USHER 1F COLLABORATIVE

NEWSLETTER
Spring 2026

*Alessandro celebrates his 1st birthday with his parents Sara and Dylan*

**BETWEEN HOPE AND FEAR:**

# Alessandro's Story

*By Sara Dominguez*

For the past two years, my husband Dylan and I have been living in Esslingen, Germany, after moving here from Barcelona, Spain. Our son Alessandro was born on April 19, 2024, in Nürtingen, Germany. The day after he was born, his first hearing test came back abnormal.

At first, we thought it must be a mistake. We even joked, "What luck that he doesn't wake up every time the dog barks or when I play music to clean - does he even care about the noise?" The doctors reassured us that early hearing tests can sometimes be misleading. It could simply be that his ears were blocked. So while each appointment brought new worries, we held onto hope.

When Alessandro was about four or five months old, we underwent genetic testing in Tübingen. That is when we received the diagnosis: Usher syndrome type 1F.

It was impossible to believe. No one in our family is deaf. I remember asking my mother again and again, "Are you sure no one in the family is deaf?" Somehow, I convinced myself that this meant Alessandro couldn't be either. But the results were clear. We later learned that both my husband and I are carriers.

The diagnosis was a shock, completely unexpected and deeply painful. For our whole family, it felt as if the world fell on us. I felt overwhelming sadness, and also guilt, wondering how this could have happened. Thankfully, with the support of my husband and our family, we found our footing again.

And then, Alessandro showed us who he is.

He is a very special child, full of joy, laughter, and curiosity. He is affectionate, quick to learn, and fully engaged with the world around him. He now shares his life with his younger brother, who arrived unexpectedly soon after. They play together, learn from each other, and share a beautiful bond.

Sometimes, Alessandro gently offers his little brother one of his cochlear implant processors, as if saying, "Here, so you can hear me." When it doesn't stay in place, he looks at him with a quiet sadness. His younger brother, thankfully, has no health concerns.

At eight months old, on December 16, 2024, Alessandro underwent surgery at the University Hospital in Tübingen, where he received cochlear implants in both ears. On January 21, 2025, they were activated for the first time. From that moment on, he has loved wearing them and only takes them off to sleep.

*Alessandro Continued on page 2*

*Alessandro Continued from page 1*

In just two weeks, he began saying simple words like “bebé” and “papá.” Every day since, he continues to learn, grow, and surprise us.

With this journey comes a constant balance of hope and fear. We follow promising research developments that give us real hope for the future. At the same time, we worry - will these breakthroughs come in time for Alessandro?

We are learning to live in that space between hope and uncertainty, holding both with as much calm and gratitude as we can.

Recently, I saw a video of a mother complaining that her baby starts talking at 6:00 in the morning. And I thought, “How lucky you are,” because there are mothers like me who live with the fear that their child might stop making sounds or may never learn to speak at all. That moment stayed with me, reminding me how deeply this journey has shaped the way I see the world.

Alessandro himself is a little miracle. I had been on birth control for many years, so his arrival was completely unexpected. It feels as though he chose to come into this world, to live it fully, and that is exactly what he is doing.

He is strong. He is joyful. And he is surrounded by a family who is endlessly proud of him.

Today, Alessandro is growing and developing beautifully, supported by his medical team, his rehabilitation program, and now physiotherapy to help with balance. He is thriving, not in spite of his diagnosis but with it as part of his story.

Our greatest wish is simple: that Alessandro continues to grow as the happy, curious child he is, that he keeps learning, exploring, and enjoying the world around him. And we hope, with all our hearts, that advances in research will come in time to preserve his vision and open even more possibilities for his future.

*Alessandro*

Families like ours live every day between hope and urgency. Progress in research is not abstract to us - it is deeply personal. It represents time, possibility, and the chance for our children to live full and limitless lives.

If there is one thing this journey has taught us, it is that progress only happens because people choose to care, to support, and to invest in a future that feels just out of reach. For families like ours, that support means everything.

Alessandro reminds us every day what strength, joy, and resilience look like. And because of him, we will keep hoping and keep believing that the future will come in time. ◆

*Alessandro and his large, supportive family*

RENEWING MOMENTUM:

# Advancing the Usher 1F Gene Therapy

## INTRODUCING OUR NEW CONSULTANT, VIRGINIA HAURIGOT, PHD

We are delighted to share that Usher 1F Collaborative has engaged Dr. Virginia Haurigot as a consultant to help guide our gene therapy through the critical next phases on the path toward a clinical trial.

Trained as a biochemist at the Universidad Nacional de Rosario in Argentina, Dr. Haurigot launched her scientific career in Barcelona, where her doctoral research focused on understanding the abnormal blood vessel growth that damages the eyes of people with diabetic retinopathy. It was during this time that she discovered her passion for gene therapy as a way to treat eye diseases.

