

USHER SYNDROME COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

GROUNDING IN SCIENCE: November 2024

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

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This year is flying by, and we want to take a moment to pause and reflect on what we're grateful for. At the top of our list is YOU, our Usher syndrome community. Thanks to your support, we held our largest USH Connections Conference yet, in Rochester, New York, and online. If you missed it, you can catch all the highlights and recorded presentations on our [USH2024 Connections Conference Recap](#) page.

As we approach the year's end, we hope you'll consider supporting the Usher Syndrome Coalition in this season of giving. By becoming an USH Visionary and making a monthly donation, you can make a lasting impact on our ability to bring this community together. [Become an USH Visionary here.](#)

Your donations help us do all we can to find, support and empower everyone living with Usher syndrome around the world. This includes hosting the USH Connections Conferences, sharing these Grounded in Science newsletters, regularly restructuring and updating our website, providing accessibility at our advocacy days on Capitol Hill, and so much more. Thank you for being part of our journey.

RESEARCH SPOTLIGHT

Progress toward treatment of Usher syndrome type 3A

The [Usher III Initiative](#) announced the start of its first Phase 1 [clinical trial](#) in humans to test a new oral drug called [BF844](#). BF844 is considered a small-molecule drug therapy. This trial will study BF844 for the potential treatment of Usher syndrome type 3A (USH3A). USH3A is caused by mutations in the Clarin 1 (CLRN1) gene. Usher syndrome type 3 causes the progressive loss of hearing, vision, and balance.

This Phase 1 trial will assess the safety and tolerability of BF844 in 74 volunteers who **do not have Usher syndrome**. It will also examine how the drug is absorbed and moves through the body ([pharmacokinetics](#)). This trial will take place in Perth, Australia.

The Usher III Initiative is hopeful that BF844 will prove to be both safe and well-tolerated. Positive results will allow them to advance quickly into the next phases of development. The results from this Phase 1 trial are expected by late spring 2025.

Cindy Elden, president and co-founder of the Usher III Initiative, shared her excitement: "This is a huge step in our more than 20-year effort to find a treatment for Usher syndrome type III. If BF844 proves to be safe, we hope to move quickly to trials involving people with USH3."

Dr. David Saperstein, a board member of the Usher III Initiative, said, "This trial is the result of years of hard work. Now that we're testing this drug in humans, we're eager to make progress toward a treatment for people with Usher III."

The Usher III Initiative has worked with top scientists, academic institutions, and groups like the [Foundation Fighting Blindness](#) to get BF844 to this point.

What this means for the USH community: If this Phase I trial is successful, future studies will enroll people with USH3A to see how well the drug works to potentially slow the progression of hearing and vision loss in Usher syndrome type 3A.

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

Your Research Resource has a fresh look!

We've made a few changes to our website. You can now navigate through [research progress](#) to treat Usher syndrome more easily! Check out the "[Current USH Research](#)" page to learn more about [clinical trials](#) and **progress in research to treat Usher syndrome**.

Research is organized by treatment approaches for all subtypes (gene-specific) of Usher syndrome, as well as **gene-independent** approaches that have the potential to benefit anyone with USH (i.e. cell therapy, neuroprotection, optogenetics, etc.)

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. As always, consult with your trusted healthcare provider if you have questions or concerns about your situation.

ON WELL-BEING:

The Positive Impact of Practicing Gratitude & Kindness

As we approach the season of giving thanks, it can be helpful to remember that gratitude and kindness are simple practices that can have a positive impact on how we feel. Research shows that regularly feeling grateful and doing kind things for others can make us happier and reduce feelings of stress. For people with Usher syndrome, a condition that affects hearing, vision, and balance, these practices can help build inner strength and create a sense of community.

What is Gratitude?

Gratitude means being thankful for the good things in life. This could be people who help us, things that make us happy, or small moments of joy. When we feel grateful, our brain releases chemicals like dopamine and serotonin, which make us feel good ([Fox et al 2015](#)). The more we practice gratitude, the more our brain gets used to focusing on the positive things in life. This can help reduce stress and even make us less likely to feel anxious or sad.

