usher syndrome society

Impact Report 2025

AWARENESS • RESEARCH • CURE

A non profit bringing light to Usher syndrome -
the leading genetic cause of combined deafness and blindness.

Our Mission

AWARENESS.
RESEARCH.
CURE.

The Usher Syndrome Society is a 501(c)(3) nonprofit dedicated to raising awareness and funding research for all types of Usher syndrome to find treatments and ultimately a cure.

As the leading genetic cause of combined deafness and blindness, Usher syndrome remains widely unknown.

Through film, photojournalism, and experiential events, we educate the public and grow a community of support, ensuring that awareness leads to action and critical research funding.

Our Vision

We envision a future where Usher syndrome is universally recognized, understood, and treatable world wide.

By sharing powerful stories, we foster connection and urgency.

Our scalable funding model directs donations into vetted scientific grants, so as contributions increase, our impact expands, accelerating groundbreaking research to stop, reverse, and possibly cure both hearing and vision loss due to Usher syndrome.

About Us

We understand because we're fighting with you.

In 2011, founder Nancy Corderman's eldest daughter, Hannah, noticed that the stars were disappearing. After intensive testing and a genetic diagnosis, Nancy and her husband, David, found out that two out of their four children have Usher syndrome and are progressively losing both their eyesight and hearing.

Motivated by this profound challenge, the Usher Syndrome Society was established to raise awareness and drive research forward, critical steps toward developing effective treatments.

usher syndrome society

Image of the Corderman Family

Together, we can make this invisible disease visible.

Rare diseases like Usher syndrome often go unnoticed, receiving little attention, research, or funding. When something isn't widely seen or understood, it's easy to overlook.

By sharing our personal stories, we make Usher syndrome visible, creating understanding, connection, and the crucial momentum needed to drive meaningful action.

Our Team

The Usher Syndrome Society is a growing community of individuals, families, clinicians, and scientists united to change the future of Usher syndrome. Together, we raise awareness, fund critical research, and work toward a cure.

Board of Directors

Nancy Corderman
Founder & President

David Corderman
Board Chair

Rebecca Alexander
Director of Education

Alan Pinto
Director of Research

Hannah Corderman
Director of Marketing & Strategy

Peggy Borst
Director of Advocacy

Tori Banu
Director of Public Relations

Sophia Boccard
Board Director Advisor

Jon Schultz
Director of Strategic Initiatives

MIchael Conn
Director of Donor Engagement

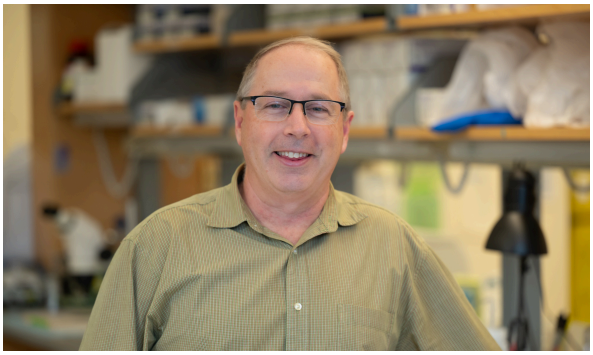
Operations

Eliza Corderman
Creative Director

Christel Morley
Director of Finance

Karen Head
Executive Manager

Scientific Advisory Board (SAB)



