The Coalition for Usher Syndrome Research

You are the cure
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
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
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.
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
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
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.
I want to help

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