

American Society of Pediatric Nephrology

KIDney Notes

FROM THE PRESIDENT



Jodi Smith, MD, MPH, President

"Be better. Do better." One of the many Brophyisms that has guided us not only in our work as pediatric nephrologists but as individuals. At the memorial service for Patrick Brophy, our friend and colleague who died on October 6, I shared my heartfelt sympathies and deep gratitude to his family on behalf of ASPN. The video of the service is available on his caring bridge site - <u>https://</u> <u>www.caringbridge.org/public/patbrophy9990</u>.

At the upcoming ASN meeting, we will spend some of our time together remembering Pat's dedication to the care of children, his unflagging support of those in our field, and his larger-than-life spirit. For those of you attending, please join us Thursday evening at the ASPN Member's Reception from 6:45pm to 8:15pm. Bring your memories and stories and we'll raise a glass to one of the superheroes of pediatric nephrology.

Pat was passionate about the workforce issues that face our pediatric nephrology community. In May, he was interviewed by Danielle Soranno and Shina Menon for an ASPN Workforce Committee Webinar - his 'mic drop' as he left Rochester to go back to Saskatchewan. I encourage you to take a moment to watch the interview at the link above. In 2019, Pat convened the first ASPN Workforce Summit where we tackled important issues to help us move forward as a field. Building on the foundation he built, we are holding the ASPN Workforce Summit 2.0 at ASN, led by Danielle Soranno and the workgroup leaders; Isa Ashoor, Alex Kula, Shina Menon, Michelle Starr, and Darcy Weidemann. A small but mighty group of 35 of your colleagues are working on 5 areas of focus: 1) Defining a clinical FTE, 2) Academic RVUs, 3) Institutional value of nephrology programs, 4) Salary equity for pediatric nephrologists, and 5) Pathway considerations for growth of the pediatric nephrology workforce. We are sincerely grateful to the ASPN Foundation for generously funding the Workforce Summit 2.0 - we would not be able to do this critical work without the Foundation's support.

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It has been exciting to already see the implementation of many of the Strategic Plan initiatives over the past few months! With the new academic year came the launch of the National Fellows Lectures Series led by Arwa Nada, Roshan George, John Mahan, Katherine Twombley, and Darcy Weidemann. This is a tremendous learning opportunity so please encourage all your trainees to check it out! All of us preparing for the Boards are grateful to **Christine Sethna** and the planning committee who organize the ASPN Board Review Course. The first session was in September, but you still have time to join them October 27-29th. The ASPN App Development and Implementation **Taskforce** is starting their important work on what was identified as one of our highest priority initiatives in the Strategic Plan. Please reach out if you are interested in joining this team. Huge thanks to the ASPN Foundation which is providing the funds for this important communication tool for ASPN members. Pat Brophy was a mentor to so many of us and he was very proud of all the new mentorship opportunities put forward by ASPN. Thank you to Jason Greenberg, Ken Suthna and the **Research Committee**, who led ASPN's first Mini-Mentorship Course which was filled with 4 sessions of outstanding speakers and stimulating content. Be on the lookout for a new call for mentors and mentees coming soon. Ewa Elenberg and the organizing committee have put together a tremendous program for the 11th Annual ASPN Multidisciplinary Symposium - November 9-10, 2023. Please remind your nurses, dieticians, and social workers to register.

As part of our continued commitment to be an inclusive and transparent organization, we undertook a comprehensive review of the **ASPN Bylaws** which were last modified in 2018. We thank all of you who took the time to vote and we are happy to announce that the recent updates were approved. One of the important changes to the bylaws was that those who will serve on the ASPN Nominating Committee will now be elected by ASPN members at large, rather than appointed by Council. Committee members will serve a set four-year term. This comes just in time for our call for **New ASPN Council Members** who will take office after PAS 2024! Please consider nominating yourself or a colleague using this <u>form</u>.

The amazing success of ASPN flows from all of you, who volunteer your time to help the Society meet

the needs of its members and by extension improve the health of our patients and families living with kidney disease. ASPN now has four awards to recognize our outstanding members. We hope you'll take time to nominate either yourself or your deserving colleagues for one of the awards – ASPN Founders' Award, Outstanding Service Award, Mid-Career Award, and the Equity, Social Justice, and Advocacy Award. Nominations can be made here and are due November 15th.

As I close these comments, please permit me to share a personal reflection. Our world today, sadly, is filled with much pain and sorrow. It is my continued hope that our ASPN family can come together with love and support for all of our members, our international colleagues, their families, and those whom all of you hold dear. ASPN is working with IPNA, ESPN, and ISN to provide assistance to our colleagues and the children they care for. My thoughts are with all of you at this time. Please don't hesitate to reach out to me at **jodi.smith@seattlechildrens.org**.

