Why you should attend the

International Symposium on Usher Syndrome

International Symposium on Usher Syndrome

- July 10-12, 2014
- Joseph B. Martin Center, Harvard Medical School
  - Boston, Massachusetts, USA
- Expected to be largest gathering of Usher community in history
- Estimate nearly 300 attendees
- Register online at: bit.ly/ush2014

Planning Committee

- Representative of entire community
  - Melissa Chaikof, Founder, Vision for a Cure, Parent of two children with USH
  - Charlotte DeWitt, President, International Events Limited, Aunt of adult with USH
  - Mark Dunning, Chairman, Usher Syndrome Coalition, Parent of child with USH
  - Julie Edwards, Research Assistant, Boston Children's Hospital
  - Gwen Géléoc, PhD, Assistant Professor of Otolaryngology, Boston Children's Hospital, Harvard Medical School
  - Margaret Kenna, MD, PhD, Director of Clinical Research, Dept. of Otolaryngology and Communication Enhancement, Boston Children's Hospital
  - Bill Kimberling, MD, Director, Center for the Study and Treatment of Usher Syndrome, Boys Town National Research Hospital
  - Katherine Lafferty, Genetic Counselor, Laboratory for Molecular Medicine, Partners Healthcare
  - Janet Marcous, Deaf/Blind activist, Adult with USH
  - Gail McKinnon, Parent of child with USH, Capital Finance Analyst, Ocean Spray Cranberries
  - José M. Millán, PhD, Research Group Leader, Unidad de Genetica, Hospital Universitario La Fe
  - Heidi Rehm, PhD, Chief Laboratory Director at Laboratory for Molecular Medicine, Partners HealthCare Center for Personalized Genetic Medicine, Harvard Medical School
  - Moira Shea, Vice Chair, Usher Syndrome Coalition, Adult with USH
  - Martha Steele, Deputy Director, Bureau of Environmental Health, Massachusetts Department of Public Health, Adult with USH
  - Joost Stultiens, Medical Student, Boston Children's Hospital (Dec 2013-April 2014)
  - Susie Trotochaud, Executive Director, Usher 2020 Foundation, Parent of two children with USH
  - Luk Vandenberghe, Assistant Scientist, Schepens Eye Research Institute, Massachusetts Eye and Ear
  - Krista Vasi, Executive Director, Usher Syndrome Coalition

Combined Scientific and Family Conference

- Science Conference
  - Thursday/Friday July 10-11
- Family Conference
  - Saturday July 12
- Families and researchers are invited to attend all three days
- Goal is to inform the entire Usher community
- Want researchers and families to meet

Scientific Conference

- Thursday and Friday
  - Focused on science collaboration for researchers
  - Presentation of latest in Usher syndrome research
  - 30 confirmed speakers from 7 countries
  - Poster sessions
  - Families invited to attend as observers
  - Session introductions by Usher families
- Saturday
  - Scientific Brainstorming and Roadmap Framework

Young Investigators

- Want best and brightest to pursue Usher syndrome research
- NIH identified this as a particular weakness in Usher research
- Call for abstracts
  - Dozens of poster and oral submissions
- NIDCD provided six travel awards for Graduate Students and Postdoctoral fellows
- Forschung Contra Blindheit and FAUN-Stiftung provided travel awards for European trainees and early career investigators
- Reduced rate for student attendees
- Contact Krista Vasi for more information: k.vasi@usher-syndrome.org

Roadmap Development

- Share what we know
- Identify knowledge gaps
- Develop roadmap to guide future Usher research investment
- Requested by NIH and other funding organizations
- Congressional support

Family Conference

- Science for Families
  - Dr. Margaret Kenna – Boston Children’s Hospital
  - Ilene Miner, LCSW
  - Dr. Claes Möller – Audiological Research Centre, Orebro, Sweden
  - Dr. Luk Vandenberghe - Mass Eye and Ear Infirmary
  - Dr. Gwenaelle Geleoc –Boston Children’s Hospital
  - Mark Dunning – Chairman Usher Syndrome Coalition (and Bella’s Dad)
- Family Panel
  - Elaine Ducharme, Chloe Joyner, Ryan Thomason, Mike Walsh, Molly Watt
- Breakout Sessions
  - Partners and Spouses of Adults with Usher Syndrome
  - Living and Transitioning with Usher Syndrome
  - Parents' Knowledge Exchange: Raising a Child with Usher Syndrome
  - Young Adult College & Career Chat

Childcare

- Saturday Only
- Want parents to be free to attend Family Conference
- Ages 10 and above chaperoned visit to Museum of Science
  - Maybe a Duck Tour, too
- Ages 9 and below on site with child care service
- Siblings invited to attend
- Kids LOVE these days
- Usher is normal

Evenings

- Wednesday
  - VIP reception at New England College of Optometry
  - Invitation Only
- Thursday
  - Cocktail Reception and Poster Review at Elements Café
- Friday
  - Banquet at Elements Café
- Saturday
  - BBQ at Simmons College
- Researchers and Families welcome at all events

Accessibility

- Interpreters
  - Funding provided by NIDCD
- Sighted Guides
- Assistive Listening Devices
  - Joseph B. Martin Conference Center is looped
- Braille Materials
  - Printed on request
- CART (Communication Access Realtime Translation)
- Needs Requests due June 1, 2014

Accommodations

- Discounted Hotel Rates until June 4, 2014
  - The Midtown Hotel
  - The Inn at Longwood Medical (walking distance)
  - The Colonnade Hotel (full)
- Miracle Flights for Kids
  - Round-trip commercial airline flight for child and one or both parents
  - Requires consultation with M.D. during conference documented by physician
  - Must meet eligibility requirements
  - For more info, visit bit.ly/ushtravel or call 800-FLY-1711

Conference Fees

- Professionals
  - $350 until June 4th ($400 after)
- Student/Trainee/Post Doc
  - $100 until June 4th ($150 after)
- Adult Attendee for Family and Science Conferences (3 days)
  - $150
- Adult Attendee for Family Conference
  - $75
- Child Attendee for Family Conference
  - $25
- Fees include continental breakfast and lunch
- Cocktail reception and BBQ are free to all attendees
- Friday night banquet is ticketed event ($75)

Sponsors

- Grant Funding from National Institute on Deafness and Communications Disorders and National Eye Institute
- Usher 2020 Foundation
- The Decibels Foundation
- Boston Children's Hospital Translational Research Program
- Gene Dx
- Hear See Hope
- Foundation Fighting Blindness
- Med El
- The Megan Foundation
- Vision for a Cure
- Individual sponsors: Moira Shea, Donald and Pamela Dunning, Mark Dunning
- **Sponsorships still available**
- **Currently $20,000 shortfall**

Spread the Word

- Branding Initiative
  - Usher Syndrome Coalition
  - New Logo Soon
- Social Media Initiative
- #USH2014
  - Educate Supporters about Symposium
  - Recruit new messengers and advocates for the Usher Community
  - Follow us on Twitter (@UsherCoalition)
  - Like us on Facebook
    - Goal: 800 fans
  - Join our E-mail list
    - Goal: 1200 members

There's an app for that…

…and it's coming soon.
Stay tuned for more details.

#USH2014

The World is Watching

- NIDCD and NEI are looking forward to the development of a roadmap.
- Funding organizations want to identify new investigators to support.
- Congress is supporting language for Usher syndrome funding.
- The Usher syndrome community has a voice! Let’s be heard.

We Want You at the Symposium

- Sign up today
- Contact Krista Vasi with special requests
- We will work something out to get you there