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 Gélyoc, 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 Genética, 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 Trotchaud, Executive Director, Usher 2020 Foundation, Parent of two children with USH
  - Luk Vandenbergh, Assistant Scientist, Scheepens 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