

KIDney Notes

The ASPN Newsletter

FROM THE PRESIDENT



Jodi Smith, MD, MPH, President

Happy Spring,

Hot off the press! The votes for the new ASPN Council Members are in and I am excited to share the results with all of you. Please join me in congratulating **Meredith Atkinson**, incoming ASPN President, **Sandi Amaral**, incoming ASPN President-Elect, **Gina Barletta**, the incoming ASPN Secretary, and **Annabelle Chua**, the

incoming ASPN Treasurer. Our new ASPN Councilors are **Isa Ashoor**, **Patty Seo-Mayer**, **Christine Sethna**, and **Darcy Weidemann**. Our future is bright! I want to take a moment to thank the ASPN Nominating Committee whose work was instrumental to the success of this year's election. As a reminder, as part of our continued commitment to be an inclusive and transparent organization, we undertook a comprehensive review of the **ASPN Bylaws**. One of the important changes to the bylaws was a re-structuring of the ASPN Nominating Committee such that those who serve on the Committee are now elected by ASPN members at large, rather than appointed by Council. Thanks to the dedicated members of this newly established ASPN Nominating Committee - **Michael Somers (Chair)**, **Nicole Hayde**, **Shina Menon**, **Alicia Neu**, and **David Selewski**.

We were thrilled to launch the **ASPN Go** app last month with funding support from the ASPN Foundation. Big thanks to the hardworking and dedicated ASPN App Development and Implementation Taskforce - **Amy Strong**, **Tamara Hill**, **Stephanie Nguyen**, **Brian Stotter**, **Ryan Town**, **Arwa Nada**, **Emily Steinbach**, **Ari Pollack**, **Jessica Edmondson** - for their important work on what was identified as one of our highest priority initiatives in the Strategic Plan. The app provides seamless access to webinars, committee and interest group forums and resources (ex. the popular acute care nephrology protocol repository), and lots more. Search for **ASPN Go** in your app store and check it out!

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As part of our goal to increase the diversity of our workforce, the JEDI Committee, with support from the ASPN Foundation, is participating in the **New Century Scholars Resident Mentoring Program** for the second year. This is a program established by the Academic Pediatric Association aimed at increasing the workforce diversity in academic pediatrics. We are thrilled to be sponsoring our second New Century Scholar Fellow – **Rafi Faria** who is a second year pediatric resident at Johns Hopkins. We look forward to welcoming her into the ASPN Family!



ASPN Central is busy getting ready to welcome all of you to **Toronto** for our Annual Meeting at PAS. Huge thanks to **Michelle Denburg** and the Program Committee who have done amazing work to put together an outstanding scientific meeting. We are looking forward to the **10 ASPN Committee and Interest Group** meetings that are taking place during PAS. As a reminder, all are welcome to join these meetings. Just pop in! This is a terrific opportunity to meet the group members in person and hear what they are working on to see if it aligns with your interests. At the ASPN Awards Luncheon on Saturday, May 4 at 12:30 PM, we will be paying tribute to the **2024 ASPN Founders' Award Winner Pat Brophy** as well as the winners of the **ASPN Outstanding Service Award – Kim Reidy**, the **ASPN Equity, Social Justice and Advocacy Award – Sarah Swartz**, and the **ASPN Mid-Career Award – David Hains**. We have a special additional event planned for all of us to come together to remember Pat's dedication to the care of children, tremendous mentorship of those in our field, and his larger-than-life spirit. All are welcome to join the ASPN Founders' Award Reception honoring Pat on Saturday May 4th at 7 PM at the Lucky Clover ([RSVP here by 4/17](#)). To honor Pat's Irish heritage and wish, the reception will be in the form of an Irish wake, with shared stories in addition to the food and libations. Sincere thanks to Stuart Goldstein for leading this effort. Lastly, be sure to mark your calendar for the **ASPN Business Meeting** on Sunday, May 5, at 9:30 AM where we will be sharing highlights from the launch of our Strategic Plan as well as Committee/Interest Group updates.

We are thrilled to be welcoming **12 trainees** who will be supported by **ASPN Foundation Travel Grants**. Thank you to the ASPN Foundation and all those who have donated to make this possible. Finally, we recognize that not all ASPN members are able to attend PAS due to clinical and other responsibilities. In order to ensure you are kept up to date, we will be hosting a Town Hall in the summer to share the highlights and accomplishments and gather your feedback.

