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USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDED IN SCIENCE

A balance of research news and well-being for the Usher syndrome community

Happy holiday season! We hope everyone is staying safe, warm, and well. We at the Usher Syndrome Coalition are here for you and empathize with the additional stressors that come with the holiday season.

Were you able to attend the webinar for the launch of our Usher Syndrome Data Collection Program (DCP)? If not, you can now access the recording and transcript here and learn how this valuable platform will advance research efforts for Usher syndrome.

We want to reassure you that this new platform **will not replace the Usher Syndrome Coalition's USH Trust**. We will continue to grow, build and connect our community through the USH Trust. In parallel, the Usher Syndrome Data Collection Program will allow you to contribute to, and become involved in, more research opportunities.

USHER SYNDROME DATA COLLECTION PROGRAM IS OPEN!

The Usher Syndrome Data Collection Program is open and we invite you to participate by sharing your data, which is critical for research toward treatments.

The Usher Syndrome Coalition community has partnered with RARE-X to build this data collection program for Usher syndrome individuals and families. RARE-X is a 501(c)(3) nonprofit created by leaders in the fields of patient advocacy, medical research, biopharma, and technology.

Using the Data Collection Program (DCP), the Usher syndrome community has the opportunity to share their medical journey in a comprehensive manner. More data allows the science community to gain better insight into how to structure their research and make connections that may have previously gone unnoticed.

Data collection is a crucial step in the scientific process.

Participating in this free service gives you a platform to be heard and empowered by actively encouraging researchers to prioritize Usher syndrome.

Become an Usher syndrome data sharer to help advance research and accelerate treatments.

Join Now

NATURAL HISTORY STUDY SPOTLIGHT

Uni-Rare Natural History Study for People with Inherited Retinal Diseases Caused by Rare Mutated Genes

In a recent press release, Foundation Fighting Blindness shared that they will be funding "$8.6 million for its Uni-Rare Study, a new natural history study for approximately 1,500 people with one of more than 300 rare genes associated with inherited retinal diseases (IRDs)."

Natural history studies allow for a more comprehensive understanding of retinal degeneration and disease progression by observing, collecting, and documenting clinical data.

The Uni-Rare Study will prioritize genes that do not already have studies in progress and will consist of two parts. All participants will have an evaluation to collect genetic data and clinical data. Those who have mutations in the RDH12 (LCA) and MYO7A (USH1B) genes may qualify for the second part of the study where clinical data is collected for four additional years. FFB asserts that "Additional gene cohorts for this part of the study are expected to be added in the future."

ADDITIONAL RESOURCES:

- November 10, 2022 Press Release
- ClinicalTrials.gov Study Record Detail

For more, check out our Current USH Research page specific to USH subtype as well as other gene-independent therapeutic approaches.

View Current USH Research

IN CASE YOU MISSED IT: SCIENCE NEWS FEATURE

Ultrasound gave us our first baby pictures. Can it also help the blind see?

Researchers at the University of Southern California are currently testing to see if ultrasound stimulation can use ultrasound waves to stimulate the nerves in the eye, as opposed to traditional electrical stimulation, which requires invasive surgical implants.

If we close our eyes and rub them, we see shapes and bright spots. Researchers are using this phenomenon to study how putting pressure on the eye, via ultrasound, can activate neurons and send signals to the brain.

To study this, researchers are using blind rats equipped with a small, external, ultrasound device that directs and sends sound waves to specific parts of the retina to cause this type of pressure.

This type of ultrasound device is similar to the ultrasound probe used to look at unborn babies. Researchers have discovered that the patterns of the ultrasound waves can be changed and the brain will pick up these different patterns.

What this means for Usher syndrome: This research is still in the early stages but may become a viable therapeutic option for vision loss that does not require surgery. Researchers are currently conducting studies with animal models but may expand to human clinical trials in the future.

READ ARTICLE

For more science news, check out our Science News page, organized by treatment approach and type of Usher syndrome.

ON WELL-BEING: PATIENCE AND FEELING OUT OF CONTROL

With the year 2022 coming to a close, it's important to take moments to pause and breathe. It’s easy to get overwhelmed with everything that the end of the year can bring. It may help to ask yourself, “What can I do **at this moment** to make things a little better?”

The Merriam-Webster dictionary **defines patience** as, “bearing pains or trials calmly or without complaint”.

People with Usher syndrome can sometimes feel a lack of patience or control as they experience unpredictable hearing and vision loss while knowing there is not yet a treatment or cure. Learning the art of patience is not easy, but it can be fulfilling.

Learning **patience** is vital to overcoming the fears surrounding feeling out of control.

We can’t control other people; we can’t control the rate at which research progresses; we can’t control the rate at which we experience greater vision or hearing loss, we can’t control our mother-in-law’s persistent requests for dinner.

We CAN control how we choose to respond to feelings of frustration and lack of control. If we allow ourselves to slow down, pause, and breathe, we discover that we have the ability to regain a sense of control by making conscious and well-thought-out decisions about our reactions and responses. We can even take time to develop and practice proactive responses to situations that we anticipate may arise during family gatherings and holiday celebrations.

We can understand that research is a long, slow process, and be patient as the work continues. But rather than sitting on the sidelines helpless, we CAN take active measures within our control, like participating in the Usher Syndrome Data Collection Program, as well as sharing this information with friends and family living with Usher syndrome.

USH Life Hack of the Day

Have you ever been stuck on a bus or train with an unexpected delay or maybe you missed your connection? For someone who is DeafBlind, having an accessible way to alert others about plan changes is important, particularly if options like Video Relay Service (VRS) are inaccessible or unavailable. Technology is the ultimate USH Life Hack because it has become instrumental in how we connect with others. T-Mobile IP Relay makes it easy for a DeafBlind person to contact someone using a phone, tablet, and/or computer, and any braille device. Learn more here.

Send your USH life hacks to info@usher-syndrome.org