



2025 ULF Family Conference Agenda

This agenda is subject to change. Session times, speakers, and topics may be updated as needed.

Thursday, June 27, 2025

6:00 PM	Welcome Dinner, located in the Red Oak Ballroom
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Friday, June 27, 2025

6:30-8:30 AM	Breakfast in Burnham’s Buffet, located in the lobby of the hotel
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Room	Red Oak Ballroom
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8:45 – 9:00 AM	Welcome! Diane Fennimore , Executive Director, United Leukodystrophy Foundation
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9:00 – 10:00 AM	Keynote Address: Pending Plenary Session
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Room	Red Oak Ballroom <i>Virtual/Recorded</i>	Lilac Room <i>Virtual/Recorded</i>	Hollyhock Room <i>Virtual/Recorded</i>	Violet Room <i>Virtual/Recorded</i>	Iris <i>Virtual/Recorded</i>
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10:00 – 11:00 AM	Looking Through Their Eyes: How Leukodystrophy Affects Vision – and What We Can Do About It. Pablo Altschwager Kraft, MD Department of Ophthalmology, Boston Children’s Hospital, Instructor of Ophthalmology, Harvard Medical School			ALD/AMN Community Updates Wolfgang Köhler, MD Head of the MZEB und Leukodystrophy Clinic Senior Neurologist at the Department of Neurology University Leipzig Medical Center, Germany Need Link to full list of speakers	
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11:00 – 12:00 PM	Ambassador Program: “Helping You to Achieve Greater Quality of Life” ULF Ambassadors			View Full Agenda and Speakers Here	
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12:00– 12:30 PM		4-H Update Genevieve Bernard, MD, MSc, FRCPc Full Professor, Departments of Neurology and Neurosurgery, Pediatrics, and Human Genetics, McGill University Pediatric Neurologist, Department of	MLC Update Marjo van der Knaap, MD, PhD Professor of Child Neurology Amsterdam University Medical Center Department of Pediatrics / Child Neurology		Canavan Disease Update Amanda M Nagy, MD Instructor in Neurology Massachusetts General Hospital Harvard Medical School
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		Specialized Medicine, Division of Medical Genetics, McGill University Health Center Scientist, Child Health and Human Development, RI MUHC Chair, ULF Medical and Scientific Advisory Board	Amsterdam Leukodystrophy Center Emma Children's Hospital		
12:30 – 1:30 PM	Lunch in Burnham's Buffet, located in the lobby of the hotel.				
Room	Red Oak Ballroom <i>Virtual/Recorded</i>	Lilac Room <i>Virtual/Recorded</i>	Hollyhock Room <i>Virtual/Recorded</i>	Violet Room <i>Virtual/Recorded</i>	Iris
1:30 – 2:30 PM	Scientific Symposium Summary Member of the ULF Medical and Scientific Advisory Board	VWM Families Foundation Brett Holberg, Director Allyson Buck, Director VWM Families Foundation View Full Agenda and Speakers Here	CTX Scientific & Family Meeting Jean Pickford, Executive Director View Full Agenda and Speakers Here	ALD/AMN Community Updates	MLD Community Update Session Laura Adang, MD, PhD, MSTR Division of Child Neurology Children's Hospital of Philadelphia Maria Kefalas, PhD Calliope Joy Foundation
2:30-3:30 PM	Chronic Conditions, More Than a Diagnosis: Quality of Life Kendra Bjoraker, PhD, LP Pediatric Neuropsychologist				
3:30 - 4:45 PM	Therapies and Clinical Trials for Leukodystrophies S. Ali Fatemi, MD, MBA Chief Medical Officer Blum Moser Endowed Chair, Kennedy Krieger Institute				
4:00 – 5:00 PM	Sibling Reception – All Siblings Invited Alexandra and Liam Chapleau Located in the Linden B Room				
6:00 – 10:00 PM	Dinner 6:00 PM in the Red Oak Ballroom Legacy and Service Awards: 7:30 PM				