She then joined the Children's Hospital of Philadelphia (CHOP) as a research associate supported by the Howard Hughes Medical Institute, one of the most prestigious research funding bodies in the United States. There, she worked on groundbreaking techniques to edit genes directly inside the body, specifically in the liver, and studied how the immune system responds to the viral vehicles used to deliver gene therapies.

Dr. Haurigot subsequently returned to Barcelona, joining a research center that worked at the intersection of academia and industry to develop gene therapies for patients with neurodegenerative diseases, conditions that cause progressive damage to the nervous system. She led the scientific work that brought one of these therapies all the way through the research pipeline to the point of a clinical trial application, while also teaching as an Associate Professor at UAB.

**DR. HAURIGOT HAS DEVELOPED DEEP EXPERTISE IN A BROAD RANGE OF GENE DELIVERY APPROACHES, BOTH VIRAL AND NON-VIRAL, APPLIED TO DISEASES AFFECTING THE EYES, BLOOD, BRAIN, AND METABOLISM.**

In 2018, she joined Spark Therapeutics, a pioneer in the gene therapy space best known for developing the first FDA-approved gene therapy for a single-gene inherited disorder, Luxturna, for another type of retinitis pigmentosa.

*Virginia Haurigot, invaluable new Usher 1F Collaborative consultant*

Across her career, Dr. Haurigot has developed deep expertise in a broad range of gene delivery approaches, both viral and non-viral, applied to diseases affecting the eyes, blood, brain, and metabolism. She has a strong track record of building and managing partnerships between research institutions and companies to move promising therapies forward.

Dr. Haurigot brings an intimate familiarity with our program and a career's worth of hard-won knowledge, a combination that gives us every reason to look ahead with confidence.

As we take these next steps, your support remains essential. Advancing a therapy from promising science to a clinical trial requires significant resources, and every contribution helps move us closer to treatments for individuals and families affected by Usher 1F. ◆

UNLOCKING NEW POSSIBILITIES:

# AI and the Future of Usher 1F Treatment

Almost since our inception in 2013, we have held a goal of conducting a high-throughput drug screen to test existing drugs for efficacy in Usher 1F. While no currently available drug can restore vision because it cannot replace the missing protein caused by the underlying genetic mutation, drug therapy has the potential to target key disease mechanisms, such as inflammation or oxidative stress, and meaningfully slow the progression of vision loss.

Importantly, identifying a drug already approved for another condition would represent the fastest path to patients, as its safety profile is already well established, and would buy us needed time to bring a gene therapy to clinical trial.

Several years ago, we made our first attempt at a drug repurposing initiative using our zebrafish model, partnering with a contract research organization to screen a library of 1,800 FDA-approved compounds. Despite the promise, the projected cost, $1.3 million annually over two to three years, ultimately made the effort untenable, and the project was put on hold.

Fast forward to 2026, and the landscape has changed dramatically. As AI is advancing at an unprecedented pace, new opportunities have emerged to accelerate and scale scientific discovery. Through our partnership with Unravel Biosciences, we were able to revisit drug repurposing in a way that was previously out of reach, screening approximately 40,000 compounds in just three months, at a tiny fraction of the prior cost.

In December 2025, we received a prioritized list of candidates, with nine drugs identified as the most promising. We have since engaged two leading zebrafish research labs to advance this work: the University of Oregon Institute of Neuroscience, in Dr. Monte Westerfield's lab, which developed our zebrafish model and has been a longstanding partner, and the University of Alberta, in Dr. Ted Allison's lab, supported by Usher 1F Collaborative Canada.

*Working with Unravel Biosciences to make our drug screen possible*

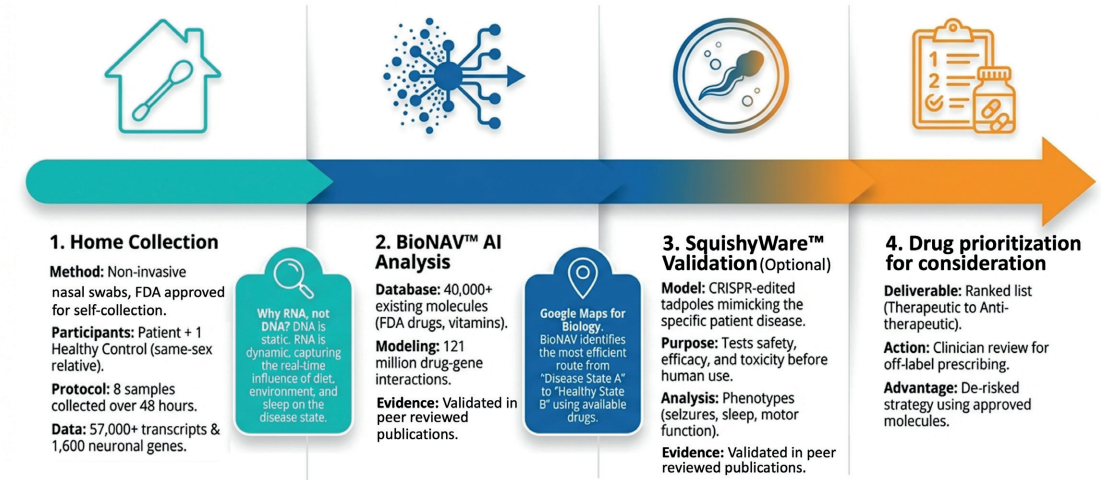
We are now entering a critical next phase: determining whether these candidates can meaningfully slow vision loss in our zebrafish model and, ultimately, whether they hold promise for people living with Usher 1F.

