

Vol. 01



# **Annual Balance**

Save Sight Now Europe CH

# 2023

**SAVE  
SIGHT  
NOW.**

**EUROPE**

We imagine a future where Usher syndrome type 1B is fully treatable — in vision, hearing, and balance — so that no child loses their sight to this condition ever again.

# Contact



Save Sight Now Europe

**Association Save Sight Now Europe  
Switzerland**

Chemin de l'Armoise, 10  
Chêne-Bougeries, Suiza

**Fundació síndrome d'Usher**

Calle Bolivia, 37  
08018 Barcelona, España



**Berta Adell** Cofounder

[berta@save sightnoweurope.org](mailto:berta@save sightnoweurope.org)

**Arnau Espinosa** Cofounder

[arnau@save sightnoweurope.org](mailto:arnau@save sightnoweurope.org)



MAKE A DONATION

**Swiss bank account**

IBAN: CH21 0021 5215 1626 4240 J

BIC: UBSWCHZH80A

HOLDER: Association Save Sight Now Europe  
(Switzerland)



**Spanish bank account**

IBAN: ES12 2100 0841 9902 0117 0842

BIC: CAIXESBBXXX

HOLDER: Fundació Síndrome d'Usher

# Table of Contents

2023 Annual Report  
Association Save Sight Now Europe  
Switzerland



## 1 The Organisation

Summary of the year: Rewriting the future 04

About the Organization 05

## 2 What is Usher Syndrome

Rare Diseases and Inherited Retinal Dystrophies (IRDs) 07

Usher Syndrome Type 1: Facing a Multisensory Challenge 08

Understanding Retinitis Pigmentosa and Usher Syndrome Type 1B 09

## 3 Scientific Research

Emerging Approaches 11

How Technologies Are Applied to Patients 12

Funded Programs 13

Current Research on Usher Syndrome Type 1B 16

Research/Trials for Retinitis Pigmentosa (RP) – Gene Agnostic 17

## 4 Activities and Fundraising

Fundraising Initiatives 19

Visibility Campaigns 21

In the Media 21

Acciones en Suiza 22

## 5 Las finanzas

Interim Report 23

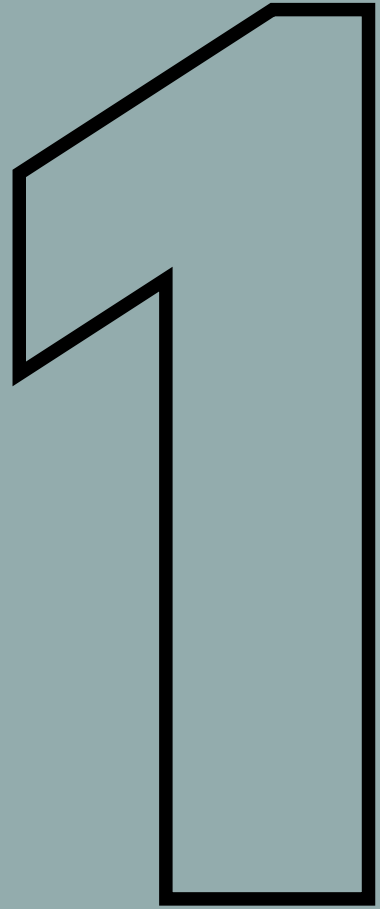
Profit and Loss 23

Balance Sheet 2023 24

Income Statement for 2023 Fiscal Year 25

## 6 Agradecimientos

Our Thanks 27



# **The Organisation**



# Summary of the Year: Rewriting the Future

In 2023, Save Sight Now Europe – Switzerland made a significant contribution to the advancement of research into Usher syndrome type 1B by funding a program at the University of Wisconsin-Madison. This program, led by Dr. David Gamm, focuses on studying gene editing in retinal degeneration, aiming to develop innovative treatments targeting the MYO7A gene, which is implicated in Usher 1B.

This collaboration underscores our commitment to supporting groundbreaking scientific research and bringing us closer to effective therapies for Usher 1B. The financial support provided by our association has been instrumental in propelling this promising research forward.

