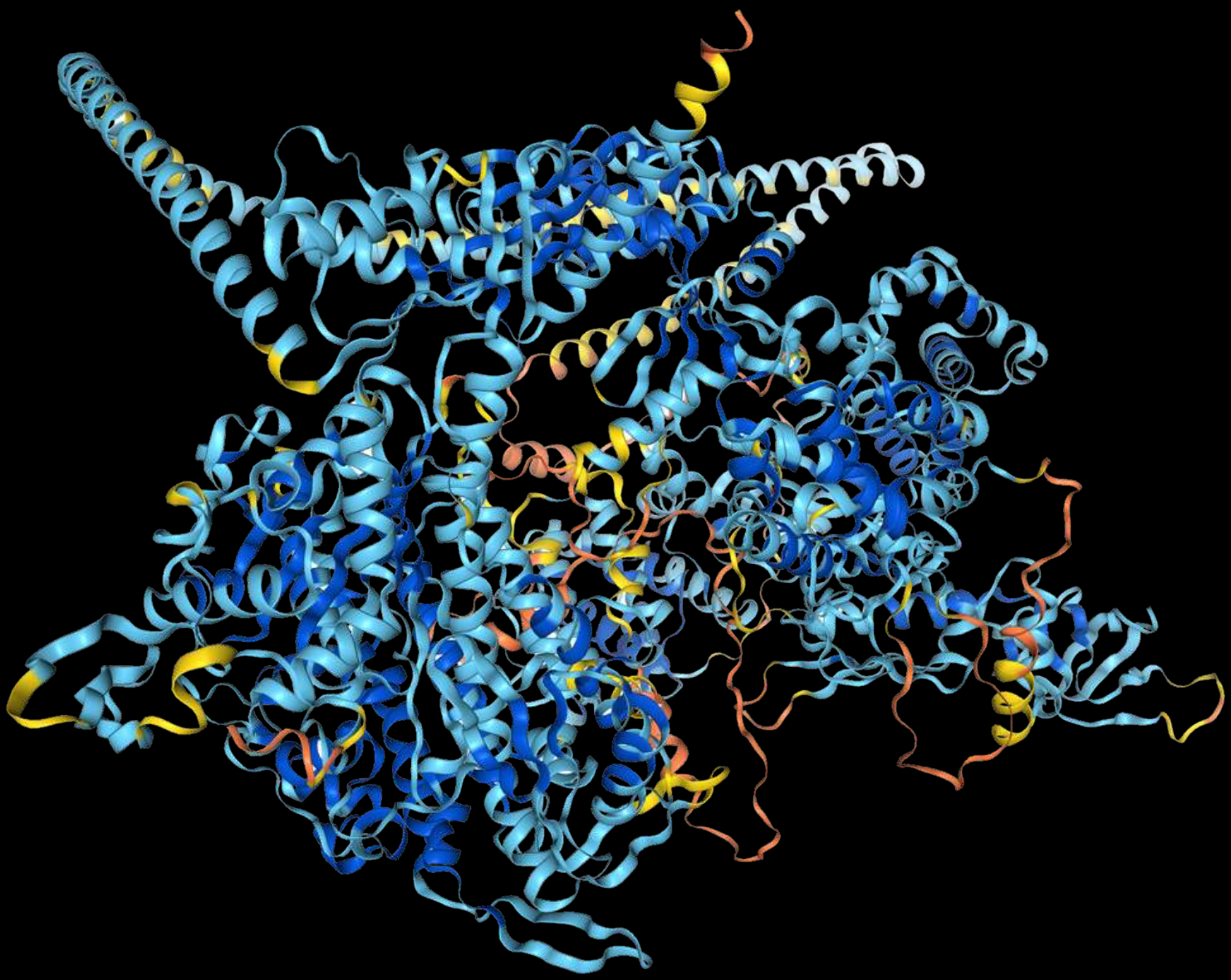

Annual Report 2025

SAVE SIGHT NOW.

EUROPE

Behind every research programme, every action and every agreement lies one certainty: time counts.

We work so that no family has to live through what we have lived, and so that girls and boys with Usher 1B can have a future with all the light they deserve.

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MAKE A DONATION

Spanish bank account
IBAN: ES12 2100 0841 9902 0117 0842
BIC: CAIXESBBXXX
Account holder: Fundació Síndrome d'Usher

Swiss bank account
IBAN: CH21 0021 5215 1626 4240 J
BIC: UBSWCHZH80A
Account holder: Association Save Sight Now Europe (Switzerland)

Giving Europe | Italy

Fondo Filantropico Italiano ETS
Adress: Via Giovanni Bovio 6, 20159 Milan
Bank: Intesa Sanpaolo
Branch 55000 – Milan – Italy
Account number: 1000/00155347
IBAN: IT04 B030 6909 6061 0000 0155 347

Payment reference: GIVING EUROPE - NAME OF THE BENEFICIARY - COUNTRY OF THE BENEFICIARY.

Index

Annual Report 2025
Save Sight Now Europe

2025

1

The Organisation

Message from the President: when everything begins to bloom

There are years that are built. And there are years that bloom. For Save Sight Now Europe, 2025 was the year in which many of the seeds we had planted with patience, urgency and a large dose of faith in science, in people, and in ourselves, began to bear visible fruit.

It is the third year of the Fundació Síndrome d'Usher and the fourth of the Association Save Sight Now Europe Switzerland. Four years since our daughter's diagnosis. Four years since that conversation with the doctor turned our lives upside down and, at the same time, sparked a determination we have not stopped feeding for a single day.

But it would be untrue to say the diagnosis was a turning point only in that moment. The truth, which isn't always easy to say out loud, is that the diagnosis continues. It is not a fact of the past: it is a reality that renews itself every day, that advances alongside our daughter, that becomes present when we see the first signs that other families already knew and that we, now, are beginning to recognise. The disease does not wait. The visual field narrows. And the urgency that led us to create the Foundation has not diminished; on the contrary, it grows.

And that is precisely why everything we have built has such deep meaning. We did not create the Foundation when the situation was urgent. We created it because we knew urgency was approaching. Because we did not want to reach the moment when our daughter would ask us if there was a treatment and have nothing to show her. Because the families who had lived what we were living taught us, with their generosity and their light, that time is the one thing that cannot be recovered.

Four years talking with researchers at six in the morning and at midnight. Four years at international conferences taking notes, asking questions, connecting the dots. Four years organising events with incredible volunteers, calling companies, explaining Usher 1B to the media again and again until the name starts to sound familiar. Four years funding research programmes that are now yielding results. Four years building a European network that, in 2025, took an unprecedented qualitative leap.

This year we signed our first agreement with the team of Dr. Aziz El Amraoui and Dr. Sandrine Vitry at the Institut Pasteur in Paris. We formalised our collaboration with RetinAI and the Institut de la Vision — an alliance that puts artificial intelligence at the service of early diagnosis and future clinical trials for Usher 1B. We continued funding Prof. Becirovic's programme in Zurich. We presented the documentary Per la Bruna, directed by Carla Roda, which tells our story with an honesty that has made us laugh and cry in equal measure. We were at ARVO, in Nijmegen, in Milan, in Paris, in Barcelona, and everywhere we planted new seeds.

And behind all of this, the community. The families who organise charity events. The 589 students in Fribourg who ran for research. The Meyer family, who year after year lead a Soirée that moves hearts and funds. The voices of Aitana Bonmatí, Berto Romero, Raquel Sans, Julio Manrique and so many others who have amplified our voice to places we could never have reached alone. And the affected families, those who came before us on this path and those joining now, who remind us every day why all of this matters.

We present this report with the truth of everything it has been: a hard year, hard-worked, full of moments of doubt and moments of light. A year that has shown that when science and community walk together, change is possible.

We do not know when the treatment will arrive. But we know we are doing everything we can to make it arrive as soon as possible. Every year that passes, we are closer.

For Bruna. For all the girls and boys like her.

Berta Adell Palau
Co-founder and President Save Sight Now Europe


Berta Adell Palau
Co-founder and President

An organisation for Usher syndrome type 1B

Four years is not a long time in the world of biomedical research, where a preclinical programme can take a decade to reach the clinic — but it is a long time when you are a family living with the disease every day, knowing the clock does not stop.

In four years, Save Sight Now Europe has gone from being an idea born of a diagnosis to being a recognised player in the international scientific ecosystem of Usher 1B. Not by chance, but because we learned quickly, built with rigour, and kept our focus constantly on what matters: getting science to patients.

1.1 What we have built so far

When we started, there was no research programme in Europe specifically dedicated to Usher 1B and funded by a patient organisation. Today, SSNEU co-drives and funds active programmes at five reference centres in Europe and North America (Institut Pasteur - reConnect, Institut de la Vision, University of Zurich, Johannes Gutenberg University Mainz, and the University of Wisconsin-Madison).

Since its founding, SSNEU's two entities have mobilised more than 2.5 million euros toward Usher 1B research. This figure includes funds raised and distributed by SSNEU's two branches (Fundació Síndrome d'Usher in Spain and Association Save Sight Now Europe Switzerland), as well as prizes and funding from larger foundations (such as the Foundation Fighting Blindness) that SSNEU has helped direct specifically toward Usher 1B.

The accounts published in Chapter 6 cover both entities separately: the Fundació Síndrome d'Usher in section 6.1, and the Association Save Sight Now Europe Switzerland in section 6.2.

There has also been a shift in our position: SSNEU is today a connection hub — a meeting point where researchers, clinicians, companies and families converge.

