

2019 Hunter's Hope Family Symposium
July 24 - 28, 2019

Wednesday, July 24th			
Start time	Finish Time	Topic/Event	Speaker & Location
All Day		Family Check-in	Tamarack Lobby
7:00 PM		Family Welcome Dinner	Fairway, 2nd Floor HV Lodge
Thursday, July 25th			
Start time	Finish Time	Topic/Event	Speaker & Location
8:00 AM	9:30 AM	Breakfast	Sunrise, 1st Floor HV Lodge
8:45 AM		<i>Kid Kamp Opens</i>	<i>Creekside</i>
8:45 AM	9:20 AM	Prayer Party, Christin Webb	Birdie, 2nd Floor HV Lodge
			Fairway, 2nd Floor HV Lodge Moderator: Bob Rauner
9:30 AM	9:45 AM	Welcome and LCN Overview	Anna Grantham & Jacque Waggoner
9:45 AM	10:05 AM	Biochemical newborn screening for MLD and beyond using the most comprehensive, cost-effective, rapid, and robust platform to date	Michael Gelb, PhD
10:05 AM	10:20 AM	Takeda Phase 2b Trial of Intrathecal Enzyme Replacement Therapy in Late Infantile MLD	Barbara Burton, MD
10:20 AM	10:50 AM	Leukodystrophy Research and ALD NBS	Ali Fatemi, MD
10:50 AM	11:00 AM	Break	
11:00 AM	11:15 AM	Outcomes after umbilical cord blood transplantation for infants with EIKD identified through Kentucky, Missouri, and Ohio NBS	Kristen Page, MD
11:15 AM	11:45 AM	Umbilical Cord Blood Transplantation and cell therapy for Krabbe Disease and related LDs	Joanne Kurtzberg, MD
11:45 AM	12:05 PM	Intrathecal AAV9 gene therapy in the canine model of Krabbe disease	Allison Bradbury, PhD
12:05 PM	12:20 PM	Adaptive Equipment	Elizabeth Bailey-Sands, PT
12:10 PM	12:20 PM	<i>Kid Kamp Closes for lunch</i>	
12:20 PM	1:30 PM	Lunch	Sunrise, 1st Floor HV Lodge
1:20 PM	1:30 PM	<i>Kid Kamp Opens</i>	
1:30 PM	1:45 PM	ALD Gene Therapy	Catie Becker, PNP
1:45 PM	2:15 PM	CPG Lead Author Panel	Presentation - 5 mins each
2:15 PM	2:45 PM	Care Coordinators Panel	
2:45 PM	3:00 PM	Break	
3:00 PM	3:30 PM	Leukodystrophy Data Registry	Mike Dean, MD
3:30 PM	4:15 PM	Family Advocates Panel	Mike and Jenna Wallace, Elisa Seeger, Kristin Malfara, Anne Rugari, Lesa Brackbill, Christina Levasheff, Lauren Hammond
4:30 PM		<i>Kid Kamp Closes</i>	
4:30 PM	5:45 PM	SC Meeting	Birdie, 2nd Floor HV Lodge
6:00 PM	6:30 PM	Group Photo	Clock Tower
6:45 PM		Dinner	Sunrise, 1st Floor HV Lodge
7:45 PM		Bingo	Sereno Family

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Friday, July 26th			
Start time	Finish Time	Topic/Event	Speaker & Location
8:00 AM	10:00 AM	Breakfast	Sunrise, 1st Floor HV Lodge
8:50 AM		Kid Kamp Opens	Creekside
9:00 AM	9:50 AM	Prayer Party	Birdie, 2nd Floor HV Lodge (Jill Kelly)
10:00 AM	11:30 AM	LCN Steering Committee Panel	Fairway, 2nd Floor HV Lodge
		LCN Subcommittees - Update	
		LCN App	
11:30 AM	11:50 AM	Newborn Screening	Monaco, Emery, and Clausen Families
<i>11:50 AM</i>		<i>Kid Kamp Closes for Lunch</i>	
12:00 PM	1:30 PM	Lunch	Sunrise, 1st Floor HV Lodge
12:00 PM	1:30 PM	Sibling Session 13 and up (Lunch)	Maple Leaf, 1st Floor HV Lodge
<i>1:15 PM</i>		<i>Kid Kamp Opens</i>	<i>Creekside</i>
1:30 PM	4:30 PM	Breakout Sessions	
		Men's Session	Moonshadow, 1st Floor HV Lodge (Drake Levasheff)
		Mom's Session # 1	Birdie, 2nd Floor HV Lodge (Nikki Monaco)
		Mom's Session # 2 (Children Transplanted/Treated)	Bunker, 2nd Floor HV Lodge (Carol Cross)
		Mom's Session #3 (Children in Heaven)	T bar, 2nd Floor HV Lodge (Christina Levasheff)
<i>4:30 PM</i>		<i>Kid Kamp Closes</i>	
6:00 PM		Balloon Release & Walk	Overlook Terrace
7:15 PM		Dinner	Sunrise, 1st Floor HV Lodge
8:15 PM		"In Jest" Funspiration	Nels Ross
Saturday, July 27th			
Start time	Finish Time	Topic/Event	Speaker & Location
8:30 AM	10:30 AM	Breakfast	Sunrise, 1st Floor HV Lodge
9:00 AM	10:00 AM	Fundraising Breakout	Maple Leaf, 1st Floor HV Lodge (Mike Wallace & Friends, Kaitlin Brunner)
10:00 AM	5:00 PM	All Day - Free Time	
		Lunch on Your Own	
5:00 PM		Dinner	Sunrise, 1st Floor HV Lodge
6:30 PM		Talent Show	
8:00 PM		Dance Party	
Sunday, July 28th			
Start time	Finish Time	Topic/Event	Speaker & Location
7:00 AM	10:00 AM	Breakfast	Snowledge, Tamarack