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2023 Family Conference: Agenda

We hope you will join us for dinner on Thursday, June 22 as we kick off the weekend!

This agenda is subject to change. Sessions listed without a speaker are tentative until speaker confirmation.

This document will be updated regularly.

Friday, June 23

7:00 AM	BREAKFAST	
8:30 – 8:45 AM	ULF Welcome	ULF Board and Staff
9:00 – 10:00 AM	Leukodystrophy 101	Dr. Jennifer Rubin, Lurie Childrens Hospital
	CADASIL	Presented by Cure CADASIL
	MLC	Presented by Alliance MLC
	Refsum	Presented by Global DARE Foundation
	LBSL	Presented by Cure LBSL
	Making Memories with Your Loved One	
	Insights from Moms Panel	
10:15 – 11:15 AM	Forming Your Medical Team	Dr. Stephanie Keller, Children’s Hospital of Atlanta
	CADASIL continued	Presented by Cure CADASIL
	MLC continued	Presented by Alliance MLC
	Refsum continued	Presented by Global DARE Foundation
	LBSL continued	Presented by Cure LBSL
	Genetic Counseling and Family Planning	Julie Cohen, Kennedy Krieger Institute
	Insights from Dads Panel	
11:15 – 11:30 AM	BREAK	
11:30 AM – 12:30 PM	Modalities of Leukodystrophy Treatment	
	CADASIL continued	Presented by Cure CADASIL
	MLC continued	Presented by Alliance MLC
	Refsum continued	Presented by Global DARE Foundation
	LBSL continued	Presented by Cure LBSL
	Caregiving the Caregiver	Marcie Flores, ULF Board & 4H Mom
	Physical Therapy Topics	

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Friday, June 23

12:30 PM – 2:00 PM	LUNCH	
2:00 – 3:00 PM	Palliative Care and End of Life Planning	
	VWM	Presented by VWM Families Foundation
	AGS	Presented by AGSAA
	H-ABC	Presented by Foundation to Fight H-ABC
	Newborn Screening	Lesla Brackbill, Leukodystrophy NBS Action Network
	Communication Aids	Beth Christiansen & Sayard Bass, Speech & Lang. Pathologists
3:15 – 4:15 PM	Anticipatory Grief, Navigating Grief	
	VWM continued	Presented by VWM Families Foundation
	AGS continued	Presented by AGSAA
	H-ABC continued	Presented by Foundation to Fight H-ABC
	Special Needs Planning for Affected Adults	
	Occupational Therapy	Michaja Johnson, Occupational Therapist
4:15 – 4:30 PM	BREAK	
4:30 – 5:30 PM	Special Needs Resources	
	VWM continued	Presented by VWM Families Foundation
	AGS continued	Presented by AGSAA
	H-ABC continued	Presented by Foundation to Fight H-ABC
	Special Needs Planning for Affected Minors	
	Vision Therapy	
5:30 – 6:30 PM	Leukodystrophy Type Specific Networking Opportunities	
6:30 PM	DINNER	
7:30 PM	Awards Ceremony and Live Auction	

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Saturday, June 24

7:00 AM	BREAKFAST	
9:00 – 10:00 AM	Scientific Symposium Session Summaries	Dr. Genevieve Bernard, ULF MSAB Chair, McGill University
	ALD/AMN	Presented by ULF
	CANAVAN	Presented by a Content Partner
	Alexander Disease	Presented by a Content Partner
	Traveling and Vacation Spots for Special Needs	
	Forward Movement in the UK	
	How to Share Your Leukodystrophy Story	
10:15 – 11:15 AM	Feeding Tube 101	
	ALD/AMN continued	Presented by ULF
	CANAVAN continued	Presented by a Content Partner
	Alexander Disease continued	Presented by a Content Partner
	Accessible Home Design	
	Brain and Tissue Banking	
	Share Your Leukodystrophy Story continued	
11:15 – 11:30 AM	BREAK	
11:30 AM – 12:30 PM	Respiratory 101	
	ALD/AMN continued	Presented by ULF
	CANAVAN continued	Presented by a Content Partner
	Alexander Disease continued	Presented by a Content Partner
	Therapy Animals	
	Share Your Leukodystrophy Story continued	
12:30 – 2:00 PM	LUNCH	
2:00 – 3:00 PM	Navigating Emergency Room and Hospital Visits	Jenny Arnold, VWM Mom
	CTX	Presented by CTX Alliance
	4H	Presented by Content Partner
	ALSP	Presented by Sister's Hope
	Supporting Unaffected Siblings	
	Support Groups	

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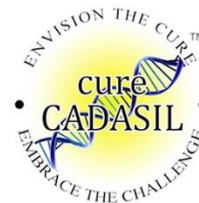


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Saturday, June 24

3:15 – 4:15 PM	Urology 101	
	CTX continued	Presented by CTX Alliance
	4H continued	Presented by Content Partner
	ALSP continued	Presented by Sister's Hope
	Accessing Your Hospital's Social Workers	Soo Shim, Lurie Childrens Hospital
	Support Groups	
4:15 – 4:30 PM	BREAK	
4:30 – 5:30 PM	Gene Therapy 101	Rachel Logan, Genetic Counselor
	CTX continued	Presented by CTX Alliance
	4H continued	Presented by Content Partner
	ALSP continued	Presented by Sister's Hope
	Building and Trusting Your Village	
	Support Groups	
5:30 – 6:30 PM	Leukodystrophy Type Specific Networking Opportunities	
6:30 PM	DINNER	
7:30 PM	Family Fun and Entertainment!	

Thank You to Our Content Partners!



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