Beyond this, we have continued our efforts to raise awareness and mobilize resources, ensuring that the voices of those affected by Usher 1B are heard and that progress towards a cure remains steadfast.

# About the Organization



## Vision.

We envision a future where Usher syndrome type 1B is fully treatable in all its dimensions: vision, balance, and hearing. We aspire to a world where no one faces blindness due to retinitis pigmentosa (RP), and where the advances in gene therapy—already restoring sight and hearing in other conditions—are extended to effectively treat Usher syndrome type 1.

## Mission.

At Save Sight Now Europe, we work to support research and clinical development through an integrated approach—one that also addresses balance, a crucial sense for the quality of life of those living with Usher syndrome type 1B. Our commitment to advanced science and global collaboration is deeply personal and rooted in the day our daughter was diagnosed at HUG in Switzerland.

Every scientific breakthrough is a step toward a fuller life for individuals and families affected by Usher syndrome type 1B.

We support research teams in the search for safe and effective treatments targeting the MYO7A mutation, helping drive progress from the lab to the end users: thousands of children affected by the disease and adults living with blindness due to retinitis pigmentosa.

Given the severity of Usher type 1 and the urgency of action, we also back the development of therapies that slow RP progression while we work toward a cure.

We also promote and strengthen SSNEU to inform and activate the community. An informed and engaged community is essential for companies to move forward and choose to invest in treatment development. It is also vital for empowering families to make decisions and take action with the knowledge needed to protect what they care about most: their children's future.

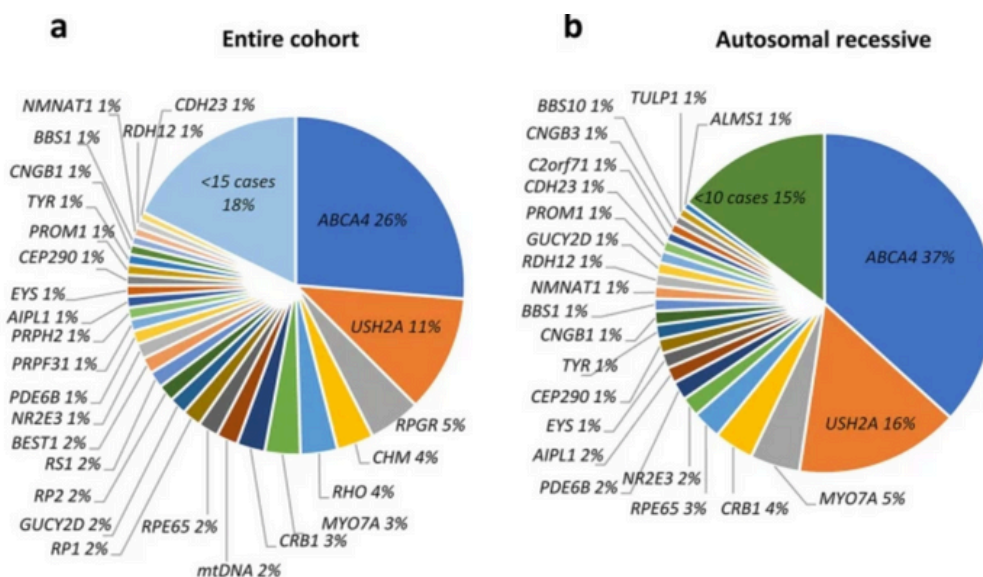


**What Is Usher  
Syndrome?**

# Rare Diseases and Inherited Retinal Dystrophies (IRDs)

Inherited retinal dystrophies (IRDs) are a group of clinically and genetically heterogeneous disorders characterized by the degeneration or dysfunction of photoreceptors. These conditions typically lead to severe and progressive vision loss, with onset ranging from birth to late adulthood.

There are over 350 identified IRDs, including albinism, aniridia, color blindness, corneal dystrophies, glaucoma, keratoconus, Leber congenital amaurosis, night blindness, retinitis pigmentosa, and retinoblastoma, among others.



