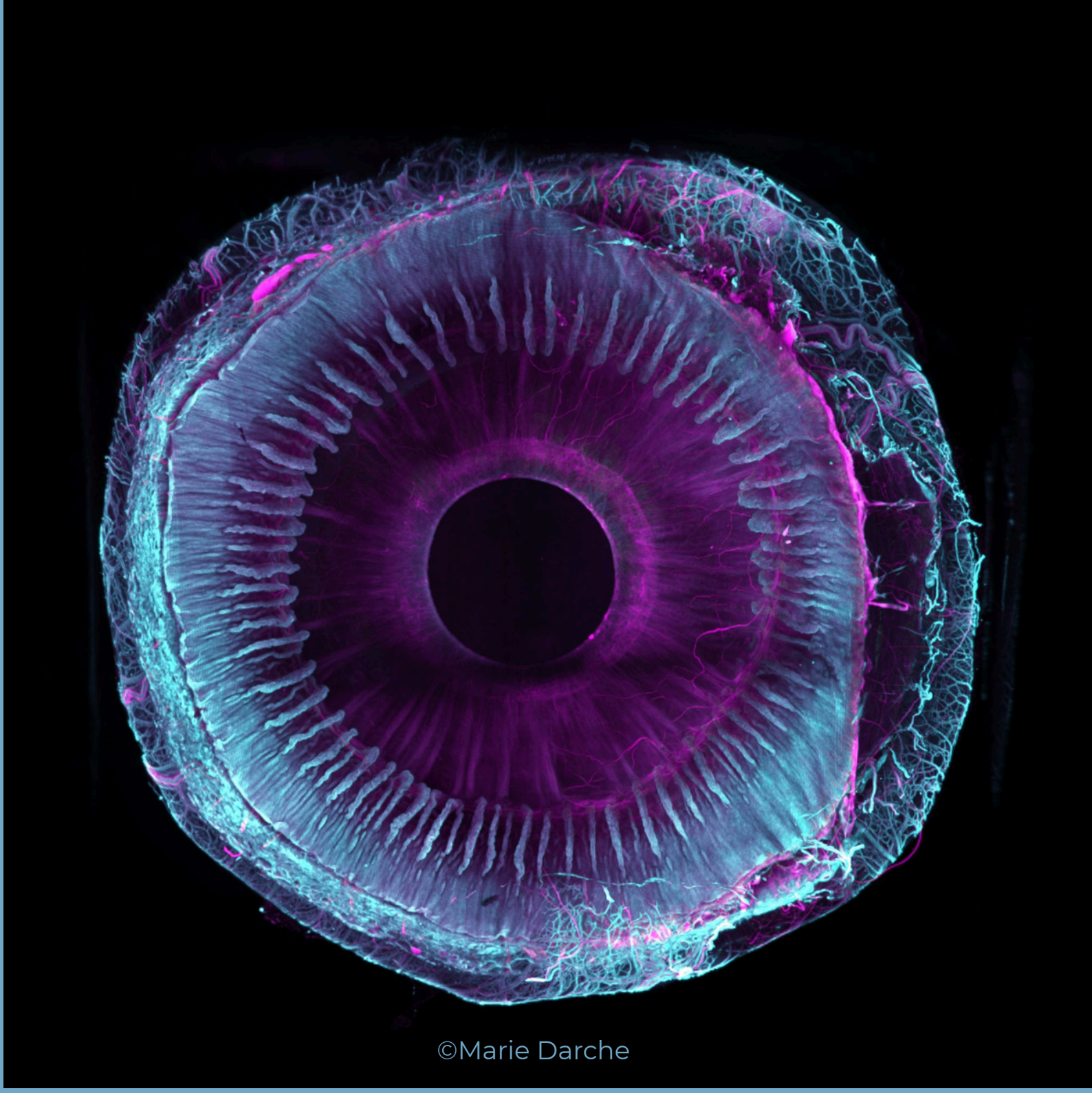

©Marie Darche

Annual Balance

Save Sight Now Europe CH

2024

SAVE SIGHT NOW.

EUROPE

We envision a future where Usher syndrome type 1B is fully treatable—in vision, hearing, and balance—and where no child ever loses their sight due to this condition. We work with urgency, science, and determination to turn this vision into reality.

Contact

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HACER UNA DONACIÓN

Cuenta bancaria Española
IBAN: ES12 2100 0841 9902 0117 0842
BIC: CAIXESBBXXX
TITULAR: Fundació Síndrome d'Usher

Cuenta bancaria Suiza
IBAN: CH21 0021 5215 1626 4240 J
BIC: UBSWCHZH80A
TITULAR: Association Save Sight Now Europe (Switzerland)