As always, thank you for all you do for our society. Please don't hesitate to reach out to me at jodi.smith@seattlechildrens.org with any questions or concerns.

Jodi

FROM THE EDITOR

Dear Friends and Colleagues,

Spring has finally sprung (at least in DC) and it brings all the potential and possibilities of a fresh start. This will be my last newsletter as Editor of KIDney Notes before handing off my friend, **Sudha Mannemuddhu**, and I look forward to the fresh perspective and attention to detail that she will bring. It has been a privilege to hear from you all and work with ASPN Leadership to help make KIDney Notes as helpful as possible. I look forward to seeing the next iteration of the newsletter.

Warmly,

Radha Gajjar

agajjar@childrensnational.org

[@DrRadhaG](#)

Associate Editor

Sudha Mannemuddhu

dr.saisudhamm@gmail.com

[@drM_Sudha](#)

Section Editor

Raja Dandamudi

dandamudi@wustl.edu

[@raja_dandamudi](#)



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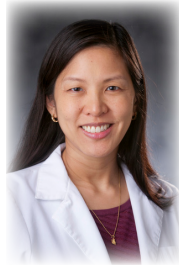
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NEWSLETTER

Raja Sekhar Dandamudi, MD
*Washington University School of
Medicine in St. Louis*

Radha Gajjar, MD, MSCE
Children's National Hospital

Sai Sudha Mannemuddhu, MD
East Tennessee Children's Hospital

ASPEN CORPORATE LIAISON BOARD



ASPEN 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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Legacies Create Futures for the ASPN

We are pleased to announce the creation of the **ASPN Foundation Legacy Circle**. The Legacy Circle is a group of supporters who have made a bequest to the ASPN Foundation through their estate plans.

Thank you to our inaugural members:

H. William Schnaper
Adrian Spitzer
Max Spitzer
Susan Thomas

If you have already made plans to include a gift to the ASPN Foundation in your estate planning, please let us know by completing [this form](#).

As you consider your retirement and estate planning, we hope that you will consider the ASPN Foundation as part of your legacy.

An important legacy opportunity is to include THE ASPN Foundation in your will. A bequest is a

permanent statement of the value you gained from our society and a means making a meaningful gift to the future care of children with kidney disease. We suggest consulting your attorney to include the ASPN Foundation in your will.

If you don't wish to revise an existing will, several alternative mechanisms exist to benefit the ASPN Foundation through legacy gifts in your estate planning. Your estate planning advisor or attorney can assist you in exploring options.

Another excellent opportunity to contribute during retirement and to gain a tax benefit at the same time is to contribute a component of your RMD, Required Minimal Distribution, from an IRA. Consult your investment advisor to utilize this contribution mechanism.

For further information contact: info@aspneph.org.

Leave a legacy for the future of ASPN.

ASPEN HISTORY PROJECT

Moments in ASPEN History: A Brief Tranche from the Development of Treatments for Nephrotic Syndrome

After the earlier International Study of Kidney Disease in Children (ISKDC) studies, nephrotic syndrome due to FSGS was considered likely to lead to kidney failure regardless of treatment (typically with oral steroids or alkylating agents). Due to perceived futility, treatment was often withdrawn if a kidney biopsy showed FSGS. In the late 1980s, however, two treatment approaches were described that showed substantially better outcomes for SRNS (with or without FSGS on biopsy) than those associated with standard therapies. These were developed using therapies originally developed for immunosuppression in other clinical contexts, as nephrotic syndrome was considered to result from immune (T lymphocyte) dysfunction.

Mendoza, Tune and their collaborators reported (1987-1995) outcomes of a growing series (up to 32) of sequential children with SRNS with biopsy-verified FSGS based on a modification of the pulse methylprednisolone (MP) treatment described earlier by Cole et al (*J Peds* 88:307, 1976) for 8 children with MPGN or necrotizing/crescentic GN. They extended the original 6-pulse course of Cole et al, eventually quite substantially (up to 82 weeks, with decreasing frequency over time), while adding one or more courses of oral alkylator treatment with cyclophosphamide or chlorambucil for patients who did not completely respond to pulse MP alone or relapsed after initial remission, along with alternate day oral low-dose prednisone. About 65% of patients achieved complete long-term remission with normal renal function, most within 3 years. Side effects were generally minor and/or reversible. A less intensive modification of pulse MP therapy (Waldo et al, 1992) was reported in a more heterogeneous small group of patients with less positive outcomes.

