



USHER SYNDROME FAMILIES: Ways to Connect and Stay Informed

Families of children and youth with Usher syndrome may be wondering, “Where do I start?” This factsheet provides practical steps to get connected and stay informed.

For more information, visit [Identification of Usher Syndrome: Information and Resources.](#)

Get Connected!

- Add your child to the [USH Trust](#), a valuable tool for building the Usher community. You’ll receive the latest information on research and be able to connect with other families and the Usher community across the country and around the world.
- If you’re interested in research, register your child in RARE-X’s free [Usher Syndrome Data Collection Platform \(DCP\)](#).
- Connect with your [state deafblind project](#). They can help you navigate services within your state.
- Check out Facebook groups for Usher parents.
- Join the [USH Blue Book](#), a private email group for families and individuals living with Usher syndrome.
- Participate in monthly calls with the Family-to-Family Communities Project (F2FC). Meet other Usher families of school-aged children and share information, resources, and support. To join, email avasvoice@gmail.com.
- Reach out to your [USH Ambassador](#), your local contact at the Usher Syndrome Coalition, who can connect you with resources in your state.
- Make lifelong friendships and access valuable resources and information at the annual [USH Connections Conference](#).
- Join the [National Family Association for Deaf-Blind](#), the largest national nonprofit organization empowering families with individuals who are deaf-blind.
- Don’t hesitate to reach out to counselors, social workers, or therapists for mental health support and help with emotional needs.

Watch and Read to Learn More

- [Watch Usher Syndrome From Their Perspective](#), a 20-minute video where kids with Usher syndrome and their parents share their thoughts and feelings.
- [Read blog posts](#) by Mark Dunning, who describes the early days of the Usher Syndrome Coalition and his journey as a dad to daughter Bella, who has Usher syndrome Type 1.
- View the webinar [Educational Considerations for Students with Usher Syndrome](#), where two mothers of children with Usher talk about accommodations their children received throughout their school years, including college.
- Learn about the [Parent and Professional Partnership](#) in this article by Pam Aasen, mom to Ethan and Gavin, who both have Usher syndrome Type 1.
- Check out this series of [ASL videos about Usher syndrome](#).
- View [“Living and Learning with Usher Syndrome”](#) in ASL or [with spoken language interpreters and captions](#), by Megan Wimberly.
- See a growing library of [portraits](#) and [interviews](#) of individuals living with Usher syndrome from the [Usher Syndrome Society](#).

For Older Kids with Usher

- If your child is 18 or older, let them know about [Just for Young Adults](#), a section of the Usher Syndrome Coalition website, with stories and suggestions from college-age students. This group also has a Facebook group and hosts monthly calls.
- [Ava's Voice](#) hosts [USHthis Summer Youth Camp](#) for youth with Usher syndrome, ages 11 to 14. Teens ages 15 to 17 can apply to be counselors in training, and young adults ages 18 to 24 can apply to be lead counselors.
- [The Helen Keller National Center for DeafBlind Youths and Adults](#) provides training and resources exclusively to those age 16 and older who have combined vision and hearing loss.

This fact sheet was written by Nancy O'Donnell, Director of Outreach for the Usher Syndrome Coalition.

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