

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

<b>Thursday, June 27th, 2019</b>			
<b>Time</b>	<b>Room</b>	<b>Topic</b>	<b>Speaker</b>
7:30 AM	Red Oak Foyer	Registration Open	
6:30 PM	Red Oak ALL	DINNER & WELCOME EVENT/SERVICE AWARD/BINGO	
<b>Friday, June 28, 2019</b>			
<b>Time</b>	<b>Room</b>	<b>Topic</b>	<b>Speaker</b>
7:00 AM	Burnham's	BREAKFAST	
8:00 AM	Red Oak Foyer	Registration Open	
8:30 AM	Arrowhead	DAYCARE - 8:30 AM to 5:30 PM	
8:30 AM	Hollyhock	TEEN ROOM - 8:30 AM to 5:30 PM	
8:45 AM	Red Oak A	Welcome/Opening Remarks/Intro of Foundation Leaders	ULF Board & Staff & Partners
9:00 AM	Red Oak A	Palliative Care	Dr. Elisha Waldman
10:00 AM	Red Oak A	LCN/International Update	Various
10:45 AM	Red Oak Foyer	BREAK	
11:00 AM	Red Oak A	Overview of Leukodystrophy	Dr. Deborah Renaud
12:00 PM	Red Oak A	Patient-As-Teacher Program	Dr. Mark Korson
12:30 PM	Burnham's	LUNCH	
1:30 PM	Red Oak A	Leukodystrophy 101	Dr. Paul Watkins
2:30 PM		BREAKOUT SESSION - DISEASE SPECIFIC	(Below)
	Red Oak A	ALD/AMN	Various
	Red Oak B	VWM	Various
	Red Oak C	Alexander Disease	Various
	Violet	4H	Various
	Iris	CTX	Various
	Fenthistle	AGS/H-ABC/Undiagnosed/Other	Various
	Aster	MLD/MLC	Various
	Indigo	PMD/PMLD	Various
	Hydrangea	Krabbe	Various
	Bluebell	Canavans	Various
	Waterleaf	CADASIL	Various
	Trillium	LBSL	Various
5:00 PM		Informal Discussion Time/Break before dinner	
6:30 PM	Red Oak	DINNER, BAR, AUCTIONS	
<b>Saturday, June 29, 2019</b>			
<b>Time</b>	<b>Room</b>	<b>Topic</b>	<b>Speaker</b>
7:00 AM	Burnham's	BREAKFAST	
8:00 AM	Red Oak Foyer	Registration Open	
8:30 AM	Arrowhead	DAYCARE - 8:30 AM to 5:30 PM	
8:30 AM	Hollyhock	TEEN ROOM - 8:30 AM to 5:30 PM	
8:45 AM	Red Oak A	Announcements	ULF Board & Staff
9:00 AM	Red Oak A	Summary of the Scientific Sessions	Dr. Gerald Raymond
9:30 AM	Red Oak A	Bone Marrow Transplant Success Stories	Various
10:30 AM	Red Oak Foyer	BREAK	
10:45 PM	Red Oak A	Gene Therapy, Stem Cell Therapy	Various
11:30 AM		BREAKOUTS - Special Interest Sessions	(Below)
	Red Oak A	NBS/Parent and Familial Advocacy	Various
	Red Oak B	Genetic Counseling & Family Planning	Dr. Julie Cohen
	Red Oak C	Physical Therapy	Jen Keller and Kathy Zackowski
	Iris	Nutrition Update	Hong Brereton
	Fenthistle	Women as Carriers	Taylor Kane
	Hydrangea	Pain Management	Dr. Deborah Renaud
	Indigo	Therapy Animals	Bridget Evans
	Trillium	Pediatric ENT/Swallowing	Dr. Lauren Orvidas
12:30 PM	Burnham's	LUNCH	
1:30 PM	Red Oak A	Clinical Trials Panel	Fatemi
2:30 PM		BREAKOUTS - Special Interst Sessions	(Below)
	Red Oak A	CBD Oil/Essential Oil	Marla Chapleau & Rita Hedrick-Helmick
	Fenthistle	Feeding Tubes	Jackie Heying
	Trillium	Special Needs Students Advocacy in School/IEP	Sharon Bergfeld
	Aster	Anticipatory Grief/Grief Counseling	Dr. Terri Daniel

\*\*SUBJECT TO CHANGE\*\*

Updated 5/22/2019

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	<i>Indigo</i>	<i>Special Needs Trusts</i>	<i>Charles Rose</i>
	<i>Hydrangea</i>	<i>Traveling/Vacationing with Special Needs</i>	<i>Allyson Buck, Meredith Maki</i>
	<i>Iris</i>	<i>Occupational Therapy</i>	<i>Stacy Cusack</i>
<b>3:30 PM</b>	<b>Red Oak Foyer</b>	<b>BREAK</b>	
3:45 PM		BREAKOUTS - Special Interst Sessions	(Below)
	<i>Hollyhock</i>	<i>Parents of Teens and Teen Discussion Panel</i>	<i>Taylor Kane</i>
	<i>Red Oak A</i>	<i>CBD Oil/Essential Oil</i>	<i>Marla Chapleau &amp; Rita Hedrick-Helmick</i>
	<i>Fenthistle</i>	<i>Feeding Tubes</i>	<i>Jackie Heying</i>
	<i>Trillium</i>	<i>Special Needs Students Advocacy in School/IEP</i>	<i>Sharon Bergfeld</i>
	<i>Aster</i>	<i>Anticipatory Grief/Grief Counseling</i>	<i>Dr. Terri Daniel</i>
	<i>Indigo</i>	<i>Special Needs Trusts</i>	<i>Charles Rose</i>
	<i>Hydrangea</i>	<i>Traveling/Vacationing with Special Needs</i>	<i>Allyson Buck, Meredith Maki</i>
	<i>Iris</i>	<i>Occupational Therapy</i>	<i>Stacy Cusack</i>
5:00 PM		Informal Discussion Time/Break before dinner	
<b>6:30 PM</b>	<b>Burnham's</b>	<b>DINNER IN BURNHAM'S/PRAIRIE RIVER FOR BAND</b>	
<b>Sunday, June 30, 2019</b>			
<b>Time</b>	<b>Room</b>	<b>Topic</b>	<b>Speaker</b>
<b>7:00 AM</b>	<b>Burnham's</b>	<b>BREAKFAST</b>	
7:30 AM	Outdoor	Healing/Memorial Ceremony (Outdoor, Lobby Back-up)	<i>Dr. Terri Daniel</i>