

The Coalition for Usher Syndrome Research

You are the cure



The Coalition for
Usher Syndrome
Research

What is the Coalition for Usher Syndrome Research

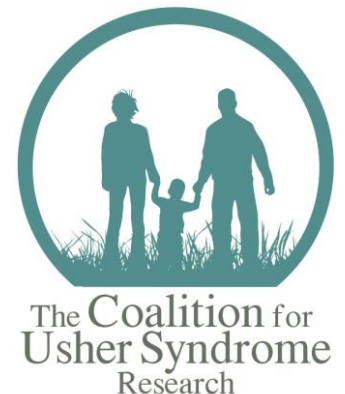
- Collection of concerned researchers, families, and organizations dedicated to building an Usher syndrome community to help support Usher research.
- All volunteer
- Not a fund raising or funding organization.
- Our members:
 - Foundation Fighting Blindness
 - Harvard Medical School Center for Hereditary Deafness
 - The Decibels Foundation
 - Hear See Hope Foundation
 - The Megan Foundation
 - Unidad de Genetica, Hospital Universitario La Fe, Valencia, Spain
 - Children’s Hospital Boston
 - The Audiological Research Center in Orebro, Sweden
 - Oregon Health and Sciences University Casey Eye Institute
 - Seattle Children’s Hospital
 - Boys Town Hospital
 - University of Iowa Carver Laboratory



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Impact on Research

- Engaged families are critical to finding treatments.
- Source of natural history information. Only way to tell if a treatment is successful.
- Source of genetic information.
- Pool of candidates for clinical trials.
- Source of funding and lobbying.
- Source of awareness which impacts funding and motivates researchers.
- Education resource
 - Doctors, friends, schools, cultural groups
- You are the cure
- We need your help



How Can I Help?

- Web site
- Registry
- Family Conferences
- Researcher Conference
- Marketing and Communications
- Outreach
- Funding



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Coalition Web Site

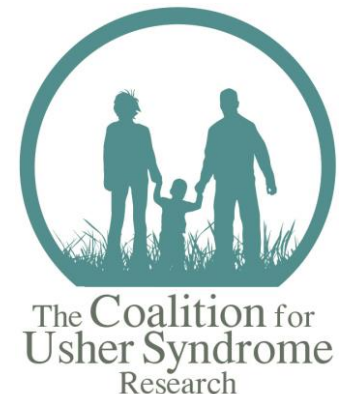
- usher-syndrome.org
- Why early diagnosis is important?
- Explanation of Usher syndrome symptoms/causes.
- Latest research news.
- Presentations and abstracts from Usher researcher and family conferences.
- Links to resources and Coalition members.
- Overall sense of hope.



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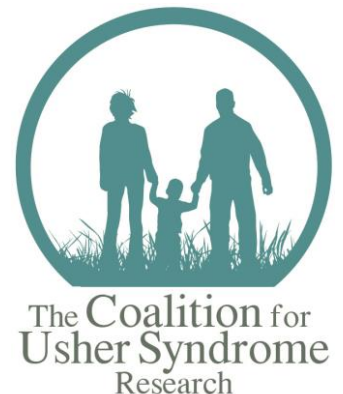
Registry

- usher-registry.org
- GOAL: Register everyone in the world with Usher syndrome
- Created by people with Usher for people with Usher
- Key components
 - Voluntary
 - Secure and controllable by individual families
 - No unsolicited contact
 - Web accessible by families and researchers
- Phase 1
 - Contact information for Usher families
 - Basic diagnosis information (what type of Usher do you have?)
 - Interests (connecting with families, hearing about clinical trials)
 - Find an Usher syndrome expert
- Phase 2
 - Integrate with Coalition web site (www.usher-syndrome.org)
 - Research questionnaires
 - Natural history/Dietary/Psycho-social



Registry Help

- Individuals
 - Register and fill-in questionnaires as appropriate
 - Join family network to build community
- Registry Development
 - Modification Testing
 - Multi-Language Translation
 - Low Vision Testing
 - Outreach



Marketing and Social Media

- Digital Marketing Strategy from GetFused
- Twitter – 2-4 times a week
- Facebook/Google Plus – 1-2 times a week
- LinkedIn – 2 times a week
- Blog – Once a week
- Constant Contact Newsletters – Once a month
- New Registrant and Family Network e-mails – Once a week



Family Conference

- One day event for families held annually in the US
- Portland, Oregon in 2013, Boston, Massachusetts in 2014
- Where we need help
 - Identify location one year in advance
 - Begin coordination six months in advance
 - Registration setup
 - Marketing and communications
 - Speakers
 - Identify and coordinate interpreters and CART
 - Identify venue and coordinate meals (and dietary needs)
 - Accommodation arrangement and communication
 - Child care planning and volunteer coordination
 - Funding is usually private



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Researcher Conference

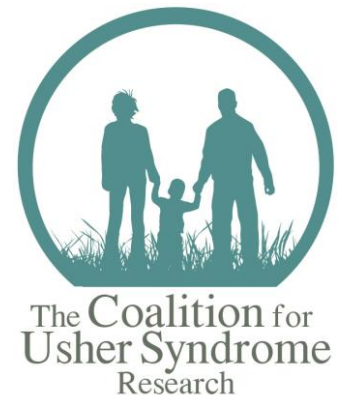
- Researcher Conference
 - Boston 2014?
 - Multi-day event
- Where we need help
 - Begin grant writing two years in advance
 - Planning and coordination 18 months in advance
 - Identify topics and speakers
 - Marketing and communications
 - Identify venue and coordinate meals (and dietary needs)
 - Entertainment for attendees
 - Accommodation arrangement and communication
 - Coordinate speaker travel and expenses
 - Identify and coordinate interpreters and CART
 - Will require combination of grant and private funding



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Coalition Membership

- Membership Committee
- Encourage research, support, and diagnostic organizations to join Coalition.
- Liaise with member organizations.
- Coordinate two-way communication.



Funding

- Usher syndrome and related diseases impact more people than ALS (Lou Gehrig's Disease, Duchene Muscular Dystrophy, and Huntington's Disease).
- Line Item Yearly NIH funding for ALS (\$47M), Duchene's (\$34M), Huntington's (\$65M).
- Line Item Yearly NIH funding for Usher - \$0
- NIH funded research for Usher in 2012 - \$3M-\$15M
- NIH Funding Committee
 - Letter writing
 - Representative visits
 - Washington D.C.



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I want to help

- Send an e-mail with your interests
 - M.dunning@lek.com
 - K.scheall@decibelsfoundation.org

