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USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDING IN SCIENCE: January 2023

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

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Happy New Year! Can you believe it's already January 2023? It feels like time is flying by. We have some amazing things planned for this upcoming year and we can't wait to share it all with time.

Before diving in, we want to first update you on the launch of the Usher Syndrome Data Collection Program.

USHER SYNDROME DATA COLLECTION PROGRAM

In November, the Usher Syndrome Coalition hosted a webinar announcing the launch of a new [Usher Syndrome Data Collection Program \(USH-DCP\)](#), powered by RARE-X. To date, 64 people from 14 countries have already registered! For more information, watch [our informational webinar](#).

[Join Now](#)

RESEARCH SPOTLIGHT

Westerfield Drug Screening

2023 is the second year of the Usher Syndrome Society (USS) Translational Research Grant program. To date, USS has funded \$625,900 in Preclinical Research and/or Mechanism-based Therapeutic

Development. One of the projects it is helping to fund is led by [Dr. Monte Westerfield](#). Using zebrafish that have the mutations in their genes that cause Usher syndrome, Dr. Westerfield is testing already FDA-approved drugs to see if they have the ability to help Usher syndrome symptoms. Because zebrafish models can “grow quickly and are inexpensive,” Dr. Westerfield will be able to test many drugs for many types of Usher syndrome including USH1F, USH1B, USH1C, USH1D, USH1G, USH2A, USH2C, and USH3A. In addition, the Usher Syndrome Society funded a new USH3A Zebrafish model to add to the drug screening panel.

ADDITIONAL RESOURCES:

- [Usher Syndrome Society Translational Research Grants](#)
- [Westerfield Lab](#)

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

UW Study Finds Photoreceptor Cells From Retinal Organoids Can Replicate Key Functions Of Vision

Researchers at the University of Wisconsin School of Medicine and Public Health, including [David Gamm, MD, PhD](#), were able to create retinal cells from human stem cells that can detect light and change it to electrical waves. These retinal cells grow as three-dimensional mini retinas called organoid cone photoreceptors, and are the first of their kind made from stem cells that can respond to light. This is the first time scientists were able to obtain photoreceptors that can be activated by this natural stimulus. These new retinal cells have responses that were light-specific, which is what should happen in an eye that does not need stem cell therapy. The researchers want to improve on these cells and will use them in models that resemble retinas with degenerative diseases like retinitis pigmentosa.



What this means for Usher syndrome: This research is still in its early stages but it could be a potential therapy in the future to replace damaged cells in the retina of individuals with Usher syndrome.

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: BALANCE

What does balance mean to you?

Usher syndrome is the leading genetic cause of combined deafness and blindness. It can also cause vestibular dysfunction, most often in Usher Type 1 and Usher Type 3.

Vestibular dysfunction affects an individual's sense of balance. Our brains receive information from our bodies to piece together a puzzle of what the world looks like. It takes cues from the environment and cues from our five senses to guide us through the world. Our brains also take cues from proprioception, our body's ability to sense movement, action, and location, present in every muscle movement we make.

If we have Usher syndrome and our vision and hearing are failing, and our vestibular system is dysfunctional, it is very difficult to find balance in this wobbly spinning earth.

Sometimes that means we need to close our eyes, dig deep, find those proprioception muscles, and learn new ways to balance.

It's scary. To balance the old way of seeing the world and a new way of seeing the world.

Thankfully, we have a strong community to lean on while we each learn to find a way to balance on our own.

We are here for you to help you find what you need to be able to achieve balance in your life.

USH Life Hack of the Day

"If you have difficulty moving through a dark room or along a path in very dim light - like at dusk under trees, put your smartphone in camera mode and hold it in front of you. The phone displays a continuous updating image automatically adjusted for low light levels, hence is brighter and has more contrast, allowing you to see the path ahead of you." - LC

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

