



2025 ULF Family Conference Agenda

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

Thursday, June 26, 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 Kreft, MD Boston Children's Hospital Harvard Medical School View Bio			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 View Full Agenda and Speakers Here	
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11:00 – 12:00 PM	Ambassador Program: "Helping You to Achieve Greater Quality of Life" ULF Ambassadors View Bio				
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12:00– 12:30 PM		4-H Update Genevieve Bernard, MD, MSc, FRCPc McGill University View Bio	MLC Update Marjo van der Knaap, MD, PhD Emma Children's Hospital/ Amsterdam University Medical Center View Bio		Canavan Disease Update Amanda M Nagy, MD Massachusetts General Hospital Harvard Medical School
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12:30 – 1:30 PM	Lunch in Burnham's Buffet, located in the lobby of the hotel.
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1:30 – 2:30 PM	Scientific Symposium Summary Nicole I. Wolf, MD, PhD Emma Children’s Hospital/ Amsterdam University Medical Center View Bio	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 CTX Alliance View Full Agenda and Speakers Here	ALD/AMN Community Updates	MLD Community Update Session Laura Adang, MD, PhD, MSTR 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 View Bio				
3:30 - 4:45 PM	Therapies and Clinical Trials for Leukodystrophies S. Ali Fatemi, MD, MBA, Kennedy Krieger Institute View Bio				
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 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				



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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: From Silence to Science: How Speaking for My Son Helped Me Find My Voice in Rare Disease Research Mousumi Bose, PhD Montclair State University View Bio	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-Langenfeld President, KrabbeConnect	Foundation to Fight H-ABC Community Meeting Michele Levoir Sloan 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 View Bio				
11:30 – 12:30 PM	Special Education Advocacy Ages 3-22: Best Practices for Parents (Including Early Intervention 0 – 3 years old with Developmental Delays $\geq 30\%$) Sarah Hess, Senior Staff Attorney, Legal Council for Health Justice View Bio				Grief Support Group LuAnn Schwartzlander, ULF Ambassador Soo Shim, MBA, MS, LCSW Ann & Robert H Lurie Children's Hospital of Chicago
					Mothers of Affected Children Support Group <i>"In the heart of every mother lies a quiet strength"</i> Marla Chapleau, Lead ULF Ambassador Soo Shim, MBA, MS, LCSW Ann & Robert H Lurie Children's Hospital of Chicago
12:30 – 1:30 PM	Lunch in Burnham's Buffet, located in the lobby of the hotel.				



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1:00 PM	Silent Auction Ends!				
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1:30 PM – 2:30 PM	Balance and Leukodystrophy for Children and Adults <i>Attendees will receive a promo code for a complimentary on-line Tai Chi session with Jen</i> Jennifer Keller, MS, PT Kennedy Krieger Institute View Bio	End AxD Community Meeting Jen Pearson, Board Member End AxD View Full Agenda and Speakers Here	PMD Foundation Community Meeting Storm Greenway, Executive Board Chair PMD Foundation View Full Agenda and Speakers Here	LCC Foundation Community Meeting Ashley Pike, Executive Director LCC Foundation Jamie Fraser, MD, PhD Children’s National Health System Washington DC View Bio View Full Agenda and Speakers Here	Affected Adults Support Group For Ages 18 and Older JoAnn Locy, ULF Ambassador Soo Shim, MBA, MS, LCSW Ann & Robert H Lurie Children’s Hospital of Chicago
2:45 – 3:45 PM	Genetic Counseling and Family Planning: Women as Carriers, Unaffected Sibling Carrier Testing Carly Rasmussen, MS, CGC Genetic Counselor Ann & Robert H Lurie Children’s Hospital of Chicago			Ultra Rare Leukodystrophies Paul Watkins, MD	Fathers of Affected Children Support Group Ron Chapleau, ULF Ambassador ULF Board President
4:00 – 5:00 PM	Communing with the Community! 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				



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