

**2019 ULF Family Conference  
General Sessions and Breakout Agenda**

<b>Thursday, June 27th, 2019</b>		
<b>Time</b>	<b>Topic</b>	<b>Speaker</b>
7:00 AM	Registration Opens	
6:30 PM	DINNER & WELCOME EVENT/SERVICE AWARD/BINGO	
<b>Friday, June 28, 2019</b>		
<b>Time</b>	<b>Topic</b>	<b>Speaker</b>
7:00 AM	BREAKFAST BUFFET OPENS	
7:30 AM	Registration Opens	
8:30 AM	Kids Room Opens	
8:45 AM	Welcome & Opening Remarks	ULF Board & Staff & Partners
9:00 AM	Palliative Care	Dr. Elisha Waldman
10:00 AM	Patient-As-Teacher Program	Dr. Mark Korson
10:45 AM	BREAK	
11:00 AM	Overview of Leukodystrophy	Dr. Deborah Renaud
12:00 PM	LUNCH	
1:00 PM	Leukodystrophy 101	Dr. Paul Watkins
2:00 PM	LCN/International Update	Various
2:30 PM	BREAKOUT SESSION - DISEASE SPECIFIC	(Below)
	<i>ALD</i>	<i>Various</i>
	<i>VWM</i>	<i>Various</i>
	<i>Krabbe</i>	<i>Various</i>
	<i>4H</i>	<i>Various</i>
	<i>MLD</i>	<i>Various</i>
	<i>Canavans</i>	<i>Various</i>
	<i>CADASIL</i>	<i>Various</i>
	<i>Alexanders</i>	<i>Various</i>
	<i>CTX</i>	<i>Various</i>
	<i>PMD</i>	<i>Various</i>
	<i>MLC</i>	<i>Various</i>
	<i>LBSL</i>	<i>Various</i>
	<i>AGS</i>	<i>Various</i>
	<i>H-ABC</i>	<i>Various</i>
	<i>Undiagnosed/Other</i>	<i>Various</i>
5:00 PM	Informal Discussion Time/Break for Dinner/Kids Room Pick-Up	
6:30 PM	DINNER & AUCTIONS	
<b>Saturday, June 29, 2019</b>		
<b>Time</b>	<b>Topic</b>	<b>Speaker</b>
7:00 AM	BREAKFAST BUFFET OPENS	
7:30 AM	Registration Opens	
8:30 AM	Kids Room Opens	
8:45 AM	Announcements	ULF Board & Staff
9:00 AM	Summary of the Scientific Sessions	Dr. Gerald Raymond
9:30 AM	Bone Marrow Transplant Success Stories	Various
10:30 AM	BREAK	
10:45 AM	BREAKOUTS - Special Interest Sessions	(Below)
	<i>Physical Therapy</i>	<i>Jennifer Keller and Kathy Zackowski</i>
	<i>Massage Therapy</i>	<i>TBD</i>
	<i>Therapy Animals</i>	<i>Bridget Evans</i>
	<i>Nutrition Update</i>	<i>Hong Brereton</i>
	<i>Women as Carriers</i>	<i>Taylor Kane</i>
	<i>Urology</i>	<i>TBD</i>

\*\*SUBJECT TO CHANGE\*\*

Updated 4/2/2019

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	<i>Pulmonologist</i>	<i>TBD</i>
	<i>Feeding Tubes</i>	<i>TBD</i>
	<i>Pediatric ENT/Swallowing</i>	<i>Dr. Lauren Orvidas</i>
<b>12:00 PM</b>	<b>LUNCH</b>	
1:00 PM	Clinical Trials Panel	Various
2:00 PM	Gene Therapy, Stem Cell Therapy	Various
<b>3:00 PM</b>	<b>BREAK</b>	
3:15 PM	BREAKOUTS - Special Interst Sessions	(Below)
	<i>Parents of Teens and Teen Discussion Panel</i>	<i>Taylor Kane</i>
	<i>NBS/Parent and Familial Advocacy</i>	<i>Seeger, Moser, Hong, Basheeruddin</i>
	<i>CBD Oil/Essential Oil</i>	<i>TBD/Marla Chapleau</i>
	<i>Special Needs Students Advocacy in School/IEP</i>	<i>Sharon Bergfeld</i>
	<i>Anticipatory Grief/Grief Counseling</i>	<i>Dr. Terri Daniel</i>
	<i>Special Needs Trusts</i>	<i>Charles Rose</i>
	<i>Traveling/Vacationing with Special Needs</i>	<i>Allyson Buck, Meredith Maki</i>
	<i>Occupational Therapy</i>	<i>Stacy Cusack</i>
4:30 PM	BREAKOUTS - Special Interst Sessions	(Below)
	<i>NBS/Parent and Familial Advocacy</i>	<i>Seeger, Moser, Hong, Basheeruddin</i>
	<i>CBD Oil/Essential Oil</i>	<i>TBD/Marla Chapleau</i>
	<i>Special Needs Students Advocacy in School/IEP</i>	<i>Sharon Bergfeld</i>
	<i>Anticipatory Grief/Grief Counseling</i>	<i>Dr. Terri Daniel</i>
	<i>Special Needs Trusts</i>	<i>Charles Rose</i>
	<i>Traveling/Vacationing with Special Needs</i>	<i>Allyson Buck, Meredith Maki</i>
	<i>Occupational Therapy</i>	<i>Stacy Cusack</i>
5:30 PM	Informal Discussion Time/Break for Dinner/Kids Room Pick-Up	
<b>6:30 PM</b>	<b>DINNER &amp; ENTERTAINMENT</b>	
<b>Sunday, June 30, 2019</b>		
<b>Time</b>	<b>Topic</b>	<b>Speaker</b>
<b>6:00 AM</b>	<b>BREAKFAST BUFFET OPENS</b>	
7:30 AM	Healing, Memorial Ceremony	Dr. Terri Daniel

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