

So a child in my classroom may have Usher Syndrome ... What do I do next?

Encourage the parents to visit an ophthalmologist.

This person can:

- Check the health of the retina
- Check on alterations in peripheral vision/field of vision
- Make a referral to a geneticist

The geneticist will be able to:

- Take a blood sample (Note: genetic testing takes time!)
- Determine whether or not the child has Usher Syndrome
- Have parents and child participate in genetic counseling (if diagnosed)
- With signed parent permission, be able to let the teacher know

You can:

- Learn more about Usher Syndrome yourself and help educate the parents too
- Explain to the parents about the National child registry for deafblindness
- Contact the state's Deafblind Project to register the child
- Ask the state project for consultation or training for yourself, the child's team, and the family

With the family and child:

- If at all possible, have parents who have a child with Usher Syndrome meet with the parents of the child in your classroom.
- Have a person with Usher Syndrome who is willing to answer questions, meet with the person just diagnosed

While all the above are happening, there are still things you can do:

- Consult with the child on his/her seating in the classroom, keeping in mind possible issues with glare. Also be aware of glare outside the classroom.
- If the child works with an interpreter, find out from where in the room the child can best see this person. Depending on the extent to which vision is affected, this could be from further back, and not front row. It may be close up...It depends on the child's residual vision.
- If peripheral vision is affected, consult with an Orientation and Mobility instructor on possible strategies a child might use.
- If the child is having problems with areas of the school that are dull/dark, or is uncertain in the dark, check with the O & M instructor for what could help.

If the diagnosis is confirmed, encourage parents to register with the COALITION FOR USHER SYNDROME RESEARCH so they can stay updated: <http://www.usher-syndrome.org>