Jodi

FROM THE EDITOR



Dear Friends and Colleagues,

I hope you had a restful and reinvigorating Summer. As always, the fall brings a busy season. First year fellows are learning the ropes, senior fellows are working towards their first faculty positions, , and faculty are busy with the many balls they juggle including clinical work, grant application deadlines, and recruitment for fellows and residents.

We hope that the weekly KidneyBriefs bulletin has made information more accessible and timely. I wanted to take the opportunity here to highlight some topics from recent KidneyBriefs that are not to be missed.

• PAS Abstracts: the deadline has been adjusted for this year; abstracts are due November 1. Keep an eye out for the Works in Progress option for fellows to submit work that may not yet have data/analysis completed

- ASPN Awards Nominations are due November 15 this is a great opportunity to recognize our colleagues and their contributions
- The ASPN is seeking applications for the Chair of the ASPN Foundation; the deadline for current and former Board and Council members to apply is November 15.
- Fellow and early career faculty should consider applying for the CHOP Pediatric Center of Excellence in Nephrology (PCEN) Grant Writing Workshop – Deadlines for application is November 13 for February 2024 or later grant cycles

Warmly, Radha Gajjar <u>agajjar@childrensnational.org</u> <u>@DrRadhaG</u>

Associate Editor Sudha Mannemuddhu <u>dr.saisudhamm@gmail.com</u> <u>@drM_Sudha</u>

Section Editor Raja Dandamudi dandamudi@wustl.edu @raja_dandamudi





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NEWSLETTER

<u>Raja Sekhar Dandamudi, MD</u> Washington University School of Medicine in St. Louis

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Sai Sudha Mannemuddhu, MD East Tennessee Children's Hospital

ASPN CORPORATE LIAISON BOARD



ASPN Central Office

Connie Mackay | Executive Director 6728 Old McLean Village Drive | McLean VA | 22101 Phone 703-556-9222 | Fax 703-556-8729 info@aspneph.org | www.aspneph.org

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COMMITTEE UPDATES

<u>Click here</u> to learn more about ASPN committees and their membership!

ASPN App Task Force Volunteers Needed

We are excited to announce that we are in the process of developing the new ASPN App. The app is made possible through generous funding from the ASPN Foundation.

Volunteers are needed to help in developing and implementing the app. They will assist in determining content, testing and roll out. Experience in app development is not required. If you are interested, **please click** here to provide your information. Meetings with the App provider will begin in the next couple of weeks.

ASPN FOUNDATION



American Society of Pediatric Nephrology FOUNDATION

Foundation Update

The Foundation is pleased to welcome Kathryn (Katie) Schubert as a public member on our Board of Directors. Katie has a long-standing relationship with the ASPN as a governmental liaison and advisor of the John L Lewy Foundation for Children's Health. She is an expert in women's health and a nonprofit association leader. Her contributions as an advocate, executive and coalition builder will be a great asset to the Foundation. She is past President of Women in Government Relations, Chair of the Board of the Maternal Mental Health Leadership Alliance, and former Coalition for Health Funding Board member. She has also spent time working in key legislative roles on Capitol Hill. She received her BA from Mary Washington College and her Masters of Public Policy from George Washington University.

Women's health expert and nonprofit association leader. Advocate. Executive. Coalition Builder. Past President of Women in Government Relations. Chair of the Board of the Maternal Mental Health Leadership Alliance. Advisor to the ASPN Foundation's John E. Lewy Fund for Children's Health. Former Coalition for Health Funding Board member #FundHealthjoined the Society for Women's Health Research (SWHR) as President and CEO in April 2020. Under Katie's leadership SWHR developed a strategic plan focused on fulfilling the organization's mission of promoting research on biological sex differences in disease and improving women's health through science, policy, and education. She previously worked for the Society for Maternal-Fetal Medicine (SMFM), where she served as the organization's chief advocacy officer, growing SMFM's role nationally and building its reputation in women's health.

Katie is a trusted leader and consensus builder among women's health stakeholders, particularly in the policy arena. She has served in multiple Board roles for nonprofit organizations in the Washington, DC-area, including as Chair of the Board of the Maternal Mental Health Leadership Alliance and as advisor to the John E. Lewy Fund for Children's Health. She is a past president of Women in Government Relations. Prior to SMFM, Katie served as senior vice president at CRD Associates, where she advised clients including nonprofit patient advocacy groups, medical professional organizations, and private companies — on government relations and public policy related to health and biomedical research issues, among others. Katie lives in Virginia with her husband, three children, and dog George.

