliminary materials you may have by mid-August. Final grant materials for review should be submitted by mid-September.*

Chair: Tammy Brady, MD, PhD, Co-Chairs: Brad Dixon, MD, FASN and Michelle Denburg, MD



## Workforce Committee Update

### Webinar Announcement

The Workforce committee would like to invite you to join us for our next webinar on Thursday July 9, 2020 at 1200 EST/ 1100 CST/ 0900 PST titled: "Taking Control of Your Student Loans: Advice for the Pediatric Nephrologist"

This webinar is intended to provide education and address your concerns about student loans. The organizers would like to hear from you about specific questions you may have about loan repayment. Please submit questions to [dkweidemann@cmh.edu](mailto:dkweidemann@cmh.edu) by July 3<sup>rd</sup>, 2020.

### Request for Volunteers

We are recruiting fellow and faculty volunteers to work on a variety of workforce related initiatives. There are 4 workgroups including: trainee education and exposure, reimbursement and policy issues, fellowship training issues, and retention of the current workforce. All levels of experience are welcome. For more information on this initiative or to volunteer please direct your correspondence to [lashoo@lsuhsc.edu](mailto:lashoo@lsuhsc.edu)

Submitted by Isa Ashoor, MD on behalf of the ASPN Workforce Committee

# Benefits of Membership

We would like to note that all ASPN members have access to free previously recorded webinars on the ASPN website. Webinars on the following topics are posted and can be accessed after logging to the ASPN website, and then go to About --> Affiliates --> Webinar Recordings

### Webinar Topics:

1. [Pediatric Intradialytic Parenteral Nutrition](#)
2. [Preparing Adolescents for Adult Renal Care: Multidisciplinary Transition Programs](#)
3. [Office Pediatric Nephrology Problems for NPs](#)
4. [Ambulatory Blood Pressure Monitoring](#)

Optimal care for all  
children with  
kidney disease.

**JOIN US  
TODAY!**



## ***ASPEN Pathology & Radiology 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 2019 webinar series has closed and we will move forward with the 2020-2021 Academic Year webinar series. ASPN members will continue to have access to the content through the ASPN website.

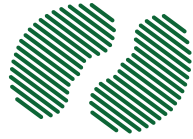
If you are interested in claiming MOC 20 Part II credit in the upcoming 2020-2021 academic year series, you must complete 10 webinars and answer a total of 50 question/answers (5 per webinar) via REDCap. For this series you will be required to remit payment of \$50 (credit card or cash) to the Children's Hospital of Philadelphia (to cover the cost of managing the MOC points). [Click here for payment instructions](#). 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, [ruebne1@jhmi.edu](mailto:ruebne1@jhmi.edu).

### **ASPEN Pathology Webinar**

**Date:** July 6, 2020, 3:00pm ET  
**Topic:** 4 Year Old with Proteinuria

All pathology and imaging webinars can be viewed online on the ASPN website under the Member Education Committee page. You can earn up to 20 Part II MOC points by participating in the webinars! You can either participate live or watch online. Then answer 5 questions on the REDCAP Database (link below). You can earn 20 MOC points if you answer a total of 50 questions from 10 webinars. <https://redcap.chop.edu/surveys/?s=WAEWFTLPD9>





## American Society of Pediatric Nephrology FOUNDATION

### ASPEN Foundation Updates

#### Adrian Spitzer Honorary Lecture

We are pleased to announce the Adrian Spitzer Honorary Lecture to commence at the 2021 annual ASPEN Scientific Meeting honoring Adrian for his seminal work in the field of Developmental Nephrology. The impetus for this initiative evolved from the ASPEN's goal to assist in raising support for endeavors consistent with the mission of the ASPEN while recognizing our most cherished colleagues. As such, while working on the ASPEN History Project with Robert Chevalier, Douglas Silverstein and Connie MacKay last February at the ASPEN office, we were reminded of the numerous contributions of Adrian Spitzer, Past-President of the ASPEN and his vision to create a global international forum for investigators in the field culminating in the First International Workshop of Developmental Nephrology "The Kidney During Development: Morphology and Function," in honor of Henry L. Barnett, in New York City, 1980. In 2007 the IWDN was designated the official satellite meeting of the IPNA Congress and remains a prestigious scientific conference to advance the field.

Adrian's scientific impact can best be appreciated by his many seminal publications characterizing the importance of developmental renal physiology to our understanding of renal maturation and sodium and phosphate homeostasis in health and disease. This consummate basic investigator also distinguished himself with his leadership in the International Study of Kidney Disease and the International Study of Vesicoureteral Reflux in Children. As the Director of the Division of Pediatric Nephrology of the Albert Einstein College of Medicine and its NIH T32 Training Grant for over 35 years, he guided the career training of many trainees some of whom became outstanding leading investigators in Pediatric Nephrology.

