

Patient and Family Summit

October 6th- 7th, 2023 Draft Agenda

FRIDAY

5:00 PM Welcome Reception
Meet and Greet

SATURDAY

8:30 AM Registration and Continental Breakfast
Sign in and network!

9:00 Welcome
Summit kick-off and icebreaker, Kim Hollander (OHF, Executive Director)

9:10 Keynote Speaker
Robert M. Long (Uplifting Athletes, Executive Director)

9:30 The Rare Odyssey
One individual's extraordinary journey, Matthew Breeggemann, MD (Assistant Professor, Medicine, University of California, San Francisco)

UNDERSTANDING HYPEROXALURIA

9:40 Hyperoxaluria 101
Primary and enteric hyperoxaluria primer: two rare diseases with similar outcomes, John C. Leiske, MD (Professor of Medicine, Division of Nephrology and Hypertension, Director Rare Kidney Stone Consortium, Mayo Clinic, Rochester, MN)

9:50 What is Excellence in Care?
Current Standard of Care in Hyperoxaluria, David J. Sas, DO, MPH (Associate Professor, Division Chair, Pediatric Nephrology and Hypertension, Mayo Clinic, Rochester, MN)

10:00 Making Strides Together
How the rare disease registries make a difference, Carly Banks, Certified Clinical Research Coordinator (Mayo Clinic, Rochester, MN)

10:05 What is Hyperoxaluria to me?
Community round table discussion

10:35 Ask the Expert
Community panel discussion, Matthew Breeggemann MD, Kristi Ouimet, Martin Leenen, Beth Kissinger

11:05 BREAK

LIFE AND CARE STAGES

11:30 Mind Matters: Nurturing Your Inner Strength
Building emotional resilience with strategies and techniques, Sarah R. McCarthy, PhD, MPH, LP (Pediatric Psychologist, Rochester, MN)

11:45 Rare & Resilient: Mastering the Art of Thriving with Uniqueness
Balancing the individual challenges of rare disease, Sarah R. McCarthy, PhD, MPH, LP

12:00 Empowering Hearts and Minds: Navigating the Extraordinary Journey Together
Community activity, celebrating victories and finding joy, Sarah R. McCarthy, PhD, MPH, LP

12:30 LUNCH

HORIZONS IN MANAGING HYPEROXALURIA

1:30 Unveiling the Therapeutic Treasure Chest
Exploring the drug discovery journey, David S. Goldfarb, MD (Professor, Department of Medicine and Physiology, NYU Grossman School of Medicine, Clinical Chief of Nephrology, NYU Langone Health, and Chief of Nephrology, NY Harbor VA Medical Center NY)

1:50 Guiding Through the Healthcare Maze
Navigating the insurance system with confidence, Robin Goldwater (Patient Services Consultant)

2:10 The Care Team Quest: Uncovering Your Ideal Healthcare Partners
Community member and clinician panel, Kevin Koo, MD, David J. Sas, DO, John C. Leiske, MD, Kristina Penniston RD, David S. Goldfarb, MD

2:35 BREAK

TAKING ACTION

3:00 Advocacy for Change
Amplifying your voice in legislation, EveryLife Speaker

3:10 Joining Forces for A Cure
Taking action to drive positive change for hyperoxaluria, Courtney Nagle (Patient Advocate)

3:30 The Colors of our Journey
Embracing your brilliance, Community activity

NEXT STEPS

4:15 Closing & Thank You
Summit closer, Kim Hollander (OHF, Executive Director)

4:30 Group Picture



Oxalosis &
Hyperoxaluria
Foundation

STEPPING STONES TO A CURE

Empowering All
Finding strength and community
(young adult table)

Beyond the Ordinary:
Extraordinary Explorers Unite!
Discovering your unique strength
through creativity and connection
(young person break out session)

Join us for a community dinner
after the Summit on October 7th!