ASPN Foundation Board Chair Position - Call for Applications

The ASPN Foundation serves as the fundraising arm of the entire ASPN. Through the Foundation, support of research and educational programs of all kinds for trainees, practitioners, and scientists within the field of Pediatric Nephrology is made possible.

Since the Foundation's inception in 2015, Bruder Stapleton has served as Chair of the Board of Directors. Under his leadership the Foundation has flourished and had great success in implementing a Named Trainee Travel program, endowing the H. William Schnaper Lectureship, and becoming fully self-sufficient, not relying on funding from ASPN.

Dr. Stapleton's term concludes in May of 2024. We are currently seeking applications/nominations for a new Chair to join the Board in the spring and take over as Chair in June. Applicants should be experienced in fundraising and have served either on the ASPN Council or ASPN Foundation Board. Both current and former Board and Council members are eligible for the Chair position.

To apply, please send a letter of interest and your CV to connie@aspneph.org. The deadline to apply is November 1, 2023. A review committee will review applications and make a recommendation to the ASPN Foundation Board for approval.

Thank you and please let us know if you have any questions.

Sincerely,

Eileen Brewer, MD, ASPN Foundation Treasurer Rick Kaskel, MD, PhD, ASPN Foundation Vice Chair

H. William Schnaper Lectureship **Endowed in Perpetuity**

It is a rare and exceedingly rewarding opportunity when a society can remember one of its most cherished members with a lecture in their name for perpetuity. We are pleased to announce that the H. William Schnaper Lectureship which began in 2021, has reached its endowment goal of \$150,000 through the generous support of the ASPN community and Bill's family, and will be part of all future ASPN Annual Meetings. The memory of this wonderful leader in our field both nationally and internationally, will be acknowledged for all current and future pediatric nephrologists as an example of a dedicated and compassionate human being who touched us all in one way or another.

H. William (Bill) Schnaper was the Irene Heinz Green and John LaPorte Given Chair in Pediatric Research and Tenured Professor and Vice Chair, Department of Pediatrics, Feinberg School of Medicine, Northwestern University. Distinguished service was part of Bill's DNA, as exemplified by his long tenure of service to the American Society of Pediatric Nephrology (ASPN) and the International Pediatric Nephrology Association (IPNA). His contributions are truly too numerous to count but what the ASPN is what it is today is in part for his vision and engagement of everyone whom he met and mentored. Let us celebrate his journey and express our commitment to his memory by being grateful to have known Bill and his loving family.

Bill was an amazing leader in our field, both nationally and internationally. He will always be remembered for his dedication to his research, his patients and his friends and family. The ASPN Foundation would like to thank the many generous donors, including Bill's family, who enabled us to create the first endowed ASPN lectureship. Please see the appreciation of Bill published in Pediatric Nephrology or the ASPN website In Memoriam.

ASPN Foundation 2023 Donors -Thank you!

(as of 9/13/23)

Carolyn Abitbol Sabahat Afshan Isa Ashoor David Askenazi Meredith Atkinson Jennifer Charlton Olga Charnava Annabelle Chua Donna Claes Marisa Curiel Garcia Keefe Davis Joseph Flynn Ron Frankel Larry and Jordan Greenbaum Coral Hanevold **Erum Hartung** Wendy Hsiao Julie Ingelfinger Kathy Jabs Frederick Kaskel Megan Lo Connie Mackay John Mahan Mohammad Malekzadeh Franhe Melean Joel Melnick Erika Miller Lieuko Nguyen Kelsev Richardson Jesse Roach Eloise Salmon The Samuels Family Foundation Lauren Schnaper and James Carlton Kathryn Schubert Douglas Silverstein Irving Smokler Max Spitzer Bruder F. Stapleton Michelle Starr Caroline Straatmann Louise Strauss Agnieszka (Agnes) Swiatecka-Urban Diane Tenenbaum The Estate of Susan Thomas Priva Verghese Darcy Weidemann Lynne Weiss Katherine Westreich Lynne Yao

JELF SCHOLARS UPDATE

JELF Scholars started this year with an interactive webinar focused on Kidney Transplantation: All Things OPTN (Organ Procurement and Transplantation Network). We had the opportunity to learn from Dr. Rachel Engen who discussed important topics including the National Organ Transplant Act of 1984, OPTN Strategic Plan, OPTN vs UNOS, NASEM 2022, and Securing the US OPTN Act $- \frac{9}{2}/2023$. As Scholars, we learned about the history and regulatory environment surrounding OPTN, and it put into perspective how far we have come through advocacy. It increased the sense of pride and duty surrounding my own experience participating in the Advocacy Hill Day in May 2023 in Washington DC, where Scholars had the unique opportunity to advocate for transplant-related initiatives through discussion of the Living Donor Protection Act with US Congressional and Senate representatives.

