



# Hunter's Hope Foundation

16<sup>th</sup> Annual Symposium for Krabbe & Leukodystrophy Families  
*Addressing medical and emotional needs, sharing, and encouraging family involvement*

## DAILY PROGRAM

### DAY 1 Wednesday July 24, 2013

#### WELCOME!!

All Day	Family Registration & Check-In .....	Lobby, Tamarack Lodge
4:00 p.m.	Hunter's Hope Board of Directors' Meeting.....	Sand Trap
7:00 p.m.	<b>Welcome Dinner</b> .....	Fairway, 2 <sup>nd</sup> Floor HV Lodge

## DAY 2 Thursday July 25, 2013

### CLINICAL & SCIENTIFIC RESEARCH

- 8:00 a.m. **Breakfast Buffet** .....Fairway, 2<sup>nd</sup> Floor HV Lodge  
8:50 a.m. Kid Kamp Opens ..... Birdie & Mulligan, 2<sup>nd</sup> Floor HV Lodge  
*AM Activities Planned*  
\* *Mini-Manis for the Girls* \* *Cereal Necklaces* \* *Hovercraft Balloons*  
9:00 a.m. Prayer Party lead by Christina Levasheff ..Foxfire, 1<sup>st</sup> Floor HV Lodge

#### SESSION I

**MODERATOR: Terry Hammonds**

**Explorer Conference Room 1<sup>st</sup> Floor, Holiday Valley Lodge**

- 10:00 a.m. Welcome/Introduction.....Jacque Waggoner  
10:05 a.m. *Transplant & Exploratory Treatment*..... Dr. Joanne Kurtzberg  
10:45 a.m. *Psychosine Research Update* .....Dr. Joe Orsini  
11:30 a.m. **Break** – Refreshments  
11:45 a.m. *Pompe Recommendation to RUSP*.....Dr. Priya Kishnani  
  
12:20 p.m. Kid Kamp – Pick up kids.....Birdie & Milligan, 2<sup>nd</sup> Floor HV Lodge  
12:30 p.m. **Lunch Buffett** .....Fairway, 2<sup>nd</sup> Floor HV Lodge  
1:30 p.m. Kid Kamp Opens ..... Birdie & Milligan, 2<sup>nd</sup> Floor HV Lodge  
*PM Activities Planned*  
\* *Charlie & Checkers Clown Show* \* *Celebration of Life Visors* \* *Crafts*

#### SESSION II

**MODERATOR: Tammy Wilson**

**Explorer Conference Room 1<sup>st</sup> Floor, Holiday Valley Lodge**

- 1:45 p.m. HJKRI, Recap of Medical Symposium.....Dr. Laura Feltri  
2:45 p.m. HJKRI, Clinical Science .....Dr. Tom Langan  
3:45 p.m. **Break** – Refreshments  
4:00 p.m. HJKRI, Basic Science ..... Dr. Larry Wrabetz  
  
5:00 p.m. Kid Kamp Closes.....Birdie & Milligan, 2<sup>nd</sup> Floor HV Lodge  
5:30 p.m. Hunter's Hope Family Photograph.....TBD  
**6:00 p.m. Dinner Buffet** ..... **Sunrise Deck, 1<sup>st</sup> Floor HV Lodge**

## DAY 3 Friday July 26, 2013

### FAMILIES ENGAGED

- 8:00 a.m. **Breakfast Buffet** .....Fairway, 2<sup>nd</sup> Floor HV Lodge  
8:50 a.m. Kid Kamp Opens ..... Birdie & Mulligan, 2<sup>nd</sup> Floor HV Lodge  
*AM Activities Planned*  
\* Scavenger Hunt \* Water Balloons \* Stars of Hope  
9:00 a.m. Prayer Party lead by Jill Kelly .....Foxfire, 1<sup>st</sup> Floor HV Lodge

### SESSION III

**MODERATOR: Rod Scott**

**Explorer Conference Room 1<sup>st</sup> Floor, Holiday Valley Lodge**

- 10:00 a.m. NBS Legislation.....Anna Grantham & Panel  
11:00 a.m. **Break** – refreshments  
11:15 a.m. FUNdraising – Working Together..... Andrea Moran & Kaitlin Brunner  
  
