

USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDING IN SCIENCE: September 2023

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

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Usher Syndrome Awareness Day is in six days! So far, the Usher community has received proclamations from 11 states. Here's the [full list](#) (found on the right side-bar). Have we missed any? Send proclamations our way at info@usher-syndrome.org.

How are you recognizing the global day for USH this year? Be sure to tag the Usher Syndrome Coalition and use the hashtag #USHDay2023 so we can share your activities with the community!

There will also be a few USH Local Socials taking place on or near that day, September 16th - check out some locations [here](#).

Where in the world is USH?

Let's show where our #USHFamily is for this global Usher Syndrome Awareness Day! You have **two more days** to send in your short (8-10 second) video to help

Follow the example in [this video](#) to be featured in a reel shared on Usher Syndrome Awareness Day, September 16, 2023! Videos must be received by September 12th to be included. Send to @UsherCoalition via Direct Messenger on [Instagram](#) or [Facebook](#).

Usher Syndrome Data Collection Program

If you haven't logged into your account in the [Usher Syndrome Data Collection Program](#) (USH DCP) lately, now is the time to do so! Be sure to upload your genetic reports and fill in the new surveys as they appear on your portal. We will start compiling some of the de-identified data to share this month.

Have you joined the Usher Syndrome Coalition [Discord](#) Community Server? It's a safe place for the community to connect with each other. Join here: <https://discord.gg/czwHGaDu7W>

RESEARCH SPOTLIGHT

Kiora's Investigational Treatment for Retinitis Pigmentosa, KIO-301, Demonstrates Visual Function Restoration in Patients Who Are Blind

[Kiora Pharmaceuticals](#) is an ophthalmic specialty pharmaceutical company with one product in clinical research intended to treat retinitis pigmentosa. In April 2023, Kiora Pharmaceuticals released preliminary data from an ongoing clinical trial for the drug KIO-310.

They consider KIO-310 a “[Molecular Photoswitch](#)” drug, a small light-sensing molecule with the potential to restore light perception in patients who are blind or living with ultra-low vision due to retinitis pigmentosa. This small molecule works with a different type of cell in the retina, retinal ganglion cells, turning them into makeshift light-sensing cells. Preliminary data demonstrated that patients experienced improved light sensation, thus improving functional vision. This treatment approach is gene agnostic, meaning that it has the potential to be a viable treatment for the Usher syndrome community down the road.

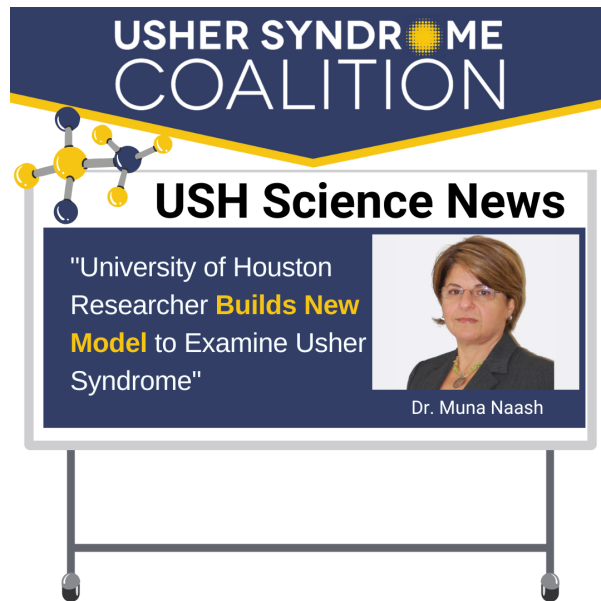
For more, check out our Current USH Research page specific to [USH subtype](#) as well as [gene-independent therapeutic approaches](#).

[View Current USH Research](#)

IN CASE YOU MISSED IT: SCIENCE NEWS FEATURE

University of Houston Researcher Builds New Model to Examine Usher Syndrome

April 17, 2023: An important component in the journey to developing treatments for Usher syndrome is having an animal model to understand what is happening on a cellular and genetic basis. With Usher syndrome specifically, it has been historically challenging to produce a model that has both the hearing loss and visual problems reported in patients. [Dr. Muna Naash at the University of Houston reported](#) successful design and generation of a model with a specific gene mutation found in USH2A (c.2299delG) that shows retinal degeneration.



What this means for Usher syndrome: Having a model that reproduces the USH2A retinal phenotype is a solid starting point for designing future therapeutic interventions. It also allows Naash's team to study the mechanism of the disease more thoroughly.

[READ ARTICLE](#)

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

DISCLAIMER: The Usher Syndrome Coalition does not provide medical advice nor promote treatment methods. USH Science News is intended to help summarize more complex literature for the community to use at their own discretion.

ON WELL-BEING: Internalized Ableism

What does "ableism" mean to you? What does the phrase "internalized ableism" make you think about? Perhaps the beliefs and values society holds about disabled people?

[Merriam-Webster's definition](#) of the word "ableism" is: "*discrimination or prejudice against individuals with disabilities.*" Ableism is often deeply embedded in culture where disabilities are something to "overcome," or are tolerated at best.

Failure to comply with disability rights laws, like the Americans with Disabilities Act (ADA), often stems from ableism. Smaller, sometimes subconscious examples of ableism, called *microaggressions*, include but are not limited to:

- Ignoring requests for accommodations (i.e., captions during virtual meetings).

- Refusing to acknowledge someone's disability.
- Saying, "You don't look disabled," as though this is a compliment.
- Using words like "normal" and "healthy" to describe non-disabled people.
- Viewing a person with a disability as inspirational for doing typical things, such as having a career.

The effects of ableism may be so prevalent that people with disabilities may impose society's ableist standards on themselves.

This is known as ***internalized ableism***.

Internalized ableism can have various impacts. It can cause people to struggle to advocate for their needs because they've internalized the sense of not wanting to "be a burden."

Internalized ableism can be experienced in different ways, including feeling like you don't fit into the disability community, feeling that you don't "deserve" accommodations, etc. "When emulating the norm, the disabled person is required to embrace an identity that is not one's own." ([Jóhannsdóttir, 2022](#))

The effects of internalized ableism may also be compounded by a feeling of injustice, a sense of frustration with having to educate others about your disability, the accommodations you need, and sometimes the need to remind others that you do indeed have a disability. ([Kattari, 2018](#))

Usher syndrome can be considered an "[invisible disability](#)" because, to an outsider, you "look normal." Do you ever feel like you have to "prove" your disability? Do you ever struggle to ask for accommodations?

We are here to remind you that you are worthy, you are valued, and you are not alone.

USH Life Hack of the Day

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

[SignUp](#) is a free-of-charge Google Chrome Extension that provides sign language interpretation on Disney+ and Netflix videos. SignUp is currently available in the UK and USA, in British and American sign languages. India, Pakistan, Canada, and Australia are their next launches.

"We've introduced SignUp Captions on Disney+ to enhance our son's language development. While he currently relies on oral language for communication, we believe it's crucial for him to have exposure to signed captions as he begins to learn ASL. We're incredibly thankful for the opportunity to offer him this valuable resource."



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