

Registration

Name: _____

Address: _____

City: _____

State/Zip: _____

Phone: _____

Email: _____

Interpreter needed: No Yes

Describe: _____

Childcare needed: No Yes Ages: _____

Lunch Preference: Non-vegetarian Vegetarian

Registration must be received by June 18, 2010 to guarantee special accommodations & lunch.

Registration _____ at \$50 = _____

Adults Saturday BBQ _____ at \$10 = _____

Children (ages 3-10) BBQ _____ at \$5 = _____

Detach this registration form and send or fax to:
The Hear See Hope Foundation
17837 1st Ave So, PMB 2
Normandy Park, WA 98148
lane@hearseehope.com
206-708-6690 (fax)

Credit Card (Circle One): MC / VISA / AMEX

Name on Card _____

Number _____

Expiration Date _____ Security Code _____

Amount to Charge _____

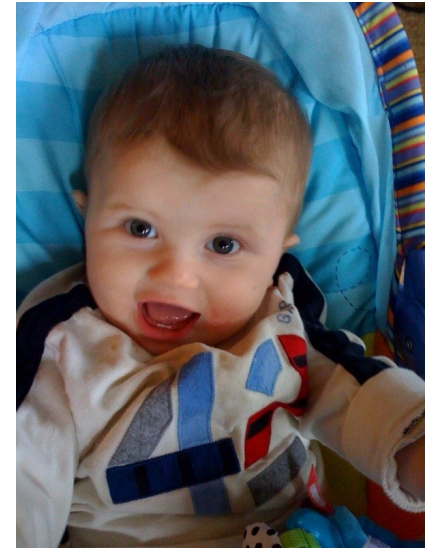
Signature _____



Hear See Hope Foundation
17837 1st Avenue South, PMB 2
Normandy Park, WA 98148

Childhood Communication Center presents...

2nd Annual Usher Syndrome Family Conference



Saturday, July 10, 2010
Seattle Children's Hospital

4800 Sandpoint Way NE
Seattle, WA 98105

Generously supported by:



About Usher Syndrome

Usher syndrome is a genetic disorder causing various degrees of congenital hearing loss and deafness, a progressive debilitating vision disorder known as retinitis pigmentosa (RP), and in many cases, vestibular dysfunction. Usher syndrome is the leading cause of deaf-blindness in the western world. Hearing aids and cochlear implants are often successful in hearing loss. To date, no proven therapies exist for RP. This presentation offers talks that emphasize both research and living with Usher syndrome.

Intended Audience

Families of children and adults with Usher syndrome, ophthalmologists, otolaryngologists, geneticists, genetic counselors, teachers of deaf-blind, and service providers

Program Objectives

Participants will:

1. Learn about current research and therapies for Usher syndrome.
2. Understand and navigate current and upcoming clinical treatment trials.
3. Network with other families and professional regarding Usher syndrome.
4. Learn about research and treatments for Usher syndrome.
5. Identify strategies for living with Usher syndrome.

Information

- Childcare and accommodation requests must be received no later than **Friday, June 18th**.
- Detailed directions to Seattle Children's main campus can be accessed at www.seattlechildrens.org/home/about_childrens/maps_directions.asp
- For additional questions, contact Lane McKittrick at lane@hearseehope.com.
- Online registration at www.hearseehope.com.

Schedule of Events

Saturday Evening Family Barbeque at Golden Gardens Beach Park



When: 5:00 pm –Dark
Where: 8498 Seaview PI NW, Seattle
What: Wrap up the Usher Conference with a barbeque for the entire family. Enjoy good food, fun and friendship!
Cost: \$10.00 Adults
\$5.00 Children



Parking is limited at this location so carpooling is recommended.



Saturday Conference

- | | |
|-------------|--|
| 8:30-9:00 | Conference Check In |
| 9:00-9:10 | Welcome |
| 9:10-9:40 | Usher Syndrome, an Overview
Dr. William Kimberling, University of Iowa |
| 9:40– 10:10 | Genetics Testing and Counseling
Linda Ramsdell, Seattle Children's |
| 10:10-10:35 | Q&A/Break |
| 10:35-11:15 | Treatments
Dr. Peter Francis, Casey Eye Institute |
| 11:15-12:00 | Vestibular Testing
Dr. Jim Phillips, Seattle Children's |
| 12:00-12:45 | Lunch |
| 12:45-2:15 | Panel Discussion,
Living with Usher Syndrome |
| 2:15-3:00 | Breakout Sessions |

(Participants select one session to attend)

1. **The Scoop on Schools: Accommodations and Adaptations for the Classroom**
Nancy Hatfield and Katie Humes, Washington Sensory Disabilities Services
2. **Rap Session: Young Adults with Usher Syndrome (geared toward children and young adults)**
Amelia Westerfield, Young Adult with Usher Syndrome
3. **Research Update**
Dr. Richard Weleber, Casey Eye Institute