What once felt financially and logistically out of reach is now moving forward with speed, precision, and real possibility. If even one of these compounds demonstrates efficacy, it could dramatically shorten the timeline to treatment, bringing us closer to a future where vision loss from Usher 1F can be slowed, and lives meaningfully improved.

As this work progresses, continued support will be essential to carry these promising candidates through validation and toward clinical testing. The opportunity in front of us is no longer theoretical. It is tangible, and within reach. ◆

Please visit unravel.bio to learn more about Unravel's unique approach to drug repurposing.

*How the drug repurposing screen works*



A WINNING RUN

# Catch the Ace Raises $49,100 for Usher 1F Canada

You may have heard the excitement surrounding Usher 1F Collaborative Canada's participation in the Catch the Ace Lottery in 2025—and what an incredible run it was!

Catch the Ace is a progressive lottery where participants purchase a ticket and select a charity for their purchase to benefit.  Each week, one ticket is drawn, and if the selected envelope contains the Ace of Spades, the winner receives the jackpot. If not, the prize continues to grow for the following week.

In the most recent round, the game extended an astonishing 51 weeks (out of a possible 52) before the Ace was finally revealed. This not only built a substantial jackpot for the lucky winner, but also significantly increased funds raised for participating charities—truly a win-win for everyone involved.


*Usher 1F Collaborative treasurer Nic Forte and members of the Kin Club of Russell with the actual check for the Catch the Ace lottery winnings*

Thanks to the generosity of supporters, Usher 1F Collaborative Canada raised $49,100 CAD.

The next round is already underway! Residents of Ontario can participate by purchasing tickets online or at select retail locations.

We are immensely grateful to the Kin Club of Russell for once again selecting Usher 1F Collaborative Canada as a beneficiary of this impactful initiative. ◆

For more information, please visit usher1f.ca

*Usher 1F Collaborative Canada treasurer, Nic Forte, receives the Catch the Ace check from members of the Kin Club of Russell in Ontario*


# Dream Getaway Fundraiser Raises Over $10,200 for Usher 1F Research

During the month of April, Usher 1F Collaborative hosted a Vacation Getaway Fundraiser, offering supporters a chance to make an impact while dreaming of their next adventure.

With each donation, participants were entered into a drawing to win a customized getaway package valued at $5,000. Designed around the winner's personal interests and travel style, the experience promised not just a trip, but a truly memorable escape - all while supporting life-changing research.

**DESIGNED AROUND THE WINNER'S PERSONAL INTERESTS AND TRAVEL STYLE, THE EXPERIENCE PROMISED NOT JUST A TRIP, BUT A TRULY MEMORABLE ESCAPE - ALL WHILE SUPPORTING LIFE-CHANGING RESEARCH.**

This exciting opportunity was made possible through the generosity of Sonja and Randall Mitchell, an Usher 1F family, who fully underwrote the vacation in honor of their daughter, Olivia, who lives with Usher 1F. As a result, every dollar raised directly benefited Usher 1F Collaborative's mission.

The fundraiser was a tremendous success, with donors from around the world entering to support our work. The drawing was live streamed on May 1, and our lucky winner was Contrara Harlan.

*Olivia Mitchell, the inspiration for the vacation getaway fundraiser*

The event raised more than $10,200 for Usher 1F Collaborative! ◆

**Attention New Jersey and New York Residents!**

*Don't miss registration*

# 3RD ANNUAL GOLF, TENNIS & PICKLEBALL OUTING

USHER 1F COLLABORATIVE

*Featuring Cards & Mahjong*

**June 8, 2026**

**Mountain Ridge Country Club**
**West Caldwell, NJ**

**usher1f.org/outing**

USHER 1F COLLABORATIVE

# SEEING FORWARD

*OUR 3-YEAR MAJOR-GIFT FUNDRAISING INITIATIVE TO MEET OUR NEXT BOLD GOALS ON A RAPID PATH TOWARD A CURE*

## FUNDRAISING UPDATE

$0 **$1,813,200+** $3,015,000

updated on May 4, 2026

usher1f.org/seeingforward