Based on the use of CsA as an immunosuppressive medication in kidney transplantation, Tejani and colleagues reported a number of placebo-controlled and uncontrolled studies of children with SRNS, SSNS or SDNS (some with sub-nephrotic proteinuria) and varying biopsy findings using blood-level targeted CsA. They found most patients with SRNS went on to eventual kidney failure, but about 40% (treated initially with either CsA or placebo) experienced long-term remission with stable kidney function. Most of their studies were of limited duration (up to 6 months) due to concerns about long-term nephrotoxicity of CsA. In most cases, NS relapse occurred upon discontinuation of CsA.

ASPN MEMBER OF THE MONTH

The Communications Committee is excited to announce the most recent Members of the Month, highlighting different ASPN members and recognizing the amazing work that they are doing to support ASPN and the larger nephrology community. We hope you enjoy getting to know your fellow members a little better!

Dr. Abbie Bauer (April/May 2024)

Dr. Bauer is an Assistant Professor of Pediatrics at Oregon Health and Science University (OHSU) in Portland while also serving as the Medical Director of Outpatient Hemodialysis. She completed medical school at the University of Texas Health and Science University in San Antonio before locating up to the Pacific Northwest. She completed her pediatric residency at OHSU and pediatric nephrology fellowship at Seattle Children's Hospital, before returning to Portland. Her clinical interests include dialysis, quality improvement, quality of life improvement, and medical education. With the latter interest culminating in her receiving the Joseph Bilderback Faculty Teaching Award at OHSU this past year.

Dr. Bauer has been a member of ASPN since 2015 and has found the Society to be an important source of mentoring, both as a trainee and as a faculty member. She has been an active member of the ASPN Workforce Committee, having worked on resident/trainee/fellow activities at the national conference for the past 4 years and counting. She is also the current nephrology liaison to FLEXpeds (Female Leadership and Excellence in Pediatric Subspecialties).



Although she is originally from Texas, she loves living in the Pacific Northwest with her husband Will and daughter Rosalind (above left). She enjoys spending time outdoors, whether it be gardening at home, commuting to work on her bike (which she does almost exclusively year-round), or enjoying the natural beauty that her now home state offers to her and her family (above right).

Dr. Diego Aviles (May/June 2024)

Dr. Aviles is a Professor of Pediatrics at the School of Medicine for LSU Health Sciences Center in New Orleans. He completed medical school and his pediatrics residency at the University of Puerto Rico in San Juan, before pursuing his pediatric nephrology fellowship at Georgetown University/ Children's Medical Center in Washington, DC. While there, the mentorship of Drs. Pedro Jose and Robert Fildes convinced him to pursue an academic career, while spending 30 years at LSU Health Sciences Center and Children's Hospital of New Orleans. He currently serves as the Division Director at LSU Health Sciences Center while he is also the Service Line Chief and Medical Director for Dialysis, Apheresis, and Kidney Transplant at the Children's Hospital.

Dr. Aviles' primary research interest is Nephrotic Syndrome and mechanisms of podocyte injury. He is the primary investigator for the CureGN study at his institution. However, he continues to be recognized for his clinical and advocacy work, being awarded the Master Pediatrician Award by the Louisiana Chapter of the American Academy of Pediatrics (AAP) this past year for his contributions to advancing the care for children in his home state.

Dr. Aviles has been a long-standing ASPN , whom he credits with giving him opportunities to both network with and present his research work to colleagues across the country. He is a member of the Clinical Affairs and Practice Management Committee as well as the Division Chiefs Interest Group.