HACER UNA DONACIÓN

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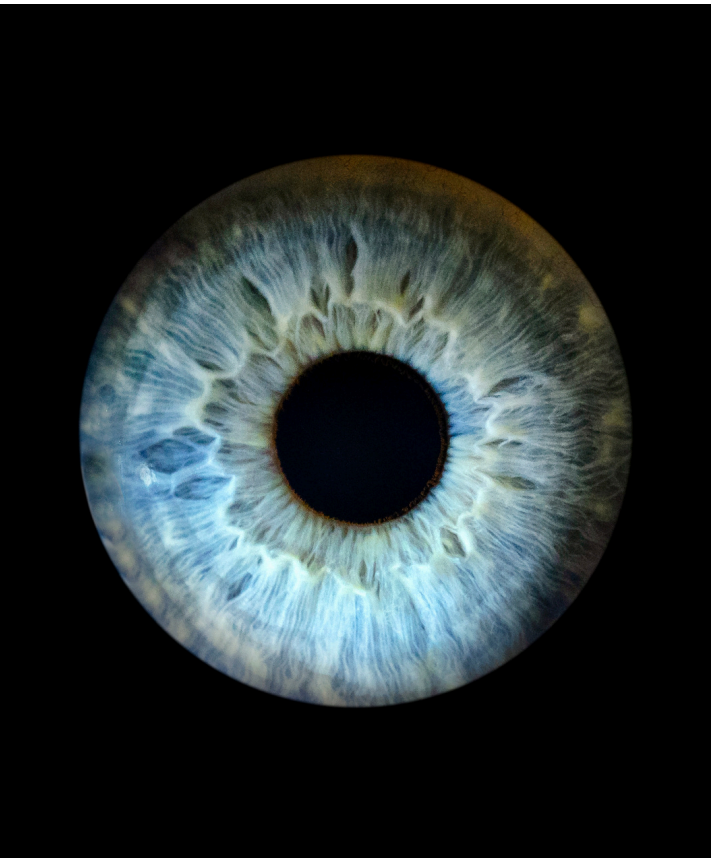
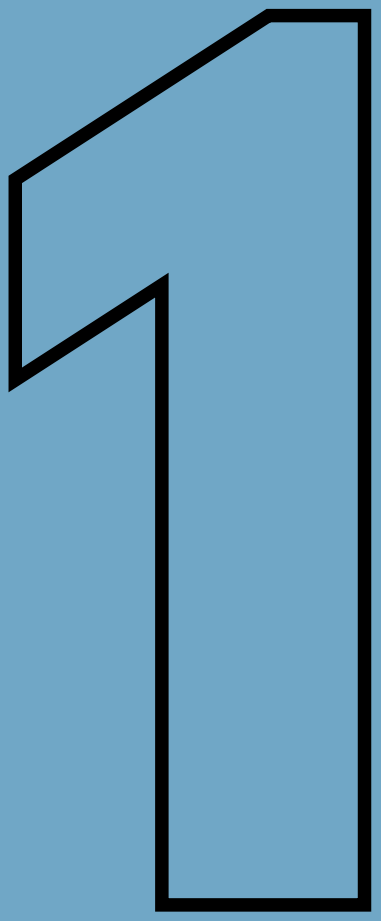
Save Sight Now Europe Switzerland





An Organisation

Message from the President: Rewriting the Future

In 2024, Save Sight Now Europe continued to rise as a leading scientific foundation and a catalyst for strategic alliances in the fight against childhood blindness caused by Usher syndrome type 1B. Our commitment remains unwavering, driven by rigor, perseverance, and responsibility.
Throughout the year, we maintained a strong presence at key scientific forums such as ARVO, EURETINA, and the International USH2025 Congress in Nijmegen. We deepened collaborations with world-class research teams including the Institut de la Vision in Paris and the IOB in Basel, and actively partnered with research groups and companies to combat blindness from multiple angles.
Significant progress was made toward agreements with leading hospitals and research centers focused on Usher syndrome, while we also advanced the integration of artificial intelligence tools to analyze data, identify patterns, and accelerate milestones on the path toward future therapies.
Our role as a patient organization enables us to identify dedicated researchers, foster genuine scientific synergies, and amplify efforts so that progress reaches further, faster, and with greater impact.

We recognize the path ahead is challenging and demands time, commitment, and coordination. But every step forward counts, with our eyes fixed firmly on the goal.
Behind all our work lies a profound reality: the daily life with Usher syndrome. As a mother of a child affected, rest is elusive. Yet, we refuse to retreat. We accept the diagnosis and choose to transform it. Working for the health of children fills our hearts. Our daughter is the engine of this fight, and our family's commitment is relentless, steady, and filled with love, joy, and determination.
We present this annual report with pride in what we have accomplished, and with a steadfast gaze toward the future — because children like our daughter, and so many others, deserve a horizon filled with light.

Berta Adell Palau
Cofounder and President

An Organization for Usher Syndrome 1B

Our vision. We envision a future where Usher syndrome type 1B is fully treatable in all its dimensions: vision, balance, and hearing. A future where no child loses their sight due to this disease, and where scientific advances translate into accessible therapies for all families.
We work to change the natural course of the disease, driving real solutions with the urgency felt by those living with Usher 1B. Our vision is born from a personal experience but aspires to a collective mission: transforming isolation into action, ignorance into research, and waiting into progress. We believe in science that listens, connects with patients, understands complexity, and embraces collaboration.

VWe envision an international network committed to a cure: researchers, doctors, companies, donors, and families united by a common purpose.
Because every day counts. Because every child affected deserves to see, hear, move, and live. And because we know that together, we can accelerate the arrival of that future.

Our Mission. Usher syndrome type 1B entered our family as a diagnosis, but we did not wait for answers — we set out to build them.

Our mission is clear: to accelerate the development of treatments that halt — and one day reverse — childhood blindness caused by this disease. To achieve this, we connect science and community, foster strategic alliances, fund research programs, and work to ensure Usher 1B occupies its rightful place on the international scientific and medical agenda.

Our daughter showed us the void. Our determination is transforming it.

Usher Syndrome

Usher Syndrome Type 1B and Inherited Retinal Dystrophies: A Scientific and Social Urgency

Usher syndrome type 1B is an ultra-rare but devastating disease that affects hearing, balance, and vision from birth or early childhood. It is the most common cause of genetic deafblindness and accounts for up to 50% of all cases of deafblindness worldwide. Its progression is relentless: children are born profoundly deaf, with a compromised vestibular system (lack of balance), and during childhood, they begin to progressively lose their vision due to retinitis pigmentosa.

Usher Syndrome 1B: From Ultra-Rare to Priority

Although Usher 1B is considered ultra-rare (1 in 130,000), it stands at the frontier of scientific interest, viability, and transformation. Supporting research into this condition is not only a matter of justice but also a strategic investment with global impact.

This multisensory nature and early onset of the disease result in a profound social, familial, and economic impact throughout a person's life, with significant cumulative costs. At a time when healthcare systems are seeking efficiency and prevention, accelerating treatments for diseases like this is not only urgent but also strategic and wise.