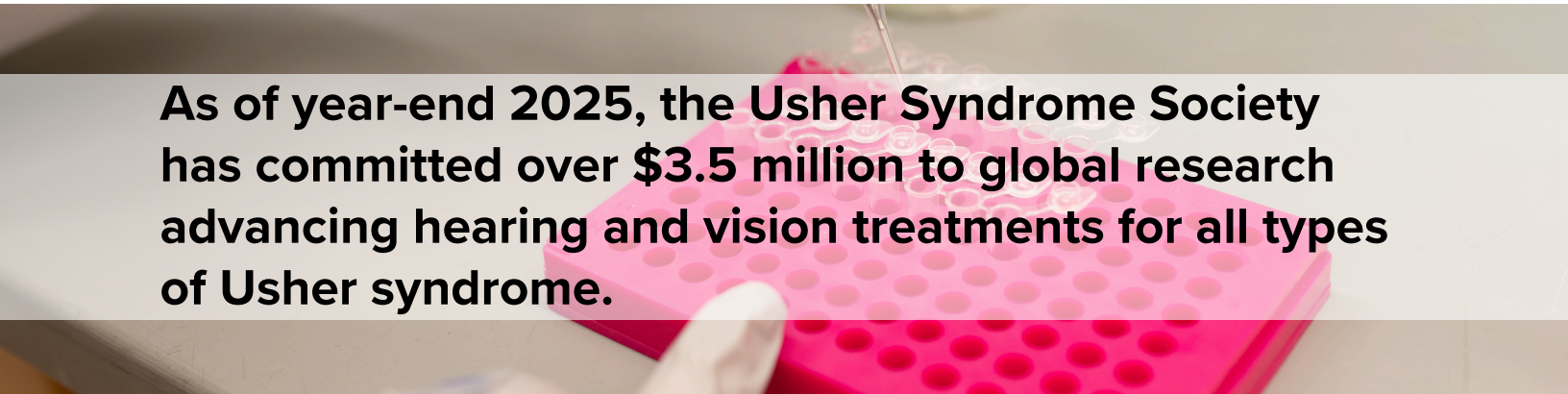
Dr. Jeffrey Holt:
Chair of SAB

The Usher Syndrome Society's Scientific Advisory Board, comprised of world-renowned experts in hearing and vision research, was established to guide us in identifying and supporting the most promising research initiatives, ensuring that our efforts are strategically directed toward effective treatments and a cure for Usher syndrome.

Dr. Mike Bowl

Dr. Teresa Nicolson

Dr. Bence Gyorgy



As of year-end 2025, the Usher Syndrome Society has committed over $3.5 million to global research advancing hearing and vision treatments for all types of Usher syndrome.

Awareness 2025

Let’s shine a light on who we are.

Usher syndrome often goes unseen and unheard. Through powerful storytelling, captured in portraits, film, and real-life experiences, we bring visibility to the lived experience of deafblindness and drive support for research toward effective treatments.

Shine A Light

For the past ten years, the Usher Syndrome Society has curated "Shine a Light on Usher Syndrome," the world's largest portrait collection of individuals and families affected by Usher syndrome. In June 2025 we photographed at the International Usher Syndrome Research Symposium in Nijmegen adding to our global representation.

We are celebrating ten years of our beautiful portraits and will be featuring individuals weekly on social media throughout 2026.

Sankaty talks

NBC’s Chief White House Correspondent and TODAY Show host, Peter Alexander, spoke with his sister and our ambassador and board member, Rebecca Alexander, for the Sankaty Talks Speaker Series in Nantucket, MA. During this conversation, they explored what it means to stay grounded when the future feels uncertain, how to hold both joy and grief at once, and how to find meaning and purpose in life’s most challenging moments.