JELF Scholars have continued to acquire the skills and tools needed to make our voices heard through advocacy. It is exciting to think that just after a year as a JELF Scholar, I have acquired such a wealth of knowledge plus increased boldness to speak up on behalf of children. Listening to the monthly conference calls helps me stay up to date on important legislative bills and opportunities to network, thanks to our DC Advocacy staff. In addition to educational sessions, I have attended two virtual town hall meetings on general aspects of the community and voting maps/redistricting in North Carolina. The formal training and hands-on mentored experiences focusing on governmental processes and pertinent health policies affecting children's health have been instrumental in my advocacy journey. The JELF Program provides the opportunity to learn from our JELF mentors, their advocacy journeys, and experiences and I am excited to follow in their footsteps to one day also tell my story of persistence and perseverance in advocating for children with kidney disease.

The next opportunity for the JELF Scholars past, present, and mentors to meet will be during ASN Kidney Week in November 2023 in Philadelphia!

Sincerely, Hostensia Beng-Ongey

ASPN HISTORY PROJECT

Moments in ASPN History

Did you know the ASPN started as a club, with an annual meeting held in conjunction with the SPR. Chester Edelmann, Professor and Chief of Pediatric Nephrology at the Albert Einstein College of Medicine in the 1970s, who conducted pioneering research in the role of the immature kidney on acidbase balance and who followed the legendary Dr. Henry Barnett, proposed the idea to his Pediatric Nephrology colleagues in 1967, suggesting they model the club after the European Pediatric Nephrology Club. In this letter, he mentioned Dr. Robert Vernier, who was the chief of Pediatric Nephrology at the University of Minnesota Medical School.

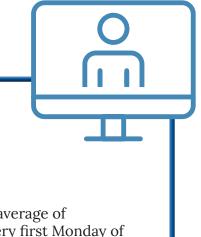
Dear Colleague:

A number of us have thought that it would be enjoyable to hold annually, in conjunction with the meeting of the Society for Pediatric Research, a dinner meeting of pediatric nephrologists in the United States. Bob Vernier has agreed to join me in organizing such a venture. As you may know, a European Pediatric Nephrology Club was formed recently and held its first meeting in Glasgow in September. In contrast we are not attempting to form a new scientific society, but rather an informal Pediatric Nephrology Club which would meet annually for dinner and to listen to an invited speaker.

SONp 75th Anniversary Commentary

For the 75th anniversary of *Pediatrics*, a group of senior nephrologists from the ASPN History Project Group were asked to choose and briefly comment on about a dozen of the most important nephrology articles to appear in the journal, picking some from each 25 year era. The piece was published several days ago. It may make interesting reading for fellows and others. You can read it <u>here</u>.

ASPN WEBINARS



ASPN Webinar

Radiology Webinar Date: November 6 at 3 PM EST Subject: 14-year-old boy with proteinuria

The ASPN webinars are thriving in the zoom meetings with an average of 50+ participants per session and will continue to be offered every first Monday of the month at 3pm ET.

ASPN CALL FOR NOMINATIONS

Two Opportunities for Leadership Roles

The ASPN Council is pleased to announce that the recent changes to the <u>ASPN Bylaws</u> were approved by vote of the ASPN membership.

One of the changes is that the **ASPN Nominating Committee** will now be *elected* by ASPN members instead of being *appointed* by Council. The role of ASPN Nominating Committee is to prepare a slate of candidates for officers and at least two candidates for each open Council and Nominating Committee position.

Call for ASPN Nominating Committee Members.

We are seeking candidates to serve on the **ASPN Nominating Committee**. You can self-nominate or nominate a colleague. For this initial election, 2 Committee members will be elected for 2-years terms and 2 Committee members will be elected for 4-year terms. This allows for the bi-annual rotation of two committee members moving forward. In the future, every other year, two Nominating Committee members will be elected to serve four-year terms.

The committee will be chaired by the immediate ASPN Past President; Michael Somers for this cycle. The role will consist of participating in conference calls, reviewing nominations, preparing the slate of candidates and results notifications. The work will be done in January 2024. **Deadline to apply to** serve on Nominating Committee is November 10, 2023 <u>via this form</u>.

<u>Call for New ASPN Council Members</u>. Candidates are now being sought for: two non-officer **Council Members** to serve four-year terms. They will take office immediately following the PAS meeting in May 2024.