Inherited retinal dystrophies (IRDs), such as Usher 1B, have begun to receive renewed momentum thanks to advances in gene and cell therapies. Multiple research teams are already working on potential solutions, including gene editing, dual vectors, antisense therapy, optogenetics, and combination therapies. For the first time, the possibility of treating genetic blindness is within reach.

This new context coincides with a historic milestone: in May 2025, the World Health Organization (WHO) formally adopted its first resolution on rare diseases, recognizing their global priority and the need to promote access to diagnosis, treatment, and care.

For more information about Usher syndrome, visit www.savesightnoweurope.org

Childhood Blindness: Retinitis Pigmentosa in Usher 1B

Retinitis pigmentosa (RP) is the most common inherited retinal dystrophy. It causes progressive degeneration of the photoreceptors, beginning with night and peripheral vision loss, eventually affecting central vision and often leading to complete blindness.

In Usher syndrome type 1B, this visual loss starts in childhood, with a progressive narrowing of the visual field—known as tunnel vision—that can lead to total blindness before adulthood. It is also frequently associated with cystoid macular edema (CME), a complication that further impairs central vision.

A severe, early-onset, and neglected form

Although Usher 1B is considered an ultra-rare disease, it represents one of the most severe and early-onset forms of retinitis pigmentosa. The combination of childhood onset, rapid progression, and multisensory involvement has, until now, led to its exclusion from most clinical trials.

A Key Element for the Future of Vision

Research into childhood retinitis pigmentosa not only represents an opportunity to change the course of a devastating disease but also has the potential to lay the groundwork for therapies applicable to other forms of retinal degeneration. Its monogenic nature, early onset, and the availability of robust animal models make it a scientific and strategic priority within the current biomedical ecosystem.

Fortunately, the landscape is changing:

1.Gene therapies targeting the MYO7A gene, the cause of Usher 1B, are currently in development. Notably, programs using dual AAV vectors such as the LUCE clinical trial (by Avantgarde Bio) and the preclinical program by Atsena Therapeutics show promise. Academic collaborations, including the laboratories of Dr. Elvir Becirovic at the University of Zurich and Dr. David Gamm at the University of Wisconsin, hold significant potential to cure or reverse blindness in Usher 1B.

2. Other advanced-stage treatments for retinitis pigmentosa target genes like RHO, RPGR, or PDE6B, potentially paving the way for combination strategies and regulatory models that could also apply to Usher 1B.

3. Cutting-edge approaches such as optogenetics, precision gene editing (base editing) —with ongoing research at the IOB in Basel and companies like Rhygaze Therapeutics— and cell therapies aimed at patients without functional photoreceptors, like those proposed by BlueRock Therapeutics, are also under exploration.

Research and Science

Research into inherited retinal dystrophies, including Usher Syndrome Type 1B, is yielding increasingly solid results. However, turning these advances into available therapies depends on our collective ability to sustain, guide, and bring them to patients. Science is progressing; now we must accompany it to the finish line: the patients.

Scientific Drive: Advocacy and Activity for Usher 1B

In 2024, we consolidated our role as an active and recognized player in international research on Usher syndrome type 1B. Our participation in top-tier scientific congresses has been key to fostering alliances, accelerating strategic projects, and raising global awareness of Usher 1B.

We were present at ARVO 2025, the largest ophthalmology research congress, with a busy agenda of meetings and presentations. We participated in the FFB Summit in Salt Lake City, organized by the Foundation Fighting Blindness, where we shared progress alongside international leaders in the field. We also attended the USHER2025 Congress in the Netherlands, which combined science and community to strengthen the global response to Usher syndrome.

These efforts have allowed us to strengthen collaborations with centers of excellence in inherited retinal dystrophies (IRD), including:

- Institut de la Vision (Paris) and its dedicated Usher syndrome team.
- IOB Institute of Ocular Microsurgery (Basel) and the base editing program led by Dr. Bence György (in collaboration with RhyGaze).
- Hospital Sant Joan de Déu (Barcelona) and Dr. Jaume Català, with the UNICAS project for rare diseases.
- Hospital La Fe (Valencia), in contact with Dr. José María Millán, current Scientific Director of CIBERER.
- Jules-Gonin Eye Hospital (Lausanne), renowned for its leadership in ocular genetics.
- University of Zurich, where we fund Dr. Elvir Becirovic's program for the development of gene and epigenetic therapy targeting MYO7A.
- Dr. Jordi Monés, a leading retina and degenerative disease expert from Macula Retina Barcelona.

Each of these contacts and collaborations represents necessary steps toward achieving greater and faster impact in developing effective treatments for children and adults affected by Usher syndrome type 1B.

Emerging Therapies for Vision: Base Editing and Gene Therapy

Base Editing in Ophthalmology

- A technology that enables correction of point mutations without breaking the DNA strand.
- By 2025: editing rates of 75% in cone cells and 87% in retinal pigment epithelium (RPE) in primates (targeting the ABCA4 gene).
- Vision restoration observed in animal models of retinitis pigmentosa (RP) and Leber congenital amaurosis (LCA).
- High potential for future therapies in inherited retinal dystrophies (IRD) and Usher syndrome type 1B.

Advanced Gene Therapies

- Luxturna® (RPE65) maintains efficacy in improving night vision.
- New optimized AAV vectors enable treatment of a broader range of genes.
- LUCE-1 (Phase 1/2 clinical trial for MYO7A - Usher 1B) employs dual AAV vectors.
- Key companies involved include Atsena Therapeutics and various academic collaborations.

Application by Disease Stage

STAGE	New Therapies Available
Early Stage	Base editing, Luxturna®, oligonucleotides, NACA
Intermediate Stage	Neuroprotection, optogenetics, slowing (of degeneration)
Advanced Stage	Transplants, advanced Optogenetics, cellular Integration

Note: Although still in the preclinical phase, base editing shows very promising results for future application in the retina.