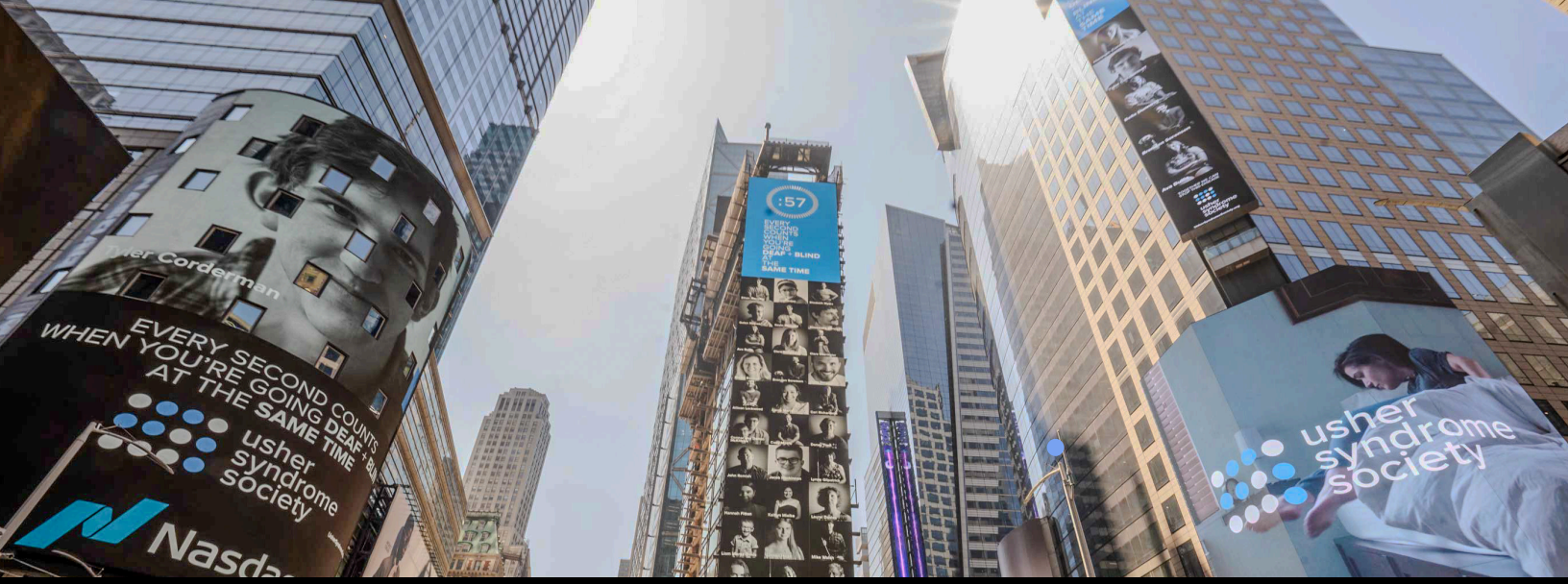
Continuing to Shine A Light.

See US, Hear US Immersive Exhibition in New York City

A creative dream come to life, where the Usher Syndrome Society showcased over a decade of film, photography, and scientific imagery highlighting the powerful stories of our Usher syndrome community and the science happening behind the scenes to find treatments and a cure. This event was attended by several hundred people, including biotech/pharma company representatives, donors, and our Usher syndrome community.

USH X Urban Wild Sight Sound & Strength

The Annual Sight, Sound, & Strength Boston Fundraiser was held at Urban Wild on Tuesday, December 2nd in honor of Giving Tuesday. With over 270 attendees and a special performance from singer/songwriter Mark Erelli, who is living with Retinitis Pigmentosa and shared his remarkable story and music.



Every Second Counts Campaign

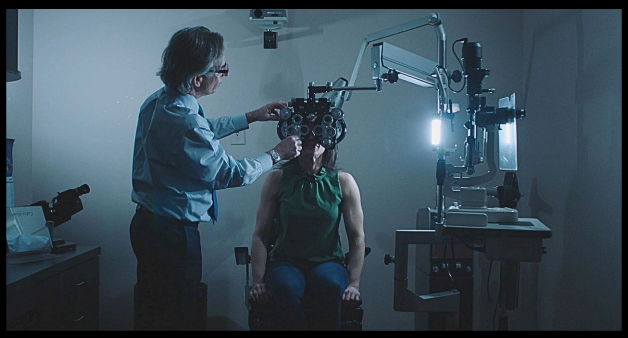
Spanning 2024, 2025, and now 2026. This multi-award-winning campaign highlights the urgency of those going deaf and blind from Usher syndrome, while fighting for meaningful lives and the hope for effective treatments. This campaign has appeared on Times Square billboards, major media outlets, and streaming platforms, reaching millions worldwide and continuing to grow.

30-Second Commercials

Two 30-second commercials, one featuring Rebecca Alexander and the other, the Mullarkey family, sharing their experiences with Usher syndrome, are airing on major streaming platforms and national television.

Times Square Takeover

The Every Second Counts campaign took over nine Times Square billboards, 2 years in a row featuring portraits from "Shine a Light on Usher Syndrome" and our commercial footage.



Major Networks & Digital Media

The Every Second Counts campaign was featured on the Today Show, NBC News Now, ABC News, NewsMax, streaming networks like Hulu & Disney +, and digital media, including online banners, Out Of Home Billboards and Taxi tops.