We organise, we fund, we connect, we push forward. And increasingly, when a researcher wants to know where the Usher 1B patient community is in Europe, they talk to us.

1.2 What matured in 2025

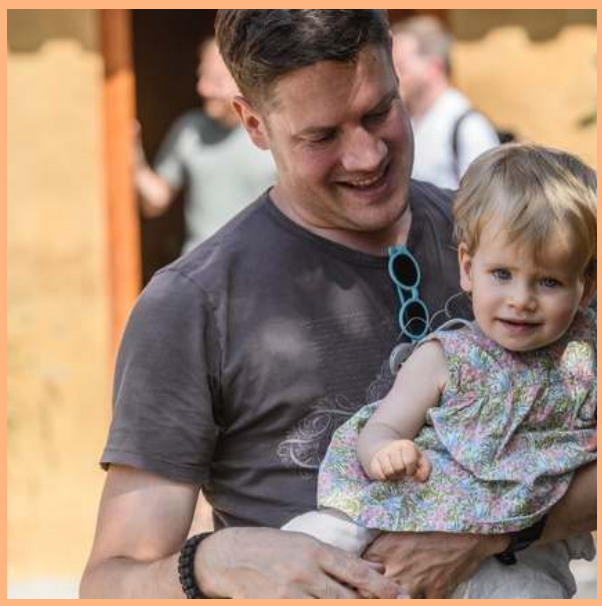
This year, the network expanded in two new directions. Scientifically, we formalised collaborations that until now were only conversations: the programme with the Institut reConnect (Institut Pasteur) is now a contract, not a promise. And we continued broadening the range of therapies we follow closely — from dual-AAV gene therapy to antisense oligonucleotides, from NACA neuroprotection to the possibilities of base editing, because in ultra-rare diseases no promising avenue can be ruled out.

Geographically, at the end of the year, we began our presence in Italy. Through the Giving Europe platform, which allows Italian donors to make tax-deductible donations to SSNEU, we will be able to fund part of the requirements needed to move forward the UNI-RARE programme at Dr. Giacomo Calzetti's centre in Brescia. Italy has an active Usher community and committed researchers, and this step opens a door we did not have before.

1.3 What has not changed

Urgency. Determination. And the conviction that a small, agile and focused organisation can move more than much larger structures, if it knows where and when to push.

Our daughter showed us the void. Four years later, the void is much smaller.



Usher Syndrome

A disease that does not wait

Usher syndrome type 1B is an ultra-rare genetic disease caused by mutations in the MYO7A gene. It affects three senses at once: hearing, balance, and vision. Children are born with profound bilateral deafness and impaired vestibular function (without the natural sense of balance most of us take for granted from day one of life). And during childhood, progressive vision loss begins due to retinitis pigmentosa: first night vision, then peripheral field, eventually leading to tunnel vision and, in many cases, complete blindness before adulthood.

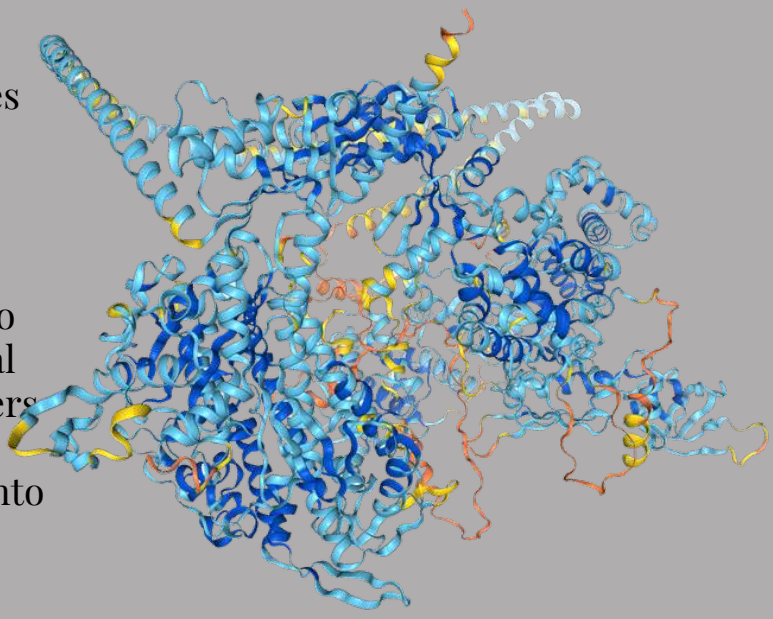
Usher syndrome is the most common cause of genetic deafblindness in the world. It accounts for up to 50% of all cases of deafblindness, and yet, until relatively recently, specific research into this form of the disease was almost non-existent.

2.1 Why the MYO7A gene complicates everything

Most current gene therapies use AAV vectors — small modified viral vehicles — to carry a functional copy of the affected gene into retinal cells.

The problem with Usher 1B is that the MYO7A gene is exceptionally large: too large to fit inside a single conventional AAV vector. This has forced researchers to develop dual-vector (dual-AAV) strategies, in which the gene is split into two parts that must correctly reassemble inside the cell.

An elegant solution, but a technically far more complex one, which explains why the field has taken longer to advance and why every milestone reached carries special value.



MYO7A structure © 2021 DeepMind Technologies Limited — AlphaFold DB (alphafold.ebi.ac.uk), CC-BY 4.0.

MYO7A Gen
Find out about the programs and how we work to address mutations in this gene at www.savesightnoweurope.org

2.2 The beginning of the clinical era

2025 marked a turning point that must be named clearly: for the first time in history, there is an active human clinical trial for Usher 1B. The LUCE-1 trial, led by AAVantgarde Bio using dual-AAV technology developed by Dr. Alberto Auricchio (TIGEM, Naples), treated the first patients and presented positive 60-day safety data at ARVO 2025.

In January 2026, enrolment was completed with 15 adult patients. It is not an approved treatment. It is not a cure. But it is proof that the chain from laboratory to patient is real and passable.

At the same time, the field has opened up in several directions at once. Antisense oligonucleotides (ASOs), an approach not previously considered viable for Usher 1B, have entered the scientific agenda. Antioxidant therapies such as NACA have shown in a controlled trial that they can reduce loss of the ellipsoid zone — the strip of retina where photoreceptors still function — by more than 50% in patients with Usher syndrome, regardless of the specific mutation. And gene editing, which allows correction of a single letter of the genome without cutting both strands of DNA, is already achieving very high correction rates in preclinical models, although so far in other retinal diseases.

None of this existed as a real option four years ago.

2.3 What it means to live it

Statistics and scientific advances explain the field. But they do not fully explain what it means to grow up and live with Usher 1B.

Affected children arrive at school with cochlear implants that have opened up the world of sound. They learn to communicate, to socialise, to run and play with an energy that defies any preconceived idea about the disease. But retinitis pigmentosa progresses in silence, below the threshold of everyday awareness, until suddenly an unseen step, an unrecognised face in the dim light, or a visual field that has narrowed once again, reminds the family where the clock stands.

It is a disease that combines the extraordinary resilience of the girls and boys who live with it with the constant pressure of time. And it is precisely this combination — the full life that is possible today, and the threat that grows if we do not act — that gives meaning to everything Save Sight Now Europe does.

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

2.4 From ultra-rare to strategic priority

> **Usher 1B affects approximately one in every 130,000 people.** Rare enough to stay off the radar of the conventional pharmaceutical industry. But common enough to have a community, committed researchers and robust animal models.

Today, Usher 1B is well characterised genetically: it is a monogenic disease, caused by a single gene — an excellent candidate for the new precision therapies. And severe and early-onset enough to justify all the urgency in the world.

In May 2025, the World Health Organization adopted its first formal resolution on rare diseases, recognising the global need to promote access to diagnosis, treatment and care. It is an important institutional recognition. But for the families living with Usher 1B every day, urgency did not wait for any resolution. We had been acting for years.

Research and Science

Science advances; we accelerate it.

Driving research into an ultra-rare disease is not just about funding laboratories. It is about understanding where the field stands, identifying the gaps, connecting teams that don't always know each other, and pushing in the right direction at the right time. 2025 was the year this task — invisible to many, central to us — bore its most tangible fruit yet.

Six words to understand these pages

1. **Gene / protein** — the gene is the instruction; the protein is the tool that results from it. In Usher 1B, the MYO7A tool is missing.
2. **AAV** — the viral "envelope" that delivers a gene into a cell. The problem: the MYO7A gene does not fit inside it.
3. **Dual-AAV** — splitting the gene into two envelopes and letting them reunite inside the cell.
4. **Gene editing** — correcting the wrong letter of the gene, rather than replacing it entirely.
5. **Organoid** — a lab-grown "mini-retina" cultured from a patient's cells.
6. **Explant** — donated human retinal tissue, kept alive for a few weeks to test treatments on.

3.1 Scientific presence: where we've been and why it matters

SSNEU's presence in the spaces where the future of Usher 1B is decided is not symbolic: it is strategic. Every congress, every bilateral meeting, every hallway conversation between scientific sessions is an opportunity to learn, to connect, and to accelerate treatments for the thousands of children living every day with the challenges of a triple sensory loss.

For them, the Foundation keeps working year after year, without rest, so that Usher stops being a disease without an answer.

ARVO 2025 — Salt Lake City, May 2025

The annual congress of the Association for Research in Vision and Ophthalmology is the largest meeting point in the world for eye research. In 2025 we saw the first clinical data in history for Usher 1B: results from the first two patients treated in the LUCE-1 trial, with good safety at 60 days and the first signs of functional improvement.

