



United Leukodystrophy Foundation

Family Conference Agenda

Friday, June 28, 2024

Room	Red Oak Ballroom				
08:30 – 08:45 AM	Welcome! <i>Ron Chapleau, Board President</i>				
Room	Red Oak Ballroom	Bluestem	Hazelnut	Hollyhock	Iris
09:00 – 10:00 AM	Zebrafish, Mice, and More: Research Strategies for Leukodystrophies <i>Dr. Josh Bonkowski, Utah Health</i>	Leukodystrophy 101 <i>Dr. Ali Fatemi, Johns Hopkins and Kennedy Krieger Institute</i>	Gene Therapy for MLD Updates, Life After Diagnosis: Building Resilience as a Family, and Standards of Care Update <i>Orchard, Asmahan Safi and Cure MLD</i>	ALSP Presented by the ULF Click here for more info!	MLC Presented by Alliance MLC Click here for more info!
10:15 – 11:15 AM	Unlocking Your Family History and Decoding Genetic Inheritance <i>Rachel Hickey, Genetic Counselor</i>	What to Expect? Anticipatory Guidance for Parents of Affected Children <i>Lindsey Topping Schuetz, Courageous Parents Network</i>	State-by-State Plan for Introducing and Implementing Screening for MLD by 2029 <i>Cure MLD and Lesa Brackbill, Leukodystrophy Newborn Screening Action Network</i>		
11:30 – 12:30 PM	Rehabilitation for Adults <i>Dr. Kathy Zackowski and Jennifer Keller, Kennedy Krieger Institute</i>	Forecasting Interventions for Pediatric Patients <i>Dr. Stephanie Keller, Emory University</i>	Supporting the Siblings: Managing a New Normal and Caring for the Unaffected Sibling <i>Sarah Stoney, CHOP, and Loren Mirsky-Piatkin, Breakthrough Coaching Center</i>		
12:30 – 01:30 PM	Lunch in Burnham's Buffet, located in the lobby of the Eaglewood Resort.				



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01:30 – 02:30 PM	LCC, Labrune Syndrome <i>Dr. Jamie Fraser, Children's National Hospital</i>	Mental Health for Parents of Affected Children: Processing a New Diagnosis <i>Sarah Stoney, CHOP, and Soo Shim, Lurie Children's Hospital</i>	CTX Presented by CTX Alliance Click here for more info!	ALD/AMN Presented by the ULF Click here for more info!	VWM Presented by VWM Families Foundation Click here for more info!
02:45 – 03:45 PM	Managing Caregiver Burnout <i>Marla Chapleau, MLC Mom Caregiver</i>	Mental Health for Affected Adults: Processing a New Diagnosis <i>Sarah Stoney, CHOP, and Soo Shim, Lurie Children's Hospital</i>			
04:00 – 05:00 PM	Choosing Medical Equipment <i>Dr. Kathy Zackowski and Jennifer Keller, Kennedy Krieger Institute</i>	Making the Most of Your Wish: Make a Wish Alumni Panel <i>Dina Thachet, Make-a-Wish IL and Wish Alumni</i>			
05:00 – 06:00 PM	<i>Evening Break</i>				
06:00 PM	<i>Drink Stations Open in Red Oak Foyer</i>				
06:30 PM	<i>Dinner in Red Oak Ballroom</i>				
07:30 PM	<i>Legacy Awards & Live Auction</i>				



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08:30 – 08:45 AM	Announcements <i>Ron Chapleau, Board President</i>				
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09:00 – 10:00 AM	Introducing: The ULF's Ambassador Program <i>Marla Chapleau and the ULF Ambassadors</i>	Treatment Modalities for Leukodystrophies <i>Dr. Ali Fatemi, Johns Hopkins and Kennedy Krieger Institute</i>	Grief Roundtable <i>LuAnn Swartzlander</i>	Krabbe Disease Presented by KrabbeConnect Click here for more info!	CADASIL Presented by Cure CADASIL Click here for more info!
10:15 – 11:15 AM	Advancements in Gene Therapy <i>Dr. Florian Eichler, Mass. General Hospital</i>	Anticipatory Grief <i>Nicollette Vasquez, Lightways Joliet</i>	Spouses & Partners Roundtable <i>Margaret Halter and Roger Locy</i>		
11:30 – 12:30 PM	Bioethics: Understanding the Importance of Informed Consent <i>Melody Kisor, Cure LBSL</i>	Utilizing Palliative Care and Hospice for Quality of Life <i>Dr. Erin Flanagan, Lightways Joliet</i>	Research and the Ultra-Rare <i>Dr. Paul Watkins, Kennedy Krieger Institute</i>		
12:30 – 01:30 PM	Lunch in Burnham's Buffet, located in the lobby of the Eaglewood Resort.				
01:00 PM	Silent Auction Ends!				



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01:30 - 02:00 PM	Scientific Symposium Session Summaries <i>Dr. Ali Fatemi, Johns Hopkins and Kennedy Krieger Institute</i>				
02:00 - 04:00 PM	Updates from our Industry Partners: Mirum Pharmaceuticals, Vigil Neuroscience, Ionis Pharmaceuticals, Minoryx Therapeutics, BridgeBio/ASPA, Spur Therapeutics, Forge Biologics				
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04:15 - 05:15 PM	Exploring the Benefits of Hippotherapy, or Therapeutic Horseback Riding. <i>Christine Hanebury, Sebastian Riding Associates</i>	Speech Therapy Topics <i>Tempe Thomas, Vox Chicago</i>	Newborn Screening Crash Course - Get Involved in Your State! <i>Lesa Brackbill, Leukodystrophy Newborn Screening Action Network</i>	Affected Women Roundtable <i>JoAnn Locy, Jamie Barlow, and LuAnn Swartzlander</i>	CADASIL Community Conversation (4 PM to 5:30 PM)
05:15 - 06:00 PM	Evening Break				
06:00 PM	Drink Stations Open in Red Oak Foyer				
06:30 PM	Dinner in Red Oak Ballroom				