Candidates for **ASPN Council** positions should have the interest, commitment, and experience to provide effective leadership for our Society. Applicants should embody the values of the ASPN, including a commitment to diversity, equity, inclusion, and antiracism. Please refer to the list of responsibilities of Council members <u>https://www.aspneph.org/</u> <u>about-us/council-members/</u> as you form your nominations. **Deadline for ASPN Council Nominations is December 1, 2023 <u>via this</u> <u>form.</u>**

For questions contact Connie Mackay, <u>connie@</u> <u>aspneph.org</u>.

#FOAMed and #SoMe! What's brewing!!!

Dear PedNeph nephrons,

We are delighted to bring this new free open access medical education (#FOAMed) and social media (#SoMe) section to you. This will include all the related announcements and projects related. Please submit your or any interesting projects, suggestions and feedback to Sudha Mannemuddhu.

1. ASPN social media (#SoMe) accounts

Twitter: <u>@ASPNeph</u> IG: <u>aspneph</u> Facebook: <u>aspneph</u>

2. Tweetorials:



Latest: CKD-MBD by Sasha Pannu

Don't use Twitter?

You will find all the mini-reviews in **PDF format**, along with additional FOAMed resources, on the <u>'#ASPNFOAM group'</u> webpage. If you are interested in joining the group, please get in touch with <u>Sudha M</u>.

3. Blogposts

Little Been

The 'LITTLE BEANS' community delivers 'Nephron-size' concepts in pediatric nephrology useful for

N

the wards and the boards.

New posts:

Syndrome by Salar Bani Hani

<u>Oral Complications of Chronic Kidney Disease</u> by Patricia Sousa, Shweta S. Shah

Follow <u>@LittleBeans22</u>

If you are interested in writing about interesting or less discussed nephrology topics, join this group amazing group.

- KIReports Community
- The Renal Fellow Network
- 4 The Nephron Power
- \rm 🛓 <u>AJKD Blog</u>
- PBfluids.com
- 4. New Nephrology learning tools



https://www.visualnephron. com/



Kidney.wiki

Established in 2021, kidney. wiki is a free, open-access

medical education resource for pediatric nephrology intended for use by practitioners and learners at all levels of training. Created by <u>Ryan Town</u>

5. Journal Clubs

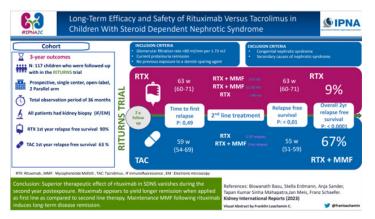


IPNAJC: The official Twitter journal club of the International Pediatric Nephrology Association. #IPNAJC Twitter: <u>@IPNAJC</u> Latest JC - Jul 2023: Longterm efficacy & safety of Rituximab

versus Tacrolimus in children with Steroid dependent nephrotic syndrome. <u>Summary</u> Infographics.

10-Tweet JC: <u>https://x.com/ipnajc/status/169838</u> 0716789370922?s=20

Previous JC can be located at **IPNAJC** Upcoming JC: in Nov 2023





NephJC is an online medical journal club that utilizes the nephrology (and related specialties) Twitter community to generate discussion and review current literature related to

nephrology. *#NephJC* Twitter: <u>@NephJC</u>

6. Nephrology Podcasts:



The Kidney Chronicles by **Emily Zangla** is a pediatric nephrology podcast that discusses various PedNeph topics with experts. Latest: Episodes 18-21 on **Applying to Pediatric Nephrology fellowship**,

IgA Nephropathy, PTLD, & Division Directorship available on <u>Pod bean</u> and <u>Spotify</u>! *email*: <u>doctoremilyz@gmail.com</u>.



The Sediment – the official ASPN Podcast for PAS meeting-Season 3 – from Washington, DC. **#TheSediment** #ASPN23 Editor: Sudha Garimella 4 episodes available on Podbean &

Spotify

Episode 1 "The Ethics of caring for Neonatal Kidneys"

Episode 2 "Advances in Therapeutics for Kidney Diseases"

Episode 3 "Clinical Nephrology-For the children living with kidney disease"

Episode 4 "Is Faculty Development giving you a headache? Or is it Hypertension?"

THE SEDIMENT- season 4 will return in 2024 from Toronto, CA. If you would like to co-host or volunteer, please contact Sudha Garimella at <u>Sudha.Garimella@prismahealth.org</u>.

