

USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDING IN SCIENCE: September 2024

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

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

Usher Syndrome Awareness Day is September 21st!

September 21, 2024, marks the tenth year of celebrating Usher Syndrome Awareness Day. This special day for our global community is held on the third Saturday of September each year. This is near the autumnal equinox in the northern hemisphere, which marks the beginning of days with more darkness than light, a powerful metaphor for the threat of Usher syndrome. By raising awareness worldwide, we connect those living with Usher syndrome, building a global community that speeds the search for treatments.

We created a new T-shirt design in honor of this day. With each purchase, a portion of the proceeds goes back to the Coalition to help us continue to grow, connect, and support the Usher syndrome community. Snag yours here!

<https://www.bonfire.com/usher-syndrome-awareness/>

Proclamations for Usher Syndrome Awareness Day

So far, members of our USH community have secured [proclamations for 2024](#) in the following states:

1. Illinois
2. Nebraska

If you have received a proclamation, please [share it with us!](#)

Usher Syndrome Awareness Day Events

Canada:

The CN Tower in Toronto, Canada, will light up blue and gold on September 21, 2024, to raise awareness for Usher syndrome on Usher Syndrome Awareness Day! Lighting begins at sunset and will be fully visible as the sky darkens. [Stay tuned for live views on the CN Tower website!](#)

Mexico (Modalidad Virtual): Webinar “[Síndrome de Usher: ¿Dónde estamos in Mexico?](#)” | “Usher Syndrome: Where are we standing in Mexico?”

Webinar organizado por asociaciones, especialistas médicos y aliados para conmemorar el día del síndrome de Usher en México, con el fin de proveer información de actualidad a los pacientes y familiares.

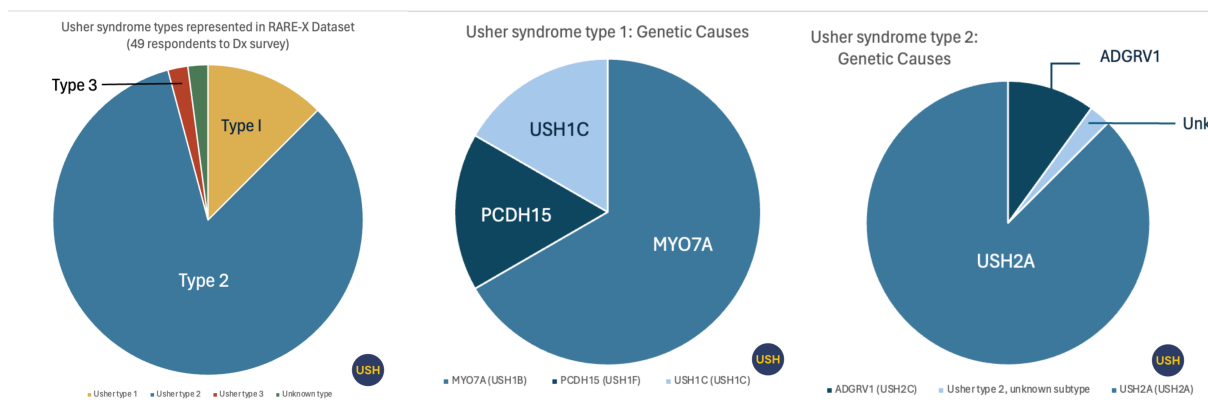
[Webinar hosted by organizations, medical specialists and allies to celebrate Usher Syndrome Day in Mexico, with the goal of providing up-to-date information to the Usher patients and families.]

[Aprender más | Learn more](#)

Usher Syndrome Data Collection Program (USH DCP)

As the world continues to get to know the individuals living with Usher syndrome, it's a great time to join the [USH Trust](#) and [USH DCP](#) so researchers can better understand this diagnosis. If you'd like additional support enrolling, please [fill out this form](#).

Once you've signed up for the USH DCP, make sure to fill out the **Diagnosis Survey**, so you'll be counted in data like this:



For additional USH DCP sign-up support please [fill out this form](#).

RESEARCH SPOTLIGHT

The Lived Experiences of Transition-Age Youth with Usher Syndrome Preparing for Postsecondary Education: A Retrospective Study

Dr. Tara Brown-Ogilvie of the Helen Keller National Center recently published her dissertation entitled, “*The Lived Experiences of Transition-Age Youth with Usher Syndrome Preparing for Postsecondary Education: A Retrospective Study.*”

She conducted interviews and focus groups with 10 college students with Usher syndrome about their transition experiences from high school into college and explored six themes:

1. Limited K-12 educational supports for postsecondary preparation
2. Perceived lack of transition planning and postsecondary preparation
3. Parents as the strongest support system
4. Discrepancy in Deaf/Hard of Hearing and vision services (more D/HH than VI)
5. The multifaceted impact of USH
6. Navigating the medical diagnosis

Additionally, implications for practice from this study include:

1. Promoting earlier diagnosis by creating resources and better USH screening processes
2. Having a DeafBlind specialist on the educational team
3. The importance of an individualized transition plan
4. Recognizing that the USH population is evolving

Read Dr. Brown Ogilvie's paper by following the link [here](#).