In summary, we are pleased to have the opportunity to contribute to the ASPEN Adrian Spitzer Honorary Lecture Donation so that we may recognize his contributions. We hope you will join us by contributing to this important recognition.



### JELF Scholars Update

#### Reflections on Being a JELF Scholar – A Foundation for Policy Fellowship

*Kiri Bagley, MD MPH*

This September, I will begin a fellowship with AAAS Science & Technology Policy Fellowships (STPF), a few months after graduating from pediatric nephrology fellowship alongside completion of my time as a JELF scholar (2018-2020). As a fellow with AAAS, I will train in the Department of Health and Human Services (DHHS). My position will be in the Office of the National Coordinator for Health Information Technology (ONC). Housed within DHHS, ONC promotes adoption of health IT and nationwide health information exchange to improve health care. I will serve as Clinical Informatics Fellow, taking a lead role in alleviation of clinician burden related to health IT. This role includes communicating with various stakeholders and analyzing outstanding priority areas for burden reduction. I look forward to opportunities for creative, thoughtful conversation with clinicians, nurses, patients and families, and other stakeholders in the year ahead!

Following a competitive application and selection process, STPF provides opportunities for scientists to learn first-hand about policymaking while contributing their knowledge and analytical skills to the federal policymaking process. Fellows spend one to two years in a federal government assignment.

Participating in the JELF program, within a supportive nephrology fellowship environment, truly paved the way for my successful application to STPF. Interacting regularly with persons who are both well-versed in federal policy and committed to passing along this body of knowledge has been an invaluable opportunity. These remarkable individuals include our ASPEN Washington representatives, nephrologists serving in federal positions, and practicing pediatric nephrologists with years of experience speaking out on behalf of our patients and their families. In didactic sessions, one-on-one meetings with mentors, and small group activities, JELF scholars review the policy process. We devote particular attention to understanding healthcare policy and its implications for nephrologists. Participating in ASPEN's Public Policy Committee enabled me to soak up details of ongoing policy efforts in DC, by listening to monthly conference calls and contributing to sub-committee projects. Attending Hill Day events demystified the experience, allowing me to observe and join advocacy in action.

The JELF program helped grow my understanding of policy work and further bolster my enthusiasm about contributing to future policy. I am immensely grateful for my time with JELF, and for all the support I've received during that time.

# Corporate Liaison Board Perspective

## Alnylam Pharmaceuticals

### Is it more than a kidney stone?

Kidney stones affect 8% of people in the United States.<sup>1</sup> Of those, up to 4% are children<sup>2</sup> and 34% of pediatric stones may be linked to a metabolic condition.<sup>3</sup> Primary hyperoxaluria type 1 (PH1) is a genetic disease caused by deficiency of alanine-glyoxylate aminotransferase (AGT) and characterized by hepatic overproduction of the toxic metabolite oxalate. PH1 often presents with kidney stones, nephrocalcinosis and kidney failure.<sup>4-6</sup> PH1 is rare, with a diagnosed prevalence of 1-3 cases per one million.<sup>6</sup> However, a recent analysis in the US shows that the genetic prevalence could be two to six times greater, suggesting that PH1 remains underdiagnosed in clinical practice.<sup>7</sup> PH1 has a low index of suspicion due to unspecific and heterogeneous clinical manifestations and patients may present with one or more of the following: failure to thrive in infancy, nephrocalcinosis, family history of kidney stones, recurrent kidney stones, and progressive kidney function decline.<sup>4,5</sup> As kidney function declines, oxalate excretion is compromised and calcium oxalate crystals deposit into tissues throughout the body, a devastating disease state recognized clinically as systemic oxalosis.<sup>5,6</sup> PH1 presents many challenges to patients and caregivers due to the intensity of required medical care and limitations of the current management options. The emotional stress resulting from diagnosis and disease management is frequently expressed by patients and there is a high unmet need for therapies which would reduce oxalate levels and methods to preserve current kidney function.<sup>8</sup> Several new therapies are currently under development for PH1.<sup>9</sup>

Lack of familiarity with PH1 among US nephrologists often leads to delayed diagnosis and more than 30% of patients diagnosed in childhood with PH1 present with end stage kidney disease by the time they are diagnosed.<sup>10,11</sup> A survey of physicians around the world revealed that a single stone event in children and recurrent events in adults should trigger suspicion and evaluation for an underlying genetic cause, such as PH1.<sup>12</sup> Early use of genetic testing can accelerate diagnosis, help ensure appropriate management<sup>13</sup> and, recently, a consortium of kidney disease specialists prioritized the understanding of genetic causes of chronic kidney stone disease in their recommendations.<sup>14</sup> Alnylam is committed to increasing awareness of rare diseases such as PH1 and created the Alnylam Act® program to reduce barriers to genetic testing and counseling to help people make more informed decisions about their health. Alnylam Act® provides genetic testing and counseling at no charge for individuals who may carry a gene mutation known to be associated with PH1.