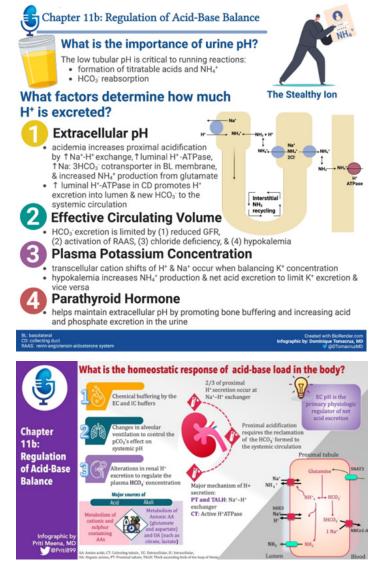


Channel your enthusiasm

The Burton Rose book Club is a podcast that discusses chapters from 'The Clinical

Physiology of acid-base and electrolyte disorders'. Twitter <u>@BookBurton</u>.

Diuretic draft from 2023 NKF meeting & **Chapter 11-part B** on 'Regulation of Acid-Base balance' **available on <u>multiple platforms.</u>**





<u>Freely filtered</u> is a twice monthly podcast (that is aspirational, not a promise) which discusses recent NephJC journal clubs. They also discuss other significant

events in the world of nephrology. **Latest episodes 59** - Furosemide vs. Torsemide, The diuretic comparison project. Twitter: <u>@NephJC_Podcast</u> Available on <u>multiple platforms</u>.

7. ASPN at ASN Kidney Week 2023

#PedNeph content at ASN Kidney week #ASNKids23

- Release a tutorial prior to the meeting on 'how to tweet/ live-tweet, how to schedule a tweet, etc.'
- Incorporate new ideas of dissemination like short videos, TikTok, etc.
- Contact Andrew South or Sudha Mannemuddhu if interested.

8. Learn Peritoneal Dialysis

Check out this free interactive training tool aimed at teaching families the basics of peritoneal dialysis, developed by **Drs. Debbie Stein and Kaitlyn Order** from Boston Children's Hospital. This is released on OPENPediatrics and includes animated videos and interactive instruction to teach the basics of PD care and is written at a 6thgrade level. It was peer reviewed by a few members of the SCOPE collaborative, and I presented it at their Spring meeting this past May.

This can be accessed at <u>https://www.</u> openpediatrics.org/learnperitonealdialysis



See you in next KIDney notes. S. Sudha Mannemuddhu, MD, FAAP, FASN <u>@drM_Sudha</u> <u>dr.saisudhamm@gmail.com</u>

Corporate Liaison Board Corner

From our CLB Partner:

Now Enrolling: The EPPIK Clinical Study for Children with Rare Glomerular Diseases



Travere Therapeutics is now enrolling a Phase 2, open-label, single-arm, cohort study to evaluate the safety, efficacy, and pharmacokinetics of sparsentan in pediatric patients (ages 1 to 17) with selected proteinuric glomerular diseases. The focus of the study is on younger children aged <8 years, with >70% of enrollment slots reserved for patients between 1 and <8 years.

What is Sparsentan?

Sparsentan is a novel Dual Endothelin Angiotensin Receptor Antagonist (DEARA). It is a dual acting, highly selective antagonist of both the endothelin A receptor (ET_AR) and the angiotensin II subtype 1 receptor (AT_1R) .

EPPIK Study Details

The EPPIK Study is evaluating 2 patient populations:

Population 1: Patients with FSGS or MCD



Population 2: Patients with IgA nephropathy, IgA vasculitis, or Alport syndrome

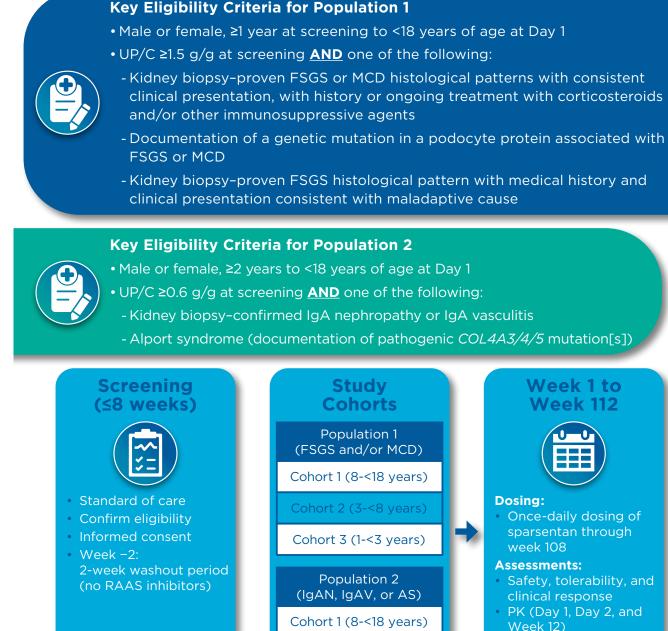
All patients receive a once-daily oral administration with sparsentan as a liquid at a dose determined by the study population and calculated based on weight. The study, including screening and treatment period, lasts up to 120 weeks and includes approximately 18 study visits. The primary endpoints are the incidence of adverse events as well as change in UP/C from baseline over the 108-week treatment period. Approximately 60 children will participate in study sites in Europe and the United States.