For SSNEU, ARVO is also where relationships with researchers from the programmes we drive are maintained and deepened, where we take the pulse of new projects, and where the connections that later become collaborations are born.

USH2025 — Nijmegen, June 2025

The global Usher syndrome congress brought together the scientific community and families from around the world for the first time since Mainz in 2018. Seven years on, the balance was different: the field has matured, has entered the clinic, and no longer debates whether treatments will arrive, but which ones and when.

For SSNEU, it was also a place of work. From those conversations emerged, a few weeks later, the consortium of five research groups that today makes up a large part of our portfolio.

3.2 Active programmes

Programa	Centre	Focus	Estat
reConnect	Institut reConnect, Paris	Dual-AAV MYO7A gene therapy	NEW Q4 2025
RetinAI + Institut de la Visió	Bern / Paris	Data and AI	NEW 2025
Becirovic	U. of Zurich	Dual-AAV + CRISPRa	Ongoing
Wolfrum	JGU Mainz	Pig model + organoids	Ongoing
D. Gamm	U. of Wisconsin-Madison	Organoids and interactome	Currently funded by FFB

NEW IN 2025

Dr. Aziz El Amraoui and Dra. Sandrine Vitry
Institut reConnect (Paris)

This is the most important new programme of the year.

Dr. Aziz El Amraoui is one of the world's leading experts on the MYO7A protein: what it does in the cells of the inner ear and the balance organ, what it does in retinal photoreceptors, and why its absence causes the simultaneous loss of hearing, balance and sight. Dr. Sandrine Vitry brings expertise in vectors and animal models.

The problem, in one sentence: the MYO7A gene is too large to fit inside the vehicle that gene therapy uses to enter cells. The whole challenge is delivering it intact despite this limitation.

What they've tried, and what works: the team compared three strategies head to head. Forcing the whole gene into a single vector did not work. Shortening it to fit recovers some of the protein's functions, but not all. Splitting it into two halves that reunite inside the cell — known as dual-AAV — does work, and is where all the effort is now concentrated.

The 2025 result: with this strategy, the team has managed to restore balance robustly and reproducibly in two mouse models, one of which carries a real human mutation. Hearing recovery remains an open question.

Why it matters, even though our priority is sight: for two reasons. First, children with Usher 1B are born without vestibular function, and there is no implant to replace it, unlike hearing. It is the sense almost no one talks about, and for which, today, there is absolutely nothing. Second, the inner ear gives answers within weeks, whereas the retina takes months or years. If the vector arrives, if the two halves reunite, and if the protein does its job, the ear tells us first — saving time and money before betting everything on the eye.

And the retina: 2026 has begun the proof of concept in the eye. The next step, and the most important for us, is validating the vectors in donated human retina, with Dr. Bence György (IOB Basel) and Dr. Arnold Szabo (Semmelweis University).

A milestone that often goes unnoticed: the patent. The Institut Pasteur has patented this strategy. It may seem like an administrative detail, but it is not: no company invests the hundreds of millions it costs to bring a treatment to market without a patent to support it. Its existence means what we have funded has a possible path to the pharmacy, not just to a scientific journal.

It is the only programme in the world working on both the eye and the inner ear at once. The two companies currently leading the field treat only the retina. A treatment that restores sight but leaves the child deaf and without balance solves part of the problem, not the problem.

RetinAI + Institut de la Visió (Paris) Strategic agreement

For a treatment to be approved, it is not enough for it to work: you must be able to prove it works, with measures that drug agencies will accept. Today, in Usher 1B, these measures are not yet fully defined. This agreement with RetinAI and the Institut de la Vision exists to solve that.

RetinAI is a Swiss company specialising in retinal image analysis and clinical data management using artificial intelligence. Its technology processes large volumes of images in a structured, comparable way across centres. In October 2025 it was acquired by EssilorLuxottica, making it one of the major players in digital eye health worldwide.

The Institut de la Vision in Paris is a world reference centre for inherited retinal dystrophies. The team linked to Usher 1B includes Dr. Isabelle Audo, Dr. Deniz Dalkara and Dr. Serge Picaud, the institute's scientific director.

With this agreement we have launched joint work to organise and analyse imaging data from people with Usher 1B: detecting evolution patterns, defining reliable biomarkers and building the foundation that will allow rigorous clinical trial design and evaluation. **Images from 22 patients are already on the analysis platform, and the funding commitment runs for five years. It is the least visible piece of infrastructure in our entire portfolio and one of the most necessary.**

ONGOING PROGRAMMES

Prof. Elvir Becirovic
University of Zurich

What makes this programme unique is that the laboratory does not apply a third-party technique — it has invented its own.

Facing the same problem (a gene that is too large), the whole field splits the gene into two halves and lets them reunite inside the cell. The difference between teams lies in the exact moment at which they reunite, and this seemingly minor detail determines the efficacy and safety of the entire treatment. This laboratory's technology, called **REVeRT**, performs the union at the RNA level: the intermediate message the cell produces from the gene, just before building the protein.

Why this matters to us now: because REVeRT is no longer a laboratory promise — it is being tested in people, in a clinical trial for another inherited retinal disease, with authorisation from the US drug agency since late 2024. The principle of getting an oversized gene into a human cell is already being tested in real patients. What we fund is adapting it to our gene.

A second path, in case the first doesn't reach everyone: the MYO7B gene performs a structural function very similar to MYO7A, but is switched off in the retina. The team is working to switch it on — without modifying its sequence — and has already shown this activation is possible. If it ends up compensating for the missing function, the advantage would be enormous: it would work for any patient, whatever their mutation. It's a riskier bet, which is why we keep it running in parallel rather than as a replacement.

In 2025, the laboratory published the international reference protocol for designing and evaluating this type of vector (the manual the rest of the field will use) and a method for reaching a genetic diagnosis for people who had been left without an answer, which directly affects many families with an incomplete diagnosis.

The specific work on the MYO7A gene is ongoing and has not yet been published. The next step is moving from small models to large animal models, the required bridge before any trial in people.

ONGOING PROGRAMMES

Dr. Uwe Wolfrum i Dra. Kerstin Nagel-Wolfrum — Johannes Gutenberg University Mainz · Dr. Zdenka Ellederová — IAPG, Czech Republic

The Mainz team maintains the preclinical pig platform for Usher 1B, in collaboration with Dr. Zdenka Ellederová of the Institute of Animal Physiology and Genetics (IAPG) in the Czech Republic, who provides expertise in generating and maintaining genetically modified pig models. The pig matters because its eye is human-sized and because its photoreceptors have structures the mouse lacks, which depend precisely on the MYO7A protein. It is the right place to ask whether a treatment reaches where it needs to in a real-size eye.

Where we stand, without embellishment: the animals carry a natural mutation of the MYO7A gene. At 9 months, they clearly show the balance problem, but no retinal damage yet, and retain 20% functional protein. This allows two readings: that retinal degeneration is slower, and we must wait, or that this 20% is enough to maintain vision, in which case the model would not be useful for testing eye treatments. The 18-month reading will decide. Until then, we are not committing further resources to experiments that depend on it.

What this team has taught the field in 2025: their work on how a treatment is injected under the retina has produced two uncomfortable and necessary results: the more volume injected, the thinner the retina becomes; and in a gene therapy study in pigs with Usher, the surgery itself caused damage in all groups, including the control group, to the point of masking any benefit. These aren't headline-grabbing findings, but they change how all future trials will need to be designed. It is exactly the kind of knowledge that justifies funding preclinical research.

The second line: human mini-retinas. In parallel, Dr. Kerstin Nagel-Wolfrum develops retinal organoids from patient cells. In 2026, her team published the complete characterisation of Usher 1C, identifying that a type of retinal support cell loses its ability to maintain structure. The same platform must now be applied to Usher 1B.

Three things we still don't know, and which shape everything:

1. No one in the world has yet demonstrated vision recovery in an Usher 1B model. We have protein production, balance recovery, and safety in patients. The proof of vision does not yet exist

2. Our pig model has not yet developed retinal damage. The 18-month data will tell us whether it is useful or whether we need to change platform.

3. We don't know which of the two forms of the MYO7A protein needs to be administered. The programmes currently in the clinic are chosen by convention and not by evidence. SSNEU is working on this.

3.3 New avenues explored in neuroprotection: more paths to slow degeneration

One of SSNEU's strategic decisions from the start has been not to bet on a single path. In ultra-rare diseases, a diversity of approaches is a way of managing risk: if one path meets obstacles, others are underway. In 2025, we expanded our scope toward treatments that can slow degeneration while gene therapies mature.

NACA — N-acetylcysteine amide

Nacuity Pharmaceuticals presented the results of its SLO-RP trial, conducted at four centres in Australia with 49 people with Usher syndrome over two years. The oral treatment reduced loss of the ellipsoid zone (the strip of retina where photoreceptors still function, and the measure that best tracks disease progression) by more than 50%, and slowed sensitivity loss by nearly 30%.

It is the first treatment with a demonstrated effect in a controlled study in the Usher population, and it works regardless of the mutation. It does not repair anything: it slows it down. The company has announced a confirmatory study beginning in 2026. We are following it closely with BeRare Onlus in Italy.