Advances in Gene Therapies for Usher Syndrome 1B and Inherited Retinal Dystrophies (IRD)

Innovation and Perspectives in the Fight Against Childhood Blindness

Usher syndrome 1B and inherited retinal dystrophies (IRDs), the group to which it belongs, have traditionally been untreatable. However, recent advances in biotechnology are transforming the therapeutic landscape. This year, research has taken decisive steps toward effective and personalized treatments, thanks to the combination of advanced gene therapies, precision gene editing, and the involvement of leading international companies.

1.Gene Therapies with Dual-AAV Vectors:

The size of the MYO7A gene exceeds the capacity of conventional viral vectors, driving the development of dual AAV (Adeno-Associated Virus) vector strategies. These allow the therapeutic gene to be split into two parts that reassemble within retinal cells after administration.

AAVantgarde Bio leads with its AAVB-081 program (LUCE-1), currently in Phase 1/2, specifically targeting Usher 1B. Early preclinical results show up to 70% restoration of the protein in target cells and functional improvements in animal models.

Atsena Therapeutics has demonstrated in other retinal diseases (such as LCA1 and XLRS) that its dual-AAV technology can restore visual function and close retinal breaks in most treated patients, with plans to expand toward Usher 1B in collaboration with the RD Fund.

2. Precision Gene Editing: CRISPR and Base Editing

- CRISPR/Cas9: This technology enables direct correction of disease-causing mutations. In animal models of Usher 1B, gene editing has restored up to 40% of MYO7A protein function, paving the way for permanent and personalized therapies.
- Base Editing: Base editing represents the cutting edge in gene editing, allowing modification of a single DNA base without creating double-strand breaks. Preclinical trials have achieved correction rates above 70% in human retinal cells and animal models, with high safety profiles and no detectable off-target effects. This technology is especially promising for correcting common point mutations in Usher 1B and other IRDs.

3. Other Research Lines and Complementary Therapies

- Antisense Oligonucleotides: Companies such as Sepul Bio and Théa are developing therapies targeting specific mutations in the USH2A gene, with trials in advanced stages.
- Neuroprotective and Antioxidant Therapies (NACA): Trials continue to slow retinal degeneration and improve the cellular environment before or alongside gene therapy.
- Optogenetics and Cell Transplantation: For advanced stages, regenerative techniques and functional restoration using progenitor cells or optogenetic devices are being explored.

Challenges and Future Directions

- Optimization of Gene Delivery: Improve diffusion and assembly of dual vectors in the human retina.
- Combination Therapies: Synergize gene editing, neuroprotection, and cellular regeneration.
- Pediatric Trials: Including children in trials is crucial to prevent blindness before irreversible photoreceptor loss.
- Personalization: Patient and therapy selection based on genetic profile and disease stage, supported by natural history studies such as RUSH2A.

Conclusion

The year 2024 marked a turning point in the research of inherited retinal dystrophies and Usher syndrome 1B. The combination of dual-AAV gene therapies, base editing, and CRISPR, along with the leadership of companies such as Atsena Therapeutics, AAVantgarde Bio, and Sepul Bio, places the scientific and medical community on the brink of a real possibility to halt and potentially reverse childhood blindness associated with these diseases. The coming years will be critical for consolidating these advances into clinical practice and improving the quality of life for patients and their families.

Research Funded by Save Sight Now Europe

At Save Sight Now Europe, we remain steadfast in our commitment to advance research aimed at curing childhood blindness caused by Usher syndrome type 1B, a genetic disease affecting hearing, balance, and vision from early childhood.
In 2024, we continued funding cutting-edge scientific projects, such as the one led by Dr. David Gamm, focused on MYO7A gene editing using organoid models and advanced techniques, aligned with FDA guidelines. The team is now working to expand gene expression studies and functional validations to move closer to clinical trials.
We also promote participation in international studies such as UNI-RARE, which is key to gathering the necessary data for treatment approvals. European clinics have started enrolling patients, and we keep our community informed about every new opportunity.

Driving Artificial Intelligence in Research:

At Save Sight Now Europe, we are actively promoting the application of artificial intelligence (AI) in the analysis and generation of data from natural history studies of Usher syndrome type 1B. The use of AI enables us to process large volumes of clinical and genetic data more efficiently and accurately, facilitating the identification of patterns and prediction of disease progression.
This strategy accelerates the validation of new therapies and optimizes clinical trial design, reinforcing our commitment to innovation and scientific excellence as we advance toward effective treatments for patients.

Investment and Collaborations to Advance Research

In 2024, we continued to drive key scientific projects that bring us closer to real therapies for Usher syndrome type 1B.

Dr. Becirovic Program – University of Zurich

Our support has been consolidated through the program led by Prof. Elvir Becirovic, which combines two complementary strategies to address the MYO7A gene:

- Gene supplementation therapy using dual AAV vectors with trans-splicing to deliver the full MYO7A gene.
- Epigenetic activation (CRISPRa) of the functionally related MYO7B gene as a therapeutic alternative.

This program, developed on robust preclinical models, is preparing to advance toward regulatory validations and trials in large animal models.

Dr. Gamm Program – University of Wisconsin-Madison

Over the past year, we successfully completed the collaborative program with Dr. David Gamm, a world leader in gene therapy and stem cell research, based at the University of Wisconsin-Madison (USA). This project focused on developing a gene supplementation strategy using lentiviral vectors to treat mutations in the MYO7A gene, which causes Usher syndrome type 1B.

The results have been positive, and all objectives of the work plan have been met, including:

- The production of functional lentiviral vectors capable of carrying the full MYO7A gene.
- Preclinical validation in patient-derived stem cells with Usher 1B, demonstrating sustained expression and therapeutic potential.

