

USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDING IN SCIENCE: July 2024

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

[Access the archives in English](#) | [Acceder al PDF en español](#)

USH Connections Conference | July 19-20, Rochester, NY + Online
Hosted in partnership with the National Technical Institute for the Deaf

[Register here.](#)

Sign up to have your Portrait Taken for the Usher Syndrome Society's Shine A Light on Usher Syndrome Exhibit!

Our USH Partner, the Usher Syndrome Society, will be photographing portraits for the Shine a Light on Usher Syndrome Exhibit! If you have Usher syndrome and would like to have your portrait taken for the Shine a Light on Usher Syndrome Portrait Exhibit, please sign up for a time slot on July 19th or 20th!

[Sign up link](#)

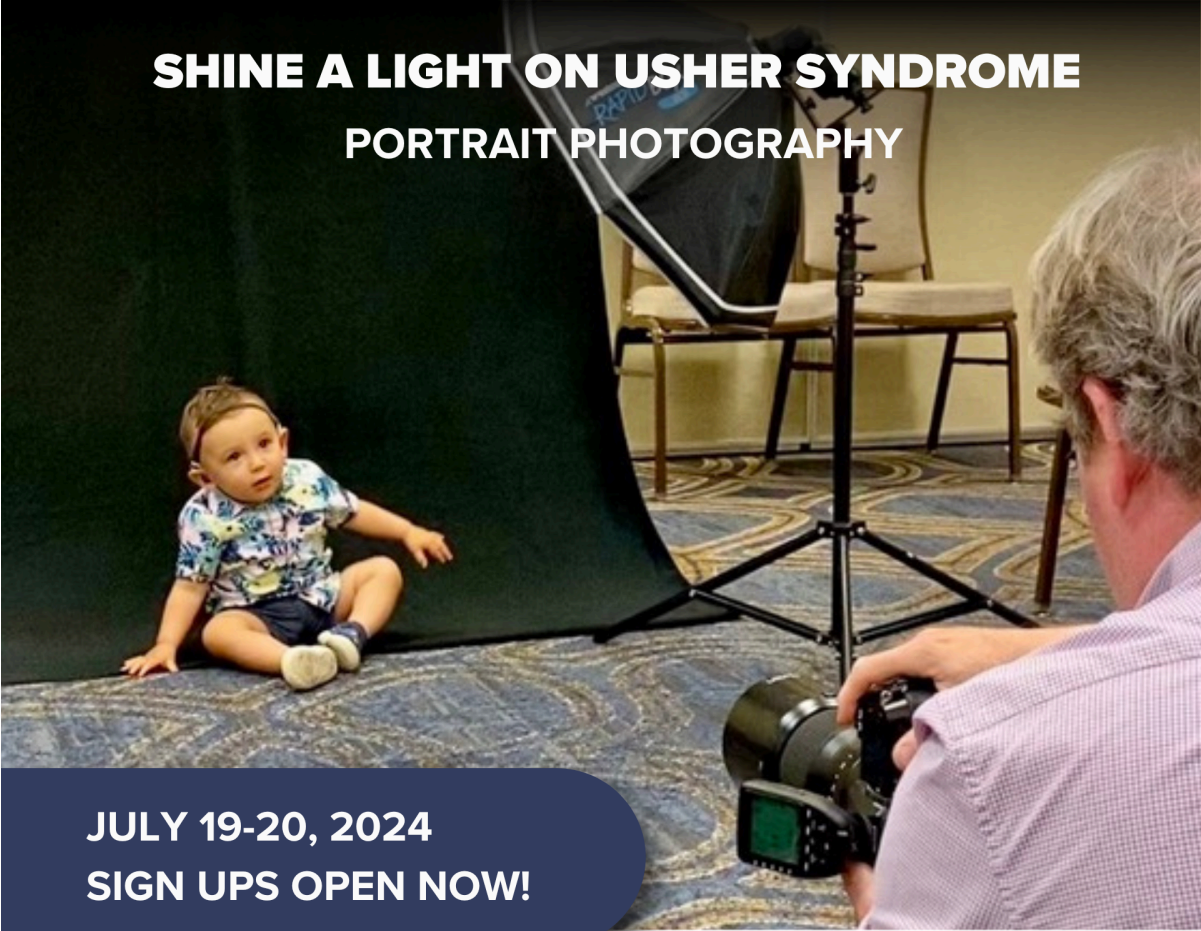
What is the Shine a Light Exhibit?

