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USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDING IN SCIENCE: August 2025

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

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We are wrapping up our lighter programming for summer as fall approaches. In last month's newsletter, we shared how we're excited to bring you timely and relevant content that keeps you connected to the latest developments in the field. We will return to regularly scheduled programming in September. We want to hear from you! What topics would you like us to explore in future newsletters? What research areas are you most curious about? Which aspects of science would you like us to dive deeper into? Your input helps us create content that truly serves our community's interests and needs. [Let us know here.](#)

Usher Syndrome Awareness Day is September 20th this year. It occurs on the third Saturday each September. We will share USH meet-ups, community events, and fundraisers hosted by our incredible USH community. If you are hosting a social event or fundraiser, please email communications@usher-syndrome.org so we can share it with the USH community.

We hope you enjoy this summer edition and look forward to your feedback and suggestions. Thank you for being part of the Usher Syndrome Coalition community.

Join the USH Trust to stay updated on clinical trials and new participant criteria. Only ten questions need to be answered to register.

Join the USH Trust

RESEARCH SPOTLIGHT: TIGEM Presents Promising Results for LUCE-1 Gene Therapy Clinical Trial for Usher Syndrome Type 1B

On July 29, 2025, TIGEM (Telethon Institute of Genetics and Medicine) [published an article](#) with updates on the LUCE-1 gene therapy clinical trial sponsored by AAVantgarde Bio. The new dual vector gene therapy trial has been tested for the first time at Vanvitelli University in Italy. The first patient, a 38-year-old man, showed significant improvements in his vision after a year. He reported he can now recognize faces, read subtitles, and move around more easily, even in low light.

What does this mean for the Usher syndrome community?

Usher syndrome type 1B (USH1B) is caused by mutations in the MYO7A gene, which is too large for traditional gene therapy methods. Researchers have developed a new way to deliver the gene using two virus “carriers” that work together inside the body. So far, seven additional patients have been treated in the international phase I/II clinical trial LUCE-1. The data collected to date show that the therapy is safe and may improve vision within weeks. The clinical trial is still ongoing, but these early results are an important first step in seeing how well this new technology works for patients.

For more details, refer to the [Article Link from TIGEM](#)

For more information about LUCE-1, check out the [AAVantgarde Bio website here](#).

Check out our [Current USH Research page](#) specific to USH subtype as well as other [gene-independent therapeutic approaches](#).

View Current USH Research

ON WELL-BEING

What well-being topics and professional advice would you like to dive deeper into in the coming months? As our USH community continues to grow and technology advances alongside innovations in research, we aim to provide timely resources and support. [Share your ideas and requests here](#).

USHER SYNDROME DATA COLLECTION PROGRAM

As the world continues to get to know the individuals living with Usher syndrome, it's a great time to join the Usher Syndrome Data Collection Program - the [USH DCP](#) - so researchers can better understand this diagnosis. If you'd like additional support enrolling, please reach out to Yael Saperstein, our Community Enrollment Coordinator for the USH DCP. Yael is an expert on the enrollment process, accessibility, and guiding new participants every step of the way. Contact Yael here: y.saperstein@usher-syndrome.org.

USH Tip

We're all about finding and sharing the creative ways the Usher community navigates life more easily with Usher syndrome.

Send your USH Tips to info@usher-syndrome.org

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>



Our Contact Information

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