One study by [Emmons and McCullough](#) (2003) found that people who wrote down what they were thankful for each week felt more positive and slept better. For those with Usher syndrome, practicing gratitude can shift the focus away from the daily challenges and instead highlight support from others and other positive aspects of their lives.

How Kindness Improves Wellbeing

Kindness is about doing something good for someone else, and it benefits both the giver and the receiver. When we do kind things, like helping a friend or volunteering, our body releases oxytocin, also known as the “love hormone.” ([Kagan et al, 2014](#)) This makes us feel connected to others and lowers our stress levels.

Kindness often begins with [empathy](#), the ability to understand and share the feelings of others. When we practice empathy, we become more attuned to the needs of the people around us, which encourages kind actions. By recognizing others' struggles and offering support, we create stronger connections and reduce our own stress.

Gratitude and Kindness in the Usher Syndrome Community

For people living with Usher syndrome, gratitude and kindness can be helpful tools to manage the emotional challenges that come with hearing and vision loss. Gratitude can help individuals focus on what they have, like the help they receive from family and friends or the technology that makes life easier. This mindset can reduce frustration and create a sense of peace.

Expressing gratitude to caregivers, interpreters, and advocates who provide support to individuals with Usher syndrome also strengthens relationships. Gratitude helps build a positive attitude, which can make dealing with challenges easier.

Building Resilience with Gratitude and Kindness

Gratitude and kindness don't just make us feel better in the moment—they help us build resilience, or the ability to keep going through tough times. Focusing on gratitude can help shift attention from challenges to opportunities. For people with Usher syndrome, this might mean feeling grateful for small wins, like learning a new way to communicate or connecting with others in the community.

Tips for Practicing Gratitude and Kindness

Here are some simple ways to practice gratitude and kindness:

- **Keep a gratitude journal:** Write down three things you're grateful for each day.
- **Express thanks:** Regularly tell the people in your life that you appreciate them.
- **Practice mindfulness:** Take time to savor simple pleasures and moments of joy.
- **Perform acts of kindness:** Help someone, volunteer, or simply compliment a friend.

Gratitude is not just a feeling that comes and goes—it's a choice. You can actively choose to focus on the positive aspects of your life, even when faced with challenges. By focusing on the good things in life and offering kindness to others, you can feel happier, stronger, and more connected to your community.

We are grateful for you and our growing Usher syndrome community. You are not alone.

References

- **Emmons, R.A., & McCullough, M.E. (2003).** "Counting blessings versus burdens: An experimental investigation of gratitude and subjective well-being in daily life." *Journal of Personality and Social Psychology*, 84(2), 377-389. <https://pubmed.ncbi.nlm.nih.gov/12585811/>
- **Fox, G. R., Kaplan, J., Damasio, H., & Damasio, A. (2015).** "Gratitude enhances the neural efficiency of the default mode network." *Cerebral Cortex*, 25(7), 1782-1790. <https://pubmed.ncbi.nlm.nih.gov/26483740/>
- **Kogan, A., Oveis, C., Carr, E. W., Gruber, J., Mauss, I. B., Shallcross, A., Impett, E. A., Van Tongeren, D. R., Brown, K. W., & Cheng, C. (2014).** "Vagal activity is associated with generosity." *Psychological Science*, 25(1), 223-230. http://gruberpeplab.com/pdf/2014_Kogan.Oveis.Carr.Gruber.Mauss.Shallcross.Impett.vanderLowe.Hui.Cheng.Keltner_RSAProsociality.pdf

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. Check out our mental health resources page on our [website](#). As always, consult with your trusted healthcare provider if you have questions or concerns about your situation.

USH Life Hack of the Day

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

Pouring beverage [liquid indicators](#) are a handy tool to alert you as you're pouring liquids in a cup when to stop!

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



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