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USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDED IN SCIENCE: October 2025

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

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Welcome to the third anniversary of the *Grounded in Science* newsletter. The first edition launched on World Mental Health Day, which occurs every year on October 10th. We want to thank you, our dedicated readers, for three years of continued support and engagement. Your readership has helped us grow into a trusted source for science news, research updates, and well-being resources for those living with Usher syndrome. We remain committed to sharing accurate, meaningful information that empowers our community and supports both physical and mental health. Here's to many more years of learning and connection together!

Usher Syndrome Awareness Day 2025

Thank you to our global USH Community for another incredible Usher Syndrome Awareness Day on September 20th. We loved seeing our community members gather, advocate, reminisce, and acknowledge USH Day. Here is a recap of the global observances and events this year.

Every year, many of our USH Ambassadors, USH Partners, and other interested individuals request a proclamation from their local government recognizing this day. Check out the proclamations received over the years, including the latest 2025 proclamations here.

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:
The NAC Attack study reached its recruitment goal

by Xiangrong Kong, PhD; Peter Campochiaro, MD; and Folahan Ibukun, MB.Ch.B, MPH

NAC Attack is an international phase-III clinical trial designed to determine whether taking oral **N-Acetylcysteine (NAC) 1800mg twice a day** is safe and effective in slowing vision loss in patients with retinitis pigmentosa (RP). This is the largest study ever done for RP. It is funded by the **National Eye Institute (NEI)** in the United States and led by researchers at Johns Hopkins University.

By the end of **August 2025,** the study successfully recruited **485 eligible RP patients** from **31 clinical sites** across the United States, Canada, Austria, Germany, the Netherlands, Switzerland, and the United Kingdom. This marks an important milestone for both the study and the RP community.

The support from the RP community has been extraordinary: NAC Attack would not have reached this recruitment milestone without the enthusiasm of **more than 630 patients** who underwent screening and many others who expressed interest. While not everyone could be enrolled, the study will still provide knowledge that will help people with RP and other inherited retinal diseases for generations.

Participants in the NAC Attack trial are taking study medication and will be closely monitored for **45 months**. Vision loss in RP happens slowly over decades, so long-term follow-up is needed to observe a potential effect on visual function loss. During the study period, neither participants nor their study doctors, nurses, or coordinators know who is receiving the active study medication or a placebo (a “fake pill”). This is to minimize any potential subconscious bias so the study can objectively measure changes in visual function in the participants.

With recruitment now complete, the study will have an interim readout of progression data in **early 2028**. The final results - answering the question of whether NAC is safe and effective in slowing RP progress - will be available by the **end of 2029**. Even now, this study has already gathered valuable pre-dosing data from trial participants, helping researchers better understand RP and inform the design of future trials for potential treatments.

It is important to emphasize that **we do not yet know whether long-term use of oral NAC is safe and effective** in treating RP. It **should not be taken routinely,** because the safety of a high dose of NAC (3600mg per day) over many years is not fully known. Lower doses might not slow disease progression. Although NAC is sold as a dietary supplement in the US, supplement quality can vary, and the amount of NAC in a supplement may not be accurate because the FDA does not regulate them. Some newly marketed combination supplements contain NAC, vitamins and other ingredients that are thought to be good for eye health. However, the safety of these combination supplements is uncertain, and we do not know if there are potential drug interactions with the simultaneous use of different antioxidants.

The **NAC Attack study** is very important for the RP community, as well as for researchers and doctors working to find treatments for inherited retinal degeneration. The trial can only succeed thanks to the dedication of participants, their families and friends, study doctors, and staff. Together, we are making a real difference in medical care and advancing science for RP and other inherited retinal diseases.

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

Like NAC Attack, the next study is also studying a similar antioxidant compound called NACA to see if it can slow vision loss. Read on to learn more:

September 11, 2025: **Nacuity Pharmaceuticals Announces Positive Data from Clinical Trial Evaluating NPI-001 to Treat Retinitis Pigmentosa Associated with Usher Syndrome**

Nacuity Pharmaceuticals has shared exciting news about a potential new treatment for people with Usher syndrome. They **tested an antioxidant tablet called NPI-001** to see if it could slow down vision loss.

In this trial, 49 people with Usher syndrome in Australia participated. Half received the antioxidant tablet, and half received a fake pill (placebo) twice a day for two years. Doctors carefully tracked changes in their vision and the health of their retina, and the results were encouraging: **people who took the NPI-001 tablet had a much slower rate of photoreceptor loss** compared to people who took the placebo.

Based on these positive results, **Nacuity plans to start a larger study in 2026** to confirm these findings.

The NPI-001 tablet contains an antioxidant called NACA. NACA is very similar to another antioxidant called NAC, which is being tested in the "NAC Attack" trial that recently finished enrolling participants in the US, Canada, and Europe.

