CORRECTION:

It has been brought to our attention that the Research Spotlight included in today's Grounded in Science newsletter was outdated and misleading, given the recent press release from Frequency Therapeutics that their phase 2b clinical trials failed to reach their primary endpoints. As such, they have ended their clinical trial and the company will no longer focus on regenerative therapies for hearing loss.

Other groups are currently developing treatments for hearing loss that may one day benefit Usher syndrome patients. We hope to provide further progress updates in future Research Spotlights. Stay tuned!

Our team at the Usher Syndrome Coalition will do our best to share accurate and up-to-date research news with the Usher syndrome community. We apologize for the confusion.

WWW.USHER-SYNDROME.ORG

USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDED IN SCIENCE: March 2023

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

Access the PDF in English | Acceder al PDF en español

Can you believe it's already March? We hope you saw our last email announcing some exciting events in 2023 and the date for next year's USH Connections Conference (July 19-20, 2024). Next month, April 26-27, 2023, our USH Champions are returning to Capitol Hill to advocate for Usher syndrome research. If you're interested in joining us, fill out this form.

We also launched the Usher Syndrome Coalition Discord Community Server! Have you joined yet? It's a safe place for the community to connect with each other. Join here: https://discord.gg/czwHGaDu7W

RESEARCH SPOTLIGHT

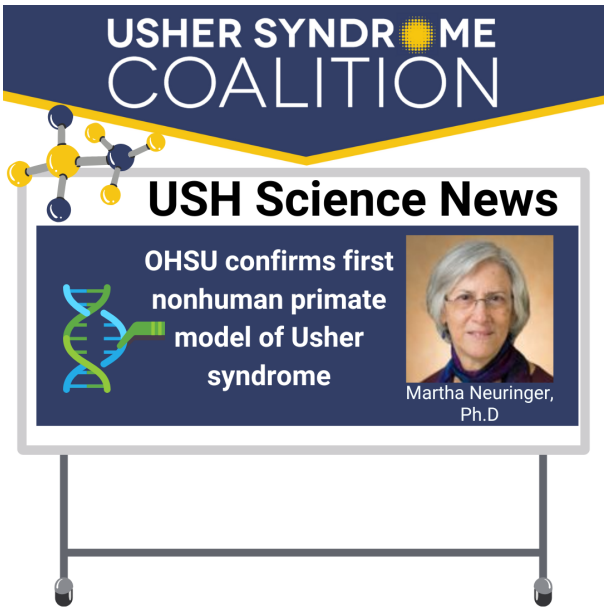
Removed due to outdated information

View Current USH Research

IN CASE YOU MISSED IT: SCIENCE NEWS FEATURE

OHSU confirms first nonhuman primate model of Usher syndrome

Martha Neuringer, Ph.D., leads the research team at OHSU, Oregon Health & Science University, that confirmed the first-ever nonhuman primate model of Usher syndrome.



Dr. Neuringer's lab created a monkey with the MYO7A mutation that causes Usher Type 1B. For the first time, an animal model demonstrates all three phenotypes of USH1B: deafness, impaired balance and retinal degeneration.

This is significant because primates are the closest genetic cousins to humans, and having this animal model allows scientists to better understand Usher syndrome and test potential treatments.

READ ARTICLE

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

ON WELL-BEING: GROUNDED IN OUR SENSES

Usher syndrome affects vision, hearing and balance. It can result in the feeling that the other senses are heightened, causing sensory overload. All of our senses have the ability to ground us in different ways, giving us the power to manage our emotional state at anytime, in any space.

A few examples are:

- Take a shower with your regular water temperature. Over time, gradually reduce the water temperature so that you can tolerate cold water for the last 30 seconds.
- Stand outside and feel the warm sun (or cool air) on your skin.
- Go to a darker room with less visual stimulation.
- Take a "hearing break" by finding a quiet room in the house to sit in. Turn off your hearing aids or remove your cochlear implants.

The key to making it work is to focus on what is happening in the present moment. Notice what your senses might be trying to communicate to you.

Are you feeling overwhelmed because there is too much going on? Or maybe you are UNDERwhelmed and need to connect to one of your senses.

Think about your favorite sensory experiences. Do you have a favorite scent? A favorite texture? Favorite sound?

Journal about it, try out some of the tips above, and figure out what works for you!

USH Life Hack of the Day

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

Usher syndrome affects hearing to various degrees, making it challenging to find an effective alarm clock to wake up even the deepest of sleepers. Because we can't all wake up naturally whenever we

feel like it, try looking for an alarm clock that wakes you up using your other senses! Some examples are vibrating alarm clocks or alarm clocks that emit light.

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