TUDCA — Tauroursodeoxycholic acid

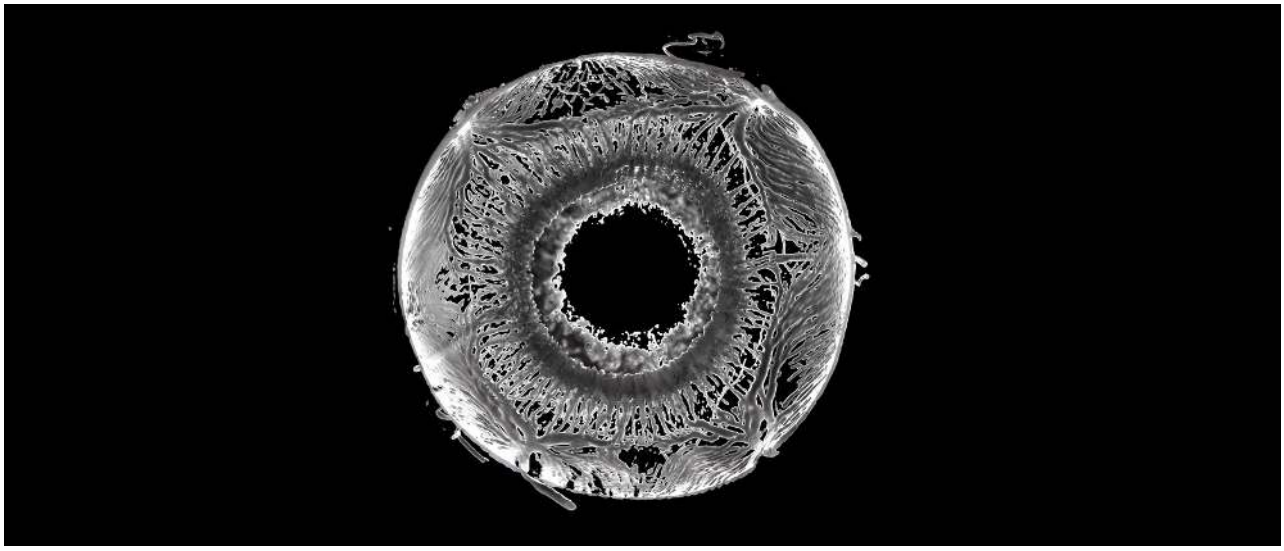
TUDCA acts on the three main pathways of retinal deterioration: oxidation, inflammation, and cell death. In animal models, it has been the most effective compound of all those tested by the University of Alicante group, with whom we work alongside Italian colleagues.

Two obstacles remain unresolved, and we prefer to state them: the effective dose in animals equates to an unfeasible orally amount in humans, requiring a local delivery method; and it has not yet been tested in an Usher model, where the underlying problem is structural rather than metabolic. Whether the project advances depends on this.

ASO — Antisense oligonucleotides

During 2025 and 2026, we have seriously opened up a path (not previously explored) for the MYO7A gene. The precedent within the Usher field is promising: the LUNA trial already has patients treated with a drug of this type for the most common form of Usher type 2.

The limits are also clear: an ASO cannot replace the missing protein (that is the territory of gene therapy), and most of these strategies only work for one specific mutation. Technically, it is complex. But it is now on the table, and for some families it could be the fastest route.



3.4 The global field: where research stands in 2025

Placing SSNEU's work in the global context is not an exercise in modesty: it is a necessity. What happens in other inherited retinal dystrophy programmes defines the tools, the regulatory precedents, and the technologies that will sooner or later reach Usher 1B.

LUCE-1 – AAVantgarde Bio

The first human clinical trial for Usher 1B is a reality. Using dual-AAV technology developed by Dr. Alberto Auricchio's team, in 2025 it presented data on the first two patients: good safety at 60 days, stable visual acuity, and improvements in low-light vision and gaze stability. In January 2026, it completed enrolment with 15 adult patients. It is not a cure, and the number of patients is small. It is proof that the path is possible. The open question is durability.

BlueRock Therapeutics CLARICO

A Phase 1/2a trial with stem-cell-derived photoreceptor precursor cells, in up to 54 adults with primary photoreceptor diseases — a category that includes retinitis pigmentosa and Usher syndrome. Rather than protecting what remains, it aims to replenish what has been lost. Mutation-independent, and therefore applicable to any subtype.

NAC Attack Johns Hopkins / NEI

A Phase 3 trial with N-acetylcysteine: nearly 440 patients across some thirty centres in the United States, Canada, Mexico and Europe, with more than 20 million dollars in public funding.

A mutation-independent antioxidant, acting through the same mechanism as NACA.

Optogenetics

Four companies — Ray Therapeutics, GenSight, Bionic Sight and Nanoscope — have active trials with a different idea: instead of repairing the gene, they make cells that have survived degeneration become sensitive to light. It works regardless of the mutation. Nanoscope began its FDA authorisation request in July 2025. It is relevant to Usher 1B at advanced stages, when gene therapy can no longer recover lost photoreceptors.

3.5. 2026, already underway

Milan, January 2026

In January, the SSNEU team met in Milan with Alessandro Mennella and Marco Tironi — two adults affected by Usher 1B — and the BeRare Onlus team. It was the starting point of an Italian collaboration that has already borne its first fruit: support for Dr. Giacomo Calzetti's UNI-RARE programme in Brescia, and the opening of a funding channel from Italy explained in Chapter 4.

Institut reConnect — Paris, July 2026

The working visit to the Institut Pasteur marked the formal start of the collaboration with the reConnect team. It was not the first meeting, but it was the first with a camera alongside: the documentary maker behind Per la Bruna accompanied the team and filmed those working hours as part of the Foundation's documentary record. A day that, in retrospect, represents one of the year's founding moments.

What's coming

Three data points will mark the coming months: the 18-month reading of the pig model, which will tell us whether it remains a useful platform; validation of the Institut reConnect vectors in human retina; and the start of the NACA confirmatory study. None of the three is a cure. All three decide where we go next.

Actions, Visibility and Fundraising

Science and community: two sides of the same fight

Driving research into an ultra-rare disease requires money. And raising money requires visibility. And real visibility, the kind that moves people, requires a story that is true. Ours is. And in 2025 we learned to tell it better than ever.

4.1 The documentary *Per la Bruna*

There are communication tools. And there are works that transcend communication and become something bigger. Per la Bruna is one of the latter.

Directed by Carla Roda and produced by Tabata Films, the documentary follows two parallel journeys: the intimate story of our family, and the scientific mobilisation that Arnau Espinosa and Berta Adell (founders of SSNEU) lead through Save Sight Now Europe. It is about Bruna, and it is about every girl and boy with Usher 1B waiting for science to arrive in time.

Carla Roda is no ordinary director. Her career includes work for Netflix (Karol G: Mañana Fue Muy Bonito), HBO Max (Menudo: Forever Young) and productions that have premiered at Tribeca, SXSW and Sundance. She has received the Orson Welles Award. Per la Bruna is her directorial debut, and she chose this story because, in her words, it is an intimate journey to document the strength of a family.

PER LA BRUNA

A documentary about love, science, and hope in a race against time.

perlabruna.com

The camera has been with us for a year and remains by our side. It has filmed laboratory meetings in Basel, scientific conferences in Denver, family moments in Catalonia and Switzerland, and the visit to the Institut reConnect (Institut Pasteur) in Paris in July (the formal start of the reConnect programme). It has seen what is not normally seen: midnight conversations with researchers, doubts, difficult decisions, and also the everyday life of a family that has not stopped for a single day.

On 26 May 2026, at the Cinema Edison in Granollers, we held the first public presentation of the project: the screening of the sizzle reel, a conversation with the director, and a presentation by Berta Adell on what the documentary captures and why this story needs to be told now.

The project remains in production. Follow us for future updates.
Visit the documentary's website: perlabruna.com

4.2 Media presence and awareness

Les Bones Causes — Catalunya Ràdio

During the 2024-2025 season, six voices from the Catalan cultural, journalistic and sporting scene brought Usher 1B into homes across Catalonia and Spain in prime time: Jordi Coll · Paula Malia · Mont Plans · Ariadna Oltra · Toni Cruanyes · Enric Agud.

Each appearance generated organic reach, new contacts and, above all, normalised the name of a disease that until recently was unknown to most people.

They are the ones who have given us a voice and support in 2025:


Jordi Coll, actor


Paula Malia, actress


Mont Plans, actress


Ariadna Oltra, journalist


Toni Cruanyes, journalist


Enric Agud, journalist

Awareness capsules

Since La Nit de la Visió in November 2025, we have begun publishing awareness capsules on social media, produced by Nuria Camp (Camp Divulgatiu). The goal is to explain Usher 1B — the disease, the science, the families, the research — clearly, consistently and shareably. A regular voice building presence and knowledge over time.

You can click on each image to view its short video clip.

Media coverage

RAC1, Catalunya Ràdio, ara.cat, La Vanguardia, EFE, Canal 21, Tele 5, Pànxing, RTS, La Liberté, Le Gruyère and more than thirty Spanish, Catalan and Swiss media outlets covered our story and our work throughout the year. The podcast La Ciència de lo Singular (Share4Rare/CIBERER) featured Berta Adell alongside Dr. Carmen Ayuso, Dr. José María Millán, Dr. Jaume Català and David Sánchez.

Lulu & Nanette — International Usher Syndrome Day

In September, the Swiss optician network Lulu & Nanette dedicated the month to raising awareness of Usher syndrome, with particular focus on Saturday 20 September, International Usher Day. A collaboration that puts our cause in direct contact with eye care professionals and their patients.