This milestone represents a key step toward advanced and targeted therapies for Usher 1B. The completion of this program has also established new foundations for future collaborations with Dr. Gamm's laboratory and other centers of excellence in gene therapy.

Institut de la Vision Program (Paris) – Dr. Isabelle Audo and Team

The research program on Usher syndrome type 1B continues at the prestigious Institut de la Vision in Paris. This international project is designed to integrate fundamental scientific discoveries with advanced therapeutic approaches, aiming to achieve concrete progress in two major areas:

- Genetic and Clinical Study of Usher Syndrome Type 1B: Analysis of genotype-phenotype correlations, natural history study through the Light4Deaf program, and characterization of Usher 1B–specific molecular signatures.
- Development of Gene Therapies: Building on a deep understanding of Usher 1B pathogenesis, the team is working on novel gene therapy strategies aimed at effectively targeting mutations in the MYO7A gene.

Additionally, in 2024, we began collaborating with researchers at the Institut de la Vision to integrate artificial intelligence (AI) tools. Our goal is to accelerate the acquisition and analysis of clinical and genomic data, optimize biomarker definition, and facilitate the design of future personalized therapeutic trials for Usher 1B.
The team is composed of prominent international experts: Dr. Isabelle Audo (MD, PhD), Dr. Deniz Dalkara (MSc, PhD), Dr. Aziz El-Amraoui (PhD), and Dr. Serge Picaud (MD) – Scientific Director of the Institut de la Vision (Paris).

Dr. Wolfrum Program – Johannes Gutenberg University Mainz

The program led by Dr. Uwe Wolfrum (Johannes Gutenberg University Mainz) continues, focusing on the natural pig model with MYO7A mutation. In 2024, sixteen Usher 1B piglets have been recorded, and work is underway on specific antibodies to study splice variants. Concurrently, Dr. Kerstin Wolfrum is developing retinal organoids with confirmed phenotypes. This preclinical platform represents a key tool for validating future therapies for Usher syndrome type 1B.

Additionally, one of our commitments is to keep all avenues open that may lead to real change in the treatment of Usher type 1B. For this reason, we maintain active communication and growing collaboration with key researchers such as Aziz El-Amraoui, Bence György, and Elvir Becirovic, whose lines of work represent complementary and highly promising approaches.

Current Research on Usher Syndrome 1B

HIGHLIGHTED CLINICAL ADVANCES 2024-2025

PROGRAMS IN CLINICAL DEVELOPMENT

AAVANTGARDE BIO, TIGEM - Alberto Auricchio

LUCE Trial – First MYO7A Gene Therapy Clinical Trial

University of Campania Luigi Vanvitelli – Francesca Simonelli

The first human clinical trial of dual AAV8.MYO7A gene therapy (AAVB-081) for Usher 1B.
Subretinal administration specifically targeting MYO7A mutations.
Results at 60 days for the first two patients:

- Excellent safety profile with minor and transient adverse events.
- Stable best-corrected visual acuity (BCVA), improvement in low-luminance visual acuity (LLVA).
- Improved fixation stability and sensitivity.
- One patient showed an increase of approximately 20 dB in white full-field stimulus testing (FST).

The dual vector technology developed by Dr. Alberto Auricchio has ushered in a new era following its success in restoring hearing in children with OTOF mutations.

ATSENA THERAPEUTICS - Shannon Boye

Usher 1B Program (ATSN-201)

Dual AAV vectors capable of delivering large genetic payloads.
Validated vector: The same vector currently used in clinical trials for LCA1, providing established safety validation.
Promising results in primate studies demonstrating strong transgene expression.

- Partial funding confirmed for Usher 1B development.

ADVANCED TRANSLATIONAL RESEARCH

OSHU Cassey Eye Institute - M. Pennesi

- Adaptation of CRISPR Gene Editing Tools for LCA Applicable to Usher 1B Patients
- Development of Edit-101 CRISPR/Cas9: The first CRISPR therapy in humans for retinal disease.
- 79% of patients showed improvement in at least one metric.
- Effects sustained after 2 years.

IOB, Institute of Molecular & Clinical Ophthalmology Basel (IOB)
Bence György - Precision Base Editing

- Base editing technology for single-nucleotide corrections.
- A system without DNA breaks using Cas9 nickase + guide RNA + deaminase enzyme.
- Third-generation AAV vectors achieve editing rates up to 87% in retinal pigment epithelium (RPE) and 61% in rod photoreceptors.
- Potential application to Usher 1B through similar base editing approaches.

WAISMAN CENTER - David Gamm

- Modeling Usher 1B Using Retinal Organoids Derived from iPSCs of Affected Individuals
- CLARICO platform for precursor photoreceptor cell therapy derived from iPSCs.
- Phase 1/2a trial specifically including patients with Usher syndrome.
- Up to 54 participants, employing a mutation-independent cell replacement approach.

INNOVATIVE GENE THERAPIES

OCU400 - Ocugen

Gene-Agnostic Modifier Gene Therapy

- Delivery of the NR2E3 gene as a "master regulator" of multiple retinal genetic pathways.
- 12-month results: 89% of subjects demonstrated preservation or improvement.
- 2-year data: 100% of evaluable subjects showed improvement or preservation.
- Phase 3 liMeliGhT trial: 150 patients, the first Phase 3 gene therapy with a broad indication for retinitis pigmentosa (RP).

Next-Generation Optogenetic Therapies

MCO-010 (Optogenetics) - Nanoscope Therapeutics

- Mutation-Agnostic Optogenetic Gene Therapy
- Results at 126 weeks: Significant and lasting improvements in visual acuity.
- High-dose group: average improvement of 0.322 ± 0.114 logMAR (P=0.007). 56% gained 3 or more lines of vision at week 76.