Awards for Every Second Counts Campaign: The Drum Awards 2024 won Gold for Media Charity and Givsly Impact Awards 2025 Winner in Resourceful Responsibility Category

Research 2025

Finding treatments and a cure is not a matter of if, but when.

The Usher Syndrome Society is dedicated to finding treatments and a cure for all types of Usher syndrome. Our two major research initiatives:

Translational Research Grants

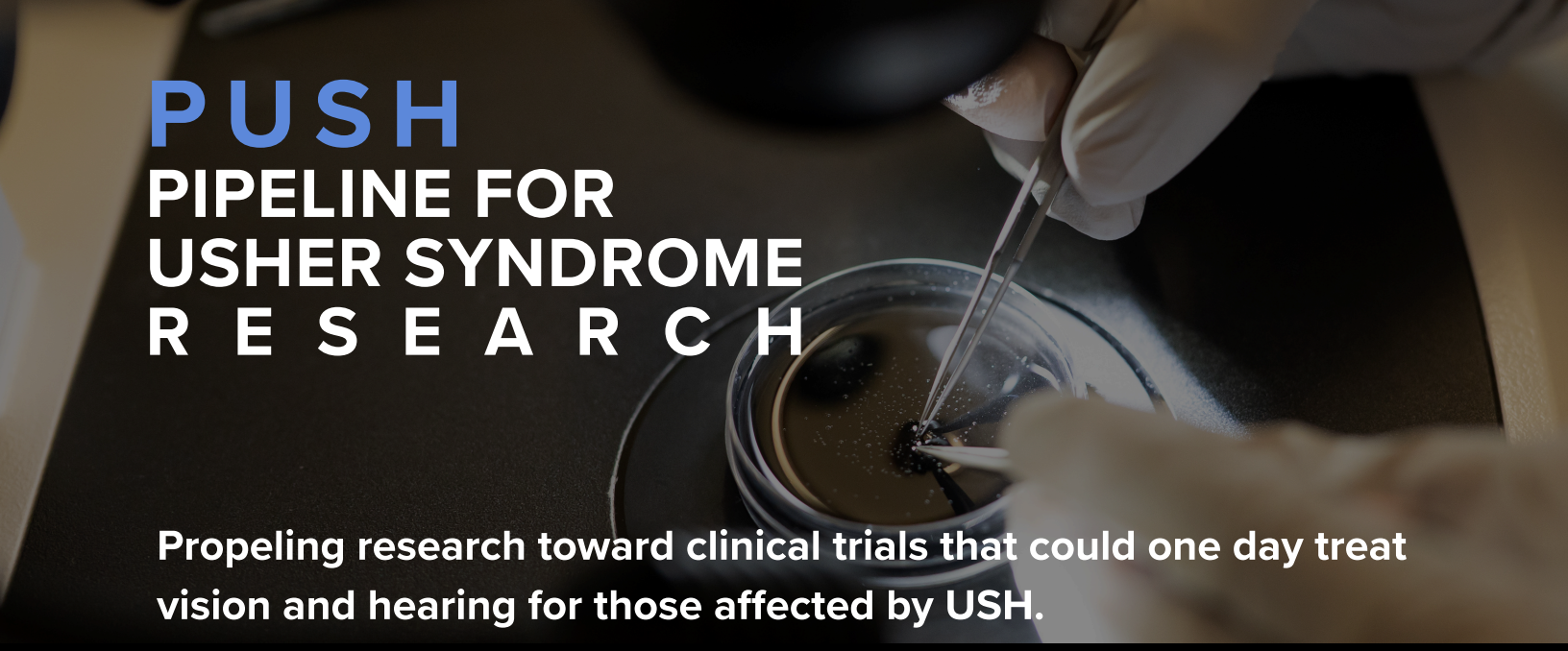
Our Global Translational Research Grants are awarded to well-documented research projects targeting cells in the eye and ear with the aim of developing therapeutic strategies and novel therapeutic agents. Emphasis is placed on collaborative efforts that extend across vision and hearing.

We have given over $2M to Translational Research worldwide. Our scalable funding model supports vetted scientific grants, ensuring that as donations grow, so does our impact to accelerate groundbreaking research. These are the current Translational Grant recipients.