Key Eligibility Criteria - Overall

- Patient has eGFR ≥30 mL/min/1.73 m² at screening
- Patient weighs ≥7.3 kg
- No kidney transplantation or dialysis
- No FSGS or MCD histological pattern secondary to viral infections,
- drug toxicities, or malignancies
- No IgA glomerular deposits secondary to another condition
- No acute onset, presentation or relapse of glomerular disease requiring new or different class of IST treatment within 6 months before screening

Please see population-specific eligibility criteria on the following page.





AS = Alport syndrome; FSGS = focal segmental glomerulosclerosis; IgAN = immunoglobulin A nephropathy; IgAV = immunoglobulin A vasculitis; MCD = minimal change disease; PK = pharmacokinetic; RAAS = renin-angiotensin-aldosterone system.

Cohort 2 (5-<8 years)

Cohort 3 (2-<5 years)

For more information, please visit <u>ClinicalTrials.gov NCT05003986</u>, <u>clinicaltrialsregister.eu</u>, <u>EudraCT 2021-000621-27</u>, <u>kidneyhealthgateway.com</u>, <u>en-us.eppikclinicalstudy.com</u>, or contact <u>medinfo@travere.com</u>.

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Safety Follow-Up:

4 weeks after last dose No study medication

Resume standard-ofcare treatment



Become a member today

Scan here to view opportunities with IPNA

Why Join IPNA? Membership benefits



2023 – IPNA Application deadlines





IPNA 2025 -

Save the Date!

Apply & Host

IPNA Teaching

Course

Membership sign up



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Contact us

office@theipna.org

More information

www.theipna.org www.ipnafoundation.org



GIPNA International Pediatric Nephrology Association great care for Little kidneys. everywhere

MEETINGS AND EVENTS

Save the Date!



American Society of Pediatric Nephrology

Pediatric Nephrology Board Review and Refresher Course

September 22-24 & October 27-29, 2023



Online Registration Now Open!

Online Course Includes:

- Virtual lectures, case-based discussion, and board-style question sessions led by expert faculty
- Study material formatted to the content specifications
- Question bank
- Available for two years

Save the Date!



American Society of Pediatric Nephrology

11th Annual

ASPN Multidisciplinary Symposium

November 9-10, 2023





Virtual Research Network Open for Membership!

Our PCORI-funded Collaborative aims to improve outcomes for patients with pediatric renovascular hypertension (pRVH), a rare but potentially life-threatening disorder.

Pediatric renovascular hypertension (pRVH), high blood pressure resulting from renal artery and aortic narrowing, risks significant morbidity and mortality. Timely detection and treatment are critical to prevent kidney injury, cardiopulmonary complications, and stroke.

The pathophysiology remains poorly defined; additionally, the low frequency of this disease limits existing data to institutional series and anecdotal case reports. As such, the optimal management of these children remains ill-defined.

Moreover, the introduction and expansion of novel open surgical and endovascular techniques for the revascularization of aortic and renal artery lesions for these children has dramatically changed the landscape of patient care in the last decade.

As multidisciplinary high volume referral centers of excellence are few and scattered across the globe, patients and families may be challenged to not only find appropriate care but also to balance vastly differing sets of recommendations.

Research is urgently needed to advance our understanding of this disease and define best practices in the care of these special children as it relates to medical therapy, patient selection for revascularization and technical approaches that consider specific patient and anatomic phenotype.

International, Collaborative Expertise

Together, with the support of PCORI, we have gathered patients, families, physicians, researchers and other advocacy partners from all over the world, to take a balanced and detailed look at the clinical landscape of pRVH. A geographically diverse, multi-disciplinary Advisory Board has drawn on the expertise of representatives from the Hospital for Sick Children (Toronto), Great Ormond Street Hospital (London), Boston Children's Hospital, Children's Hospital of Philadelphia, Seattle Children's Hospital, the University of Michigan, and Duke University. The Board is augmented by a Critical Stakeholder Group of expanded stakeholders and a growing Virtual Research Network. At more than 200 strong, we offer research tools for patient-centered outcomes and opportunities with up-to-date clinical resources and support for our expanded network of stakeholders.