ZM-02 y UGX-201 - Zhongmou Therapeutics (Xina)

- ZM-02: 83% of patients showed clinically significant visual restoration.
- UGX-201: Cohort 2 – 2 out of 3 patients regained light perception.

COMPLEMENTARY THERAPEUTIC APPROACHES

Small Molecules and Antioxidants

N-Acetylcysteine (NAC) – NACAttack

NAC ATTACK Phase 3 Trial:

- 483 target patients, 33 sites across 8 countries.
- Gene-agnostic approach targeting oxidative stress.
- Statistically significant improvements in best-corrected visual acuity (BCVA) across all dosage groups.

Nacuity Pharmaceuticals (NPI-001/NACA)

- Perfil de seguridad excelente hasta 500 mg/día en pacientes con síndrome de Usher
- Tasa de cumplimiento del 98.2%
- Fase 2: 42 de 47 sujetos eligieron continuar tratamiento más allá de 24 meses
- Ensayo Fase 3 planificado para Q1 2026 (USA & Australia)
- Primera terapia aprobada potencial específicamente probada en población Usher.

Artificial Visual Restoration

KIO-301 - Kiora pharmaceuticals

- Excellent safety profile up to 500 mg/day in patients with Usher syndrome.
- Compliance rate of 98.2%.
- Phase 2: 42 out of 47 subjects chose to continue treatment beyond 24 months.
- Phase 3 trial planned for Q1 2026 (USA & Australia).
- First potential approved therapy specifically tested in the Usher population.

(RTx-015) - Ray Therapeutics

- Next-generation optogenetic therapy without the need for light-enhancing glasses.
- 100–1000x greater light sensitivity compared to competitors.
- Operates effectively at normal ambient light levels.

Fundraising Activities and Campaigns

Social and Community Visibility

We understand that changing the future of Usher 1B requires more than advancing science: it also requires raising awareness and mobilizing society. That is why, in 2024, we strengthened our visibility efforts across multiple channels:

- We participated in the program "Les Bones Causes" on Catalunya Ràdio, alongside personalities such as Julio Manrique, Raquel Sans, Els Amics de les Arts, and Berto Romero. These prime-time broadcasts allow us to bring awareness of Usher type 1B to thousands of homes across Catalonia and Spain.
- We celebrated Rare Disease Day and a special campaign for Sant Jordi 2025, with awareness activities in public spaces and online.
- We took part in the podcast La Ciencia de lo Singular by Share4Rare in the episode on Inherited Retinal Dystrophies, featuring leading researchers: José María Millán — Director of Ciberer; Carmen Ayuso — Scientific Director of IIS-FJD and Deputy Director of Research at FJD; Dr. Jaume Català — Coordinator of the Hereditary Retinal Dystrophies Unit at SJD-HUB; as well as the President of Retina Murcia and FARPE, David Sánchez.
- We maintain contact and visibility in print and audiovisual media, which have shown growing interest in our work and story.
- Through our newsletters, press releases, and social media channels, we share testimonials, scientific news, and updates on the programs we support, mobilizing an increasingly engaged community.
- We have also consolidated our annual event, La Nit de la Visió, as a gathering space for connection, fundraising, and social outreach, bringing together science, culture, and solidarity to advance together toward a cure.

Our scientific and community momentum go hand in hand: it is the combination of cutting-edge research and a strong, informed, and active community that can change the story of Usher syndrome type 1B.

Because we know that it is not enough to wait for treatments to arrive — we are working to make sure they do.

Fundraising

As an ultra-rare disease, we know how crucial the numbers are. That's why we are growing every day—raising awareness and increasing our fundraising efforts to support science.

Fundraising Activities Save Sight Now Europe:

We raise funds through various channels: applying for research grants, conducting fundraising campaigns through the Spanish Foundation and the Swiss Association, and organizing Usher events led by families and friends. We work to empower the Usher community to push strongly toward what can become a reality.

SOIRÉE SOLIDAIRE À LA TOUR VAGABONDE (FRIBURGO)

Musical and testimonial event to raise awareness and funds for Usher 1B research.

SOLIDARITY RUN – CO SARINE OUEST (FRIBOURG, SWITZERLAND)

A 5 km charity run organized by the students of CO Sarine Ouest in Fribourg.

THE NIGHT OF VISION

2nd Edition of The Night of Vision, held at the Modernist Venue of Sant Pau.
A charity gala featuring scientific presentations, personal testimonials, and a cocktail dinner. This annual event is dedicated to fundraising for research.

ROTARY FOR USHER

Open Charity Paddle Tennis Tournament organized by the Rotary Club.
A sporting and festive event with fundraising and local awareness-raising for the cause.

ROSES TO DEFEAT USHER

2nd Edition: Roses and Solidarity Pencils to Rewrite the Future of Usher 1B on Sant Jordi Day 2025.

CINC CIMS

"Cinc Cims" Mountain Race organized to raise awareness and funds. Sport, community, and nature united in the fight against Usher 1B.

24-HOUR ULTRAMARATHON

24-Hour Ultramarathon to Raise Awareness for Usher 1B, led by deafblind athlete Mario Martínez.

CHARITY WEDDING DONATION

A charity wedding donation with high symbolic and economic value.

PETITS KINDERGARTEN: SOLIDARITY CALENDARS

Calendars from the Petits Nursery, fundraising for Usher 1B. Solidarity education and funds for research.

SOLIDARITY SANDWICH EVENT AT CEIP MIGUEL DE CERVANTES.

School Initiative: Solidarity Sandwich Breakfast Fundraiser at Miguel de Cervantes School

ZURICH MARATHON BARCELONA WITH MARIO MARTÍNEZ

Mario Martínez ran the Zurich Marathon to raise awareness for Usher syndrome. Thousands of runners and visitors learned about Usher 1B and supported our cause.