Dr. Monte Westerfield at the University of Oregon and his lab are conducting preclinical studies to identify compounds that can be used as therapeutics for treatment of vision, hearing, and balance problems in most, if not all forms of USH. This includes Types 1F, 1B, 1C, 1D, 1G, 2A, 2C, 2D, 3A.

Dr. Vasiliki at the Institute for Neurosciences of Montpellier in France aims to overcome the challenge of carrying larger Usher genes that don't fit into the currently used vehicles by testing a new, larger delivery vehicle to carry the biggest Usher gene (USH2A) into diseased eye cells.

Merel Stemerdink and Dr. Erwin van Wijk are advancing preclinical evaluation of therapeutic strategies using patient derived retinal organoids for ADGRV1- associated Retinitis Pigmentosa. New experiments are underway to explore exon skipping in additional regions of the ADGRV1 gene.



PUSH
PIPELINE FOR USHER SYNDROME RESEARCH

Propeling research toward clinical trials that could one day treat vision and hearing for those affected by USH.

About PUSH

The Pipeline for Usher Syndrome Research (PUSH) is a groundbreaking initiative at Boston Children's Hospital, launched with a commitment of $1.5M by the Usher Syndrome Society, to accelerate treatment development for Usher syndrome (USH). This innovative program brings together six world-class scientists in one academic institution, Harvard University, each a leader in their field with complementary expertise.

PUSH is uniquely designed to address multiple forms of Usher Syndrome in parallel, identifying specific subtypes and mutations that may respond to cutting-edge therapies and speed the translation of therapies to clinical application.

While labs worldwide are working on USH treatments, PUSH is the first collaborative effort of this scale working both domestically in the U.S. and internationally with recognized investigators across genetics, inner ear and retina scientists to help advance discoveries efficiently from the lab to potential treatments.

PUSH Year Two

The PUSH team achieved important scientific milestones across several USH targets

USH2A Therapeutic Progress:
Researchers achieved a key validation milestone using antisense technology to restore gene function in patient-derived cells, retinal and inner-ear organoids, and zebrafish models, while simultaneously advancing and optimizing additional antisense candidates to identify the strongest lead therapy for future clinical development.

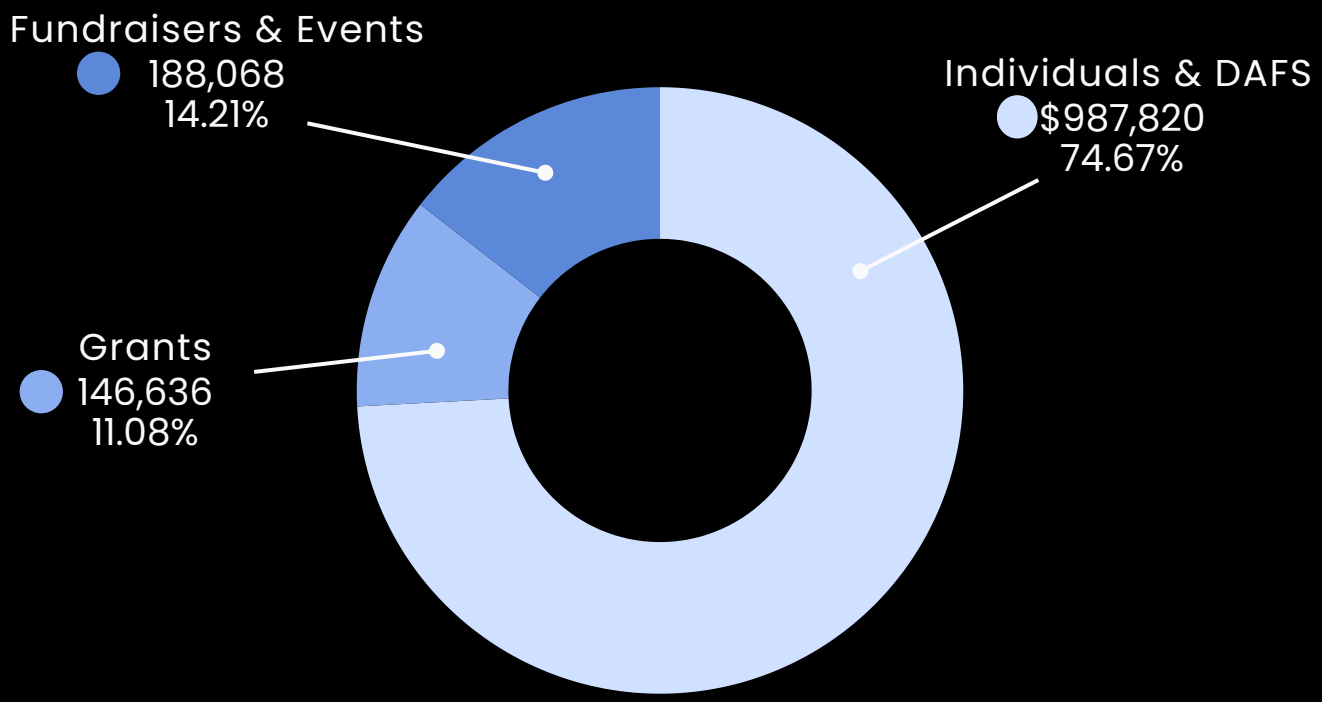
USH1B Therapeutic Progress:
Researchers have collected several USH1B samples, are developing IPSCs and have identified strategies for USH1B. In vitro testing is in progress.

