

# Hunter's Hope Foundation

20th Annual Symposium for Krabbe & Leukodystrophy Families

## DAILY PROGRAM

### DAY 1 – Wednesday July 19, 2017

#### WELCOME!!

|           |                                |   |
|-----------|--------------------------------|---|
| All Day   | Family Registration & Check-In | Lobby, Tamarack Lodge                   |
| 4:00 p.m. | Board of Directors' Meeting    | Bunker, 2 <sup>nd</sup> Floor HV Lodge  |
| 7:00 p.m. | Welcome Dinner                 | Sunrise, 1 <sup>st</sup> 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 1<sup>st</sup> floor of the Holiday Valley Lodge, the same room where we will have dinner. Indoor and outdoor fireplaces are available as well as games, snacks and activities.\**

## 2017 Hunter's Hope Family and Medical Symposium

### DAY 2 – Thursday July 20, 2017

### LEUKODYSTROPHY CARE NETWORK & LEUKODYSTROPHY RESEARCH

- 8:00 a.m. Breakfast Buffet Sunrise, 1<sup>st</sup> Floor HV Lodge
- 8:50 a.m. Kid Kamp Opens Creekside  
*AM Activities Planned*  
\*Mini Manicures/Hair Braiding \*Crafts \*Movies \*Playground
- 9:00 a.m. Prayer Party lead by Jill Kelly Birdie,  
2<sup>nd</sup> Floor HV Lodge

#### SESSION I

**MODERATOR: Chad Borodychuk**

**Fairway Conference Room – 2<sup>nd</sup> Floor, Holiday Valley Lodge**

\*Refreshments Available

- 10:00 a.m. Welcome/Introduction Jacque Waggoner  
Anna Grantham
- 10:10 a.m. Leukodystrophy Care Network (LCN) Presentations  
Duke Children's Hospital Dr. Joanne Kurtzberg  
Children's Hospital of Philadelphia Dr. Amy Waldman  
Massachusetts General Hospital Dr. Florian Eichler  
Monroe Carell Jr. Children's Hospital at Vanderbilt Dr. Kevin Ess  
Ann & Robert H. Lurie Children's Hospital Dr. Jennifer Rubin  
Children's Healthcare of Atlanta Dr. Stephanie Keller  
Children's National Health System Dr. Jamie Fraser
- 11:55 a.m. Clinical Practice Guidelines  
Treatment CPG Dr. Joanne Kurtzberg  
Musculoskeletal CPG Dr. Sally Evans  
Neurology CPG Dr. Florian Eichler  
Respiratory CPG Dr. Richard Kravitz
- 12:35 p.m. Questions

### DAY 2 – Thursday July 20, 2017 (Continued)

## 2017 Hunter's Hope Family and Medical Symposium

|            |   |   |
|------------|---|---|
| 12:45 p.m. | Lunch Buffet  | Sunrise, 1 <sup>st</sup> Floor HV Lodge |
| 1:30 p.m.  | Kid Kamp Opens<br><i>PM Activities Planned</i><br>*Therapy Dogs *Crafts *Movies *Playground | Creekside                               |

### SESSION II MODERATOR: Phil May Fairway Conference Room – 2<sup>nd</sup> Floor, Holiday Valley Lodge

|           |   |   |
|-----------|---|---|
| 1:45 p.m. | Leukodystrophy Treatment at Duke Hospital | Dr. Joanne Kurtzberg                    |
| 2:30 p.m. | Break                                     |   |
| 2:45 p.m. | Leukodystrophy Research Advancements      | 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, 1 <sup>st</sup> Floor HV Lodge |
|           | Icebreaker                                | Sunrise, 1 <sup>st</sup> Floor HV Lodge |

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## DAY 3 – Friday July 21, 2017 HUNTER'S HOPE UPDATES & BREAKOUT SESSIONS

|           |                  |   |
|-----------|------------------|---|
| 8:00 a.m. | Breakfast Buffet | Sunrise, 1 <sup>st</sup> Floor HV Lodge |
|-----------|------------------|---|

## 2017 Hunter's Hope Family and Medical Symposium

|           |  |   |
|-----------|--|---|
| 8:50 a.m. | Kid Kamp Opens<br><i>AM Activities Planned</i><br>*Music with Mar *Crafts * Movies *Playground | Creekside                                 |
| 9:00 a.m. | Prayer Party lead by Christin Webb   | Birdie,<br>2 <sup>nd</sup> Floor HV Lodge |

### SESSION III

**MODERATOR: Christina Levasheff**  
**Fairway Conference Room – 2<sup>nd</sup> Floor, Holiday Valley Lodge**

|            |   |   |
|------------|---|---|
| 10:00 a.m. | LCN Overview and Update   | Anna Grantham                           |
| 10:20 a.m. | LCN Family Perspective  | LCN Steering Committee                  |
| 10:45 a.m. | Sibling's Session -11 yrs. & up ( <i>Erin Kelly</i> )<br>Lodge  | Maple Leaf, 1 <sup>st</sup> Floor HV    |
| 11:20 a.m. | LCN Care Coordinator  | Family Panel                            |
| 11:45 a.m. | Opportunities for Involvement   | Family Panel                            |
| 12:15 p.m. | Kid Kamp – Pick up kids   | Creekside                               |
| 12:15 p.m. | Lunch Buffet  | Sunrise, 1 <sup>st</sup> Floor HV Lodge |
| 1:30 p.m.  | Kid Kamp Opens<br><i>PM Activities Planned</i><br>* Nature Walk/Scavenger Hunt with John and Susan - 11 years and older<br>*Punkin the Clown *Crafts * Movies *Playground | Creekside                               |

## DAY 3 – Friday July 21, 2017 (Continued)

### SESSION IV

## 2017 Hunter's Hope Family and Medical Symposium

1:45 p.m. Women's Session  
Mom Group A - Child in Heaven                      Maple Leaf, 1<sup>st</sup> Floor HV Lodge  
Mom Group B                      Moonshadow & Morning Star, 1<sup>st</sup> Floor HV Lodge

Men's Session    Birdie, 2<sup>nd</sup> 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 Creekside at 1:45 p.m. Please wear sneakers. Water provided.*

4:45 p.m. Kid Kamp Closes    Creekside

6:00 p.m. Balloon Release & Family Symposium Walk                      Overlook Terrace

7:15 p.m. Dinner Buffet    Sunrise, 1<sup>st</sup> Floor HV Lodge

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## 2017 Hunter's Hope Family and Medical Symposium

### **DAY 4 – Saturday July 22, 2017 FAMILY FREE DAY & STARS OF HOPE TALENT SHOW**

9:00 a.m.      Breakfast Buffet      Sunrise, 1<sup>st</sup> Floor HV Lodge

10:00 a.m.   Prayer Party lead by Kevin Cushman      Moonshadow & Morning Star,  
1<sup>st</sup> Floor HV Lodge

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

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

5:00 p.m.      Dinner Buffet      Sunrise, 1<sup>st</sup> Floor HV Lodge

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

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## 2017 Hunter's Hope Family and Medical Symposium

### **DAY 5 – Sunday July 23, 2017 SEE YOU NEXT YEAR!**

7:00 a.m. Breakfast Buffet

Snowledge & Laurel  
1<sup>st</sup> 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!**

2018 Hunter's Hope Family Symposium  
July 18-22, 2018