## CONSIDER GENETIC TESTING FOR YOUR PATIENTS when you suspect PH1

**ONE OPTION FOR TESTING IS  
THE ALNYLAM ACT® PROGRAM:**  
Third-party genetic testing and counseling  
programs offered at no charge to patients.

Alnylam Act 

- While Alnylam provides financial support for this program, tests and services are performed by independent third parties
- Healthcare professionals must confirm that patients meet certain criteria to use the program
- Alnylam receives de-identified patient data from this program, but at no time does Alnylam receive patient-identifiable information. Alnylam uses healthcare professional contact information for research and commercial purposes
- Healthcare professionals or patients who use this program have no obligation to recommend, purchase, order, prescribe, promote, administer, use, or support any Alnylam product
- No payers, including government payers, are billed for this program

Genetic counseling is only available in the US. Genetic testing is available in the US and Canada.

**For more information, visit [AlnylamAct.com](https://AlnylamAct.com)**

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# Announcements

The **National Kidney Foundation** and **NephCure Kidney International** are happy to announce our joint hosting of an Externally Led Patient-focused Drug Development (EL-PFDD) Meeting on focal segmental glomerulosclerosis (FSGS). This virtual meeting will be on Friday August 28 from 10:30 AM – 3:30 PM Eastern.

This will be a landmark meeting for the FSGS community because it will convene patients and caregivers living with FSGS, representatives from the US Food and Drug Administration (FDA), the pharmaceutical industry, patient advocacy groups, and other stakeholders interested in FSGS. It will be a unique opportunity for FSGS patients and care-partners to tell the FDA and Pharma what it is like to live with FSGS – including what symptoms most affect daily life, what treatments do or do not work, what treatment-related trade-offs are acceptable to patients, what new therapies patients feel would make meaningful improvements in their lives, and what patients' preferences are regarding participating in clinical trials for FSGS.

The FDA will use the patient input from this meeting when they evaluate, for potential approval, new drugs for FSGS and when advising Pharma on clinical trials for these potential medicines. Pharma will use this input to guide their drug development efforts in FSGS and for testing these new treatments in clinical trials.

We will use a novel meeting format – it will be broadcast as a newscast, with the moderator in an anchor chair in a “news” studio. Expert lectures will be Zoomed in, ten patient panelists will present pre-recorded testimonies, and live polling will be conducted with responses displayed instantaneously. Audience discussions will be moderated using a “Larry King call-in” format.

For more information and to register for the meeting, [click here](#). Please join us for this important meeting for the FSGS community!



## NEW RESOURCES FOR TEENS

These booklets were developed for tweens and teens who learn their kidneys are not working and they will need dialysis or a transplant. The booklets provide a brief overview of coping with kidney disease, being part of their health care team, the importance of diet, taking medication, and treatment methods. They also touch on feelings related to having a chronic illness, family and friends, and being a teen.

The development of both booklets included input from kids currently on dialysis, parents, adults who had kidney disease as children, and nephrologists. Although both booklets are similar, one focuses on teens who learn they have kidney disease and the other is for teens who already have cystinosis and learn they now have kidney disease as well.

Download these booklets at:  
[dpcedcenter.org/teenbook](https://dpcedcenter.org/teenbook)

# Meeting & Lecture Announcements

## Upcoming Meeting Dates\*

Meeting	Place	Meeting Dates	Abstract deadline	Online registration opens	Early bird registration ends
<b>Now Virtual:</b> ASN Kidney Week 2020	Virtual	Oct 20-25, 2020	May 28 <sup>th</sup> , 2pm EST	June 3 <sup>rd</sup> , 10 am EST	Aug 12 <sup>th</sup> , 11:59pm EST

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

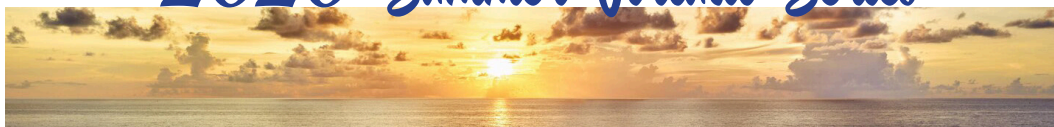
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American Society of  
Pediatric Nephrology



## 2020 Summer Virtual Series



ASPN is excited to offer a portion of the content from the 2020 PAS Meeting in a virtual four session series in July combining pre-recorded talks and a live question and answer session.

CME and MOC credit will be available for ASPN members.

Please note that registration for each session is separate: registration links are below.