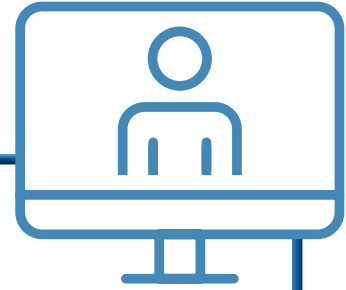
In his free time, Dr. Aviles enjoys spending time with friends, family (seen below), and travelling. He may be followed on X at his handle [@DiegoAvil01](https://twitter.com/DiegoAvil01).



PAS 2024 SCHEDULE

Friday, May 3	Saturday, May 4	Sunday, May 5	Monday, May 6
<p>8:00 am – 1:30 pm ASPEN Program Committee Meeting/ Council Meeting</p> <p>12:00 pm – 1:30 pm Workshop 1: Case Studies in Pediatric Kidney Diseases: Who, When and How to Order Genetic Testing?</p> <p>2:00 pm – 3:30 pm PAS Opening General Session</p> <p>3:45 pm – 5:15 pm Nephrology Platform I: Clinical Science</p> <p>5:15 pm – 6:45 pm Scholarly Session 1: New insights into the development and progression of kidney disease in sickle cell disease</p> <p>5:15 pm – 7:15 pm Poster Session I</p>	<p>7:00am – 8:00am ASPEN Resident-Student Mentorship Breakfast/ Small Group Interest Group/ Research Committee Meetings</p> <p>8:00 am – 9:30 am Scholarly Session 2 Critical care nephrology</p> <p>11:00 am – 12:30 pm Scholarly Session 3: Association of social determinants of health with access and outcomes in kidney disease</p> <p>12:30 pm – 2:00 pm ASPEN Awards Luncheon</p> <p>2:00 pm – 3:30 pm Nephrology Platform II: Neonatal Nephrology/AKI</p> <p>3:30 pm – 5:00 pm Scholarly Session 4: Kidney transplant in special populations</p> <p>3:30 pm – 6:00 pm Poster Session II Nephrology Posters Included</p> <p>6:00 pm – 11:00 pm Ancillary Event Time</p>	<p>8:00 am – 9:30 am Scholarly Session 5: New insights into UTI mechanisms, prevention and long-term management of severe bladder dysfunction</p> <p>9:30 am – 11:00 am ASPEN Presidential Address and Business Meeting</p> <p>11:00 am – 12:30 pm Workshop 2: Urine the Know: Vaccine Considerations in Pediatric Kidney Disease</p> <p>12:30pm – 1:30pm ASPEN Clinical Affairs/Public Policy/ Training Program Directors Committee Meeting</p> <p>12:30pm – 2:00pm ASPEN CPC Fellow's Luncheon: Battle of the Brains</p> <p>2:00 pm – 3:30 pm Nephrology Platform III Basic and translational science</p> <p>3:30 pm – 5:00 pm Scholarly Session 6: Using big ideas and big data to study small numbers of small patients</p> <p>3:30 pm – 6:00 pm Poster Session III Nephrology Posters Included</p> <p>6:30 pm – 7:30 pm ASPEN Fellows Job Search and Speed Mentoring Event</p> <p>7:30 pm – 9:00 pm ASPEN Member Reception</p>	<p>7:00am – 8:00am ASPEN Communications/ Global Health Committee Meetings</p> <p>8:00am – 9:30am Platform IV: Hypertension</p> <p>9:30 am – 11 am Scholarly Session 7: Pediatric chronic dialysis: Old dog, new tricks</p> <p>9:30am – 11:30am Poster Session IV</p> <p>11:30am – 12:30pm Acute Care Nephrology/ Transplant Interest Group Meetings</p> <p>Key: Scholarly Sessions Workshops Poster Sessions Ancillary Events</p>

ASPN WEBINARS



ASPN Webinars

Date: Monday May 13th, 2024 3PM EST

Subject: [ASPN Pathology Webinar – History of HSP nephritis, dx w/ Dent disease](#)

Date: Wednesday May 15th, 2024 3PM EST

Subject: [ASPN Clinical Affairs/TIG Webinar - UNOS changes and update for the pediatric nephrologist](#)

Date: Wednesday May 22nd, 2024 3PM EST

Subject: [Pediatric Nephrology in a Small Group Webinar Series - Lupus Nephritis - Case Discussion](#)

Date: Tuesday May 28th, 2024 3PM EST

Subject: [Research Committee webinar – Selected Core Strategies to launch a Successful Career in Medical Research](#)

Committee and SIG Meeting

Date: Wednesday April 24th, 2024 4PM EST

Subject: [ASPN Advanced Practice Providers SIG Quarterly Meeting](#)

Date: Friday May 10th, 2024 2PM EST

Subject: [Transplant Interest Group Meeting](#)

Date: Thursday May 16th, 2024 4PM EST

Subject: [ASPN Communication Committee Meeting](#)

COMMUNITY ANNOUNCEMENTS

You are invited!