USH3A Therapeutic Progress:
Researchers have chosen a target for USH3A, have collected samples, are developing IPSCs and have identified Gene replacement as a possible therapeutic approach. In vitro testing is beginning.

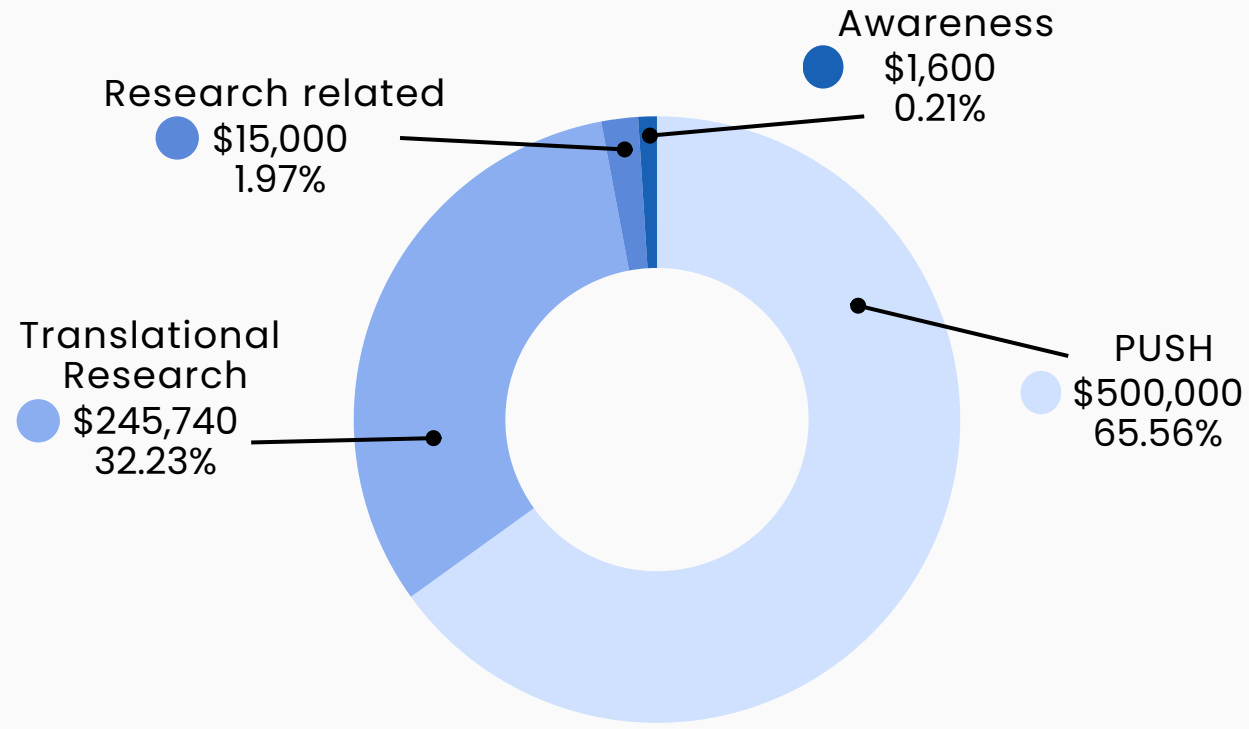
USH2C Therapeutic Progress:
Researchers have collected samples, are developing IPSCs and have identified an ASO strategy for USH2C. In vitro testing will be starting soon.