## Save the dates!

**ASPN Summer Webinar Series #1 - July 10, 2020 - 2-4pm Eastern**

*Urine in the Know - Advocacy: Past, Present and Future Perspectives*

[Click here](#) to register

**ASPN Summer Webinar Series #2 - July 17, 2020 - 2-4pm Eastern**

*Using TOD<sup>2</sup>AY to improve tomorrow's renal outcomes in childhood diabetes*

[Click here](#) to register

**ASPN Summer Webinar Series #3 - July 24, 2020 - 2-4pm Eastern**

*Is it something I ate?: Exploring the relationship between gastrointestinal and kidney health*

[Click here](#) to register

**SPN Summer Webinar Series #4 - July 31, 2020 - 2-4pm Eastern**

*Are the kids really alright?: A life-course evaluation of the long-term kidney effects of childhood-onset diseases*

[Click here](#) to register

Please visit [www.aspneph.org](http://www.aspneph.org) for more information.

## Meeting & Lecture Announcements



Children's  
of Alabama®

UAB MEDICINE

VIRTUAL  
TRAINING  
via  
**zoom**

1.5 day course

### TOPICS INCLUDE

- Acute Kidney Injury and Fluid Overload in Small Children
- End Stage Renal Disease in Neonates
- Principles of Neonatal Kidney Support Therapy
- Neonatal Kidney Support – The Neonatologist Perspective
- Neonatal Kidney Support – The Parent's Perspective
- Educating Your Team
- Caring for Your Program
- Nutrition and Medications While Providing Kidney Support
- Team-Based Simulations

### CONTINUING EDUCATION

Children's of Alabama is accredited by the Medical Association of the State of Alabama to provide continuing medical education for physicians.

**Monday, July 27 and  
Tuesday, July 28, 2020**

*Register Today!*

[give.childrens.org/NICKS](https://give.childrens.org/NICKS)

**Questions?** Contact David Askenazi, MD, MSPH [daskenazi@peds.uab.edu](mailto:daskenazi@peds.uab.edu)  
or Kara Short, MSN, CRNP [kara.short@childrensal.org](mailto:kara.short@childrensal.org)



# Meeting & Lecture Announcements



## 14<sup>th</sup> Asian Congress of Pediatric Nephrology Evidence-based clinical management in pediatric nephrology, An IPNA Scientific Workshop March 30-31, 2021 Taipei, Taiwan.

Evidence-based clinical management in pediatric nephrology is a challenging and major goal of our Society. Indeed, most diseases pediatric nephrologists deal with are severe rare diseases requiring optimal management in the face of a limited number of randomized clinical trials.

To this end, IPNA has successfully begun a new initiative with the aim of developing “IPNA Clinical Optimal Recommendations (IPNA-CPR)”, addressing important global topics in the field of pediatric nephrology. The first IPNA-CPR on steroid resistant nephrotic syndrome (SRNS) will soon be published in Pediatric Nephrology the journal of the IPNA.

To address this, the Best Practice and Standards Committee is organizing a scientific workshop solely dedicated to guideline methodology, distribution and implementation. More than 20 new guidelines will be presented by international experts. The scientific workshop precedes the 14th Asian Congress of Pediatric Nephrology (ACPN) and will be held over 1 1/2-days with symposia, invited lectures, free oral presentations, panel discussions, and guided poster walks. Since the workshop follows directly the junior master class (March 29-30) one can smoothly attend all three events.

**@Taipei Grand Hotel**  
10F Grand Ballroom

**2021.**  
**March**  
**30-31**

### [ Important Dates for Registration ]

**January 10, 2021**  
Deadline for Early Bird Registration

**February 28, 2021**  
Deadline for Standard Registration

### Important Dates for Abstract Submission

July 01, 2020	Online System Opens for Abstract Submission & Travel Grants
November 01, 2020	Deadline for Abstract Submission & Travel Grants Application
November 24, 2020	Notification of Abstract Acceptance & Travel Grants
January 31, 2021	Deadline for Abstract Author Registration

More information: [www.acpn2020.com](http://www.acpn2020.com)



**Taipei Grand Hotel**  
Muslim Friendly Restaurant (MFR)  
Muslim Friendly Tourism (MFT)



## Meeting & Lecture Announcements



Due to the restrictions imposed by the COVID-19 Pandemic, the **47<sup>th</sup> Miami Pediatric Nephrology Seminar: Challenges for the Next Decade** will take place November 17-19, 2021 at the historic Royal Palm Hotel in Miami Beach. It is a unique international forum for pediatric and adult nephrologists, renal pathologists, pediatricians, pediatric urologists, transplant surgeons and other health professionals from all over the world. The **Pediatric Nephrology Critical Care Workshop** will follow on Sunday afternoon at the Holtz Children's Hospital. Please follow us closely and we will keep the tradition going!!

## 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](http://www.renalmd.org).

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

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## KIDney NOTES

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