The Shine a Light on Usher Syndrome is one of the Usher Syndrome Society's primary awareness initiatives designed to share the faces and stories of the Usher syndrome community. Over the last 8 years, the Usher Syndrome Society has worked with renowned photographers to curate the largest collection of portraits documenting the individuals and families around the world living with this rare disease.

The Shine a Light exhibit is designed to travel the world and has been featured in universities, building lobbies, outdoor parks, museums, conference centers, and more. In May 2024, portraits from the Shine a Light collection were debuted

across 9 Times Square billboards in New York City as part of the Usher Syndrome Society's groundbreaking awareness campaign called Every Second counts.

SHINE A LIGHT ON USHER SYNDROME PORTRAIT PHOTOGRAPHY



JULY 19-20, 2024
SIGN UPS OPEN NOW!

USHER SYNDROME
COALITION
USH2024
a hybrid event

● ● ● ● usher
● ● ● ● syndrome
● ● ● ● society

RUN FOR USHER SYNDROME

We are proud to announce that we are a charity partner with the Marine Corps Marathon, taking place on Sunday, October 27 near the Pentagon in Arlington, Virginia!

Are you hoping to run “The People’s Marathon” or know anyone who wants to and needs a bib? 25 runners can claim their bibs and fundraise for the Usher Syndrome Coalition! [Sign up here](#) or email Sarah Jordan scjord00@gmail.com with any questions!

Deadline to sign up is August 31st.

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

Akouos announces the Resonate® program: genetic testing and counseling for individuals with sensorineural hearing loss

[Akouos](#) is a precision genetic medicine company that is focused on developing potential gene therapies to improve hearing. They have recently launched the [Resonate](#) program for individuals with sensorineural hearing loss. This program provides genetic testing for almost 300 genes linked to hearing loss at no cost to you, your insurance, or your healthcare providers.

What are the potential benefits of genetic testing for hearing loss?

Genetic testing has the possibility to provide a diagnosis for individuals who still do not have a diagnosis for their hearing loss. This diagnosis can provide information about additional symptoms individuals may experience later in life (for example, loss of vision). Genetic testing may also help determine if the degree of hearing loss an individual experiences is expected to be stable or progressive. Genetic testing may also provide insight into whether children of an individual with hearing loss may also experience hearing loss. Overall, genetic testing may provide individuals with the potential to make more informed decisions.

How does the Resonate program work?

Individuals under 40 years old in the US with bilateral sensorineural hearing loss (ranging from moderate to profound) and/or auditory neuropathy may qualify and should reach out to their healthcare providers to discuss this program if

interested. The Resonate program provides two testing options. The first option is ideal if your healthcare provider (including your audiologist) does not have experience with genetic testing or counseling, since it allows your healthcare provider to refer you (or your child) to a genetic counselor from InformedDNA at no cost to you, your insurance, or your healthcare providers (available via telehealth). The genetic counselor will review your health history, the genetics of hearing loss, and the limitations of genetic testing with you. If you wish to move forward after this meeting, you will receive a testing kit from PreventionGenetics to collect a cheek swab sample at home. After your sample is analyzed, you will have another appointment with your genetic counselor to discuss the test results (typically 3-4 weeks after PreventionGenetics receives your sample). Your genetic counselor will also send a report to your hearing healthcare provider to facilitate any follow-up care. In the second option, healthcare providers who are familiar with genetic testing and counseling will directly order the genetic test for you.

If you are interested in participating in the Resonate program, reach out to your healthcare provider.

