WWW.USHER-SYNDROME.ORG

USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

The Usher Syndrome Coalition is the core of the global Usher syndrome community, working to connect those living with Usher syndrome to resources, research, and each other. The Coalition uses the power of two data collection tools to build the community, leading to a better understanding of Usher syndrome, improved quality of life, and treatments for hearing, vision, and balance issues associated with Usher.

BRIDGING THE GAP BETWEEN RESEARCHERS AND FAMILIES

The USH Trust is the largest international contact database of individuals with Usher syndrome, and our most powerful tool to connect, inform, and support individuals within the Usher community. Participants include children and adults with Usher syndrome from more than 70 countries. They are the first to learn about the latest research opportunities.

RARE-X Usher Syndrome Data Collection Program (DCP) Health information entered into this secure platform becomes part of a global database of de-identified information available to researchers worldwide. As the DCP grows, more researchers will become aware of Usher syndrome, leading to the development of clinical trials and treatments for the associated vision loss, hearing loss, and balance issues.

CONNECTING THE GLOBAL USHER COMMUNITY

USH Blue Book: a private email group created to connect individuals with Usher syndrome, family members, and friends in a global network of support.

Usher Syndrome Coalition Discord Server: a private, accessible online space for the community to chat in real time. Created by and for the Usher community.

The Usher Syndrome Coalition - Building the Usher community, one person at a time.

USHER SYNDROME COALITION

TOGETHER WE CAN MAKE USHER SYNDROME HISTORY

The Usher Syndrome Coalition strives to be THE source of information about all things related to Usher syndrome. Here are some of our many resources that may be of interest to you. All can be found on the Coalition's website: https://www.usher-syndrome.org

- Get answers to your *frequently asked questions*
- Stay up-to-date on the **latest research**.
- Read information, tips, and resources **Just for Parents**
- Learn from and connect with **young adults**
- Find ***information about Usher syndrome in ASL***
- Follow us on ***social media***
- Email us: *info@usher-syndrome.org*

Join the Usher Syndrome Coalition	Learn about genetic testing	Find Your USH Ambassador!

LEARN MORE: USHER-SYNDROME.ORG

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