



USHER 1F
COLLABORATIVE

NEWSLETTER FALL 2026



**THE THERAPY EXISTS.
THE PATH FORWARD IS DEFINED.**

One final round of preclinical testing can bridge
the gap from the laboratory to patients.

HELP FUND THE FINAL STEP

A THERAPY WITHIN REACH:

How a Decade of Discovery Brought Usher 1F to the Threshold of a Clinical Trial

Since our founding in 2013, Usher 1F Collaborative has worked toward one clear goal: making a treatment for the vision loss caused by Usher 1F a reality.

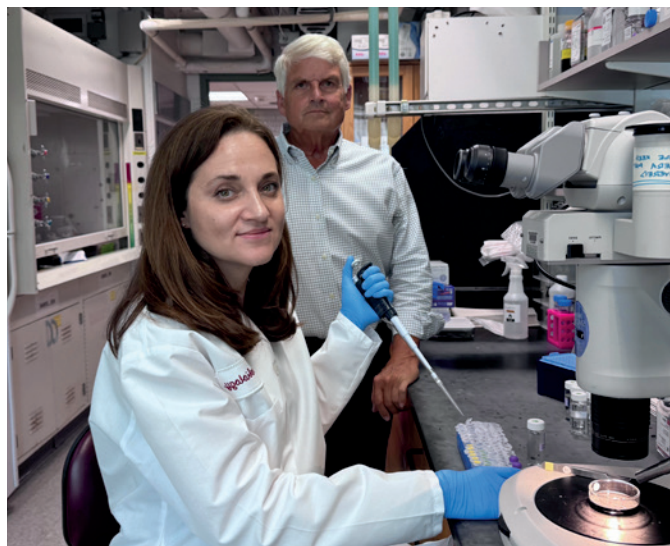
We began by building the essential tools for the job, zebrafish and mouse models that allow researchers to develop and test potential therapies. With those models in place, our scientists began pursuing gene therapies and drug treatments.

In 2017, that work gained critical momentum. At our first Usher 1F scientific research conference, cofounder Elliot Chaikof, MD, PhD, invited interested colleagues from the Harvard Stem Cell Institute to join the discussion. David Corey, PhD, of Harvard Medical School, saw the announcement. For years, his laboratory had studied PCDH15, the gene responsible for Usher 1F, and the role its protein plays in the inner ear.

After attending the conference and meeting young people living with Usher 1F, Dr. Corey took on the challenge.

“We realized we ought to be able to use this information to do something for patients with Usher 1F. We chose this problem not because it’s easy, but because it’s hard. We’re trying to get the cells in the eye to make the normal copy of the missing protein. Normally, we would use a small, harmless virus to carry the gene into the cells, but the gene for Usher 1F is too large to fit in this virus, and so we had to get clever.”

Today, Dr. Corey and Maryna Ivanchenko, MD, PhD, have developed an Usher 1F “mini-gene”— a



Drs. Maryna Ivanchenko and David Corey, Harvard Medical School

streamlined version of PCDH15 that retains the parts needed for vision. In early testing, this therapy restored hearing function in our mouse model and vision function in our zebrafish model. Though small, zebrafish eyes share important similarities with human eyes, making them a valuable model for vision research. **Further preclinical results have been described as “stunning” and “exquisite.”**

At the same time, we partnered with Foundation Fighting Blindness on an Usher 1F natural history study. Forty-four patients with Usher 1F enrolled across 11 sites worldwide to document how vision loss progresses without treatment. This study provides critical baseline data for a future clinical trial and may allow every participant in that trial to receive the therapy, rather than assigning some participants to a placebo group. We anticipate receiving the final report in the second half of 2027.

Now comes the final step before a clinical trial: one additional round of preclinical testing to generate the data the FDA will require. Reaching this point is a major achievement. But this final study is very costly, in part because it requires manufacturing a human-grade version of the gene therapy.

The science is ready for this next phase. What is needed now is the funding to complete it. ♦

TO EVERY DONOR WHO HAS HELPED BRING THIS WORK FORWARD: THANK YOU. YOUR SUPPORT BUILT THE FOUNDATION, ADVANCED THE RESEARCH, AND BROUGHT A POTENTIAL THERAPY WITHIN REACH. WE ARE ASKING YOU TO HELP CLEAR THIS FINAL PRECLINICAL HURDLE SO PEOPLE WITH USHER 1F AND THEIR FAMILIES CAN MOVE CLOSER TO A FUTURE WITH VISION.

