Resources Available Through the Usher Syndrome Coalition

Opening screen: Kevin (a male with short brown hair and black shirt) sits in front of a dark blue background and signs to the camera.

TRANSCRIPT: I'd like to share some resources provided by the Usher Syndrome Coalition. It's important for you to know about these so that you can take advantage of them. And there are quite a few! First - the USH Blog. These are short posts in English on the Coalition website. Some of the topics addressed in the blogs are individual's experiences with Usher syndrome, their hopes for the future, the latest research and treatments for Usher syndrome, or things that you should be aware of. Another resource is the USH Blue Book. This is like an online support group where the Usher community can share, experiences, ideas and information. The group includes parents of children with Usher syndrome, medical professionals, and many others. It's a great support system for the community. Another resource is called "Unraveling USH." This initiative supports genetic testing so individuals can find out what type of Usher syndrome they have. That's a wonderful resource! So important! For that initiative, the Usher Syndrome Coalition partners with the University of Iowa which has expertise in genetic testing. If you check the Unraveling USH part of the website you'll find lots of information about genetic testing. There are even sample letters that you can download to share with your doctors, or the insurance companies. If your insurance doesn't pay for genetic testing, the University of Iowa has funds to help those who need it. That's a great resource so we want to make sure to share that one! Have you heard about our "USH Talks?" Those are monthly presentations with PowerPoints, captions and voice. Presenters are experts in Usher syndrome: researchers, doctors, or a person living with Usher syndrome. The presentations are brief but rich in ontent! One of the benefits of the USHTalks is that instead of waiting for the yearly conference, you can get that information now! What a great resource - every month! It's a good one! So those are just some of the great resources we provide. If you want to know more. go to the USC website - http://www.usher-syndrome.org Enjoy...and don't forget to share! Thank you!