

Patient and Family Summit

June 27- 28, 2025 Draft Agenda



Oxalosis &
Hyperoxaluria
Foundation

FRIDAY

1:00 PM

Registration/Information

3rd Floor / Meadow D Foyer

Please stop by the Registration Desk to check in and pick up your welcome information, agenda, t-shirts, and name badges.

Childcare is available, inquire at registration if you are interested!

2:00

State of the OHF

3rd Floor / Ballroom Meadow D

Kim Hollander, Oxalosis and Hyperoxaluria Foundation & Tiffany Reid, Patient Advocate

Hear from Leaders in the OHF and OHF community about 2025 and the future of hyperoxaluria.

2:30

Icebreaker

3rd Floor / Ballroom Meadow D

Kim Hollander, Oxalosis and Hyperoxaluria Foundation

Connect with your fellow attendees!

Check out the young adult (YA) Track for the OHF Patient and Family Summit!

YA

2:30

Nashville Scavenger Hunt: Monuments and Majesty

3rd Floor / Meadow D Foyer

Embark on an exciting journey learning about Nashville's rich history with the "Monuments and Majesty" scavenger hunt! Explore iconic landmarks, uncover hidden stories, and discover the grandeur of Nashville's monuments. From the former farmland turned fairgrounds to Tennessee's historical gems, this scavenger hunt combines culture, fun, and friendly competition. It's a fantastic way to immerse yourself in the city while building connections with fellow attendees! Runs until about 5:00 pm.

3:00

Deciphering Your Diagnosis: What Every Hyperoxaluria Patient Needs to Know

3rd Floor / Ballroom Meadow D

John Lieske, MD, Mayo Clinic

Whether you were diagnosed this year or have been navigating the diagnosis for decades, this session will provide essential information about hyperoxaluria. Learn about the condition, treatment options, and how to effectively manage your health moving forward.

3:15

Break and Exhibitor Tables

3rd Floor / Meadow D Foyer

3:35

People Like Me

3rd Floor / Choose Your Breakout Session

Kelley Coleman, Patient Advocate

What it's Like to Care for Someone With a Rare Disease

This breakout session invites caregivers of individuals with hyperoxaluria to discuss the challenges they've faced in the past year. Connect with others who understand the unique demands of caregiving, share experiences, and offer insights for better managing the journey. This is an opportunity for support, validation, and constructive conversation.

Angela Baggett, RN, Boston Children's Hospital

What it's Like to Live with Hyperoxaluria

This breakout session offers individuals with hyperoxaluria the opportunity to share their experiences, challenges, and triumphs over the past year. Participants will connect with others facing similar health and emotional hurdles, providing a space for mutual support and constructive discussion. Share, listen, and learn from those who truly understand the journey.



4:30

Transforming Hyperoxaluria Care: The Future of the OHF Registry

3rd Floor / Ballroom Meadow D

Leah Knoke, Mayo Clinic

Learn how the OHF Registry is advancing hyperoxaluria care through research and patient data. This session will cover the importance of registry participation, how to keep your records up-to-date, and the reconsenting process. Discover how your involvement helps drive better treatments and outcomes for the hyperoxaluria community.

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4:50 **Day One Wrap-Up**
3rd Floor / Ballroom Meadow D
Kim Hollander, Oxalosis and Hyperoxaluria Foundation

5:00 **Welcome Reception and Exhibitor Tables**
30th Floor Floor / The Overlook

SATURDAY

Grab breakfast between 7:00–8:30 AM — best part, it's included in your stay!

8:30 AM **Registration/Information**
3rd Floor / Meadow D Foyer

Please stop by the Registration Desk to check in and pick up your welcome information, agenda, t-shirts, and name badges.

9:00 **Summit Keynote**
3rd Floor / Ballroom Meadow D

Kevin Koo, MD, MPH, Mayo Clinic

Join Dr. Kevin Koo for a powerful keynote highlighting the strength, resilience, and empowerment of patients living with hyperoxaluria. Dr. Koo will share inspiring insights on overcoming challenges and the importance of patient advocacy in driving change. This session is a celebration of the remarkable courage and determination of the hyperoxaluria community.

YA
9:00 **Words of Worth**
3rd Floor / Riverbed C

Believe Team

Session continues through about 12:00 pm.

9:20 **Icebreaker**
3rd Floor / Ballroom Meadow D

Kim Hollander, Oxalosis and Hyperoxaluria Foundation

Connect with your fellow attendees!

9:30 **Basic Research is Not so Basic: Strides in Research and Hyperoxaluria Representation**
3rd Floor / Ballroom Meadow D

Todd Lowther, MD, PhD, Wake Forest University School of Medicine, John Knight, PhD, University of Alabama Birmingham

Dr. Lowther and Dr. Knight will provide accessible insights into current basic research initiatives and OHF's support for ongoing research efforts and will highlight this year's grants, cross-kidney collaborative initiatives, and the importance of participation in advancing the field. The session will also emphasize the significance of representation in research discussions and the impact of advocacy at key meetings and boards.