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

[View Current USH Research](#)

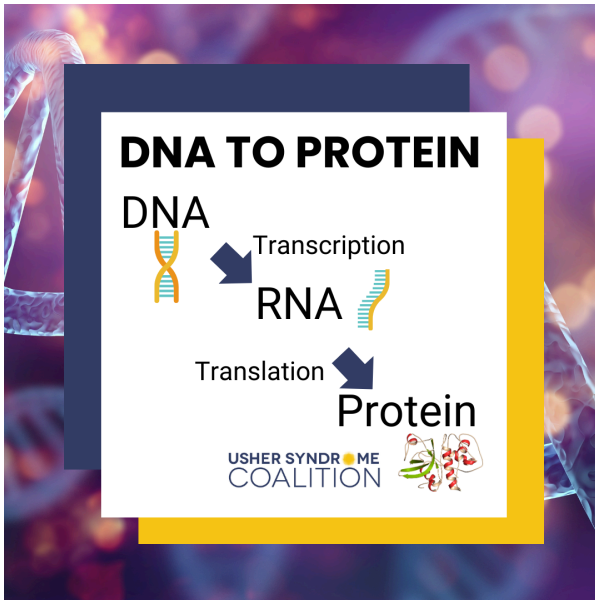
IN CASE YOU MISSED IT: SCIENCE EDUCATION SERIES

The Science Behind Usher Syndrome

This past month, we have shifted from sharing weekly science news featuring summaries of published research to go back to the basics.

We've started a science education series on social media to help you better understand the complex science behind Usher syndrome. You may have seen our posts about the difference between DNA and RNA, and how DNA makes proteins.

Just to recap, **DNA** (deoxyribonucleic acid) is a stable, double-stranded molecule that holds the genetic instructions for all living things. **Transcription** is the process where information from DNA is copied into RNA (ribonucleic acid).



RNA is a single-stranded molecule that uses this genetic information to make proteins.

Translation is when the RNA helps put together amino acids to build specific proteins. These **proteins** are like building blocks that fold into special 3D shapes to do important jobs in the body, like giving cells structure. This structure is important for vision and hearing to work properly!

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: Equity in the Workplace

By Lawreen Asuncion, Usher Syndrome Coalition Volunteer

Living with Usher syndrome challenges us all. Navigating daily life often requires various adjustments and accommodations, which can be taxing and stressful. Fortunately, we can adapt as needed—whether exploring hearing aids or cochlear implants for hearing impairments or using glasses, canes or guide dogs for visual impairments.

However, this freedom doesn't always extend to the workplace, where many in our community struggle with disability equity. A pressing concern is how to address disability needs in the work environment—whether as a candidate or employee—without risking conscious or subconscious discrimination.

This issue arises during the application process, where it's common to encounter voluntary Equal Employment Opportunity (EEO) questions about gender, race, veteran status, and disability. The list of disabilities is extensive, ranging from migraines to cancer, and it includes hearing loss and blindness. As an applicant, you're asked to respond: a) Yes, I have or have had a disability; b) No, I do not have a disability; or c) I do not wish to answer.

This creates a dilemma:

- If you answer "a," you may risk discrimination.
- If you answer "b," you could be perceived as dishonest.
- If you choose "c," it might imply you have a disability but prefer not to disclose it.

Since responding to these questions is voluntary, what's the best approach for our community? Let me share my story before offering my recommendation.

Recently, as I've navigated the job market, I've struggled with how to best answer the disability question. Historically, I answered "b" or "no," focusing on my qualifications rather than my need for accommodations, which were minimal at the time. However, as I've grown older and required more accommodations, I believed full transparency was the best approach. I had nothing to hide and still brought the same qualifications to the table, so I changed my response to "a" or "yes."

Unfortunately, I discovered that despite progress in diversity, equity, inclusion (DEI), and disability awareness, human bias persists. These biases can stem from upbringing, ingrained beliefs, or assumptions—whether right or wrong. In my case, I faced discrimination based on the assumption that my disability would prevent me from performing the job despite my years of proven experience.

According to a [5-year United Kingdom Longitudinal Study](#) published in 2020, perceived disability-related discrimination significantly impacts well-being. In this cohort study, over 13% of participants who self-reported their disability experienced disability-related discrimination, leading to depression, poor health,

greater psychological distress, worsening mental function, and low life satisfaction.

So, what does this mean for our USH community? How should we approach the EEO disability question?

I revised my strategy and now select "b" or "No" to the voluntary disability question. By controlling my narrative as an applicant, I minimize the potential for bias or discrimination from the outset, reducing unnecessary stress. As an employee, I request accommodations as needed to ensure I perform and deliver my best.

Our disabilities do not define who we are nor limit what we can achieve. By controlling our narrative, we can manage perceived discrimination and, consequently, our own well-being.

How have you handled this disability question? Have any of you experienced disability-based discrimination? How did you feel, and how did you overcome it?

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

“Use a [Phonak](#) pen in a car to help reduce the car noise so you can have conversations easier!” - USH Community Member

While we share information on assistive hearing technology that may be beneficial, the Usher Syndrome Coalition does not endorse or promote any specific product.



Our Contact Information

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