86th Bol d'Or du Léman 2025 — Sailing yacht Adrénaline

The Bol d'Or du Léman is the world's largest closed-water regatta: every year, more than 500 boats and 3,500 sailors leave Geneva, cross Lake Léman to Le Bouveret and return. In 2025 the Save Sight Now Europe logo flew on the sail of the Adrénaline, skippered by Thierry Campiche, and the collaboration continues in 2026.

But it goes beyond a single race: throughout the season, the Adrénaline carries our colours to the various regattas on Lake Léman. It gives us visibility in one of Switzerland's most active sporting and social environments, on the water in front of thousands of spectators and on social media, where both organisations share posts.

A simple and effective collaboration that places our cause at the heart of the Swiss community.

4.3 Fundraising: the USH Movement and Usher Partners

Funding research into an ultra-rare disease without structural support from states or European bodies requires creativity, persistence and a genuinely committed community. 2025 confirmed we have all three.

La Nit de la Visió 2025 — 3rd edition

14 November · Recinte Modernista de Sant Pau, Barcelona.

The third edition of La Nit de la Visió consolidated the event as the annual meeting point for the SSNEU community: a seated dinner, musical opening, live concert, and the usual thread; science, testimonies and solidarity under one roof. This year's novelty was the addition of an online charity auction through BiddingOwl, live in the weeks beforehand, with a special evening closing, featuring lots including experiences, art, wellness, gastronomy, and sports memorabilia.
Total funds raised: €37,700, going entirely to research.

The evening was made possible by Original's Catering, the Fundació Hospital de la Santa Creu i Sant Pau (the event's venue), Compañía Eléctrica Panamericana, and Anima el Musical.

Gold Sponsors for Innovation: Almenibor by StiviBags · Tectrol SA, Love for a Walk | Silver and Bronze Sponsors: Emerge 4 Life, Bon Preu SAU, Instituto Médico Privado · Atma obra · Pymej SL · Idun Nature.

Solidarity auction collaborators

The online charity auction was also supported by the generosity of numerous companies and professionals who contributed lots of experiences, art, wellness, gastronomy and sports memorabilia: AIRE Ancient Baths, Fútbol Club Porto, FC Barcelona, Toulouse Football Club, Teatre Akadèmia, Cinema Maldà (75 anys), Sala Beckett – Obrador Internacional de Dramatúrgia, El Menjador de la Beckett, Oasis Wellness & Spa by Natura Bissé, Sport Hotel Hermitage & Spa, Koy Hermitage, Sol i Neu Club Hermitage, Grup Confiteria, Comics Barcelona, Bizarre Escape Room, MS Marly Saravia (coach), bijhein., Semproniana, Disfrutar Restaurant Barcelona, Castro Xatruch Casañas, Maite Soldevila, Abacus, Rebel Genetics, Can Mas Vila, Fundación PortAventura, Ibaya, Casa Güell, El Celler de Can Roca (Girona), Emma Clarós, emiliacraft, TOUS, Kinefis – Terapia del Bienestar, Palabras Cómplices con Eva Lleonart, Vallesana – Vins, Caves, Licors, El Celler d'en Medir, La Queixalada, La Bodegueta del Carrer Major, Cottet, Textura Profesionales, Little Creative Factory, Desarrolladoras de Talento, Sensas, Balah Jewelery, Wherteimar.

Soirée Solidaire La Tour Vagabonde — Fribourg, March

For the second consecutive year, the Meyer family organised a musical and testimonial evening in Fribourg, with a scientific round table and a concert by Melissa Kassab. Funds raised: CHF 27,000, an extraordinary result reflecting the Swiss community's growing commitment to the cause.

CO Sarine Ouest Charity Run — Fribourg, June

589 students from the CO Sarine Ouest school ran for Usher 1B research. Inspired by the story of the Meyer family and their son Félix (six years old, Usher 1B), they raised CHF 14,430.

Roses to Beat Usher — Sant Jordi 2025

Third edition of the Sant Jordi campaign in the Jardinets de Gràcia, Barcelona. Charity roses and pencils, awareness-raising and fundraising during one of Catalonia's most iconic holidays.

*You can view our past and future events on the SSNEU website in the **events section.***

Funds raised in Spain are received by the Fundació Síndrome d'Usher, and those raised in Switzerland by the Association Save Sight Now Europe Switzerland. Each entity presents its accounts separately in the sections of Chapter 6 · Finances.

4.4 Usher Partners 2026: structuring fundraising to grow

2025 was the year we made an important decision: to stop improvising fundraising and instead structure it. The result is Usher Partners 2026: an annual sponsorship programme with a target of €150,000 to sustain continuity of active research programmes, the data and biomarker work with RetinAI, and SSNEU's international presence at the scientific venues that matter.

The programme offers companies and organisations the chance to link their brand to a concrete, measurable and urgent cause. It is not abstract philanthropy: it is funding real science, with the names of researchers, laboratories and results that can be explained.

The 2026 action plan includes:

- Roses to Beat Usher (April · Sant Jordi)
- Costa Brava Charity Market (June · Port de la Selva)
- Padel for Usher (September · several affiliated clubs)
- La Nit de la Visió 2026 (November)

Giving Europe — Tax-deductible donations across Europe. First country: Italy

An important addition to our fundraising architecture: in 2025, SSNEU worked to join the Giving Europe platform, which allows European donors to make tax-deductible contributions to our organisation.

We launch this option in Italy, where the local community continues to support research through Save Sight Now Europe, with the No Limits initiative and the legacy of the Rare Partners organisation, which drove this collaboration for years.

Thanks to this mechanism, we have already received support from the Italian community and have been able to fund part of the requirements needed to advance the UNI-RARE programme at Dr. Giacomo Calzetti's centre in Brescia. It's a small step in appearance but strategically significant: Italy has an active and generous Usher community, and opening this channel means we can grow there sustainably.

*You will find all the **events and collaborators** on our website.*

Governance and Transparency

An organisation that grows with rigour

Save Sight Now Europe operates through two complementary legal entities: the Fundació Síndrome d'Usher (NIF G-13876362), registered with the Catalan Government's register of foundations and based in Barcelona, and the Association Save Sight Now Europe Switzerland (CHE-080.124.875), based in Geneva.

This dual structure is not an administrative complexity: it is a tool. It allows us to operate within the Swiss scientific and philanthropic ecosystem (home to a good part of our research partners) and within the Spanish legal and tax framework, where our community is based.

In 2025, we took a concrete step to expand our capacity to receive donations across Europe through the Giving Europe platform. We are beginning in Italy with this strategic move, where we have an active Usher community, committed researchers, and a solid tradition of health-related philanthropy.

5.1 Board of the Fundació Síndrome d'Usher

The Board is the governing body of the Fundació Síndrome d'Usher (as established by the Catalan Government's foundation regulations): it approves the accounts, sets the lines of action, and is responsible for fulfilling the Foundation's aims. Its members serve without remuneration.

The Board oversees compliance with the Foundation's aims, approves the annual accounts, and ensures the proper management of the entity's resources.

During 2025, it was composed:

- Berta Adell Palau — Co-founder and President
- Arnau Espinosa Manzanal — Co-founder and Secretary
- Júlia Espinosa Manzanal — Co-founder and Vice-President
- Hermès Solé — Co-founder and Member

The Board met three times during the 2025 financial year.

5.2 Management Committee of the Association SSNEU Switzerland

The Management Committee is the executive body of the Association Save Sight Now Europe Switzerland. Its mandate was renewed at the General Assembly of 6 October 2025. In 2025, the Committee comprised: Berta Adell Palau — President (re-elected), Arnau Espinosa Manzanal — Secretary, Júlia Espinosa Manzanal — Vice-President.

5.3 General Assembly - Association SSNE Switzerland

The General Assembly of the Swiss branch was held on 6 October 2025. The main points approved were:

- Annual accounts for the 2024–2025 financial year and application of income to foundational activities.
- Renewal of the management committee.
- Update of the strategy for scientific collaborations and fundraising for 2025–2026.
- Reaffirmation of the commitment to transparency and accountability as a central pillar of governance.

5.4 Scientific Advisory Board (SAB): how we decide where to direct funds

We are a small foundation funding expensive science in a field where mistakes cost years. The SAB exists to ensure no investment decision depends solely on our own judgement. It brings together external scientists with complementary expertise — gene therapy, paediatric ophthalmology, rare disease genetics and trial design — none of whom have any financial interest in the programmes they evaluate.

When a proposal arrives, the team prepares a file, and the SAB evaluates something specific: whether it answers a question no one else is addressing, and whether the result, whatever it may be, will lead us to make a different decision. No programme receives an open-ended commitment: funding is staged, with a specific data point as the condition to continue. Sometimes this means halting a line of work until a pending reading arrives. Saying so is as important as announcing what we have funded.

Dr. Bence György

Institute of Molecular and Clinical Ophthalmology, Basel (IOB) · University of Basel

A physician and researcher trained in Budapest with a postdoctoral stint at Harvard, he leads Clinical Translation at IOB and is a professor at the University of Basel. His group works on precision gene editing applied to the retina: technologies that correct a single letter of the genome without cutting double-stranded DNA, with a safety and specificity previous tools lacked.

In 2025, his laboratory published results in primates with correction rates of up to 87% in retinal pigment epithelium cells and 61% in rod cells, using third-generation AAV vectors. It was for a different inherited disease, but the technology is the same one that could apply to point mutations in the MYO7A gene, with a limit he himself highlights: it is only useful for patients whose mutation this specific tool can correct.