Cystinosis Symposium

A Rare Disease Model for Comprehensive Care

- May 31st, The New York Academy of Medicine
- Bridging the gap to construct multidisciplinary healthcare teams extending from primary care to specialized support
- **Who should attend?** Healthcare providers with a desire to learn more about comprehensive care in rare disease



Scan QR code for
agenda & registration details
or visit: cystinosis.org/event



CYSTINOSIS
RESEARCH NETWORK

Corporate Liaison Board Corner

From our CLB Partner:

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



Traverse Therapeutics, Inc. is enrolling a phase 2, open-label, cohort study to evaluate the safety, efficacy, and pharmacokinetics of sparsentan in pediatric patients (aged 1-17 years) with selected proteinuric glomerular diseases. The focus is on children aged <8 years, with >60% of enrollment slots reserved for this group.

What is sparsentan?

Sparsentan is a dual endothelin angiotensin receptor antagonist (DEARA) selective for endothelin type A and angiotensin II type 1 receptors.

EPPIK study details

The EPPIK study is evaluating sparsentan oral suspension and tablets in the following patient populations:

Population 1	Population 2	Population 3
<ul style="list-style-type: none">FSGS or MCDSparsentan oral suspensionUS, UK, and Europe	<ul style="list-style-type: none">IgAN, IgAV, or Alport syndromeSparsentan oral suspensionUS, UK, and Europe	<ul style="list-style-type: none">IgANSparsentan tabletsUS and UK only

Approximately 70 children will receive sparsentan once daily for up to 108 weeks.

The primary endpoints are the incidence of adverse events and change in UPCR. Including screening, the study comprises approximately 18 study visits over 120 weeks.

Key eligibility criteria for all patients

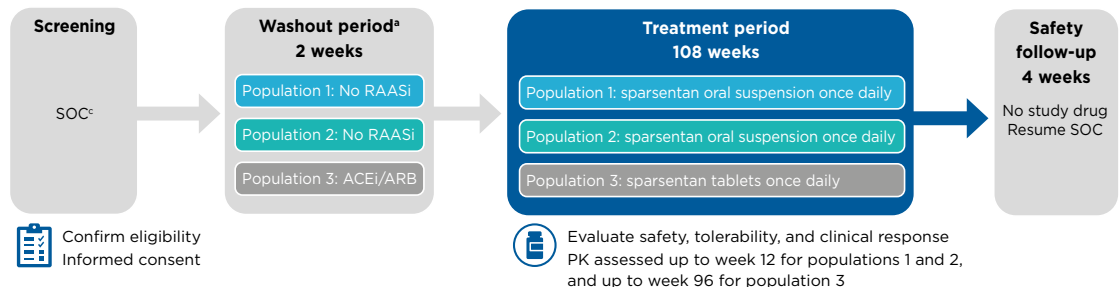
- eGFR of ≥ 30 mL/min/1.73 m² at screening
- No FSGS, MCD histological pattern, or IgA glomerular deposits secondary to another condition^a
- No chronic IST without a stable dose for ≥ 1 month
- No new IST for glomerular disease within 6 months before screening^b

Additional population-specific key eligibility criteria

Population 1	Population 2	Population 3
<ul style="list-style-type: none">FSGS or MCDUPCR of ≥ 1.5 g/g at screeningAge ≥ 1 to <18 yearsWeight ≥ 7.3 kg	<ul style="list-style-type: none">IgAN, IgAV, or Alport syndromeUPCR of ≥ 0.6 g/g at screeningAge ≥ 2 to <18 yearsWeight ≥ 7.3 kg	<ul style="list-style-type: none">IgANUPCR of ≥ 1.0 g/g at screeningAge ≥ 8 to <18 yearsWeight ≥ 40 kg

^a Patients with FSGS or MCD histological pattern secondary to viral infections, drug toxicities, or malignancies and those with IgA glomerular deposits secondary to another condition are excluded.