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

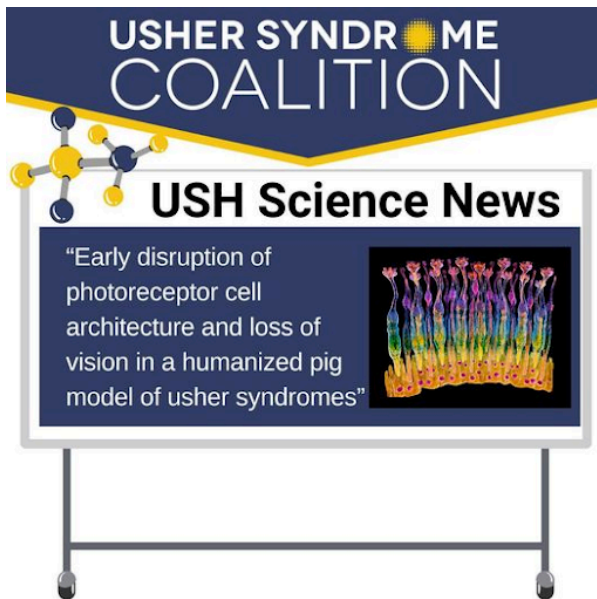
View Current USH Research

IN CASE YOU MISSED IT: SCIENCE NEWS FEATURE

Early disruption of photoreceptor cell architecture and loss of vision in a humanized pig model of usher syndromes

March 7, 2022: The researchers conducting this study aimed to develop a new animal model of Usher syndrome using pigs because pig eyes are more similar to human eyes compared with other small animal models like mice or fish. To mimic the human condition, they made a specific genetic change that is found in patients to the USH1C gene in pigs.

The USH1C pigs showed similar symptoms to humans with USH1C, including the loss of hearing, balance, and vision. They also found disruptions in the structure of the photoreceptors, which are the light-sensitive cells in the retina. Additionally, the researchers tested a potential new gene therapy treatment in the eyes of the USH1C pigs which showed promise in restoring their vision.



What this means for Usher syndrome:

Overall, this study aimed to create a more accurate animal model for studying Usher syndrome to improve our knowledge of the disease course and to test new treatments. Accurate animal models will allow researchers to understand more about Usher syndrome and test potential treatments in the future.

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: DeafLEAD

DeafLEAD: Comprehensive Support for the Deaf Community

Founded in 1995, DeafLEAD provides extensive support to Deaf, Hard of Hearing, Late-Deafened, and DeafBlind individuals. Originally established to manage a substance use prevention camp for teens, DeafLEAD has grown into a vital organization offering a range of services to address trauma and distress. They provide emotional support, access to resources and provide services including crisis intervention, safety planning, advocacy, and more.

Living in a hearing world requires Deaf people to continually advocate for accessible communication. DeafLEAD's trauma-informed approach ensures that individuals receive culturally competent support, helping transform negative situations into positive outcomes. This advocacy can lead to significant life changes, such as escaping abusive relationships, regaining child custody, and accessing better housing and financial stability; all of which may have been previously inaccessible due to cultural and language barriers. In addition to

advocating for individuals, DeafLEAD also provides educational training for shelter and service providers as a way of advocating for their clients.

DeafLEAD offers Trauma Center Trauma Sensitive Yoga (TCTSY), an empirically validated clinical intervention for complex trauma and chronic, treatment-resistant post-traumatic stress disorder (PTSD). All practices are online, with no special equipment needed beyond internet access, giving one full autonomy over their space and body positions.

For nearly 30 years, DeafLEAD has been a beacon of support, ensuring that Deaf individuals have access to the resources they need to thrive in a predominantly hearing world. Through dedicated advocacy and specialized programs, DeafLEAD continues to make a profound impact on the lives of those they serve.

Deaf Crisis Line (DCL)

DCL supports callers who are facing a variety of challenges and are victims of crimes.

Videophone: 321-800-3323

[DCL ASL Now](#)

988 Suicide & Crisis Lifeline

988 supports callers in suicidal crisis or emotional distress.

[Chat](#), Text, Call or

[Videophone 988](#)

[988 ASL Now](#)

Disaster Distress Helpline (DDH)

DDH supports callers struggling with distress or other mental health concerns related to any natural or human-caused disaster.

[Call, Text or Videophone 1-800-985-5990](#)

We share the research and peer-reviewed literature that offers insight into well-being: the science behind staying grounded. Fill out this [poll](#) to request a topic.

Check out our Mental Health Resources webpage

DISCLAIMER: The information and resources on this website are provided for educational and informational purposes only and do not provide medical or treatment advice.

USH Life Hack of the Day

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

"Keep the floors of your home tidy to minimize trip hazards." - USH Community Member



Our Contact Information

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