



# Conference Agenda

Friday, April 5, 2024			
Time	Topic	Speaker	Room Location
11:30 am - 7:30 pm	Registration open		Edgewater Foyer
<b>fNIRS Research Study (for pre-enrolled study participants only)</b>			
3:00 pm-6:00 pm	fNIRS testing sessions	Kosar Khaksari, Ph.D., Children's National Hospital	Waterlily
<b>Day 1 Workshops</b>			
1:30 pm - 2:30 pm	<b>Kick Off Session:</b> Conference orientation Patient Story Rare Disease Advocacy	Tresa Warner, NUCDF Kristy McCracken – UCD patient expert Marifi Escobar – UCD parent expert	Star Grass
2:30 pm - 3:30 pm	Approaches to UCD Treatment and Management	Lindsay Burrage, M.D., Ph.D. Baylor College of Medicine, Houston TX	Star Grass
<b>Welcome Reception</b>			
6:30 pm - 9:00 pm	Welcome reception - Tribute to Cindy Le Mons for families, children, speakers, panelists	Hosted by Dr. Brendan Lee, M.D., Ph.D. Baylor College of Medicine, Houston, TX	Edgewater Ballroom
8:15 pm - 9:00 pm	Lantern release		Woodlands Waterway
Saturday, April 6, 2024			
7:15 am - 7:45 am	Conference registration and check-in		Edgewater Ballroom
7:15 am - 7:45 a.m	Childcare sign-in; pre-registration required		Presidential Suite
<b>fNIRS Research Study (for pre-enrolled study participants only)</b>			
8:00 am - 3:00 pm	fNIRS testing sessions	Kosar Khaksari, Ph.D., Children's National Hospital	Waterlily
<b>General Session (All registered participants)</b>			
7:30 am - 8:00am	Continental breakfast (for general session attendees only)		Edgewater Ballroom
8:00 am	Welcome remarks	Tresa Warner, NUCDF President	
8:00 am - 8:30 am	Keynote address: Legacy of Hope	Sandesh Nagamani, MBBS, MD, Baylor College of Medicine, Houston, TX	
8:30 am - 9:00 am	Emerging knowledge from MRI imaging studies: Is ammonia control enough?	Andrea Gropman, MD, Children's National Hospital, Washington, DC	

9:00 am - 9:30 am	New insights on liver disease in urea cycle disorders	Lindsay Burrage, M.D., Ph.D. Baylor College of Medicine, Houston TX	
9:30 am - 10:00 am	Panel discussion	Dr. Sandesh Nagamani Dr. Andrea Gropman Dr. Lindsay Burrage	
9:50 am - 10:00 am	Industry update - Zevra (maker of OLPRUVA)		
10:00 am - 10:30 am	Improving diagnosis with the awesome power of yeast genetics	Aimee Dudley, PhD, Pacific Northwest Research Institute	
10:30 am - 11:00 am	Liver transplantation for urea cycle disorders: Lessons from the past 30 years	George Mazariegos, MD, UPMC Children's Hospital of Pittsburgh, Pittsburgh, PA	
11:00 am - 11:30 am	Making the choice between medical management and liver transplant: The family experience	Nicholas Ah Mew, MD, Children's National Hospital, Washington, DC	
11:30 am - 11:55 am	Liver transplant panel discussion	Dr. George Mazariegos Dr. Nicholas Ah Mew Patient community: Lori Shockey Michelle Dinon	
12:00 pm - 1:15 pm	Luncheon for Families/Children and Speakers		Sorriso Restaurant
General Session (For UCD patients, parents/caregivers, clinicians, and speakers/panelists only)			
Tribute to Deb Hook - NUCDF Dietitian			
1:15 pm - 1:45 pm	Fork in the road: Improving your UCD diet	Erin MacLeod, RD, Children's National Hospital, Washington, DC	
1:45 pm - 2:15 pm	Gene therapy - is it the new frontier?	Dr. Shawn McCandless, MD Children's Hospital of Colorado, Aurora, CO	
2:15 pm - 2:45 pm	Hope happens here - Understanding and participating in clinical trials for urea cycle disorders	Susan Berry, MD, University of Minnesota Medical School Minneapolis, MN	
2:45 pm - 3:00 pm	Discussion panel	Dr. Shawn McCandless Dr. Susan Berry Erin MacLeod	
3:00 pm - 3:10 pm	Industry update/Ultragenyx (conducting OTC gene therapy clinical trial)		
3:10 pm - 3:20 pm	Afternoon break		

Breakout Sessions (Families, speakers/panelists only)			
3:20 pm - 4:00 pm	Breakout Session 1 Optimizing UCD management/ managing the effects of UCD	<b>Panel Moderator</b> <i>Dr. Sandesh Nagamani</i> Dr. Lindsay Burrage Dr. Susan Berry	Edgewater Ballroom
	Breakout Session 2 Understanding treatment options	<b>Panel Moderator</b> <i>Dr. Andrea Gropman</i> Dr. Shawn McCandless Dr. Gerry Berry Dr. Uta Lichter-Konecki Dr. Sara Elsbecker	Iris
4:00 pm - 4:30 pm	Breakout Session 1 My UCD perspective and insights for parents: Transition to adult care	<b>Panel Moderator</b> <i>Dr. Sandesh Nagamani</i> Dr. Gerry Berry Erin MacLeod, RD Patient community: Kristy McCracken Maria Escobar Lori Shockey (NUCDF Board member)	Edgewater Ballroom
	Breakout Session 2 Family planning	<b>Panel Moderator</b> <i>Dr. Susan Berry</i> Dr. Andrea Gropman Dr. Shawn McCandless Dr. Aimee Dudley Dr. Uta Lichter-Konecki Kara Simpson	Iris
4:30 pm - 5:00 pm	Breakout Session 3 Stronger together: looking to the future	NUCDF Board Members	Edgewater Ballroom
5:00 pm	End Day 1 Sessions		
Sunday, April 7, 2024			
8:30 am - 10:00 am	Join us for continental breakfast/networking		
11:00 am	End of Conference		

**Thank you for participating in the 2024 Family Conference**

