SAVE SIGHT NOW.

We are a parent-led organization dedicated to saving the vision of thousands of children around the world.

Two Bay Area Parents Lead Charge in Fight Against Blindness and Advancement of Genomic Medicine

Medicine is undergoing a transformative shift as the field of genomics continues to advance. The success of the COVID-19 RNA vaccine has demonstrated the power and efficacy of gene therapies and has shown that this approach can be used to tackle even the most challenging of diseases. With the power to edit genes and create tailored treatments for individual patients, the future of medicine is promising, but will it arrive in time for those who need it today?

Two Bay Area parents are at the forefront of this medical evolution as they race to save their daughter's vision and advance treatments that could impact countless lives. Their tireless efforts to drive and fund the future of cell and genomic medicine are an inspiration to us all. After a devastating diagnosis of Usher syndrome type 1B, they formed the parent-led organization - Save Sight Now - to bring desperately needed funding to the fight against blindness. Despite the incredible progress being made in the field, funding remains a major roadblock to realizing treatments; especially for rare diseases like Usher syndrome – the leading cause of deaf-blindness. These parents serve as a reminder that those with the most at stake, such as those with children suffering from rare diseases, can be the greatest drivers of research and progress.

Who Are We

We are two parents who created a charitable organization to save our our daughter's vision. We started Save Sight Now to fund research and find treatments for Usher syndrome type 1B, a rare genetic disorder that is the leading cause of childhood combined deaf-blindness. We aren't trained scientists or researchers, but we've educated ourselves in order to understand the primary hurdles that researchers face when investigating new retinal treatments associated with Usher syndrome, and we absolutely feel it is our responsibility to support these researchers working to save our daughter's vision any way we can.

Rosalyn Porcano | Mom & Co-founder
Rosalyn has been a successful private chef for over 17 years in the Bay Area. She now splits her time between cooking for clients, supporting Lia's hearing and mobility needs, all while supporting multiple Save Sight Now tasks and obligations.

Justin Porcano | Dad & Co-founder
Justin is hardware and experience designer. When not working full-time, he is researching the latest USH therapeutic strategies, contacting researchers, and designing outreach and fundraising events.

Our Story

August 3rd, 2018 – 5 months after Lia's birth, and after learning of her profound deafness, we received Lia's genetic test results. Lia was diagnosed with a rare genetic disease – Usher Syndrome Type 1B - due to variants in the MY07A gene. In addition to congenital deafness and severe balance issues, Lia was also progressively losing her vision. We were devastated. Most children with USH1B are legally blind before they graduate high school.

There is currently no treatment for Usher syndrome type 1B, and time is not on our side; but we fight to save her vision and thousands of others, because how could we not?

[WATCH THIS VIDEO - OUR STORY]

Contact Us

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Our Mission

Rare diseases like Usher Syndrome are underserved and poorly-funded, which is why the burden of funding research often falls on the shoulders of patient led organizations like Save Sight Now.

Our goal is to ensure that thousands of children living with Usher syndrome type 1B do not lose another critical sense for experiencing and navigating the world around them. We know this is achievable because we've already seen successful treatments approved by the FDA, such as Luxturna. The science is there, but the funding is not, and we won't quit until a treatment is found.

What is Save Sight Now

Save Sight Now is a parent lead organization whose primary goal is identifying and funding promising research that can benefit those living with Retinitis Pigmentosa due to Usher syndrome Type 1B.

In 2019, we partnered with the Foundation Fighting Blindness, the world's leading inherited retinal disease foundation, to advance our mission. The FFB are not only our partners in this fight, but also our fiscal sponsors - as well as an invaluable source of scientific information and administrative support.

Usher syndrome Type 1B

Usher syndrome is a rare genetic condition characterized by partial or total hearing loss and vision loss that worsens over time. Usher syndrome is the most common form of deaf-blindness. There are 3 types – type 1, 2 and 3 – categorized by severity of hearing loss and speed of vision loss. Type 1 is the most severe – type 1b is the most prevalent – leading to significant and rapid progression of vision loss in childhood.

Individuals with Usher syndrome type 1B are born with profound hearing loss and progressive vision loss caused by Retinitis Pigmentosa which becomes apparent in childhood, starting with a loss of night vision (For Lia, this began at age 3), progressively worsening tunnel vision and eventually blindness. USH1B also causes significant abnormalities of the vestibular system, resulting in severe balance issues.

"The science is there, but the funding is not"

Notable Achievements

- We are the first and only parent-led organization to partner with the Foundation Fighting Blindness in their 51-year history
- We've raised over $1,500,000 in 4 years all through grassroots fundraising
- We funded the first ever CRISPR-cas9 gene-edited primate with an inherited retinal disease (USH1B) to be used for testing new therapies.
- We have become the first touchpoint for newly diagnosed families with USH1B
- In 2022, we partnered with two new USH1B families in Switzerland, officially becoming an international organization

Research We Fund

- **Martha Neuringer, Oregon Health Science University and Casey Eye Institute** - Creation and characterization of a non-human primate USH1B model
- **Mark Pennesi, Oregon Health Science University and Casey Eye Institute** - Creation of USH1B retinal organoids to develop therapies
- **Isabelle Audo, Deniz Dalkara, Aziz El Amraoui, Serge Picaud, Institut de la Vision Paris** - Development of gene therapies based on understanding USH1B pathogenesis
- **Uwe Wolfrum & Kerstin Wolfrum, Wolfrum Lab, Institute of Molecular Physiology, JGU** - Characterization of naturally occurring USH1B pig model

Links: Images, Videos, Etc

Image Links

- Porcano family and Lia Images
- Save Sight Now Logos
- Save Sight Now Videos
- Children w/ USH1B Images
- Save Sight Now Europe - Family Images

Video Links

- Feeling The Impacts of USH1B, and Pushing On
- Our Save Sight Now Story
- Lia's Trip to OHSU - Contributing to Research

Save SIght Now Press:

- CBS News - Bay Area couple raises funds to research rare genetic disorder that causes blindness and deafness
- Marin parents rally for deaf toddler facing blindness
- Rare Leader: About Justin Porcano, Co-founder and Executive Director, Save Sight Now
- Foundation Fighting Blindness: Causes for Cures

Social Links

- Facebook
- Instagram
- Linkedin
- YouTube

Featured Save Sight Now News Articles

- First Ever USH1B Non Human Primate Model Created!
- We Are Going International

"Save Sight Now is helping the Foundation accelerate USH1B research from basic science to translational approaches, and their involvement has grown our USH1B grant portfolio by 40% in just three years."

Dr. Amy Laster
SVP, Science Strategy and Awards of the Foundation Fighting Blindness