Sibling's Session-11 yrs. & up (*Sam & Erin*) .Foxfire, 1<sup>st</sup> Floor HV Lodge  
  
12:15 p.m. United Health Care Medical Grants.....Jamie Steinwachs  
  
12:30 p.m. Kid Kamp – Pick up kids..... Birdie & Milligan, 2<sup>nd</sup> Floor HV Lodge  
12:35 p.m. **Lunch Buffett** .....Fairway, 2<sup>nd</sup> Floor HV Lodge  
1:30 p.m. Kid Kamp Opens ..... Birdie & Milligan, 2<sup>nd</sup> Floor HV Lodge  
*PM Activities Planned*  
\* Making Hamburger Cookies \* Afternoon Movie \* Crafts

### SESSION IV

- 1:45 p.m. Women's Session (*Jill Kelly*) .....Foxfire, 1<sup>st</sup> Floor HV Lodge  
Men's Session (*Jim Kelly*) .... Explorer/Maple Leaf, 1<sup>st</sup> Floor HV Lodge  
  
*\*\* Sibling Hike – 11+ yrs. - John & Susan K. will take 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.*  
  
3:15 p.m. **Break** – refreshments  
3:30 p.m. Lighten Up! (*Rod & Kathleen Scott*) .....Explorer, 1<sup>st</sup> Floor HV Lodge  
*\* This session is for parents, grandparents, etc.*  
  
5:00 p.m. Kid Kamp Closes..... Birdie & Milligan, 2<sup>nd</sup> Floor HV Lodge  
5:30 p.m. **Every Step Walk**.....Holiday Valley Plaza  
**6:00 p.m. Dinner Buffet** ..... **Sunrise Deck, 1<sup>st</sup> Floor HV Lodge**

## DAY 4 Saturday July 27, 2013

### FREE TIME & STARS OF HOPE TALENT SHOW

- 8:00 a.m. **Breakfast Buffet** ..... Snowledge & Laurel, **Tamarack**  
10:00 a.m. Prayer Party lead by Drake Levasheff .....Foxfire, 1<sup>st</sup> 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 10:00am – 1:00pm\*  
*If you would like a ride with your family, please go to  
the parking lot across the street from Holiday Valley.*

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

## DAY 5 Sunday July 28, 2013

### TRAVELING HOME...

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

**Snacks for your travel home – please pick up during checkout**

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

## 2013 FAMILY & MEDICAL SYMPOSIUM SPEAKERS & PRESENTERS

**Laura Feltri, M.D.**, Principal Investigator, Hunter James Kelly Research Institute; Professor of Biochemistry, University at Buffalo School of Medicine, Buffalo, New York

**Priya Kishnani, M.D., MB BS**, Division Chief, Medical Genetics, Department of Pediatrics, Division of Pediatrics-Medical Genetics, Duke University Medical Center, Durham, North Carolina

**Joanne Kurtzberg, M.D.**, Professor of Pediatrics and Pathology; Director, Pediatric Blood and Marrow Transplant Program; Director, Carolinas Cord Blood Bank at Duke, Duke University Medical Center, Durham, North Carolina

**Thomas Langan, M.D.**, Clinical Director, Hunter James Kelly Research Institute; Professor of Neurology and Pediatrics, University at Buffalo School of Medicine, Buffalo, New York

**Joe Orsini, PhD**, Newborn Screening Program for Krabbe Leukodystrophy, Wadsworth Center, New York State Department of Health

**Jamie Steinwachs**, Buffalo Service Center Employee Engagement Lead, United Healthcare

**Lawrence Wrabetz, M.D.**, Inaugural Director, Hunter James Kelly Research Institute; Professor of Neurology and Biochemistry, University at Buffalo School of Medicine, Buffalo, New York

**NBS Legislation** – Anna Grantham, Hunter's Hope Newborn Screening Representative; Phil May, Family Advocate – Tennessee; Christina Levasheff, Family Advocate – California; Elisa Seeger, Family Advocate – New York

## HUNTER'S HOPE STAFF

**Kaitlin Brunner**

Development, Media, PR

**Laura Egan**

Executive Assistant

**Anna Grantham**

Newborn Screening

**Andrea Moran**

Executive Director

**Kathleen Scott**

Family Support

**Michelle Watt**

Development Assistant

## HUNTER'S HOPE BOARD OF DIRECTORS

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