A Winning Day for Usher 1F

The Usher 1F Collaborative Golf, Tennis & Pickleball Outing, featuring Cards & Mahjong, brought friends, families, and supporters together on June 8th for a memorable day at Mountain Ridge Country Club in West Caldwell, NJ. Centered on a shared commitment to finding a cure for Usher 1F, the outing combined friendly competition, community and generosity in support of the research that is bringing us closer to saving vision.

The day began with brunch before golfers headed to the greens, while canasta and mahjong players gathered around the tables. Tennis and pickleball participants arrived in the afternoon for their tournaments, and the day concluded with a dinner reception and awards celebration.

The reception was especially meaningful this year as Usher 1F Collaborative presented the *Hear-O Award* to **Tom Roland, MD**, and **Bill Shapiro, AuD**, in recognition of their extraordinary impact on the lives of children born deaf. Decades ago, pioneers in cochlear implantation like Drs. Roland and Shapiro helped transform what was possible for these children, giving them access to sound and opening doors that once seemed out of reach. Today, Usher 1F Collaborative is working toward that same kind of transformation for vision—advancing research with the goal of ensuring that children and adults with Usher 1F do not lose their sight.

**THROUGH SPONSORSHIPS,
REGISTRATIONS, AND THE
TREMENDOUS GENEROSITY OF OUR
DONORS, THE OUTING RAISED AN
INCREDIBLE \$404,000 TO ADVANCE
USHER 1F RESEARCH.**

We are deeply grateful to the board members, event committee, volunteers, sponsors, participants and donors who made the June 8th outing such a success. Their generosity, time and enthusiasm made the day possible, and the dollars raised will help propel the research that we believe will change the future for everyone living with Usher 1F. ♦



Dorie, Zachary, Rachel, and Jessica - Living with Usher 1F



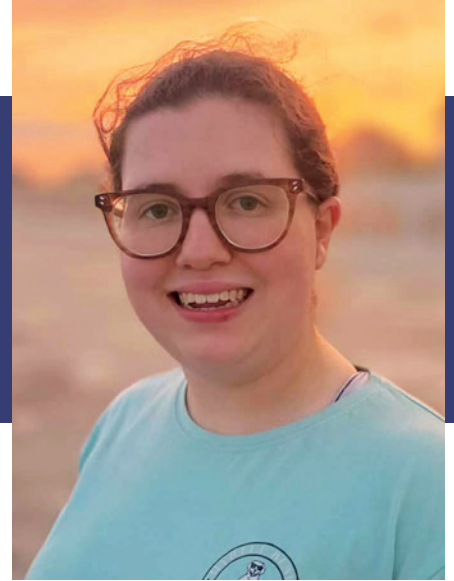
Dr. William Shapiro speaks while Dr. J. Thomas Roland looks on



The O'Kane and Lamberth family enjoying a beautiful day of golf

Resilience, Hope, and Olivia's Future

By Sonja Mitchell



Olivia is an independent 17-year-old young lady who enjoys her alone time and loves animals, quilting, cooking, and being outdoors. She is incredibly resilient and has never allowed her hearing or vision challenges to slow her down.

Our journey with hearing loss began when Olivia was very young, but her story has been anything but typical. She actually passed her newborn hearing screening. At 14 months old, she was diagnosed with mild-to-moderate hearing loss, which progressed to severe hearing loss by her second birthday. Despite the severity of her hearing loss, Olivia did not experience the balance difficulties that are associated with Usher syndrome.

For many years, we knew very little about Usher syndrome. We focused on helping Olivia navigate her hearing loss and watching her grow into the strong, independent young woman she is today. We never imagined that another diagnosis was waiting for us.

In December 2025, macular edema was discovered during a routine eye examination. We were referred to a retinal specialist, and that appointment changed everything. It was there that we learned Olivia had Usher syndrome type 1F.

The day we received her diagnosis was absolutely devastating. Olivia had already overcome so much with her hearing loss. To learn that

she now faced another potential obstacle, one that would affect her vision, felt incredibly unfair. She didn't deserve another challenge.

As her mother, one of the hardest feelings I have ever experienced is knowing that I cannot fix this for her. I would take this from her in an instant if I could. Instead, we live with uncertainty. Each day feels like waiting—waiting to see what might come, hoping for good news and fearing the possibility of bad.

The challenges she faces are numerous, and one is simply accessing the specialized care Olivia needs. Finding a retinal specialist with the experience and expertise to provide knowledgeable care for someone with Usher syndrome requires us to travel six hours by car. We are grateful to have access to an experienced specialist, but the distance adds another layer of difficulty to navigating an already complex diagnosis.