M. Karali, F. Testa, V. Di Iorio, A. Torella, R. Zeuli, M. Scarpato, F. Romano, M. Onore, M. Pizzo, P. Melillo, R. Brunetti-Pierri, I. Passerini, E. Polo, F. P. M. Cremers, G. Esposito, V. Nigro, F. Simonelli & S. Banfi (2022), Genetic epidemiology of inherited retinal diseases in a large patient cohort followed at a single center in Italy, *Nature, scientific Reports* 12, 20815.

## Rare Diseases

Rare diseases affect fewer than 1 in 2,000 people. There are between 6,000 and 8,000 known rare diseases, many of which are severe or potentially life-threatening, and most have a genetic origin.

Gene therapy is therefore a promising approach for treating rare diseases, as it allows for the direct correction of the underlying genetic mutations that cause these conditions —potentially offering long-term solutions or even a cure.

# Usher Syndrome Type 1: Facing a Multisensory Challenge

**Usher syndrome** is a rare disease that affects three main senses: hearing, balance, and vision.

It is an autosomal recessive inherited disorder caused by mutations in at least one of the 13 known associated genes.

Usher syndrome was first described in 1858 and genetically characterized in the 1990s.

- **It is the most common cause of deafblindness.**
- **It accounts for 3%–6% of childhood deafness and 50% of all cases of deafblindness worldwide.**
- **Its estimated prevalence is 1 in 30,000.**

For more information about Usher syndrome, visit [www.savesightnoweurope.org](http://www.savesightnoweurope.org)



## Hearing

Children are born with severe to profound deafness. Cochlear implants are currently the only option for hearing. Today, gene therapy is successfully restoring hearing in other genetic mutations, showing great promise.

**Cochlear implants**



## Vision

Retinitis pigmentosa (RP) manifests in early childhood. It begins with degeneration of the retina's photoreceptors, causing night blindness in the initial stages, followed by tunnel vision (narrowing of the visual field), and eventually complete blindness.

**No treatment currently available**



## Balance

Types 1 (and 3) experience severe balance issues due to vestibular dysfunction.

Physiotherapy and occupational therapy aimed at stimulating proprioception—alongside reliance on vision—are currently the only strategies available.

**No treatment currently available**

# Understanding Retinitis Pigmentosa and Usher Syndrome Type 1B



**Retinitis pigmentosa (RP) is the most common retinal dystrophy.**

Retinitis pigmentosa (RP) is a degenerative disease that affects the photoreceptors in the retina—initially the rods, and later the cones—exhibiting high clinical and genetic heterogeneity. The age of onset and prognosis depend on the mode of inheritance.

In Usher syndrome, the death of photoreceptors causes early-onset loss of night vision and peripheral (side) vision, typically beginning between the ages of 4 and 5. As RP progresses, the visual field gradually narrows, leaving only central vision—known as tunnel vision—by adolescence. Over time, this remaining field also diminishes, often leading to complete blindness.

**Despite this, there is strong hope in the advancement of gene therapy research, aimed at halting the progression of RP and even restoring vision.**

Scientists around the world are working on various techniques to slow RP progression and to correct or replace the genetic mutations associated with Usher syndrome.



3

**Scientific Research**

# Emerging Approaches: Gene Editing, Cell-Based Therapies, and Small Molecules

DNA contains the genes that encode RNA, which is essential for producing proteins—the building blocks of life responsible for carrying out vital functions.

The photoreceptors in the retina rely on hundreds of proteins that must work in perfect coordination to convert light into electrical signals sent to the brain, enabling vision. Any disruption in these steps can lead to vision loss.

## Gene Therapy

**Repairing the Mutated Gene (the gene where the mutation is located):**

- Gene replacement/augmentation: replacing the faulty gene with a healthy copy (e.g., Luxturna).
- Gene editing: correcting the mutation directly in the patient's DNA.
- RNA therapy: correcting the mutation at the intermediate level between DNA and proteins.

