



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	Cottonwood
09:00 – 10:00 AM	Exploring the Benefits of Hippotherapy, or Therapeutic Horseback Riding. <i>Speaker TBA</i>	Leukodystrophy 101 <i>Dr. Ali Fatemi, Johns Hopkins and Kennedy Krieger Institute</i>	MLD Presented by Cure MLD	ALSP <i>Speakers TBA</i>	MLC <i>Speakers TBA</i>	Affected Women Support Group
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>				Affected Men Support Group
11:30 – 12:30 PM	Introducing: The ULF's Ambassador Program <i>Keely Mata and the ULF Pilot Ambassadors</i>	Forecasting Interventions for Pediatric Patients <i>Dr. Stephanie Keller, Emory University</i>				Grief Support Group
12:30 – 01:30 PM	Lunch in Burnham's Buffet, located in the lobby of the Eaglewood Resort.					



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Room	Red Oak Ballroom	Bluestem	Hazelnut	Hollyhock	Iris	Cottonwood
01:30 – 02:30 PM	Newborn Screening Crash Course – Get Involved in Your State! <i>Lesa Brackbill, Leukodystrophy Newborn Screening Action Network</i>	Mental Health for Parents of Affected Children: Processing a New Diagnosis <i>Sarah Stoney, CHOP, and Kat Renick, Breakthrough Coaching Center</i>	CTX Presented by CTX Alliance	ALD/AMN <i>Speakers TBA</i>	VWM Presented by VWM Families Foundation	Caregiving Moms Support Group
02:45 – 03:45 PM	Mental Health for Affected Adults: Processing a New Diagnosis <i>Sarah Stoney, CHOP, and Kat Renick, Breakthrough Coaching Center</i>	Managing Caregiver Burnout <i>Marla Chapleau, MLC Mom Caregiver</i>				Siblings (for Siblings) Support Group
04:00 – 05:00 PM	The Unaffected Sibling(s): a Session for Parents <i>Alex and Liam Chapleau, MLC Siblings</i>	Making the Most of Your Wish: Make a Wish Alumni Panel <i>Dina Thachet, Make-a-Wish IL and Wish Alumni</i>				Caregiving Dads Support Group
05:00 – 06:00 PM	Evening Break					
06:00 PM	Drink Stations Open					
06:30 PM	Dinner					
07:30 PM	Live Auction					



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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	Physical Therapy for Adults <i>Dr. Kathy Zackowski and Jennifer Keller, Kennedy Krieger Institute</i>	Treatment Modalities for Leukodystrophies <i>Dr. Ali Fatemi, Johns Hopkins and Kennedy Krieger Institute</i>	CADASIL Presented by Cure CADASIL	Krabbe Disease Presented by KrabbeConnect	PMD <i>Speakers TBA</i>	Affected Women Support Group
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>				Affected Men Support Group
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 and Elise Hallez, Lightways Joliet</i>				Grief Support Group
12:30 – 01:30 PM	Lunch in Burnham's Buffet, located in the lobby of the Eaglewood Resort.					



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Room	Red Oak Ballroom					Cottonwood
01:30 – 02:00 PM	Scientific Symposium Session Summaries <i>Dr. Genevieve Bernard, ULF MSAB Chair</i>					Caregiving Moms Support Group
02:00 – 03:45 PM	Updates from our Industry Partners <i>Panelists TBD</i>					Siblings (for Siblings) Support Group
Room	Red Oak Ballroom	Bluestem	Hazelnut	Hollyhock	Iris	Cottonwood
04:00 – 05:00 PM	Zebrafish, Mice, and More: Research Strategies for Leukodystrophies <i>Dr. Josh Bonkowsky, Utah Health</i>	Choosing Medical Equipment <i>Dr. Kathy Zackowski and Jennifer Keller, Kennedy Krieger Institute</i>	Speech Therapy Topics <i>Tempe Thomas, Vox Chicago</i>	Alexander Disease <i>Speaker TBA</i>	To Be Announced: Additional Type-Leukodystrophy Content	Caregiving Dads Support Group
05:00 – 06:00 PM	Evening Break					
06:00 PM	Drink Stations Open					
06:30 PM	Dinner					
07:30 PM	Awards					