

Hunter's Hope Foundation

19th Annual Symposium for Krabbe & Leukodystrophy Families

DAILY PROGRAM

DAY 1 Wednesday July 27, 2016

WELCOME!!

All Day	Family Registration & Check-In	Lobby, Tamarack Lodge
4:00 p.m.	Board of Directors' Meeting	Bunker, 2 nd Floor HV 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.*

The Family 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 as well as games, snacks and activities.

2016 Hunter's Hope Family and Medical Symposium

DAY 2 Thursday July 28, 2016

LEUKODYSTROPHY CARE NETWORK & LEUKODYSTROPHY RESEARCH

- 8:00 a.m. **Breakfast Buffet** Sunrise, 1st Floor HV Lodge
- 8:50 a.m. **Kid Kamp Opens** Creekside
AM Activities Planned
Making Kelly Tough Walk Signs * Decorating Cookies * Music with Mar * Card Making
- 9:00 a.m. Prayer Party lead by Kathleen Scott Moonshadow & Morning Star,
1st Floor HV Lodge

SESSION I

MODERATOR: Rod Scott

Fairway Conference Room 2nd Floor, Holiday Valley Lodge

**Refreshments Available*

- 10:00 a.m. Welcome/Introduction Jacque Waggoner
- 10:10 a.m. **Leukodystrophy Care Network Candidate Centers**
- | | |
|---|----------------------|
| Children's Hospital of Philadelphia | Dr. Amy Waldman |
| Ann & Robert H. Lurie Children's Hospital of Chicago | Dr. Barbara Burton |
| Kennedy Krieger Institute | Christopher Joseph |
| Monroe Carell Jr. Children's Hospital at Vanderbilt | Dr. Kevin Ess |
| Lucille Packard Children's Hospital/Stanford University | Dr. Keith Van Haren |
| University of Utah/Primary Children's Hospital | Dr. Gary Nelson |
| Massachusetts General Hospital | Catherine Becker |
| Duke University Medical Center | Dr. Joanne Kurtzberg |
- 12:25 p.m. Kid Kamp – Pick up kids Creekside
- 12:25 p.m. **Lunch Buffet** Sunrise, 1st Floor HV Lodge
- 1:05 p.m. **Kid Kamp Opens** Creekside
PM Activities Planned
** Create backdrop for Talent Show * Game * Charlie & Checkers Show * Movie: Home**

2016 Hunter's Hope Family and Medical Symposium

DAY 2 Thursday July 28, 2016 (Continued)

SESSION II

MODERATOR: Phil May

Fairway Conference Room 2nd Floor, Holiday Valley Lodge

- 1:15 p.m. **Leukodystrophy Care Center Panel**
- | | |
|---|----------------------|
| Children's Hospital of Philadelphia | Dr. Amy Waldman |
| Ann & Robert H. Lurie Children's Hospital of Chicago | Dr. Barbara Burton |
| Kennedy Krieger Institute | Christopher Joseph |
| Monroe Carell Jr. Children's Hospital at Vanderbilt | Dr. Kevin Ess |
| Lucille Packard Children's Hospital/Stanford University | Dr. Keith Van Haren |
| University of Utah/Primary Children's Hospital | Dr. Gary Nelson |
| Massachusetts General Hospital | Catherine Becker |
| Duke University Medical Center | Dr. Joanne Kurtzberg |
| Golisano's Children's Hospital | Dr. Jennifer Kwon |
| Women's and Children's Hospital of Buffalo | Dr. Khalid Kakish |
- 2:15 p.m. Break
- 2:30 p.m. Improving Outcomes for Krabbe NBS Dr. Jennifer Kwon
- 3:00 p.m. Updates in Leukodystrophy Research Dr. Lawrence Wrabetz
- 4:15 p.m. Kid Kamp Closes Creekside
- 5:30 p.m. Hunter's Hope Family Photo Clock Tower, behind HV Lodge
- 6:15 p.m. **Dinner Buffet** Sunrise, 1st Floor HV Lodge
- Icebreaker - Christina Levasheff Sunrise, 1st Floor HV Lodge

The Family 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 as well as games, snacks and activities.

2016 Hunter's Hope Family and Medical Symposium

DAY 3 Friday July 29, 2016

HUNTER'S HOPE UPDATES & BREAKOUT SESSIONS

8:00 a.m. **Breakfast Buffet** Sunrise, 1st Floor HV Lodge

8:50 a.m. Kid Kamp Opens Creekside
AM Activities Planned
Water Balloons * Egg Toss/Bubbles * Manicures * Craft

9:00 a.m. Prayer Party lead by Kevin Cushman Moonshadow & Morning Star,
1st Floor HV Lodge

SESSION III

MODERATOR: Christina Levasheff

Fairway Conference Room 2nd Floor, Holiday Valley Lodge

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

11:00 a.m. **Break**
Sibling's Session -11 yrs. & up (*Erin Kelly*) Bunker, 2nd Floor HV Lodge

11:15 a.m. Leukodystrophy Care Network Jacque Waggoner

11:35 a.m. Fundraising Jessica Spino, Emily Carrier,
Bryanna Gwitt & Justin Wisnousskas

11:55 a.m. Family Care Programs Kathleen Scott

12:15 p.m. Kid Kamp – Pick up kids Creekside

12:15 p.m. Lunch Buffet Sunrise, 1st Floor HV Lodge

1:30 p.m. Kid Kamp Opens Creekside
PM Activities Planned
** Punkin the Clown * Movie: Inside Out**

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DAY 3 Friday July 29, 2016 (Continued)

SESSION IV

1:45 p.m. Women's Session Birdie, 2nd Floor HV Lodge
Men's Session Moonshadow & Morning Star, 1st Floor HV Lodge
** 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.*

5:30 p.m. Kid Kamp Closes Creekside

6:00 p.m. **Balloon Release & Kelly Tough Walk** Overlook Terrace

7:15 p.m. **Dinner Buffet** Sunrise, 1st Floor HV Lodge

The Family 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 as well as games, snacks and activities.

DAY 4 Saturday July 30, 2016

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 Drake Levasheff Moonshadow & Morning Star,
1st Floor HV Lodge

**** FREE Time for Families ****

Grab 'n Go Boxed Lunch will be available from 12:00 – 1:30 p.m. in the Tamarack Room, which is located down the hall from the Lobby in Tamarack.

5:00 p.m. **Dinner Buffet** Sunrise, 1st Floor HV Lodge

6:00 p.m. Stars of Hope Family Talent Show Sunrise, 1st Floor HV Lodge

The Family 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 as well as games, snacks and activities.

2016 Hunter's Hope Family and Medical Symposium

DAY 5 Sunday July 31, 2016
SEE YOU NEXT YEAR!

7:00 a.m. **Breakfast Buffet** Snowledge
Breakfast Buffet is available until 10:00a.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!

2017 Hunter's Hope Family Symposium
July 19-23, 2017