**(Objective: to normalize the production of the altered protein in order to stop or reverse degeneration, allowing cells to function properly.)**

- Optogenetics: Converts other retinal cell types, such as ganglion cells, into light-sensitive cells. This approach is a form of rehabilitation when no photoreceptor cells remain. (IOB)
- Neuroprotective and regenerative therapies: Substances that act as antioxidants or anti-inflammatories and may slow down degeneration (e.g., NAC, NACA – Nanoscope Therapeutics, Endogena Therapeutics), as well as advanced biotechnologies such as genetic biofactories to deliver growth factors and neuroprotective agents.\*

## Cell Therapy

- -Neuroprotective and regenerative therapies: Focused on neuroprotection and the delivery of growth factors (injected into the eye). (e.g., Nanoscope Therapeutics, Endogena Therapeutics)
- Repair: Regeneration of lost retinal tissue — the ultimate goal of regenerative medicine.

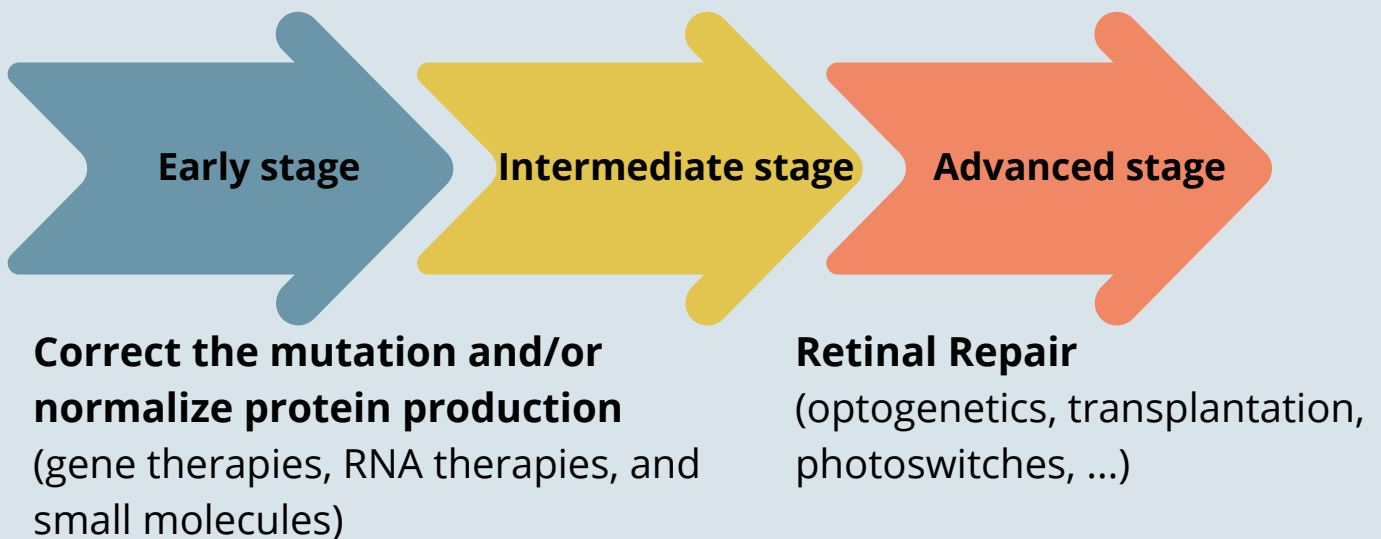
## Small molecules

Neuroprotective and regenerative therapies: Aim to provide neuroprotection and promote growth factors (administered via intraocular injection).\* (e.g., Nanoscope Therapeutics, Endogena Therapeutics)

\*Advanced and complementary therapeutic strategies aimed at slowing degenerative processes through various biochemical and biotechnological methods. These include antioxidant, anti-inflammatory, and cutting-edge biotechnological therapies designed to protect and treat retinal degeneration, and even to deliver growth factors.

# How Technologies Are Applied to Patients

Depending on the patient's condition, different therapies may be applied — always with the goal of maximizing patient benefit.