^b Patients with acute onset, presentation, or relapse of glomerular disease requiring new or different class of IST treatment within 6 months before screening are excluded.



^a Patients in population 3 must be on an ACEi/ARB for ≥ 12 weeks prior to screening and will remain on an ACEi/ARB until the start of the study treatment period (no washout).

For more information, please visit [ClinicalTrials.gov NCT05003986](https://ClinicalTrials.gov/NCT05003986), [clinicaltrialsregister.eu, EudraCT 2021-000621-27](https://clinicaltrialsregister.eu/2021-000621-27), [kidneyhealthgateway.com, en-us.eppikclinicalstudy.com](https://kidneyhealthgateway.com/en-us/eppikclinicalstudy.com), or contact medinfo@traverse.com.

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Corporate Liaison Board Corner

From our CLB Partner:

SAVE
THE
DATE

May 7 is Cystinosis
Awareness Day



This annual celebration brings recognition and awareness to this rare lysosomal storage disorder that affects the kidneys, eyes, and other organs.



Cystinosis affects
~500 to 600 individuals
in the USA¹



95% of cases
are diagnosed
during infancy or
early childhood^{2,a}



Without treatment,
patients may reach
kidney failure by
10 years of age³



Cystine accumulation
leads to progressive
multiorgan damage³

RECENT CYSTINOSIS-RELATED PUBLICATIONS

- Gastrointestinal challenges in nephropathic cystinosis: clinical perspectives ([Joseph MW, et al. *Pediatr Nephrol.* 2024](#))
- Fertility management in cystinosis: a clinical perspective ([Langman CB, et al. *Kidney Int Rep.* 2024](#))
- Extrarenal complications of cystinosis ([Topaloglu R. *Pediatr Nephrol.* 2023](#))
- Neuro-cognitive complications of nephropathic cystinosis ([Trauner DA. *J Rare Dis.* 2023](#))
- Multidisciplinary and multidimensional approaches to transplantation in children with rare genetic kidney diseases ([George RP, et al. *Pediatr Transplant.* 2023](#))

UPCOMING CYSTINOSIS EVENTS



Navigating the Transition From Pediatric to Adult Cystinosis Care is a webinar that will be held on June 5, 2024, focusing on transition readiness from the adult nephrology perspective; click [here](#) to register

- [Renal Physicians Association Annual Meeting](#), April 11-14, 2024, Baltimore, MD
- International Society of Nephrology's [World Congress of Nephrology](#), April 13-16, 2024, Buenos Aires, Argentina
- [Society for Inherited Metabolic Disorders Annual Meeting](#), April 14-17, 2024, Charlotte, NC
- [American Nephrology Nurses Association Annual Symposium](#), April 14-17, 2024, Orlando, FL
- [Pediatric Academic Societies Annual Meeting](#), May 2-6, 2024, Toronto, Canada
- [American Society of Gene + Cell Therapy Annual Meeting](#), May 7-11, 2024, Baltimore, MD
- [National Kidney Foundation Spring Clinical Meetings](#), May 14-18, 2024, Long Beach, CA
- [American Transplant Congress Annual Meeting](#), June 1-5, 2024, Philadelphia, PA

FOR MORE INFORMATION

[UnderstandingCystinosis.com](https://www.cystinosis.com)

[CystinosisUnited.com](https://www.cystinosisunited.com)

Contact an
Amgen Representative

Please note that many of the links above connect to non-Amgen websites operated by external parties responsible for their own content; the information and opinions expressed therein are not endorsed by Amgen.

^aSymptoms typically emerge within the first year of life and include Fanconi syndrome, failure to thrive, and rickets.³

1. Cystinosis Research Network. Accessed February 2024. <https://cystinosis.org/publications/infantile-nephropathic-cystinosis-standards-of-care> **2.** Emma F, et al. *Nephrol Dial Transplant.* 2014;29(suppl 4):iv87-iv94. **3.** Nesterova G, Gahl WA. *Pediatr Nephrol.* 2008;23(6):863-878.



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