PISTACHIN KIDS: SAVE THE COLORS – SOLIDARITY SWEATSHIRTS

The "Save the Colors" sweatshirt collection, created by Pistachín Kids, supports research efforts.

IMPRO SOLIDÀRIA X SAVE SIGHT NOW EUROPE

Charity Improvisation Show in Barcelona to Raise Awareness and Funds for Usher 1B.

REBEL GENETICS

Rebel Genetics: Solidarity Bracelets and More to Support Research for Usher 1B.

SOLIDARITY PADDLE TOURNAMENT (GRANVIAMAR SPORTS CLUB)

Charity Paddle Tournament Organized at GranViaMar Sports Club to Support Research.

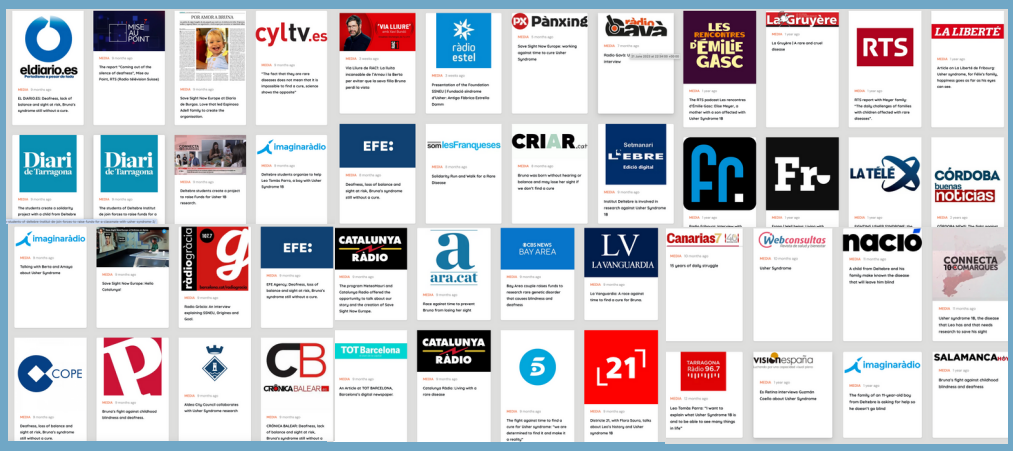
On our website, you can find information about past events and also ongoing events, as well as access the list of collaborators, where we share our commitment to transparency and accountability.

In the Media:

THE SCIENCE OF THE UNIQUE
INHERITED RETINAL DYSTROPHIES
La Ciencia de lo Singular, a podcast by Share4Rare, featured an episode on Inherited Retinal Dystrophies with leading researchers: José María Millán – Director of CIBERER; Ms. Carmen Ayuso – Scientific Director of IIS-FJD and Deputy Director of Research at FJD; Dr. Jaume Català – Coordinator of the Hereditary Retinal Dystrophies Unit at SJD-HUB; as well as David Sánchez, President of Retina Murcia and FARPE.

LES BONES CAUSES
MORNING SHOW ON CATALUNYA RÀDIO
Falques de dibugación en el programa el matí de Catalunya radio en priime time con voces de grandes personalidades del sector cutlural catalan: MARTA PONTNOU, ELS AMICS DE LES ATS, AITANA BONMATÍ, BERTO ROMERO, JULIO MANRIQUE, RAQUEL SANS, MARTA TOMASA.

PLEASE VISIT OUR MEDIA SECTION ON THE WEBSITE.
We have appeared in television and radio interviews, as well as on social media, striving to raise awareness and disseminate information about Usher syndrome type 1 and our work to find a treatment. Our presence includes outlets such as RAC1, Catalunya Radio, ara.cat, La Vanguardia, EFE, CRIAR.cat, Canal 21, Imagina Radio, El Diari, El Diario, Tele 5, Pànxing, Ràdio Gavà, Diario de Burgos, Ràdio Gràcia, Imagina Ràdio, La Télé, RTS, La Liberté, Le Gruyère, among others.



Financials

The Association presents its 2024 financial statements in this comprehensive annual report, providing a transparent overview of its accounts, activities, and fiscal year.

SSNEU Switzerland is an Association based in Geneva, Switzerland, with French and English as its official languages. We use French and also English as the general languages of communication to ensure all donors have access to information. However, official documents are drafted in French, the official language of the Canton of Geneva. For this reason, the financial information that follows is presented in French.

- Interim Report
- Profit and Loss
- Balance Sheet 2024
- Income Statement for 2024 Fiscal Year

Interim Report

Bilan intermédiaire

Actif			Précédent
1	**Actifs**	**102'359.05**	**88'557.22**
10	**Actifs circulants**	**102'359.05**	**88'557.22**
100	**Trésorerie**	**102'359.05**	**88'557.22**
1020	Compte courant UBS IBAN CH21 002	102'359.05	88'557.22
		102'359.05	88'557.22

Passif			Précédent
2	**Passifs**	**102'359.05**	**88'557.22**
28	**Capital de l'organisation**	**102'359.05**	**88'557.22**
297	**Bénéfice ou perte reporté**	**102'359.05**	**88'557.22**
2970	Bénéfice ou perte reporté	88'557.22	48'906.03
2979	Bénéfice ou perte de l'exercice	13'801.83	39'651.19
		102'359.05	88'557.22

Profit and Loss

Pertes et Profits

Charges			Précédent
6	**Autres charges d'exploitation, amortisse**	**87.19**	**11'803.74**
69	**Charges et produits financiers**	**87.19**	**154.80**
6940	Autres charges financières (frais bancai	87.19	154.80
	Différence (bénéfice)	13'801.83	
	Différence précédente (bénéfice)		51'809.08
		13'889.02	51'963.88

Produits			Précédent
3	**Produits nets des ventes de biens et de**	**13'889.02**	**51'963.88**
301	**Dons**	**13'889.02**	**51'963.88**
3010	Produits de donateurs	13'889.02	51'963.88
		13'889.02	51'963.88

