



224 N. 2ND STREET, SUITE 2, DEKALB, IL 60115 // 815.748.3211 // ULF.ORG

2020 ULF Virtual Family Conference Agenda

Subject to Change, updated on 5/12/2020

All times noted below are US Central Time.

Thursday, June 25, 2020		
Time	Stream 1	Stream 2
10 AM	MLC	Adult Onset Leukoencephalopathy
11:30 AM	ADLD	Refsum Disease
1:00 PM	Krabbe	AGS
2:30 PM	Leukodystrophy 101 and GLIA	Newborn Screening Advocacy Panel
4:00 PM	Newly Diagnosed – Pediatric Patients Panel	Newly Diagnosed – Adult Patients Panel
6:00 PM	Trivia Game Night	
Friday, June 26, 2020		
Time	Stream 1	Stream 2
10 AM	LBSL	Undiagnosed, Understanding Genetic Testing
11:30 AM	CTX	Alexander Disease
1:00 PM	MLD	4H
2:30 PM	Integrative Medicine	Genetic Counseling for the Leukodystrophies
4:00 PM	Support Group – Caregivers of Pediatric Patients	Support Group – Caregivers of Adult Patients
6:00 PM	Support Group – Female Carriers	Support Group – Diagnosed Adults
Saturday, June 27, 2020		
Time	Stream 1	Stream 2
10 AM	AMN	VWM
11:30 AM	ALD	PMD
1:00 PM	H-ABC	Feeding Tubes/Blended Diets
2:30 PM	Understanding the MRI Process	Respirators
4:00 PM	Physical Therapy	
6:00 PM	Just Dance Party – the ULF Formal	

Important notes:

- The above schedule is for the live webinar portion of the Family Conference.
- Other materials will be available through the ULF website such as pre-recorded videos and text-based materials.
- ***You must register to watch and participate in the live webinars.*** People who are registered will receive an email on June 24th with the streaming link to YouTube, and will be asked to sign in with either a YouTube account, or a Google/Gmail account. You do not need to sign in to watch the presentation, but you will need to sign in to ask questions through YouTube’s chat feature.
- The agenda is subject to change and we will keep it updated with as much information as we have available.