This is promising news for the Usher syndrome community because NPI-001 and other antioxidant therapies have the potential to help all people with Usher syndrome, regardless of subtype.

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.

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

ON WELL-BEING: USHchats
From Curing to Healing: Rethinking Healthcare for People with Usher Syndrome

Healing vs. Curing My Usher Syndrome

by Meagan M., BSN, RN, HNB-BC

In today’s healthcare system, the primary focus is often on fixing or curing illness. While this approach has value, it can also negatively shape how we view health and wellness. As a nurse, I used to feel that I was failing my patients when their illnesses couldn’t be cured, when treatments didn’t “fix” them, or when they didn’t follow the healthy lifestyle changes or medication regimens I taught.

When I was diagnosed with Usher syndrome, that same mindset turned inward. I asked myself: *How could I ever be healthy or whole if I had a progressive disease that could not be cured?* This way of thinking was toxic, unforgiving, and deeply discouraging.

A Cure-Centered System

Throughout my nursing career, I often wondered: *Is this what nursing really is?* Didn’t Florence Nightingale emphasize the environment theory—focusing on nutrition, observation, communication, and supporting the patient’s own inherent ability to heal? (Nightingale, 1860/1969).

If healing simply meant being rid of disease, then wouldn’t most people living with chronic conditions or disabilities be excluded from ever being considered healthy or well?

In nursing school, we spoke of holistic care—caring for the whole person. At first, it seemed simple, even obvious. But it wasn’t until I pursued a nine-month nurse coaching program, became board-certified in holistic nursing, and immersed myself in the holistic healthcare model that I truly began to understand the difference between our current illness-driven system and a healing-focused model.

Redefining Healing

Dr. Janet F. Quinn describes a healing healthcare system as *“a true healthcare system in which people can receive adequate, nontoxic, and noninvasive assistance in maintaining wellness and healing for body, mind, and spirit, together with the most sophisticated, sometimes invasive curing technologies available”* (Quinn, 1992, p. 29). This definition helped me realize that I could still be a healthy person, even while living with a progressive disability.

In holistic nursing, healing is defined as *“a lifelong journey into wholeness, seeking harmony and balance in one’s life and in family, community, and global relations. Healing involves the physical, mental, social, and spiritual processes of recovery, repair, renewal, and transformation that increase wholeness and coherence. It is an emergent process of the whole system—body, mind, spirit, and environment—coming together at a deep level of inner knowing. Healing can lead to greater understanding and meaning, and may occur with or without curing.”* (Dossey, Keegan, & Guzzetta, 2005, p. 7)

These perspectives allow me to view myself as whole. I can acknowledge my progressive disability while also recognizing that I am enough. My mental and emotional health matter, my spirit is resilient, and I can live in balance. I am healthy.

Living Whole with Usher Syndrome

As a nurse, I have come to embrace the importance of meeting patients where they are. Maybe they don’t want to change their lifestyle habits. Maybe their priority is improving connections and relationships. Each of us has the right to define what wellness means in our own lives.

I wonder if others share the perspective I once held - believing that health was impossible without a cure - or the frustration of hearing from a system that says *you cannot be healthy because you cannot be cured.*

Both as a nurse and as a person living with Usher syndrome, I want to empower you to be the expert on your own condition. Fiercely share with your care team, your community, and your family what being well and healthy looks like for you.

An Invitation to Reflect

How do *you* define health in your own life—especially when a cure isn't possible yet? What does being well look like for you, your family, or your community?
I invite you to reflect on this, and if you feel comfortable, share your perspective with others. In doing so, we begin to transform not only how we see ourselves, but also how healthcare systems see us.

References

Dossey, B. M., Keegan, L., & Guzzetta, C. E. (2005). *Holistic nursing: A handbook for practice* (4th ed.). Jones & Bartlett.
Nightingale, F. (1969). *Notes on nursing: What it is and what it is not* (Original work published 1860). Dover Publications.
Quinn, J. F. (1992). *The politics of caring: From healing to holism in health care*. NLN Press.

About Meagan

Meagan has worn hearing aids since she was three years old and graduated with her BSN in 2009. At 23, she was diagnosed with Usher syndrome, a moment that changed how she thought about health, healing, and life. She lives in Redmond, Oregon, with her high school sweetheart (now husband) and their three kids.

She's extremely proud of her **Awesome Moms with USH** Facebook group, where she connects with and supports other moms living with Usher syndrome. After spending a few years at home raising her children, Meagan reignited her love for nursing by becoming board-certified in holistic nursing. Today, she's back to working full-time as an RN while balancing family life, advocacy, and community building.

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

Apps such as Aira or Be My Eyes can be great resources for the low vision community. Live agents or AI can help find objects, locate, or identify what is around you.

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

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