Balance Sheet 2024

Association Save Sight Now Europe

Genève

Bilan au 31.12.2024

Actifs	Note	2024	2023
Actifs circulants			
Trésorerie		102 359	88 557
Actifs cotés en bourse détenus à court terme			
Créances résultant de la vente de biens et de prestations de services			
Autres créances à court terme			
Stocks et prestations de services non facturées	3.2		
Actifs de régularisation (actifs transitoires)			
Total actif circulant		**102 359**	**88 557**
Actifs immobilisés			
Immobilisations financières			
Participations			
Immobilisations corporelles meubles	3.3		
Immobilisations corporelles immeubles			
Immobilisations incorporelles			
Capital social (ou capital de fondation) non libéré			
Total actif immobilisé		**0**	**0**
Total actif		**102 359**	**88 557**

Passifs	Note	2024	2023
Capitaux étrangers à court terme			
Dettes à court terme résultant de l'achat de biens et de prestations de services			
Dettes à court terme portant intérêt			
Autres dettes à court terme			
Autres dettes à court terme relatives aux charges salariales (sans intérêt	3.5		
Passifs de régularisation (passifs transitoires) et provisions à court terme			
Total capitaux étrangers à court terme		**0**	**0**
Capitaux étrangers à long terme			
Dettes à long terme portant intérêt			
Autres dettes à long terme			
Provisions et postes analogues prévus par la loi	3.6		
Prêts postposés			
Total capitaux étrangers à long terme		**0**	**0**
Total capitaux étrangers		**0**	**0**
Capital de l'organisation			
Capital de l'organisation			
Réserve légale issue du capital			
< Le compte n'existe pas >			
Réserve légale issue du bénéfice			
Réserves facultatives			
Bénéfice ou perte reporté		88 557	48 906
Bénéfice ou perte de l'exercice		13 802	39 651
Propres actions, parts sociales, droits de participations (poste négatif)			
Total capitaux propres		**102 359**	**88 557**
Total passif		**102 359**	**88 557**

Income Statement for 2024 Fiscal Year

Association Save Sight Now Europe

Genève

Compte de résultat pour l'exercice clôturé au 31.12.2024

	Note	2024	2023
Produits nets des ventes de biens et de prestations de services		13 889	51 964
Variations des stocks et variation des prestations de services non facturés			
Charges directes des projets			-509
Résultat brut après charges directes		**13 889**	**51 455**
Charges de personnel			
Autres charges administratives	3.8		-11 649
Résultat d'exploitation avant amortissements et corrections de valeur, résultat financier et impôts (EBIDTA)		**13 889**	**39 806**
Amortissements et corrections de la valeur des immobilisations			
Résultat d'exploitation avant résultat financier et impôts (EBIT)		**13 889**	**39 806**
Charges financières		-87	-155
Produits financiers			
Résultat d'exploitation avant impôts (EBT)		**13 802**	**39 651**
Résultat des activités annexes d'exploitation			
< Le compte n'existe pas >			
Charges et produits exceptionnels, uniques ou hors période			
< Le compte n'existe pas >			
< Le compte n'existe pas >			
Resultat annuel avant impôts		**13 802**	**39 651**
Impôts directs			
Resultat annuel sans resultat des fonds		**13 802**	**39 651**

Our Thanks

We sincerely thank all the individuals, organizations, and partners who have stood with us throughout 2024. Thanks to your unwavering support, energy, and commitment, we continue transforming hope into action and turning challenges into real opportunities for progress—both in research and within the Usher community. United by hope and scientific advancement, we are deeply grateful.

We extend our heartfelt appreciation to the friends, families, and relatives of those affected who have chosen to join us in this daily fight, generously offering their time and talents to help steer us toward our shared goal. Your dedication is invaluable, and your generosity inspires us every day.

We are profoundly thankful to all the artists who have lent their voices and presence to our events and initiatives, amplifying our message and mission.

To our collaborators and partner organizations: your involvement has been fundamental in driving projects, campaigns, and events that bring us closer to finding a cure for Usher syndrome type 1B and halting childhood blindness associated with it.

Special thanks to Rotary Club Badalona (Joaquín Azofra, Paddle Tournament), Alexandra Gómez Pascual, Álvaro Marín, Leticia Galofré Mestre, Societat Atlètica Corbera, Rubén Jiménez Luque (Cursa Cinc Cims), Mario Raúl Martínez (24h Track Event), Raquel Camón Badi (Impro Solidària), Félix Sánchez Lladó, Granviamar Club Esportiu, Elise and Xavier Meyer (Soirée Solidaire La Tour Vagabonde), and the Mas Gea family (Rebel Genetics). To the companies, foundations, and private donors whose generosity and vision sustain our efforts and dreams—every contribution, every gesture, every collaboration builds a future without barriers for those affected by Usher syndrome. Special thanks to Almenibor SL, Tectrol SA, Pymej SL, Atma Obra, Instituto Médico Privado, Bon Preu SAU, and Fundació Recinte Modernista de Sant Pau.

Our deepest gratitude goes to the families and the entire Usher community, whose trust and active involvement empower us to build a better future for their loved ones and all those affected. Special recognition to the Freixes, Campolier, Mas Gea, and Meyer families.

This year, we have advanced research, awareness, and outreach, woven new alliances, and strengthened the solidarity network that unites us. We face the future with optimism and determination, working with transparency, rigor, and passion—bridging science, institutions, and people.
We safeguard every possible path toward treatment, and none of this would be possible without the support of our collaborators, partners, donors, friends, and families.
We look ahead with hope.
Thank you for being part of this transformative journey that will change the future of childhood blindness.

ARNAU ESPINOSA AND BERTA ADELL
COFOUNDERS OF SAVE SIGHT NOW EUROPE