Hunter's Hope Foundation

18th Annual Symposium for Krabbe & Leukodystrophy Families

DAILY PROGRAM

DAY 1 – Wednesday July 8, 2015 WELCOME!!

All Day Family Registration & Check-In Lobby, Tamarack Lodge

4:00 p.m. Board of Directors' Meeting Bunker, 2nd Floor HV Lodge

7:00 p.m. **Welcome Dinner** Sunrise & Foxfire, 1st Floor HV Lodge

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

* The "Hangout" Room will be in Sunrise on the 1st floor of Holiday Valley Lodge, the same room where we will have dinner. Indoor and outdoor fireplaces are available.

Games, snacks and activities.*

2015 Hunter's Hope Family and Medical Symposium

DAY 2 – Thursday July 9, 2015 SCIENTIFIC & CLINICAL RESEARCH

8:00 a.m.	Breakfast Buffet	Sunrise, 1st Floor HV Lodge
8:50 a.m.	Kid Kamp Opens	Maple Leaf & Explorer, 1st Floor HV Lodge
	AM Activities Planned	
	* Making Every Step Signs	*Cookie Decorating *Water Balloons *Noah's "Art"
9:00 a.m.	Prayer Party lead by Rod	Scott Birdie, 2 nd Floor HV Lodge

SESSION I

MODERATOR: Christina Levasheff Fairway Conference Room – 2nd Floor, Holiday Valley Lodge

*Refreshments Available

10:00 a.m.	Welcome/Introduction		Dennis Sampier
10:10 a.m.	Leukodystrophy Care Ne	twork	Jacque Waggoner
10:50 a.m.	GLIA		Adeline Vanderver
11:20 a.m.	Clinical Trial For MLD		Allesandra Biffi
11:50 a.m.	Clinical Trial For Krabbe [Disease	Joann Kurtzberg
12:20 p.m.	Kid Kamp – Pick up kids	Maple Leaf & Explore	er, 1 st Floor HV Lodge
12:30 p.m.	Lunch Buffet	Sunris	e, 1 st Floor HV Lodge
1:30 p.m.	Kid Kamp Opens	Maple Leaf & Explore	er, 1 st Floor HV Lodge
	PM Activities Planned		

^{*} Punkin the Clown *Afternoon Movie – Madagascar

SESSION II

MODERATOR: Terry, Scott Hammonds Fairway Conference Room – 2nd Floor, Holiday Valley Lodge

1:45 p.m. 2:15 p.m.	Combination Therapy for HJKRI Update/Overview	r Globoid Leuko	odystrophy	Mark Sands Wrabetz
3:00 p.m.	Break			
3:15 p.m.	Overview on Medical Syr	mposium		Wrabetz
5:00 p.m.	Kid Kamp Closes	Maple Leaf &	Explorer, 1st Flo	or HV Lodge
5:30 p.m.	Hunter's Hope Family Pho	oto		TBD
6:15 p.m.	Dinner Buffet		Sunrise, 1st Flo	or HV Lodge
	Icebreaker - Christina Lev	vasheff	Sunrise, 1st Flo	oor HV Lodge

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Games, snacks and activities.*

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DAY 3 – Friday July 10, 2015 HUNTER'S HOPE UPDATES & BREAKOUT SESSIONS

8:00 a.m. Breakfast Buffet Sunrise, 1st Floor HV Lodge Maple Leaf & Explorer, 1st Floor HV Lodge 8:50 a.m. Kid Kamp Opens

AM Activities Planned

* Nail Spa * Animal Parade Craft/Songs

Birdie, 2nd Floor HV Lodae 9:00 a.m. Prayer Party lead by Jenna Wallace

SESSION III **MODERATOR: Drake Levasheff** Fairway Conference Room – 2nd Floor, Holiday Valley Lodge

10:00 a.m. NBS Anna Grantham & Panel

11:00 a.m. **Break** – refreshments

11:15 a.m. Legacy Dennis Sampier

> Birdie, 2nd Floor HV Lodge Sibling's Session-11 yrs. & up (Erin Kelly)

11:45 p.m. Every Step Walk/Kelly Tough 12K Dennis Sampier/Kaitlin Brunner

Kid Kamp – Pick up kids Maple Leaf & Explorer, 1st Floor HV Lodge 12:30 p.m. Sunrise, 1st Floor HV Lodge 12:35 p.m. **Lunch Buffet** Maple Leaf & Explorer, 1st Floor HV Lodge 1:30 p.m. Kid Kamp Opens

PM Activities Planned

* Scavenger Hunt * Edible Rainbows * Afternoon Movie

SESSION IV

Birdie, 2nd Floor HV Lodae 1:45 p.m. Women's Session Fairway, 2nd Floor HV Lodge Men's Session

* This time is reserved for family members of an affected child.

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

Maple Leaf & Explorer, 1st Floor HV Lodge 5:00 p.m. Kid Kamp Closes Balloon Release & Every Step Walk 5:30 p.m. Overlook Terrace 6:30 p.m. **Dinner Buffet** Sunrise, 1st Floor HV Lodge

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DAY 4 – Saturday July 11, 2015 FAMILY FREE DAY & STARS OF HOPE TALENT SHOW

9:00 a.m. **Breakfast Buffet** Sunrise, 1st Floor HV Lodge 10:00 a.m. Prayer Party lead by Christina Levasheff Birdie, 2nd Floor HV Lodge

** FREE Time for Families **

Grab 'n Go Boxed Lunch will be available from 12:00 – 1:30 p.m. in the Snowledge & Laurel Conference Rooms – in **Tamarack** Lodge

5:00 p.m. Dinner Buffet Sunrise Stars of Hope Family Talent Show Sunrise

DAY 5 – Sunday July 12, 2015 SEE YOU NEXT YEAR!

6:00 a.m. **Breakfast Buffet** Snowledge & Laurel, **Tamarack**

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

10:00 a.m. Checkout

** Please turn keys & name tags into the front desk of Tamarack**