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	Live Auction: 8:00 PM				
Saturday, June 28, 2025					
6:30-8:30 AM	Breakfast in Burnham's Buffet, located in the lobby of the hotel				
All Day	Please visit the "All About Me" posters created by our kids, outside of the Red Oak Ballroom				
Room	Red Oak Ballroom				
8:45 – 9:00 AM	Welcome! Diane Fennimore , Executive Director, United Leukodystrophy Foundation				
Room	Red Oak Ballroom <i>Virtual/Recorded</i>	Lilac Room <i>Virtual/Recorded</i>	Hollyhock Room <i>Virtual/Recorded</i>	Violet <i>Virtual/Recorded</i>	Iris <i>Virtual/Recorded</i>
9:00 – 10:00 AM	Keynote Address: From Silence to Science: How Speaking for My Son Helped Me Find My Voice in Rare Disease Research Mousumi Bose, PhD Assoc. Professor, Montclair State University ULF Board Member	cureCADASIL Patient-Investigator Meeting Bertram Kasiske, MD, FACP President, Board of Trustees, cureCADASIL View Full Agenda and Speakers Here	Krabbe Disease Family Warrior Meeting Stacy Pike-Langefeld President, KrabbeConnect	Foundation to Fight H-ABC Community Meeting Michele Sloan-Levoir Co-Founder, Treasurer Foundation to Fight H-ABC View Full Agenda and Speakers Here	Sibling Support Group Liam Chapleau Alexandra Chapleau, PhD
10:00 – 11:00 AM	The Good, the Bad, and the Ugly: A Guide to Assessing Non-Prescription Approaches to Leukodystrophy Care Keith Van Haren, MD Stanford Medical Children's Health Associate Professor of Neurology and Neurological Sciences (Pediatric Neurology) and of Pediatrics				Grief Support Group LuAnn Schwartzlander, ULF Ambassador Soo Shimm, MBS, MS. LCSW Ann & Robert H Lurie Children's Hospital of Chicago
11:30 – 12:30 PM	Special Education Advocacy Ages 3-22: Best Practices for				Mothers of Affected Children Support Group



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	<p>Parents (Including Early Intervention 0 – 3 years old with Developmental Delays $\geq 30\%$)</p> <p>Sarah Hess, Sr. Staff Attorney, Legal Council for Health Justice</p>				<p>Marla Chapleau, Lead ULF Ambassador Soo Shim, MBA, MS, LCSW Ann & Robert H Lurie Children’s Hospital of Chicago</p>
12:30 – 1:30 PM	Lunch in Burnham’s Buffet, located in the lobby of the hotel.				
1:00 PM	Silent Auction Ends!				
Room	Red Oak Ballroom <i>Virtual/Recorded</i>	Lilac Room <i>Virtual/Recorded</i>	Hollyhock Room <i>Virtual/Recorded</i>	Violet <i>Virtual/Recorded</i>	Iris <i>Virtual/Recorded</i>
1:30 PM – 2:30 PM	<p>Special Needs Trust and Estate Planning</p> <p>Speaker Pending</p>	<p>End AxD Community Meeting</p> <p>Jen Pearson, Board Member End AxD</p> <p>View Full Agenda and Speakers Here</p>	<p>PMD Foundation Community Meeting</p> <p>Storm Greenway, Executive Board Chair PMD Foundation</p>	<p>LCC Foundation Community Meeting</p> <p>Ashley Pike, Executive Director LCC Foundation Jamie Fraser, MD, PhD Director, Leukodystrophy & Myelin Disorders Program Children’s National Health System Washington DC</p> <p>View Full Agenda and Speakers Here</p>	<p>Affected Adults Support Group For Ages 18 and Older</p> <p>JoAnn Locy, ULF Ambassador Soo Shim, MBA, MS, LCSW Ann & Robert H Lurie Children’s Hospital of Chicago</p>
2:45 – 3:45 PM	<p>Genetic Counseling and Family Planning: Women as Carriers, Unaffected Sibling Carrier Testing</p> <p>Carly Rasmussen, MS, CGC Genetic Counselor Ann & Robert H Lurie Children’s Hospital of Chicago</p>				<p>Fathers of Affected Children Support Group</p> <p>Ron Chapleau, ULF Ambassador ULF Board President</p>
4:00 – 5:00 PM	Communing with the Community!				



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	An opportunity to socialize, engage in activities or just chill out! All are Welcome!				
6:00 PM	Dinner				
Sunday, June 29, 2025					
6:30-8:30 AM	Breakfast in Burnham's Buffet, located in the lobby of the hotel				