

Hunter's Hope Foundation

Annual Symposium for Leukodystrophy Families

DAILY PROGRAM

DAY 1 – Wednesday July 18, 2018

WELCOME!!

All Day	Family Registration & Check-In	Lobby, Tamarack Lodge
7:00 p.m.	Welcome Dinner	Sunrise, 1 st Floor HV Lodge

**At the Welcome Dinner, each family will introduce themselves so we can get to know each other.*

**Every evening, the Family Hangout Room will be in Sunrise on the 1st floor of the Holiday Valley Lodge, the same room where we will have dinner.*

DAY 2 – Thursday July 19, 2018

LEUKODYSTROPHY CARE NETWORK (LCN) & NEWBORN SCREENING

8:00 a.m.	Breakfast Buffet	Sunrise, 1 st Floor HV Lodge
8:50 a.m.	Kid Kamp Opens <i>AM Activities Planned</i> •Charlie & Checkers Show • Crafts • Movies • Playground	Creekside
9:00 a.m.	Prayer Party	Birdie, 2 nd Floor HV Lodge

SESSION I

Fairway Conference Room – 2nd Floor, Holiday Valley Lodge

9:30 a.m.	Welcome and LCN Overview	Anna Grantham
9:40 a.m.	MLD Newborn Screening	Dr. Michael Gelb
9:55 a.m.	Krabbe and ALD Newborn Screening (NBS)	Dr. Joseph Orsini
10:10 a.m.	Krabbe NBS Clinical Practice Guidelines	Dr. Jennifer Kwon
10:25 a.m.	Guidelines for ALD NBS Follow Up	Dr. Ali Fatemi

DAY 2 – Thursday July 19, 2018 (Continued)

10:40 a.m.	LCN Centers	Dr. Stephanie Keller
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10:55 a.m.	LCN Care Coordinators	Tara West
11:10am	Treatment for Leukodystrophies	Dr. Joanne Kurtzberg
11:45 p.m.	Lunch Buffet <i>Pick up kids from Kid Kamp</i>	Sunrise, 1 st Floor HV Lodge
12:30 p.m.	Kid Kamp Opens <i>PM Activities Planned</i> • Crafts • Movies • Playground • Therapy Dogs (3PM)	Creekside

SESSION II

Fairway Conference Room – 2nd Floor, Holiday Valley Lodge

12:45 p.m.	LCN Clinical Practice Guidelines (CPGs) <ul style="list-style-type: none">• Musculoskeletal• Treatment• Neurology• Respiratory• Diagnosis	CPG Lead Authors
1:45 p.m.	Advancements in Leukodystrophies	Dr. Amy Waldman
2:15 p.m.	ALD Clinical Trial	Dr. Florian Eichler
3:30 p.m.	Kid Kamp Closes	Creekside
6:30 p.m.	Dinner Buffet	Sunrise, 1 st Floor HV Lodge
7:30pm	Charlie and Checkers Show	Sunrise, 1 st Floor HV Lodge

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DAY 3 – Friday July 20, 2018 FAMILY UPDATES & BREAKOUT SESSIONS

8:00 a.m.	Breakfast Buffet	Sunrise, 1 st Floor HV Lodge
8:50 a.m.	Kid Kamp Opens <i>AM Activities Planned</i> •Mini Manicures/Hair Braiding • Crafts • Movies • Playground	Creekside
9:00 a.m.	Prayer Party	Birdie, 2 nd Floor HV Lodge

SESSION III Fairway Conference Room – 2nd Floor, Holiday Valley Lodge

10:00 a.m.	Presentations and Updates from Leukodystrophy Families	
12:00 p.m.	Lunch Buffet <i>Pick up kids from Kid Kamp</i>	Sunrise, 1 st Floor HV Lodge
1:15 p.m.	Kid Kamp Opens <i>PM Activities Planned</i> •Nature Walk/Scavenger Hunt with John and Susan - 11 years and older •Punkin the Clown • Crafts • Movie • Playground	Creekside

*** Sibling Hike – 11+ yrs. - John & Susan K. will host an afternoon hike at Holiday Valley. Those interested in joining should meet in Creekside at 1:45 p.m. Please wear sneakers. Water provided.*

SESSION IV

1:30 p.m.	Women's Session	Birdie, 2 nd Floor HV Lodge
1:30 p.m.	Men's Session	Maple Leaf, 1 st Floor HV Lodge
	<i>*This time is reserved for family members of an affected child.</i>	
4:30 p.m.	Kid Kamp Closes	Creekside
6:00 p.m.	Group Photo, Balloon Release & Family Symposium Walk	Overlook Terrace
7:15 p.m.	Dinner Buffet	Sunrise, 1 st Floor HV Lodge

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DAY 4 – Saturday July 21, 2018

FAMILY FREE DAY, 20th ANNIVERSARY CELEBRATION & STARS OF HOPE TALENT SHOW

8:30 a.m. Breakfast Buffet Sunrise, 1st Floor HV Lodge

10:00 a.m. Prayer Party Maple Leaf, 1st Floor HV Lodge

**** FREE Time for Families **
(Lunch on your own)**

4:00pm Shuttle to Dinner Location Tamarack Lobby

4:45pm Group Photos Yodeler Lodge

5:00 p.m. 20th Anniversary Celebration Dinner & Talent Show Yodeler Lodge
to 9:00pm *Dress for a party

DAY 5 – Sunday July 22, 2018

SEE YOU NEXT YEAR!

7:00 a.m. Breakfast Buffet Snowledge & Laurel
1st Floor, Tamarack

Breakfast Buffet is available until 10:00 a.m.

10:00 a.m. Checkout
** Please turn keys & name tags into the front desk of Tamarack**

Shuttle schedule available at front desk. Meet at entrance of Tamarack Main Lobby. Please be sure to be on time to ensure a timely arrival to airport.

Save the Date!

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