9:50 **Therapeutic Frontiers: Exploring Mechanisms and Investigational Approaches in Hyperoxaluria**
3rd Floor / Ballroom Meadow D

Matthew Breeggemann, MD, University of California San Francisco

Wondering what's on the horizon for hyperoxaluria treatment? This session is perfect for you! We'll break down the newest therapies being studied, how they work, and the hope they bring for better care and brighter days ahead.

10:05 **Practical Care and Treatment: Empowering You to Advocate in Urology**
3rd Floor / Ballroom Meadow D Panel Session

Panelists: *Greg Tasian, MD, Children's Hospital of Philadelphia, Kevin Koo, MD, MPH, Mayo Clinic, David Duong, MD, PhD, Urology Associates of Nashville; Moderator: Kristina Penniston, PhD, University of Wisconsin–Madison*

Urology experts will address common concerns in managing hyperoxaluria, including the use of stents, radiation exposure over time, and the impact of multiple procedures. Patients will learn how these treatments impact kidney health and gain tools to better communicate with their urologists about their care and treatment options.

10:45 **Break and Exhibitor Tables**
3rd Floor / Meadow D Foyer

SATURDAY

11:05 **Building an Engaged Community: OHF Programs for Connection & Advocacy**
3rd Floor / Ballroom Meadow D

Sam Ekdorn, Kristi Ouimet, Rabia Zhen, Patient Advocates

Highlighting Share Your Story, Social Media Campaigns, and the Buddy Program as pathways for support, empowerment, and engagement in the hyperoxaluria community. Sign up at the meeting and make a commitment!

11:25 **Hyperoxaluria Uncovered: Nephrology Insights Live**
3rd Floor / Ballroom Meadow D Panel Session

Panelists: John Lieske, MD, Mayo Clinic, David Sas, DO, MPH, Mayo Clinic, Matthew Breeggemann, MD, Michelle Baum, MD, Boston Children's Hospital, Kristina Penniston, PhD, University of Wisconsin-Madison; Moderator: Kevin Koo, MD, MPH, Mayo Clinic

A live panel featuring expert nephrologists and a dietician answering key questions about hyperoxaluria, offering in-depth insights into diagnosis, treatment, and ongoing research.

12:05 **Words of Worth Presentation**
3rd Floor / Ballroom Meadow D

Believe Team

12:35 **Lunch and Exhibitor Tables & Group Photo**
3rd Floor / Meadow D Foyer

1:30 **Expanding Horizons: The Future of the OHF Care Center Network**
3rd Floor / Ballroom Meadow D

John Lieske, MD, Mayo Clinic, Michelle Baum, MD, Boston Children's Hospital, Matthew Breeggemann, MD, University of California San Francisco

Updates on the growth of the OHF Care Center Network, welcoming new centers, strengthening support and enhancing patient care within the PH community.

1:40 **Inside the Trial: Empowering Patients in Clinical Research**
3rd Floor / Ballroom Meadow D

Madeline Heaney, Center for Information & Study on Clinical Research Participation

A deep dive into the stages of clinical trials, highlighting how patients can actively engage in the process, from initial design to outcomes. This session will explore the vital role patients play in advancing research and the ways they can help shape the future of PH treatments.

2:00 **I can, I will, I am: How I am Making a Difference**
3rd Floor / Ballroom Meadow D Panel Session

Panelists: Kelly Gilligan, Muhammad Faraz Khaliq, Tiffany Reid, and Indra Campbell, Patient Advocates; Moderator: Gregory Tasian, MD, Children's Hospital of Philadelphia

Individuals share their personal journeys, the strength they've found through their experiences, and how they are making a difference through advocacy. Participants will offer valuable insights, wisdom, and stories of resilience that empower and inspire others in the PH community.

2:30 **Break and Exhibitor Tables**
3rd Floor / Meadow D Foyer

2:50 **Advocacy and Me**
3rd Floor / Choose Your Breakout Session

Kendly Jones, EveryLife Foundation

Advocacy & Me: Finding Your Voice, Making an Impact

Exploring personal advocacy and practical ways to drive change in the PH community.

Kelley Coleman, Patient Advocate

Navigating School Systems: Access, Accommodations & Advocacy

Guidance on securing support, accommodations, and resources for students with PH.



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Hyperoxaluria and Me

3rd Floor / Choose Your Breakout Session

John Lieske, MD, Mayo Clinic, Sonia Fargue, MD, PhD, University of Alabama Birmingham

Emerging Horizons: Updates on Enteric Hyperoxaluria

Exploring progress in understanding EH and advancements in disease management.

David Sas, MD, MPH, Mayo Clinic, John Knight, PhD, University of Alabama Birmingham

Advancing Knowledge: The Latest in PH1 Research & Care

Examining the mechanisms behind PH1 therapeutics and progress in treatment development.

Todd Lowther, PhD, Wake Forest University School of Medicine, Michelle Baum, MD, Boston Children's Hospital

PH2 & PH3: Unlocking New Insights

Discussing current understanding of PH2 and PH3 and the evolving pipeline of small-molecule therapeutics.

4:10

Reflection & Resilience

3rd Floor / Ballroom Meadow D

Kim Hollander, Oxalosis and Hyperoxaluria Foundation

4:30

Exhibitor Tables

3rd Floor / Meadow D Foyer

6:00

Farewell Dinner & Line Dancing Lesson

3rd Floor / Meadow D



Event Supported By

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