His laboratory, in collaboration with Dr. Arnold Szabo (Semmelweis University), keeps donated human retina alive for weeks to test treatments — this is where the reConnect programme's vectors will be validated.

He brings to the SAB the perspective of someone who understands the whole chain, from molecular design to the question of how a treatment reaches the clinic. He is the one who helps us assess whether a gene-editing proposal has real substance or is promising on paper but far from provable in people.

Dr. Giacomo Calzetti

Institute of Molecular and Clinical Ophthalmology, Basel (IOB) · Vista Vision, Brescia

An ophthalmologist and researcher at IOB and principal investigator at the Vista Vision clinic in Brescia, trained in Parma and at the Scheie Eye Institute at the University of Pennsylvania. He works on technologies that correct the gene rather than replace it: in 2025 he published in Nature Medicine results in primates with an 87% correction rate in retinal pigment epithelium cells.

As principal investigator at Vista Vision, he combines laboratory work with a weekly patient clinic, which lets him weigh every scientific proposal against what he sees directly in his patients. He also leads the UNI-RARE programme in Brescia (partly funded through the Giving Europe platform), and it was he who drove the January 2026 meeting in Milan with Alessandro Mennella, Marco Tironi and the BeRare Onlus team that launched our Italian collaboration.

He brings to the SAB what is least visible and most needed: knowing how to measure a slow-progressing disease in a way that drug agencies will accept. He is also our main link to the Italian Usher community.

Dr. Jaume Català-Mora

Hospital Sant Joan de Déu · Sant Joan de Déu Research Institute, Barcelona

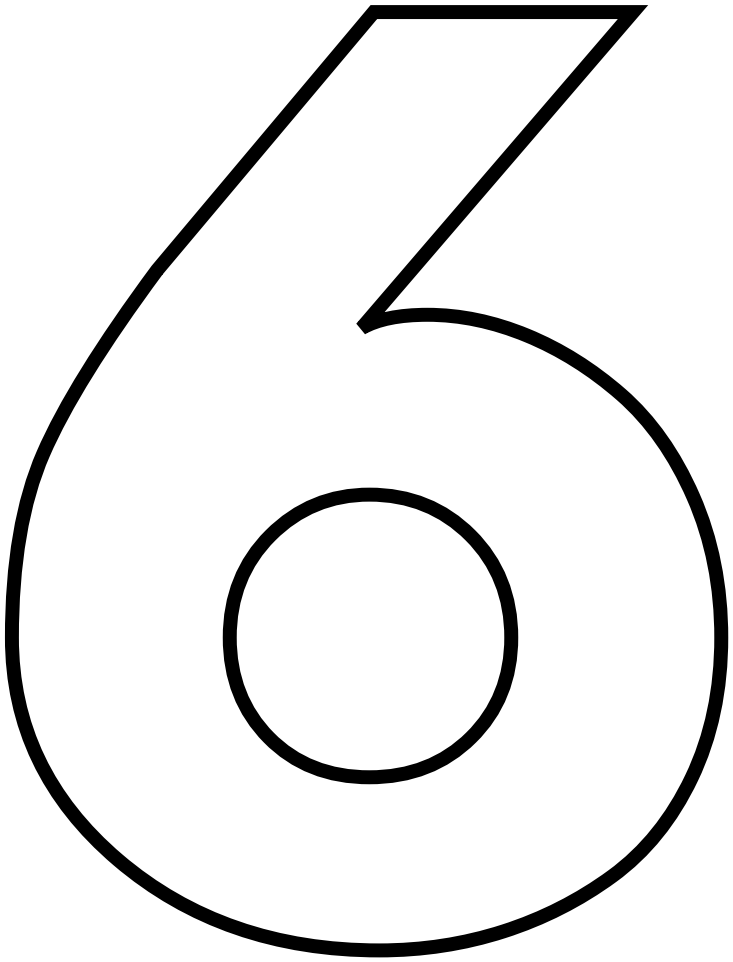
A paediatric ophthalmologist and retinal surgeon at the Hospital Sant Joan de Déu, he has built one of the largest paediatric Usher 1B cohorts in Europe. In 2024 he published a follow-up of 26 children with MYO7A mutations over more than three and a half years: he identified the earliest childhood retinal alterations, quantified their rate of progression, and showed that fluid accumulation in the macula predicts worse vision years later. He also leads an AI project to analyse retinal layers in Usher type 1. Almost all existing disease-progression data comes from adults; he brings the paediatric knowledge that the treatments we fund will need. And he is twenty minutes from our home.

Dr. José María Millán

CIBERER · La Fe Health Research Institute, Valencia

He leads the Molecular, Cellular and Genomic Biomedicine Group at IIS La Fe and, since June 2025, the scientific direction of CIBERER, Spain's national rare disease research network. His group has worked on the genetics of Usher syndrome since 1995 and is the national reference for genetic diagnosis of the disease. His contribution to the SAB underpins all the others: knowing how to interpret variants.

When a family receives a report with a "variant of uncertain significance," that report closes nothing — not the diagnosis, not access to a future clinical trial. Determining whether a specific variant causes the disease is specialised, slow work. He knows how to do it.



Finances

Save Sight Now Europe operates through two complementary legal entities.

This chapter presents each one's accounts separately: the Fundació Síndrome d'Usher (section 6.1) and the Association Save Sight Now Europe Switzerland (section 6.2).

All official documents are available in the Transparency section of www.savesightnoweurope.org.

6.1 Fundació Síndrome d'Usher (Spain)

For the year 2025, the Foundation delivers the following documents to reflect its accounts, financial year, and activity:

- **Annual Activity Report 2025** (this document)
- **Annual Accounts. Financial Year 2025**
- **Economic Report for Financial Year 2025** (for Article 3.10 of Law 49/2002, of 23 December, on the tax regime for non-profit entities and tax incentives for patronage)
-

The Fundació Síndrome d'Usher (NIF: G-13876362) is registered with the Catalan Government's register of foundations, which is why the official annual reports and accounts are drafted in Catalan.

Below are the accounts for the 2025 financial year, reflecting the economic activity of the Fundació Síndrome d'Usher (NIF G-13876362) and the use of funds received. The accounts of the Association Save Sight Now Europe Switzerland are presented in section 6.2

You will find all the documents in the **Transparency** section of www.savesightnoweurope.org.

Balance sheet

Fundació Síndrome d'Usher, 01/01/2025 to 31/12/2025

ASSETS

ACTIU	Nota	2025	2024
A) ACTIU NO CORRENT		**0,00**	**0,00**
I. Immobilitzat intangible		0,00	0,00
II. Immobilitzat material		0,00	0,00
III. Inversions immobiliàries		0,00	0,00
IV. Béns del patrimoni cultural		0,00	0,00
V. Inversions en entitats del grup i associades a llarg termini		0,00	0,00
VI. Inversions financeres a llarg termini		0,00	0,00
VII. Actius per impost diferit		0,00	0,00
B) ACTIU CORRENT		**192.287,52**	**142.431,56**
I. Existències		0,00	0,00
II. Usuaris, patrocinadors i deutors de les activitats i altres comptes a cobrar		0,00	0,00
III. Inversions en entitats del grup i associades a curt termini		0,00	0,00
IV. Inversions financeres a curt termini		0,00	0,00
V. Periodificacions a curt termini		0,00	0,00
VI. Efectiu i altres actius líquids equivalents		192.287,52	142.431,56
1. Tresoreria		192.287,52	142.431,56
2. Altres actius líquids equivalents		0,00	0,00
TOTAL ACTIU (A + B)		**192.287,52**	**142.431,56**

EQUITY AND LIABILITIES

PATRIMONI NET i PASSIU	Nota	2025	2024
A) PATRIMONI NET		**191.387,69**	**142.359,94**
A-1) Fons propis		191.387,69	142.359,94
I. Fons dotacionals o fons socials		22.700,00	15.400,00
1. Fons dotacionals o fons socials		30.000,00	30.000,00
2. Fons dotacionals o fons socials pendents de desemborsar		-7.300,00	-14.600,00
II. Fons especials		0,00	0,00
III. Excedents d'exercicis anteriors		126.959,94	34.057,00
IV. Excedents pendents d'aplicació en activitats estatutàries		0,00	0,00
V. Excedent de l'exercici (positiu o negatiu)		41.727,75	92.902,94
VI. Aportacions per a compensar pèrdues		0,00	0,00
A-2) Subvencions, donacions i llegats rebuts i altres ajustaments		0,00	0,00
B) PASSIU NO CORRENT		**0,00**	**0,00**
I. Provisions a llarg termini		0,00	0,00
II. Deutes a llarg termini		0,00	0,00
III. Deutes amb entitats del grup i associades a llarg termini		0,00	0,00
IV. Passius per impost diferit		0,00	0,00
V. Periodificacions a llarg termini		0,00	0,00
C) PASSIU CORRENT		**899,83**	**71,62**
I. Provisions a curt termini		0,00	0,00
II. Deutes a curt termini		848,83	0,00
III. Deutes amb entitats del grup i associades a curt termini		0,00	0,00
IV. Creditors per activitats i altres comptes a pagar		51,00	71,62
1. Proveïdors		0,00	71,62
2. Creditors varis		0,00	0,00
3. Personal (remuneracions pendents de		0,00	0,00
4. Passius per impost corrent i altres deutes amb les Admin. Públiques		51,00	0,00

5. Acomptes d'usuaris	0,00	0,00
V. Periodificacions a curt termini	0,00	0,00
TOTAL PATRIMONI NET I PASSIU (A + B + C)	**192.287,52**	**142.431,56**

