

## **My Child has been diagnosed with Usher Syndrome..... Where can I look for more information?**

- Register with the COALITION FOR USHER SYNDROME RESEARCH. They will help you keep track of research – and update you with information on Usher Syndrome: <http://www.usher-syndrome.org>
- Find out if your child could get a cochlear implant
- Find out if your child might become part of research studies on Retinitis Pigmentosa (e.g. Dr. Weleber's work at Oregon Health Science University)

### **Websites**

- Follow Mark Dunning's super blogs to get a family's viewpoint: <http://ushersyndromeblog.blogspot.com/>
- Read one woman's viewpoint on her own Deafblindness – Usher Syndrome – and things to think about and do: <http://www.oregondb.org/news/Winter-Spring2010.pdf>
- Usher Syndrome in the School Setting: <http://www.nationaldb.org/ISSelectedTopics.php?topicID=1257&topicCutID=13>
- Need to find out about communication equipment? <http://www.icanconnect.org/> or, in Oregon: <http://www.icanconnect.org/oregon>
- Explore Cochlear Implants: <http://www.nidcd.nih.gov/health/hearing/pages/coch.aspx>
- Find out about Genetic Clinical trials for RP at OHSU (Dr. Weleber): <http://www.ohsu.edu/xd/health/services/casey-eye/clinical-services/specialty-services/genetics/clinical-trials.cfm>
- Genetics information: <http://www.kumc.edu/gec/support/> (The Genetics Education Center at the Kansas University School of Medicine)
- What areas would counselors target? <http://pepnet.org/sites/default/files/67PEPNet%20Tipsheet%20-%20%20counseling%20students%20who%20have%20Usher%20Syndrome.pdf>
- Contact a specialist organization for assistance: [www.nationaldb.org](http://www.nationaldb.org) (the National Consortium on Deafblindness – main office in Monmouth, OR), and/or [www.hknc.org](http://www.hknc.org) (the Helen Keller National Center for Deaf-Blind Youths and Adults); In Oregon: [www.oregondb.org](http://www.oregondb.org)
- Contact the Oregon Commission for the Blind, head office in Portland, but other offices around the state: [http://www.oregon.gov/Blind/pages/about\\_us.aspx](http://www.oregon.gov/Blind/pages/about_us.aspx) or the Department of Vocational Rehabilitation: <http://www.oregon.gov/DHS/vr/Pages/index.aspx>
- National Institutes of Health Directory of Organizations for Usher Syndrome: <http://www.nidcd.nih.gov/directory/keyword.asp?keyword=74>
- Find out about Guide Dogs: <http://www.leaderdog.org/programs/deafblind/> and <http://www.guiding-eyes.org/>
- Ask.com has a lot of sites to explore: <http://tiny.cc/h5x5vw>

## **You-tube videos/ slide shows:**

About the symptoms and effects of Usher Syndrome:

- <http://www.youtube.com/watch?v=y5nBxrzybl>
- <http://www.youtube.com/watch?v=Kg4eCIXNNLw>

About Usher Syndrome, Retinitis Pigmentosa and research:

- <http://www.youtube.com/watch?v=MU1JZmUac98>
- <http://www.youtube.com/watch?v=aCm9C7lnfs8>

DB Relay service:

- <http://www.youtube.com/watch?v=X25okd6FWfo>

Deaf-Blind Falsh Mob in Seattle, WA – on White Cane Day – where there is a large population of persons with Usher Syndrome: <http://www.youtube.com/watch?v=9vbPXdeWA-k>

Seabeck Deaf-Blind Retreat – held annually: <http://www.youtube.com/watch?v=fZfHkcrDQjE>

## **Social networking, blogs and listserv sites:**

- General info: <https://www.facebook.com/pages/Usher-syndrome/112389745439680#>
- <https://www.facebook.com/pages/Proud-Moms-of-Children-with-Usher-Syndrome/177853542264934>
- Facebook Forum for teens: <http://www.usher-syndrome.org/index.cfm?pid=10840>
- Usher & Deafblind Accessible Technology: <https://www.facebook.com/pages/Usher-Deafblind-Accessible-Technology/214348761967406?fref=ts>
- UsherLife – a closed group fb page: <https://www.facebook.com/groups/usherlife/>
- US Families for Usher Syndrome: <https://www.facebook.com/groups/371009117557/>
- International Usher Syndrome Network: <https://www.facebook.com/groups/i.ushers/>
- Listservs:
  - [http://www.aadb.org/resources/email\\_lists/support\\_groups.html](http://www.aadb.org/resources/email_lists/support_groups.html)
  - DBCI (Cochlear Implant Listserv; moderator – Ilana; contact Randy Klumph at [klumphr@wou.edu](mailto:klumphr@wou.edu) if you would like to join in this very active conversation.
- Blogs: Angie Orlando is deafblind and often writes blogs: <http://dotbug3.blogspot.com/>

## **Pinterest**

Deaf/Blind Resources: <http://pinterest.com/cmormier/deaf-blind-resources/>