

# USHER SYNDROME COALITION

## You are the **EXPERT**

**TOGETHER WE CAN MAKE USHER SYNDROME HISTORY**

### **JOIN US:**

- *Register* with the **USH Trust** - be informed and involved in the latest research.
- Access genetic testing through **Unraveling USH**.
- *Find support* from the global community through the **USH Blue Book**.
- *Locate experts* in the **USH Yellow Book** - a centralized directory of researchers and resources worldwide.
- *Network* at **USH Connections Conferences**, the largest annual gathering of the Usher syndrome community.
- *Stay informed* through **USH Talks**, providing the latest in research developments.

### **THE USHER SYNDROME COALITION'S MISSION**

To raise awareness and accelerate research for the most common genetic cause of combined deafness and blindness, while providing information and support to individuals and families affected by Usher syndrome.

**LEARN MORE: [USHER-SYNDROME.ORG](https://usher-syndrome.org)**

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# USHER SYNDROME COALITION

## Join the **USH TRUST**

### UNRAVELING USHER SYNDROME **ONE PERSON AT A TIME**

Usher syndrome is the most common genetic cause of combined deafness and blindness. Researchers are working to find treatments and a cure. Their biggest challenge is finding enough people to participate in studies.

**Of the estimated 400,000 people worldwide living with Usher syndrome, researchers are in touch with less than 1%.**

The Usher Syndrome Coalition is working to change that with these valuable resources:

### **THE USH TRUST**

The **largest international registry** of people with Usher syndrome.

- Simple - only requires your name, email and type of Usher syndrome, if known.
- Confidential - You log in. You control your information.
- HIPAA compliant and secure.
- The place to be to learn about clinical trials.

### **THE USH BLUE BOOK**

A **global network of support** for the Usher syndrome community.

### **THE USH YELLOW BOOK**

A **centralized directory** of researchers and resources worldwide.

**JOIN NOW: [USHER-REGISTRY.ORG](https://usher-registry.org)**

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