Income statement

Fundació Síndrome d'Usher, 01/01/2025 to 31/12/2025

	Nota	2025	2024
1. Ingressos per les activitats		0,00	0,00
e) Donacions i altres ingressos per a activitats		0,00	0,00
2. Ajuts concedits i altres despeses		0,00	0,00
3. Variació d'existències de productes acabats i en curs de fabricació		0,00	0,00
4. Treballs realitzats per l'entitat per al seu actiu		0,00	0,00
5. Aprovisionaments		-21.805,93	-16.324,56
a) Consums i deteriorament d'existències		-1.141,97	-11,98
b) Treballs realitzats per altres activitats		-20.663,96	-16.312,58
6. Altres ingressos de les activitats		66.250,10	116.556,89
7. Despeses de personal		0,00	0,00
8. Altres despeses d'explotació		-2.716,42	-7.329,39
a) Serveis exteriors		-2.716,42	-7.249,24
a4) Serveis professionals independents		0,00	0,00
a7) Serveis bancaris		0,00	-206,04
a10) Altres serveis		-2.716,42	-7.043,20
b) Tributs		0,00	-80,15
9. Amortització de l'immobilitzat		0,00	0,00
10. Subvencions, donacions i llegats traspassats al resultat		0,00	0,00
11. Excés de provisions		0,00	0,00
12. Deteriorament i resultat per alienacions d'immobilitzat		0,00	0,00
13. Altres resultats		0,00	0,00
I) RESULTAT D'EXPLOTACIÓ (1 + 2 + 3 + 4 + 5 + 6 + 7 + 8 + 9 + 10 + 11 + 12 + 13)		**41.727,75**	**92.902,94**

14. Ingressos financers	0,00	0,00
15. Despeses financeres	0,00	0,00
16. Variació de valor raonable en instruments financers	0,00	0,00
17. Diferències de canvi	0,00	0,00
18. Deteriorament i resultat per alienacions d'instruments financers	0,00	0,00
II) RESULTAT FINANCER (14 + 15 + 16 + 17 + 18)	**0,00**	**0,00**
III) RESULTAT ABANS DE IMPOSTOS (I + II)	**41.727,75**	**92.902,94**
19. Impostos sobre beneficis	0,00	0,00
IV) RESULTAT DE L'EXERCICI (III + 19)	**41.727,75**	**92.902,94**

Allocation of income to foundational activities

Article 3.1.c of Royal Decree 1270/2003, of 10 October, sets out the reporting requirements regarding income from foundational activities: specification and calculation method of the income referred to in Article 3.2 of Law 49/2002, together with a description of its use or application.

In the 2025 financial year, the Foundation allocated 34.32% of net income obtained to fulfilling its foundational aims, as detailed below:

ALLOCATION OF INCOME TO FOUNDATIONAL ACTIVITIES

A) Ingressos meritats de l'exercici:	**66.250,10**
INGRESSOS PER ACTIVITATS	0,00
VARIACIÓ D'EXISTÈNCIES DE PRODUCTES ACABATS	0,00
TREBALLS DE L'ENTITAT PEL SEU ACTIU	0,00
ALTRES INGRESSOS D'ACTIVITATS	66.250,10
SUBVENCIONS DONACIONS TRASP. A RESULTATS	0,00
EXCÉS DE PROVISIONS	0,00
ALTRES RESULTATS	0,00
INGRESSOS FINANCERS	0,00
VARIACIÓ VALOR RAONABLE D'INSTRUMENTS	0,00
Ajustos:	**0,00**
(-) Resultat positiu alienació béns reinvertits	0,00
(-) Subvencions i donacions no reintegrables traspassats a resultats	0,00
(+) Canvis criteris comptables	0,00
INGRESSOS AJUSTATS	**66.250,10**
B) Despeses necessàries:	**2.716,42**
PROVEÏMENTS	0,00
DESPESES DE PERSONAL	0,00
ALTRES DESPESES D'EXPLOTACIÓ	2.716,42
DOTACIONS PER AMORTITZACIÓ I PROVISIONS	0,00
ALTRES RESULTATS	0,00
DESPESES FINANCERES	0,00
Ajustos:	**0,00**
(-) Dotació Amortització Element Fundacional (criteri Recursos Propis)	0,00
(-) Despeses derivades de Subvencions i donacions no reintegrables ajustades com ingres	0,00
(+) Recursos propis destinats a Elelments Fundacionals (Criteri Recursos Propis)	0,00
(+) Canvis criteris comptables	0,00
DESPESES AJUSTADES	**2.716,42**

C) Ingressos nets de l'entitat:	**63.533,68**
D) Import mínim d'aplicació obligatòria (70% de C):	**44.473,58**
E) Import destinat a finalitats fundacionals:	**21.805,93**
AJUTS CONCEDITS	0,00
PROVEÏMENTS	21.805,93
DESPESES DE PERSONAL	0,00
ALTRES DESPESES D'EXPLOTACIÓ	0,00
DOTACIONS PER AMORTITZACIÓ I PROVISIONS	0,00
ALTRES RESULTATS	0,00
DESPESES FINANCERES	0,00
INVERSIONS EN ACTIVITATS FUNDACIONALS	0,00
PERCENTATGE DE RENDES DESTINADES	**34,32%**
COMPLIMENT DEL REQUISIT / PENDENT D'APLICACIÓ	**22.667,65**

In accordance with Article 3.2 of Law 49/2002, the Foundation has the following four financial years to allocate this amount to its foundational aims, a period within which it plans to apply it in full to ongoing research programmes.

Likewise, the allocation of income to foundational activities has been as follows:

Exercici	Total d'ingressos (A)	Despeses necessàries (B)	Mínim d'aplicació [70% (A-B)]	2.023	2.024	2.025	2.026	2.027	Pendent de destinar
2.023	41.849,32	1.689,82	28.111,65	6.102,50	16.324,56	5.684,59			0,00
2.024	116.556,89	7.329,39	76.459,25		0,00	16.121,34			60.337,91
2.025	66.250,10	2.716,42	44.473,58			0,00			44.473,58
2.026	0,00	0,00	0,00				0,00		0,00
2.027	0,00	0,00	0,00					0,00	0,00
Total de recursos destinats en l'exercici				6.102,50	16.324,56	21.805,93	0,00	0,00	104.811,49

During the 2025 financial year, the Foundation did not apply more than 70% of its income to foundational aims, leaving an amount of €22,667.65 pending allocation in future years. The pending amount will be allocated within the four-year legal deadline.

Criteria for allocating expenses and investments by activity

Breakdown of income by activity and project. Exempt and non-exempt income

DETALL DE LES RENDES	Article exempció	Saldo a 31/12/2025	RENDES EXEMPTES		RENDES NO EXEMPTES
			Activitat sanitària	Ingressos Patrimonials	
			Art.7.2	Art. 6 (1/2/3)	
1. INGRESSOS PER ACTIVITATS		**0,00**	**0,00**	**0,00**	0,00
Vendes	Art. 6.4	0,00	0,00	0,00	0,00
Prestacions de serveis	Art. 6.4	0,00	0,00	0,00	0,00
Promocions, patrocinadors i col·laboracions	Art. 6.4	0,00	0,00	0,00	0,00
Subvencions oficials a l'activitat	Art. 6.4	0,00	0,00	0,00	0,00
Altres subvencions, donacions i llegats	Art. 6.1	0,00	0,00	0,00	0,00
3. VARIACIÓ D'EXISTÈNCIES DE PRODUCT. ACABAT	Art. 6.4	0,00	0,00	0,00	0,00
4. TREBALLS DE L'ENTITAT PEL SEU ACTIU	Art. 6.2	**0,00**	**0,00**	**0,00**	0,00
6. ALTRES INGRESSOS D'ACTIVITATS		**66.250,10**	**66.250,10**	**0,00**	0,00
Arrendaments	Art. 6.2	0,00	0,00	0,00	0,00
Ingressos accessoris i altres de gestió corrent	Art. 6.4	66.250,10	66.250,10	0,00	0,00
10. SUBVENCIONS DONACIONS TRASP. A RESULTATS	Art. 6.1	**0,00**	**0,00**	**0,00**	0,00
11. EXCÉS DE PROVISIONS	Art. 6.4	**0,00**	**0,00**	**0,00**	0,00
13. ALTRES RESULTATS	Art. 6.4	**0,00**	**0,00**	**0,00**	0,00
14. INGRESSOS FINANCERS	Art. 6.2	**0,00**	**0,00**	**0,00**	0,00
16. VARIACIÓ VALOR RAONABLE D'INSTRUMENTS	Art. 6.2	**0,00**	**0,00**	**0,00**	0,00
TOTAL INGRESSOS		**66.250,10**	**66.250,10**	**0,00**	**0,00**
2. AJUTS CONCEDITS		**0,00**	**0,00**	**0,00**	**0,00**
5. PROVEÏMENTS		**21.805,93**	**21.805,93**	**0,00**	**0,00**
7. DESPESES DE PERSONAL		**0,00**	**0,00**	**0,00**	**0,00**
8. ALTRES DESPESES D'EXPLOTACIÓ		**2.716,42**	**2.716,42**	**0,00**	**0,00**
9. DOTACIONS PER AMORT I PROVISIONS		**0,00**	**0,00**	**0,00**	**0,00**
13. ALTRES RESULTATS		**0,00**	**0,00**	**0,00**	**0,00**
15. DESPESES FINANCERES		**0,00**	**0,00**	**0,00**	**0,00**
TOTAL DESPESES		**24.522,35**	**24.522,35**	**0,00**	**0,00**
RENDES DE L'EXERCICI		**41.727,75**	**41.727,75**	**0,00**	**0,00**

6.2 Association Save Sight Now Europe Switzerland

The Association Save Sight Now Europe Switzerland (CHE-080.124.875), based in Geneva, presents below its accounts for the 2025 financial year. These accounts correspond solely to the Association; the accounts of the Fundació Síndrome d'Usher are presented in section 6.1. They will be presented and submitted for approval at the next General Assembly, in September 2026.