What We've Learned

By sharing their experience and thoughts surrounding the diagnosis and management of pRVH, parents and patients have shown us severe challenges in obtaining information and guidance upon diagnosis, difficulty getting referrals, and dissatisfaction with blood pressure monitoring.

We have also learned through our stakeholder survey that patients with pRVH commonly have other medical problems and genetic syndromes. Oftentimes they are affected by significant developmental delays (ie: motor, language, cognition and social) and require special education and other specialized services. Invasive procedures and surgery frequently require patients and families to travel out of state and stay in the hospital for a significant amount of time in many cases. We strongly believe that early diagnosis and treatment by teams comprised of multiple disciplines/specialties can optimize the care experienced by patients and their families.

We can do better - We need your help!

Expanded support from patients, families, clinicians, researchers and other stakeholders that care about this rare disease and these special patients remains paramount as we embrace our continued work together by responding to urgent research questions, and enhancing the engagement of front-line providers who encounter pediatric hypertension.

Please consider referencing and sharing our Collaborative's website (<u>https://www.prvh-pcor.org/</u>), and <u>JOIN OUR VRN</u> for access to expanded clinical and educational resources, patient peer support, PCORI research resources, scientific updates and guidance, and additional pRVH PCOR project information and references, including recordings from our 2nd annual pRVH Symposium, archived webinars, and a biannual Newsletter. With your help, this Collaborative will generate large-scale research, as prioritized and directed by a comprehensive group, that will decrease the number of years of life lost for these young patients, optimize sustained quality of life, and identify lessons perhaps applicable to other rare disorders impacting children.

Contact: Dawn Coleman, MD Project Lead dawn.coleman@duke.edu



FELLOWS CORNER

Dear Pediatric Nephrology Fellows,

Welcome to the Fellows Corner!

Artificial Intelligence in Medicine:

Artificial intelligence (AI) is a branch of computer science that deals with the creation of intelligent agents, which are systems that can reason, learn, and act autonomously. One of the most important goals of AI research is to create machines that can think like humans. This goal is still far from being achieved, but there has been significant progress in recent years. AI has the potential to revolutionize many aspects of our lives.

AI-powered tools are being used to improve the efficiency and accuracy of research in a wide range of fields. Here are some of the recent AI applications for academic research and medicine.

Natural language processing is being used to analyze large amounts of text data, such as scientific papers and clinical records. NLP can be used to extract information from text, identify patterns, and generate summaries.

Machine learning is being used to develop predictive models for a variety of tasks, such as drug discovery, disease diagnosis, and financial forecasting. ML models can learn from data and improve their performance over time.

Computer vision is being used to analyze images and videos. CV can be used to identify objects, track movement, and classify scenes.

Robotics is being used to develop autonomous machines that can perform tasks in the real world. Robotics can be used for a variety of applications, such as surgery, manufacturing, and search and rescue.

Below is the list of AI powered Apps that are available (this list by no means is all inclusive)

- 1. Cite This For Me: Cite This For Me is a citation generator that can help you format your citations correctly. It can also help you find the correct citation information for your sources.
- 2. **Papers**: Papers is a research assistant that can help you find and organize research papers. It can also help you track your progress and stay organized.
- **3.** Zotero: Zotero is a free and open-source reference manager that can help you collect, organize, cite, and share research.
- **4. ReadCube**: ReadCube is a PDF reader that can help you annotate and highlight research papers. It can also help you organize your papers and share them with others.
- **5.** *Cortex*: Cortex is an AI-powered writing assistant that can help you generate ideas, organize your thoughts, and write better research papers.
- 6. ChatGPT: ChatGPT a large language model that can generate text, translate languages, write different kinds of creative content, and answer your questions in an informative way.
- 7. **Bard**: Bard is a large language model from Google AI that can generate text, translate languages, write different kinds of creative content, and answer your questions in an informative way.

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- 8. Bing AI: Bing AI is a chatbot powered by OpenAI's GPT-4 language model. It can be used to answer questions, generate text, and even create images.
- **9.** *Google Cloud ML Engine*: Google Cloud ML Engine is a cloud-based platform that makes it easy to build, train, and deploy machine learning models.
- **10.** *TensorFlow*: TensorFlow is an open-source machine learning library that can be used to build and train machine learning models on a variety of platform

These are just a few of the many AI-powered apps that are available to help with academic writing. These apps can help you save time, improve your writing, and produce better research.

It is important to note that AI-powered apps are not a replacement for human intelligence. These apps can help you improve your working, but they cannot do the work for you. You still need to be able to think critically.