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USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDED IN SCIENCE: February 2023

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

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Hello! 2023 continues to be a year with promising, meaningful goals coming to fruition. We have been working tremendously hard behind the scenes on several initiatives and continue to thank you for your patience!

In the meantime, we would love to thank those who have been filling out the surveys in the Usher Syndrome Data Collection Program (USH-DCP), powered by RARE-X. The data is already showing some interesting correlations. The more who register on this platform the more data it provides to researchers, improving our understanding of Usher syndrome!

Learn more here and watch our informational webinar (ahora en español).

Join Now

RESEARCH SPOTLIGHT

RUSH2A Natural History Study: Rate of Progression in USH2A-related Retinal Degeneration

In the spring of 2017, the Foundation Fighting Blindness launched a natural history study known as RUSH2A, which spanned 20 clinical sites globally. A natural history study "is a preplanned observational study intended to track the course of the disease." Jacque Duncan, MD, chairs the

RUSH2A study, which aims to understand the natural history of disease progression in individuals with USH2A mutations, which can cause vision loss only, or both vision and hearing loss.

For people with USH2A, the progression and symptoms can vary widely, which makes it difficult to design clinical trials to test investigational products and to offer prognoses. This multi-year natural history study with 127 participants provides researchers with data to map disease progression and structural changes in the eyes over a more extended period.

Information collected from this study can be used to "accelerate the development of outcome measures for clinical trials." In this USH Talk, Dr. Jacque Duncan explains the importance of this natural history study and its impact on helping to find a treatment.

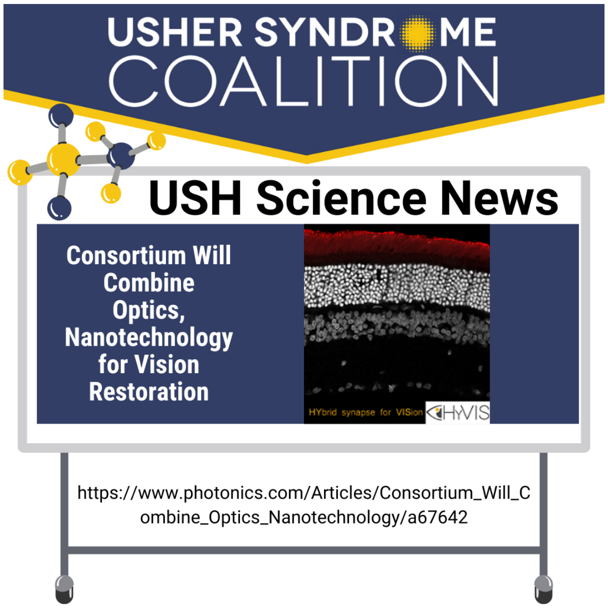
Data from the RUSH2A study should be revealed later this year, so please stay tuned to our monthly "Grounded in Science" newsletter and the Usher Syndrome Coalition website for updates!

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

View Current USH Research

IN CASE YOU MISSED IT: SCIENCE NEWS FEATURE

Consortium Will Combine Optics, Nanotechnology for Vision Restoration
HyVIS (Hybrid synapse for VISion) is an EU-funded initiative launched with the goal of developing a method to restore sight in people with degenerative eye diseases like retinitis pigmentosa. This initiative hopes to do so by restoring the photoreceptors' light sensitivity using a hybrid synapse (a small space between nerve cells and photoreceptors). The team will create a retinal neuroprosthesis that will act like the original synaptic connections using neuronal functionality that remains in the diseased retina. Researchers will create a channel that can release glutamate (a type of signaling molecule) when it receives an optical stimulus, similar to the normal response due to light stimulation. It will interact with the remaining retinal cells. HyVIS has received $3.39 million and is composed of six European institutions with expertise in material science, chemistry, physics, neuroscience, and medicine.



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USH Science News

Consortium Will Combine Optics, Nanotechnology for Vision Restoration

https://www.photonics.com/Articles/Consortium_Will_Combine_Optics_Nanotechnology/a67642

What this means for Usher syndrome: Vision loss in Usher syndrome is caused by retinitis pigmentosa (RP). This initiative is attempting to develop a therapy for RP. The project will last four years with the final goal of developing a way to restore sight. It is in its early stages but could potentially offer a way to restore vision in Usher syndrome patients.

Read our summary here.

READ ARTICLE

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

ON WELL-BEING: FEELING YOUR FEELINGS

Receiving an Usher syndrome diagnosis evokes a lot of emotions. It is overwhelming to be told that you are going deaf and blind or that your child will one day be deaf and blind. It's completely normal and acceptable to feel fear associated with these losses; fear of progressive loss, fear of the unknown.

Grief surrounds the loss of what you thought the future would be, along with new and raw grief when your vision changes. It can be just as challenging for family members - especially parents - as it is for the individual with Usher syndrome. While eagerly awaiting and hoping for research advances and news, it's important to recognize and tend to the management of heavy feelings that are being experienced now.

The grief cycle is traditionally accepted to be: Denial, Anger, Depression, Bargaining, and Acceptance. Grieving is not a linear process; you will go back and forth between these stages. You may restart these stages again every time you experience a noticeable change in your vision. You may get used to a certain plateau in your vision and then experience a change, taking you back to the beginning of the grieving process.

Your emotions won't always make sense. They are overwhelming and the best way to manage them is to give yourself permission to *feel* your feelings.

The only way out is through.

There is often a lack of closure because the future holds uncertainty. Living in the acceptance stage means that you are able to hold space for multiple emotions: hope for the future, fear of the unknown, grief and loss. The future can be exciting because there is SO much to gain, too. It is not all loss.

Having a strong #USHFamily gives us a safe space to process some of these intense feelings with people who "get it." The USH Blue Book is a private Google forum where families can connect, share experiences, ask questions, and validate each other. A sense of community with those with shared experiences is essential.

When you find each other, it is a gift to realize that your feelings are **valid** and **you are not alone**. Do whatever you can to find each other. Connection is a part of the human experience and will provide support and nurturing when you need it most.

USH Life Hack of the Day

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

Relay Conference Captioning service or RCC can help anyone who is deaf or hard of hearing engage in group conversations in a videoconference, multi-party conference call, or webinar. Using the same high-quality captioners that produce closed captioning for television, RCC users receive free, live, real-time text streamed to a computer connected to the Internet anywhere. Not all states offer this service. Here is a list of those that do:

- Arizona
- Colorado
- Delaware
- Florida
- Hawaii
- Indiana
- Maine
- Missouri

- New Hampshire

- New Jersey
- North Carolina
- North Dakota
- South Carolina
- South Dakota
- Vermont
- West Virginia
- Wyoming

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