- **Annual Activity Report 2025** (this document)
- **Cuentas Anuales. Ejercicio 2025 (en CHF)**

The accounts of the Association Save Sight Now Europe Switzerland are presented in its official languages, French (the seat is in French-speaking Switzerland) and English (as set out in its statutes). Amounts are expressed in Swiss francs (CHF).

You will find all the documents in the **Transparency** section of www.savesightnoweurope.org.

Balance sheet

Association Save Sight Now Europe Switzerland, 01/01/2025 to 31/12/2025 (in CHF)

ASSETS

Actif			Précédent
1	**Actifs**	**126'727.13**	**102'359.05**
10	**Actifs circulants**	**126'727.13**	**102'359.05**
100	**Trésorerie**	**126'727.13**	**102'359.05**
1020	Compte courant UBS IBAN CH21 002	126'727.13	102'359.05
		126'727.13	102'359.05

LIABILITIES AND EQUITY

Passif			Précédent
2	**Passifs**	**126'727.13**	**102'359.05**
28	**Capital de l'organisation**	**126'727.13**	**102'359.05**
297	**Bénéfice ou perte reporté**	**126'727.13**	**102'359.05**
2970	Bénéfice ou perte reporté	102'359.05	88'557.22
2979	Bénéfice ou perte de l'exercice	24'368.08	13'801.83
		126'727.13	102'359.05

Profit and loss account

Association Save Sight Now Europe Switzerland, 01/01/2025 to 31/12/2025 (in CHF)

Pertes et Profits

Charges			Précédent
4	**Charges directes d'exploitation**	**25'163.01**	
420	**Charges publicitaires**	**3'666.90**	
4290	Autres charges directes de publicité	3'666.90	
440	**Charges des projets**	**21'496.11**	
4405	Charges de prestations de tiers	21'496.11	
6	**Autres charges d'exploitation, amortisse**	**675.31**	**87.19**
65	**Charges d'administration et d'informat**	**208.65**	
6520	Cotisations, dons, cadeaux et pourboire	208.65	
66	**Charges de publicité**	**363.54**	
6610	Imprimés publicitaires, matériel de publi	363.54	
69	**Charges et produits financiers**	**103.12**	**87.19**
6940	Autres charges financières (frais bancai	103.12	87.19
	Différence (bénéfice)	24'368.08	
	Différence précédente (bénéfice)		13'801.83
		50'206.40	13'889.02

Produits			Précédent
3	**Produits nets des ventes de biens et de**	**50'206.40**	**13'889.02**
301	**Dons**	**50'206.40**	**13'889.02**
3010	Produits de donateurs	50'206.40	13'889.02

Income statement

Association Save Sight Now Europe Switzerland, 01/01/2025 to 31/12/2025 (in CHF)

Item	2025	2024
Net income from donations	50,206	13,889
Direct project expenses	-25,163	0
Gross result after direct expenses	25,043	13,889
Personnel expenses	0	0
Other administrative expenses	-572	0
Operating result before depreciation, financial result and taxes (EBITDA)	24,471	13,889
Depreciation and value adjustments on fixed assets	0	0
Operating result before financial result and taxes (EBIT)	24,471	13,889
Financial expenses	-103	-87
Financial income	0	0
Result before taxes (EBT)	24,368	13,802
Result from ancillary activities	0	0
Exceptional, one-off or extraordinary income and expenses	0	0
Annual result before taxes	24,368	13,802
Direct taxes	0	0
ANNUAL RESULT BEFORE FUND ALLOCATION	24,368	13,802

7

Acknowledgements

Working to accelerate any treatment for an ultra-rare disease is no easy path. There is no structural funding to sustain it. No system drives it naturally.

Every advance, every formalised research programme, every event organised, every agreement signed is the result of sustained effort built from scratch, with limited resources and an urgency that allows no pause.

That is why the thanks that close this report are not a courtesy. They are the acknowledgement that nothing we achieved in 2025 would have been possible without the people and organisations who chose to walk alongside us: the researchers who trusted a young, rigorous foundation; the families who turned their pain into action; the companies who saw in this cause a bet worth making; and the allies and friends who gave their time, the one resource no one can get back. To all of you, thank you.

To Dr. Aziz El Amraoui and Dr. Sandrine Vitry of the Institut reConnect (Institut Pasteur), Paris for opening the doors of the reConnect programme and for the trust placed in a collaboration that has just begun and holds all the potential in the world.

To Dr. Bence György of IOB Basel for his dedication to precision editing applied to the retina and for keeping the growing collaboration open.

To Dr. Isabelle Audo and the entire team of the Institut de la Vision in Paris for years of joint work and for accompanying us with rigour and generosity at every step of the way.

To Carlos Ciller and Catia Fortunato of RetinAI for smoothing our path with their tools and knowledge, and for doing so with an involvement and closeness that go far beyond what any professional agreement would require.

To Dr. Giacomo Calzetti of Brescia for opening the door to the UNI-RARE programme in Italy and for a collaboration that begins with real momentum.

To Prof. Elvir Becirovic and his team at the University of Zurich, and to Dr. Zdenka Ellederová of the IAPG in the Czech Republic. To Dr. Uwe Wolfrum and Dr. Kerstin Wolfrum of Johannes Gutenberg University Mainz. To Dr. Jaume Català of the Hospital Sant Joan de Déu, Barcelona, and Dr. José María Millán of Hospital La Fe / CIBERER, Valencia, for keeping alive the preclinical platform the field needs to validate what's coming. For being the clinical points of reference who connect research with patients and families back home.

Strategic collaborators

To RetinAI for the agreement putting artificial intelligence at the service of Usher 1B, and for believing that well-managed data can speed the path to patients.

To Alessandro Mennella and Marco Tironi and their families, to Germano Carganico and Marcella Zacariello, Usher 1B Italy / BeRare Onlus, for the generosity of their work over the years, for donating the OPTOS Daytona, for the energy they bring to the Italian collaboration, and for showing that affected individuals can be engines of change.

To Carla Roda and Tabata Films for choosing our story for her directorial debut, for the sensitivity with which she has followed our family for more than a year, and for believing that Per la Bruna can change how the world sees ultra-rare diseases.

To Nuria Camp / Camp Divulgatiu for helping us build a consistent, clear voice for Usher 1B at La Nit de la Visió and on social media.

To Nathalie Baur-Schelbert: for handling the Association's accounting pro bono, year after year, with the rigour that makes everything in this report possible.

To Lulu & Nanette (Switzerland): for dedicating International Usher Syndrome Day to our cause and for bringing it to their patients and professionals.

To Thierry Campiche and the crew of the Adrénaline: for carrying the SSNEU logo on the sail in the regattas of Lake Léman and for making our cause a visible presence on the waters of Geneva.

To Dani Pich and Giorgio Maridan of Yes We Sail: for always being by our side, sharing vision and path.

The community that makes events possible

Behind every event are people who decided our cause is theirs too. Affected families, friends, groups of volunteers who did not wait around and instead turned their reality into action: organising dinners, races, markets, tournaments and evenings that raise funds and give visibility to Usher 1B wherever they live. Friends who mobilise their networks, who create events from scratch, who call, persuade and push because they know every euro raised is science moving forward.
Our most sincere recognition goes to all of these people. Without you, the research programmes we fund would not be possible. You are a fundamental part of who we are.

The voices that amplified ours

To Jordi Coll, Paula Malia, Mont Plans, Ariadna Oltra, Toni Cruanyes and Enric Agud: for bringing Usher 1B into Catalan homes at prime time through Catalunya Ràdio's «Les Bones Causes», and for doing so with the generosity of those who understand that giving voice to a cause is also a form of urgency.

And a special thanks to Elisenda Pineda, who not only amplified our voice but was physically by our side: she hosted the 3rd edition of La Nit de la Visió 2025 with an eloquence and warmth that made that night unforgettable.

The sponsors who make research possible

To Almenibor and Tectrol SA (Gold sponsors of La Nit de la Visió 2025) for their loyalty and for believing year after year in what we do. To and Love for a Walk, to Pymej SL, Instituto Médico Privado, Emerge 4 Life, Idun Nature and Atma obra (Silver and Bronze sponsors): for joining our great cause.

To all the companies and individuals: for betting on sustained funding that allows us to plan rather than improvise.

The Usher community worldwide and the families

Our deepest recognition goes to the research teams who have made it possible for us to be where we are today, to the affected families and the Usher community who work, pave the way, and trust SSNEU. Those who have been on this path for years and those who have just arrived. Those who have taught us, with their experience and their light, what it is like to live with Usher 1B, and those working to find a solution.

This year we formalised agreements, built alliances, worked on a documentary and kept pushing science toward patients. None of this would have been possible without you. Thank you for being part of this journey.

ARNAU ESPINOSA I BERTA ADELL
CO-FOUNDERS OF SAVE SIGHT NOW EUROPE