

## The USH Trust

Video description: Kevin (a male with short brown hair and black shirt) sits in front of a dark blue background, looks into the camera and signs.

TRANSCRIPT: Today's topic is the Usher Syndrome Registry under the Usher Syndrome Coalition. If you're not familiar with it, I'll explain. This particular registry is specifically for persons with Usher syndrome. If you have a family member with Usher syndrome, or a friend of the family with Usher, please encourage them to sign up. The registry's top priority is confidentiality. It only takes a couple of minutes to fill out. It asks for basic information about the person with Usher syndrome and the type of Usher syndrome they have. That's about it. The registry has several purposes: to determine how many people have Usher syndrome; worldwide, the types of Usher syndrome that people have, as in USH1, USH2 or USH3; the ages of individuals with Usher syndrome; that type of demographic information. Your personal information is NOT shared with researchers. The registry is confidential. By registering, you help us to understand how many people have each type - USH1, USH2 or USH3 - or how many have each subtype such as A, B, etc. The more we learn from you, and from researchers who share their work with us, the more we can share back with you - which is really cool - and the better informed YOU are about what's happening in the research community like treatments, medications, a cure - whatever is being worked on. Did you know that sometimes researchers need - and will specifically seek - people with Usher syndrome, or with a specific subtype of Usher to recruit them for clinical trials or to offer them a treatment, if one is available. That is so important! The Usher Syndrome Coalition can check the registry for names of people who might be candidates to participate in trials. The Coalition - not the researcher - will let you know about these opportunities. If you decide you want more information, then you can reach out directly to the researcher, doctor or whomever. So, again, please spread the word around the world to please register! Registration is so important. It's confidential, and it helps us so that we can help you by continuing to educate the community about medication and treatments. That's information that you want, right? Thank you and again, please spread the word and also please consider making a donation. I encourage you to help us reach our goal. Thank you!