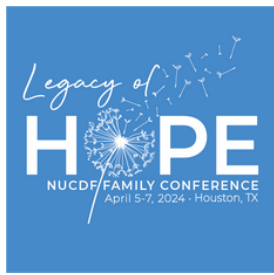


Legacy of

H O P E



National Urea Cycle Disorders Foundation
families research education support ... Hope



Conference Agenda

Friday, April 5, 2024			
Time	Topic	Speaker	Room Location
11:30 am - 7:30 pm	Registration open		Edgewater Foyer
fNIRS Research Study (for pre-enrolled study participants only)			
3:00 pm-6:00 pm	fNIRS testing sessions	Kosar Khaksari, Ph.D., Children's National Hospital	Waterlily
Day 1 Workshops			
1:30 pm - 2:30 pm	Kick Off Session: 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
Welcome Reception			
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 Foyer
7:15 am - 7:45 a.m	Childcare sign-in; pre-registration required		Presidential Suite
fNIRS Research Study (for pre-enrolled study participants only)			
8:00 am - 3:00 pm	fNIRS testing sessions	Kosar Khaksari, Ph.D., Children's National Hospital	Waterlily
General Session (All registered participants)			
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: 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, PhD, RD, LD 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	Panel Moderator <i>Dr. Sandesh Nagamani</i> Dr. Lindsay Burrage Dr. Gerry Berry Dr. Sara Elsbecker Erin MacLeod, Ph.D.	Edgewater Ballroom
	Breakout Session 2 Understanding treatment options	Panel Moderator <i>Dr. Andrea Gropman</i> Dr. Susan Berry Dr. Nicholas Ah Mew Dr. Shawn McCandless Dr. Uta Lichter-Konecki Kara Simpson MS, CGC	Iris
4:00 pm - 4:30 pm	Breakout Session 1 My UCD perspective and insights for parents: Transition to adult care	Panel Moderator <i>Dr. Sandesh Nagamani</i> Dr. Lindsay Burrage Dr. Gerry Berry Dr. Sara Elsbecker Erin MacLeod, Ph.D. Patient community: Kristy McCracken Maria Escobar	Edgewater Ballroom
	Breakout Session 2 Family planning	Panel Moderator <i>Dr. Susan Berry</i> Dr. Nicholas Ah Mew Dr. Andrea Gropman Dr. Shawn McCandless Dr. Aimee Dudley Dr. Uta Lichter-Konecki Kara Simpson MS, CGC	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		Library
11:00 am	End of Conference		

Thank you for participating in the 2024 Family Conference

