



Hunter's Hope Foundation

17th Annual Symposium for Krabbe & Leukodystrophy Families

DAILY PROGRAM

DAY 1 Wednesday July 23, 2014

WELCOME!!

- All Day Family Registration & Check-InLobby, Tamarack Lodge
- 3:30 p.m. Board of Directors' MeetingBirdie & Mulligan, 2nd Floor HV Lodge
- 4:30 p.m. Legacy Campaign Leadership Team Kick-Off Meeting.....
Birdie & Mulligan, 2nd Floor HV Lodge
- 7:00 p.m. **Welcome Dinner** Fairway, 2nd Floor HV Lodge

**At the Welcome Dinner, each family will introduce themselves so we can get to know each other. The Hunter's Hope Board of Directors, Legacy Campaign Leadership Team and staff will also be introduced.*

2014 Hunter's Hope Family and Medical Symposium

DAY 2 Thursday July 24, 2014

SCIENTIFIC & CLINICAL RESEARCH

- 8:00 a.m. **Breakfast Buffet** Fairway, 2nd Floor HV Lodge
8:50 a.m. Kid Kamp Opens.....Birdie & Mulligan, 2nd Floor HV Lodge
AM Activities Planned
* Zumba Lesson * Making Every Step Signs
9:00 a.m. Prayer Party lead by Rod Scott.....Sunrise, 1st Floor HV Lodge

SESSION I

MODERATOR: Christina Levasheff

Foxfire Conference Room 1st Floor, Holiday Valley Lodge

- 10:00 a.m. Welcome/Introduction Jacque Waggoner
10:05 a.m. HJKRI, Basic Science OverviewLawrence Wrabetz, MD
10:45 a.m. New Krabbe Mouse Model & GALC Measurement..... Dr. Wrabetz
11:30 a.m. **Break** – Refreshments
11:45 a.m. New Discoveries to Promote Myelination.....Yungki Park, PhD

12:20 p.m. Kid Kamp – Pick up kids Birdie & Milligan, 2nd Floor HV Lodge
12:30 p.m. **Lunch Buffett**..... Fairway, 2nd Floor HV Lodge
1:30 p.m. Kid Kamp Opens.....Birdie & Milligan, 2nd Floor HV Lodge
PM Activities Planned
* Punkin the Clown *Afternoon Movie – Disney's Frozen

SESSION II

MODERATOR: Rod Scott

Foxfire Conference Room 1st Floor, Holiday Valley Lodge

- 1:45 p.m. HJKRI, Clinical Science OverviewTom Langan, MD
2:45 p.m. Clinical Care Centers of Excellence – A Vision..... Erin Connors
3:45 p.m. **Break** – Refreshments
4:00 p.m. Family Participation in ResearchErin Connors & Kathleen Scott

5:00 p.m. Kid Kamp Closes Birdie & Milligan, 2nd Floor HV Lodge
5:30 p.m. Hunter's Hope Family Photo Fire Pit outside Tamarak Lodge
6:15 p.m. Dinner Buffett.....Sunrise Deck, 1st Floor HV Lodge

** The Family Fun Room will be in the Sunrise room on the 1st floor of Holiday Valley Lodge. Indoor & outdoor fireplaces are accessible after dinner until 11:00p.m. Games & activities for all ages. Late night snacks brought out at 9:00p.m. – help yourself!*

2014 Hunter's Hope Family and Medical Symposium

DAY 3 Friday July 25, 2014

FAMILIES ENGAGED

- 8:00 a.m. **Breakfast Buffet** Fairway, 2nd Floor HV Lodge
8:50 a.m. Kid Kamp Opens.....Birdie & Mulligan, 2nd Floor HV Lodge
AM Activities Planned
** Water Balloons * Stars for Hope Craft * TBD*
9:00 a.m. Prayer Party lead by Drake LevasheffSunrise, 1st Floor HV Lodge

SESSION III

MODERATOR: Drake Levasheff

Foxfire Conference Room 1st Floor, Holiday Valley Lodge

- 10:00 a.m. Take Action – Advocating for NBS Anna Grantham & Panel
11:00 a.m. **Break** – refreshments
11:15 a.m. FUNdraising – Working TogetherAndrea Moran & Kaitlin Brunner

Sibling's Session-11 yrs. & up (*Erin Kelly*) Foxfire, 1st Floor HV Lodge

11:45 p.m. Family Programs Kathleen Scott

12:30 p.m. Kid Kamp – Pick up kids Birdie & Milligan, 2nd Floor HV Lodge
12:35 p.m. **Lunch Buffett**..... Fairway, 2nd Floor HV Lodge
1:30 p.m. Kid Kamp Opens.....Birdie & Milligan, 2nd Floor HV Lodge
PM Activities Planned
** Fire Truck Visit * Afternoon Movie – Disney's Monster's University*

SESSION IV

- 1:45 p.m. Women's Session meet in Sunrise, 1st Floor HV Lodge
Men's Sessionmeet in Explorer/Maple Leaf, 1st Floor HV Lodge
** This time is reserved for family members of the 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.*

- 3:15 p.m. **Break** – refreshments available in Foxfire Conference Room
3:30 p.m. Lighten Up! (*Rod & Kathleen Scott*) Firefox, 1st Floor HV Lodge
** This time is reserved for family members of the affected child.*

- 5:00 p.m. Kid Kamp Closes Birdie & Milligan, 2nd Floor HV Lodge
5:30 p.m. **Every Step Walk** Holiday Valley Plaza
6:30 p.m. Dinner Buffet.....Sunrise Deck, 1st Floor HV Lodge

** The Family Fun Room will again be in the Sunrise room after dinner. **

2014 Hunter's Hope Family and Medical Symposium

DAY 4 Saturday July 26, 2014

FAMILY FUN DAY & STARS OF HOPE TALENT SHOW

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

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

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

Horse Drawn Wagon Rides available from 11:00 a.m. – 1:00 p.m.
If you would like a ride with your family, please meet in the parking lot of Tamack Lodge. Rides will be given in shifts.

* Tamack's indoor/outdoor pool opens is exclusive only to those staying at Tamarack Lodge. The pool is handicap accessible and Holiday Valley staff will be available to assist families as needed.
Two additional public pools are also available for all guests' use.*

- 5:00 p.m. Dinner Buffet..... Fairway, 2nd Floor HV Lodge
6:00 p.m. Stars of Hope Family Talent Show Fairway, 2nd Floor HV Lodge

* *The Family Fun Room will be on the 1st floor of Holiday Valley Lodge. Indoor & outdoor fireplaces are available. Games & activities. Late night snacks in (location) at 9:00p.m. – help yourself! **

DAY 5 Sunday July 27, 2014

TRAVELING HOME...

- 8:00 a.m. **Breakfast Buffet**Snowledge & Laurel, **Tamarack**
Breakfast Buffet is available until 10:00a.m.

Snacks for your travel home will be available at checkout

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