Financials 2025

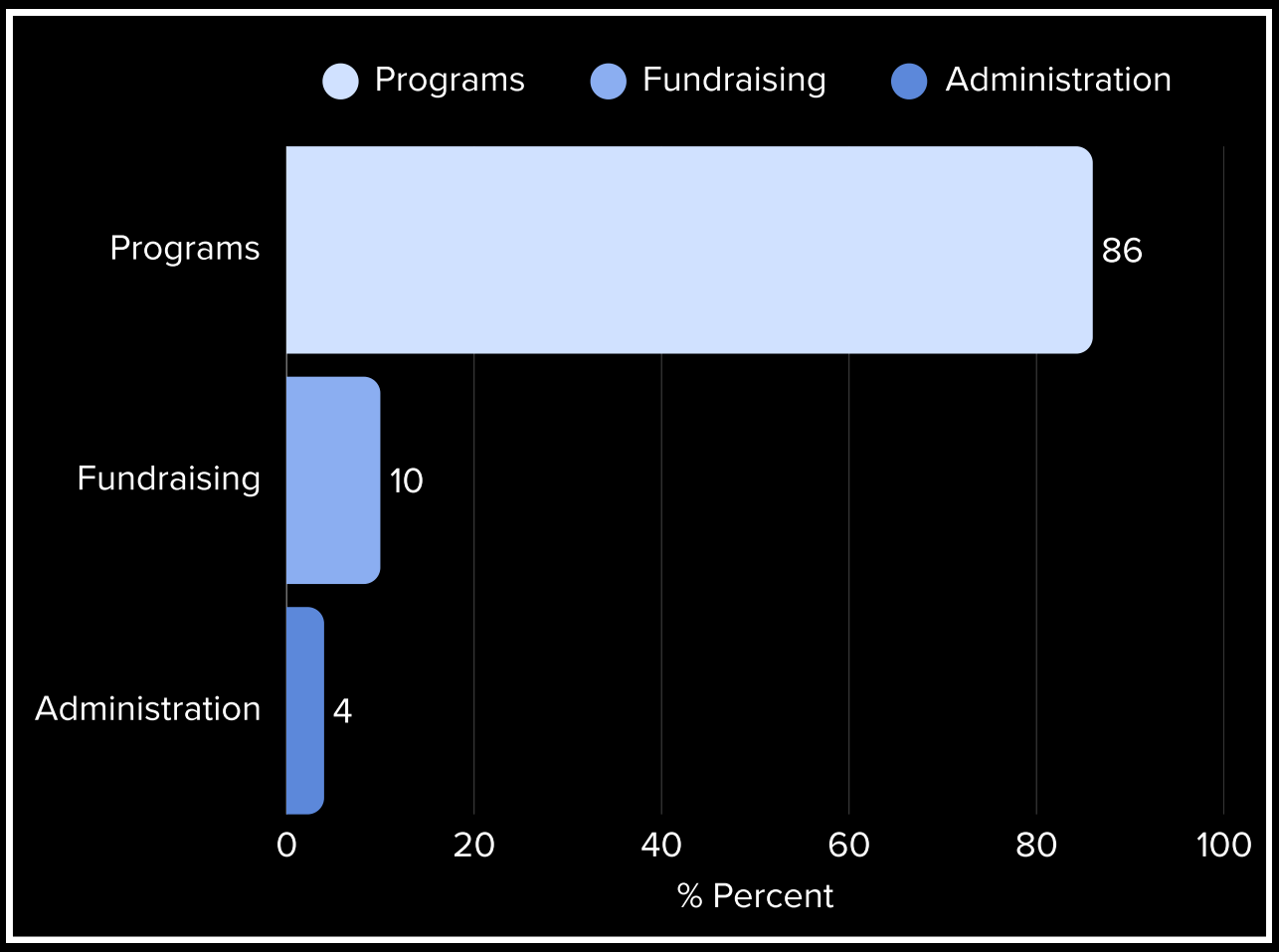
Funding raised: $1,323,043



Research & Awareness grants awarded by Usher Syndrome Society: $762,343



Expenditures by function:



Programs: 86%
$929,585

Fundraising: 10%
$113,161

Administration: 4%
$41.352 **

** Interest Income of $44K fully covered all management expenses
Administrative operations are effectively cost-neutral

Summary:

- Fiscal Year 2025 was a strategic execution year
- Strong cash conversion of prior pledges
- Significant mission investment while maintaining financial strength
- Organization enters FY 2026 well-capitalized, liquid, and positioned for sustained impact.

Treatment . Cure

Our impact to date.

Research - Translational Grants & PUSH:

The Usher Syndrome Society is the only organization dedicated to finding treatments for all types of Usher syndrome. With a progressive disease and multiple subtypes, time is critical to advancing research.

Research impact as of 2025

Overall Research Dollars committed for grants	Research Grants awarded by USS for 2025	Number of research labs funded by USS
$3.5M+	$763K +	9

Awareness - Storytelling to Educate & Raise Funds

Awareness is key to educating the public about Usher syndrome and building the support needed to drive change.

Events & Shine A Light Exhibit

# of places exhibit has traveled	# of people photographed
60	250

# of people have seen our exhibit	# impressions of stories in the media
550K+	500M

Data from campaigns and events 2024-2025

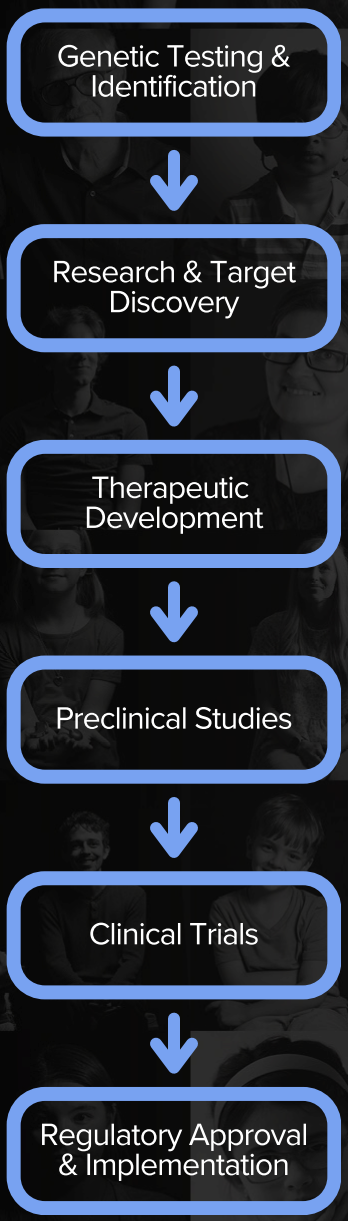
Website visitor increase :	Page views & triggered events	Donor base increase:	Donations increase:
863%	492%	118%	200%

With Your Help

We can see the future.

The Usher Syndrome Society is committed to funding research to stop, reverse, and cure Usher syndrome, but we can't do it alone. With more funding, we can accelerate breakthroughs and bring life-changing treatments faster to those who need them. Science is moving fast and every second counts when you are going deaf and blind.

Your donation helps with these steps:



Fundraising Goal for 2026

Raise $1.5 Million

for Usher syndrome research!

Contributions make it possible to identify potential therapeutic targets, develop innovative treatments, conduct essential preclinical studies to assess their safety and efficacy, initiate clinical trials and supports the rigorous process of obtaining regulatory approval and implementing new treatments in clinical practice.

Where are we now?

Currently, some of our work is in preclinical studies.

We have the power to accelerate research now.

Donate Online:
www.ushersyndromesociety.org/donate/

Grants, Donor Advised Funds, Stocks:
nancy@ushersyndromesociety.org

Checks: Usher Syndrome Society
1544 Central Ave. Needham MA 02492

When you are going deaf + blind at the same time, Every Second Counts.

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