Imagine, for a second, having to face the world without hearing any sound, without balance, and without sight.

Usher Syndrome Type 1B is a rare genetic disease that causes profound bilateral deafness, vestibular dysfunction from birth, and childhood blindness.

Save Sight Now Europe is a nonprofit organization dedicated to finding a treatment for USHER 1B.

Save Sight Now Europe was founded following the devastating diagnosis of our daughter Bruna in 2021.

Our goal: to find a cure for blindness in Usher 1B as soon as possible.

SAVE SIGHT NOW. EUROPE

Committed to curing Childhood Blindness in Usher Syndrome Type 1B.

A race against time to save the vision of all children with Usher 1B.

AN UNMET MEDICAL NEED NEED USHER SYNDROME TYPE 1B

USH1B is caused by a mutation in the MYO7A gene, which encodes a motor protein essential for the function of sensory cells in the inner ear and retina.
Prevalence: 1:50,000 people. Most common form of type 1.

3-6% of children born deaf or with hearing loss have Usher Syndrome.

There are 3 types of Usher syndrome. USH1B causes profound congenital deafness, vestibular dysfunction, and progressive childhood blindness.

RETINITIS PIGMENTOSA (RP)

RP degenerates the retina's photoreceptors, leading to night blindness and peripheral vision loss, eventually narrowing the visual field to tunnel vision.

RP causes 50% of blindness cases worldwide.

There is currently no approved treatment for blindness in Usher Syndrome.

Luxturna, already approved for another form of inherited retinal blindness, proves that curing blindness is possible. New therapies such as gene therapy, gene editing, and optogenetics offer real opportunities to slow or reverse RP.

Investing in research today gives thousands of children a real chance at sight.

WHAT DO WE DO AT SAVE SIGHT NOW EUROPE?

Save Sight Now Europe is the only organization in the world exclusively dedicated to Usher syndrome type 1B. This gives us a unique position of leadership and responsibility: we mobilize the scientific, medical, and patient communities.

We are supported by an international Scientific Advisory Board that guides our decisions, validates the projects we fund, and keeps us focused on our shared goal: **to accelerate the arrival of effective treatments as quickly as possible.**

01 PROMOTING RESEARCH

We promote advanced MYO7A therapies from animal models to clinical trials with world-leading researchers.

02 CONNECTING SCIENCE & COMMUNITY

We connect and support families with clear information, monthly meetings, and awareness campaigns.

03 MOBILIZING RESOURCES

We raise funds and link science, regulation, and investment to accelerate treatments — creating a replicable model for other rare diseases.

We are connected to leading research and biotech teams working on a cure for USH1B. We support preclinical and clinical projects with strong therapeutic potential.

CURRENT USH1B RESEARCH

We collaborate with:
Elvir Becirovic (Zurich): dual AAV gene therapy and CRISPRa activation.
David Gamm (Wisconsin): human retinal organoids and potency assays.
David Williams (UCLA): CRISPR/Cas9 editing for MYO7A.
Institut de la Vision (Paris): gene therapy development and natural history studies using AI.

Biotech & consortia working for USH1B:
AAVantgarde Bio – Auricchio (TIGEM): only active USH1B clinical trial
Atsena Therapeutics, OHSU, Moorfields Eye Hospital, and others

SAVE SIGHT NOW.
EUROPE

HOW CAN YOU HELP?

TURN SOCIAL COMMITMENT INTO REAL IMPACT

Include our cause in your CSR plan. Organize internal donations or solidarity campaigns with your team.

FROM SCIENCE TO CLINIC: NOW IS THE TIME TO ACT

Share data, tools, or strategic IP. Provide funding or technical capabilities. Support registries, clinical trials, or regulatory guidance.

CHANGE THE FATE OF THOUSANDS OF CHILDREN

Fund our research: support emerging therapies, animal models, and genetic studies.