And yet, through all of this, Olivia continues to show us what resilience looks like. We are incredibly blessed that Olivia is still able to enjoy the things she loves and live her daily life independently. Her diagnosis has not changed the person she is.

If anything, it has made us appreciate every moment even more.

I cannot put into words what a treatment would mean for Olivia

and our family. It would mean **everything**. A treatment would completely change the future for Olivia—and for so many other people living with Usher 1F. It would mean the possibility of preserving the vision and independence that allow Olivia to continue living the life she loves.

Research and development are the keys to preserving the future for every person living with Usher 1F. We cannot stop pushing forward. We cannot stop raising awareness. And we cannot stop raising the funds necessary to turn promising research into real treatments.

For families like ours, research isn't just science. It is hope. It is possibility. It is Olivia's future.

Every discovery brings us one step closer to a future where families don't have to sit in that place of uncertainty, wondering what their loved one may lose next.

Olivia has already shown us how strong and resilient she is. Now we need the research community, donors, and supporters to keep fighting alongside her.

Please keep pushing. Keep raising awareness. Keep investing in research.

Because for Olivia and every person living with Usher 1F, their future is worth fighting for. ♦



Melissa and Debbie in 1983

FULL CIRCLE:

How a Decades-Old Friendship Is Funding the Cure for Usher 1F

Shortly after entering high school in Baltimore many years ago, Usher 1F Collaborative cofounder Melissa Chaikof became friends with classmate Debbie Hirschhorn. They quickly became very close, spending countless hours at each other's homes throughout high school. Debbie was one of four children, all close in age and all attending the same school, and Melissa came to know the entire family. Debbie also became a welcome part of Melissa's family, joining Melissa and her parents on a few summer vacations.

Melissa and Debbie's friendship continued through college. They attended each other's weddings and, later, traded stories and photos of their firstborn daughters, who were born only months apart. Although they never completely lost touch, life eventually took them to different states and in different directions as they raised their families.

Shortly after founding Usher 1F Collaborative, Melissa's daughter connected with other young adults with Usher 1F. Together, they assembled a list of people who were deaf-blind, many of whom were believed to have Usher 1F. One name on the list stood out to Melissa: a man with the last name Vogelstein. Debbie's married name was Vogelstein, and Melissa believed the man might be one of Debbie's children.

Anyone who grew up in Baltimore knows the game of Baltimore geography. While searching online

for Debbie's updated contact information, Melissa discovered that Debbie served on the board of a private school where Melissa's mother had taught for many years. A few phone calls later—from Melissa to her mother, and from her mother to the school's principal—Melissa had Debbie's email address.

Melissa reached out, and Debbie was just as happy to reconnect. As they began sharing stories about their children, Melissa learned that Debbie's son had lost his hearing and vision as a result of a childhood brain tumor, not Usher 1F. Still, the experiences they shared helped renew their friendship and deepen their understanding of one another's lives.

Over the following months, Debbie learned more about Melissa's work through Usher 1F Collaborative to find a cure for her daughters. Debbie and her three siblings managed The David and Barbara B. Hirschhorn Foundation, and in 2015 they decided to award Usher 1F Collaborative a grant. The Foundation has renewed its support every year since, providing invaluable help as we advance research toward a cure.

This enduring partnership is a powerful reminder that progress is often built through personal connection. A friendship that began in a Baltimore high school found new purpose decades later, helping move urgently needed research forward and bringing hope to families affected by Usher 1F. ♦

Students Shine Light on a Cure

For the third consecutive year, students at **Passaic County Technical-Vocational Schools (PCTVS)** in Wayne, NJ, came together to raise funds and awareness for Usher 1F Collaborative.

Led by teacher **Jody Lazarski**, this year's effort brought together students from the Video Club, ASL Club and Art Club for a special event, "**Light the Way to a Cure.**" Each student created a personal fundraising page with a goal of raising \$20. Those who reached their goal earned the opportunity to participate in a luminary-making activity celebrating their collective impact.

The students' creativity and their commitment to helping others shone brightly as they created beautiful luminaries symbolizing hope for a future without vision loss from Usher 1F.

Over the past three years, **PCTVS students have raised \$5,000 for Usher 1F Collaborative**, demonstrating just how meaningful an impact young people can make when they come together for a cause.

We are incredibly grateful to Jody Lazarski and the PCTVS students for continuing to support our mission year after year and for helping us *light the way to a cure*. ♦

PCTVS students lighting the way for a cure

