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
9:30  The Rare Odyssey
One individual's extraordinary journey

UNDERSTANDING HYPEROXALURIA
9:40  Hyperoxaluria 101
Primary and enteric hyperoxaluria primer: two rare diseases with similar outcomes
9:50  What is Excellence in Care?
Steps forward in standard of care and treatment,
10:00  Making Strides Together
How the rare disease registries make a difference
10:05  What is Hyperoxaluria to me?
Community round table discussion
10:35  Ask the Expert
Panel discussion
11:05  BREAK

LIFE AND CARE STAGES
11:30  Mind Matters: Nurturing Your Inner Strength
Building emotional resilience with strategies and techniques,
11:45  Rare & Resilient: Mastering the Art of Thriving with Uniqueness
Balancing the individual challenges of rare disease,
12:00  Empowering Hearts and Minds: Navigating the Extraordinary Journey Together
Community activity, celebrating victories and finding joy
12:30  LUNCH

HORIZONS IN MANAGING HYPEROXALURIA
1:30  Unveiling the Therapeutic Treasure Chest
Exploring the drug discovery journey
1:45  Guiding Through the Healthcare Maze
Navigating the insurance system with confidence,
2:00  The Care Team Quest: Uncovering Your Ideal Healthcare Partners
Community member and clinician panel
2:25  BREAK

TAKING ACTION
3:00  Advocacy for Change
Amplifying your voice in legislation
3:10  Joining Forces for A Cure
Drive positive change for hyperoxaluria
3:30  The Colors of our Journey
Community activity, embracing your brilliance

NEXT STEPS
4:15  Closing & Thank You
Summit close
4:30  Group Picture

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