## ! Retinal Repair

- Photoreceptor replacement: does not depend on how the retina was lost or degenerated — this approach applies across all inherited retinal diseases (IRDs).
- Donor-derived cells: retinal tissue is purified to obtain retinal progenitor cells.
- Integration: These cells, which will become photoreceptors, are injected into the retina to repopulate the degenerated area and integrate to restore vision.
- (e.g., BlueRock Therapeutics, Endogene Therapeutics)



**Slowing degeneration is key. Treatments continue to advance and are evolving rapidly. Research is ongoing, and the data and results are highly promising.**

**There will be more treatments in the future —but it is in our hands to help them move forward, to protect and support them so they can reach the market and, most importantly, the patients: every individual affected by Usher syndrome type 1B.**

# Funded Programs

**Generation of a genetically edited CRXpMYO7A-HA-tagged WA09 line**  
**David Gamm Laboratory | University of Wisconsin–Madison**  
 (Funded by Save Sight Now Europe Switzerland)



The research project aims to study Usher syndrome type 1B (USH1B) using human embryonic stem cells (hESCs) from the WA09 line. The primary goal is to gain a deeper understanding of the MYO7A interactome, particularly in photoreceptor cells derived from retinal organoids.

The project is divided into two phases: in the first phase, funded by SSNEU, CRISPR/Cas9 technology will be used to edit the hESCs and isolate the MYO7A protein for future experiments.

**The relevance of this project lies in its potential to contribute to future treatments for Usher syndrome type 1B. A deeper understanding of MYO7A interactions in photoreceptor cells may uncover key molecular pathways involved in retinal function, identify therapeutic targets, and enable the development of retinal organoids that mimic early human retinal development.**

**This could lead to the identification of drugs that modulate these interactions and to genetic corrections that restore proper MYO7A function—ultimately helping to prevent vision loss..**



## **Creation of USH1B Retinal Organoids (Artificial Retinas)**

### **Oregon Health & Science University (OHSU) and Casey Eye Institute**

#### **Dr. Mark Pennesi (MD, PhD)** (Funded by Save Sight Now)

Mark Pennesi and his team are developing translational models of human retinal organoids with USH1B-associated retinal degeneration to study key aspects relevant to future therapies for Usher syndrome type 1B.

The resulting therapeutic approaches will lead to future testing in larger animal models.

#### **Objectives to be studied:**

- **Uncover previously unknown molecular disease mechanisms**
- **Determine the optimal window for gene therapy**
- **Optimize therapeutic interventions for USH1B**

## **Non-Human Primate Model for Usher Syndrome**

### **Oregon Health & Science University (OHSU) and Casey Eye Institute**

#### **Dr. Martha Neuringer (PhD)** (Funded by Save Sight Now)



Dr. Neuringer and her team are using CRISPR/Cas9 gene editing technology to develop large animal models of Usher syndrome type 1B, caused by mutations in the MYO7A gene. Improved translational models for USH1B are urgently needed to better understand disease mechanisms and to test potential therapies.

Non-human primates are more suitable than rodents because their retinas contain a macula and fovea, closely resembling human retinal anatomy and function. Additionally, they possess photoreceptor calyceal processes—structures absent in rodents but crucial to the pathology of Usher syndrome.

In May 2022, Dr. Neuringer and her team successfully created a USH1B non-human primate (NHP) model exhibiting all three hallmark phenotypes of Usher syndrome type 1B: balance impairment, profound bilateral hearing loss, and early retinal degeneration.

Martha's program requires ongoing funding to care for Gema—the primate model—and the entire cohort, ensuring the replicability and continuity of this groundbreaking work.





## **Development of Gene Therapies Based on the Understanding of USH1B Pathogenesis**

**Institut de la Vision (Paris)**

**Dr. Isabelle Audo (MD, PhD), Dr. Deniz Dalkara (MSc, PhD), Dr. Aziz El-Amraoui (PhD), and Dr. Serge Picaud (MD)**

**(Funded through a grant application by Save Sight Now Europe to the Foundation Fighting Blindness)**

This is a major 5-year, multi-track project funded by Save Sight Now and the Foundation Fighting Blindness. The project is designed to bring together fundamental scientific discoveries and innovative therapeutic interventions to ensure the timely achievement of two main objectives:

- **Genotype–phenotype correlations in USH1B, including the study of the natural history of the disease (Light4Deaf) and the identification of USH1B molecular signatures.**
- **Development of gene therapies based on a deeper understanding of USH1B pathogenesis.**

## **Characterization of USH1B Pig Models**

**Wolfrum Laboratory, Institute of**

**Molecular Physiology, Johannes**

**Gutenberg University (JGU) Mainz**

**Uwe Wolfrum and Kerstin Wolfrum**

**(Funded through a grant application by Save Sight Now Europe to the Usher Syndrome Foundation)**



This is a 3-year program funded by Save Sight Now. The Wolfrum team made an extraordinary discovery of a naturally occurring USH1B pig model and are now breeding and maintaining a colony of USH1B pigs to study, characterize, and establish a reliable large-animal model for Usher syndrome type 1B. This model will later be used to test new therapeutic approaches.



# Current Research on Usher Syndrome Type 1B



## TIGEM, AAVANTGARDE BIO

USH THER – A. Auricchio  
Clinical trial of dual AAV vector gene therapy for retinitis pigmentosa in patients with Usher syndrome type 1B (2018–2023).

EYEGET – A. Auricchio  
Gene therapy for inherited retinal diseases (2017–2021).

The dual vector technology developed by Dr. Alberto Auricchio and his team at TIGEM has ushered in a new era of hope for individuals with inherited deafness. This groundbreaking advancement has led to the restoration of hearing in children with OTOF gene mutations.

This same team is now preparing to launch a clinical trial for a promising treatment targeting Usher syndrome type 1B.



## OSHU Cassey Eye Institute – M. Pennesi

Adaptation of CRISPR Gene Editing Tools for LCA to Usher Syndrome Type 1B Patients



## Atsena Therapeutics – Shannon Boye

Dual AAV Vectors Capable of Delivering Large Genetic Payloads – USH1B Program



## OSHU Casey Eye Institute – Martha Neuringer

Creation and Characterization of the First Non-Human Primate Model of Usher Syndrome Type 1B



## Waisman Center – David Gamm

Modeling USH1B Using Retinal Organoids Derived from iPSCs of Individuals Affected by USH1B



## Institut de la Vision Paris – Audo, Delkara, el Amraoui & Picaud

Development of Gene Therapies Based on the Understanding of USH1B Pathogenesis



## The London Project to Cure Blindness – M. Moosajee (Moorfields Eye Hospital)

Development of Models to Test the Efficacy of Existing Drugs or to Explore New Therapies



## Wolfrum Lab, IMP & JGU – W. & Kerstin Wolfrum

Development of Gene Therapies Based on the Understanding of USH1B Pathogenesis



## UCLA Stein Eye Institute – D. Williams

CRISPR/Cas9 Gene Editing Technique to Correct Mutations in the MYO7A Gene (Usher 1B)



### ZipBio

ZipBio diseña terapias complejas que son pequeñas, eficaces y seguras, para abordar casos en los que el tamaño representa un factor limitante para lograr el efecto terapéutico deseado.



### Chirco, Kathleen OHSU

Developing an in vitro human USH1B model to study retinal disease features



### Clinical Trials of Natural History Studies

Universal Natural History Study – Rare Gene Study (Uni-Rare)

Jaeb Center for Health Research & Foundation Fighting Blindness

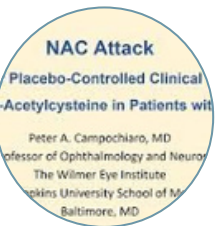
A registry and natural history study of retinal dystrophies associated with rare disease-causing genetic variants.

Natural History Study of Usher Syndrome

Light4Deaf | Centre Hospitalier National d'Ophtalmologie des Quinze-Vingts

Natural History Study in Subjects with USH1B

Fondazione Telethon



### NACAttack

Randomized, placebo-controlled multicenter trial that will test whether NAC can slow progression of RP.



### NACA Nacuity Pharmaceuticals

Developing targeted, prescription antioxidant therapies that systemically or locally boost glutathione levels to stop chemically aggressive oxygen molecules from damaging tissue.

## Research/Trials for Retinitis Pigmentosa (RP) – Gene Agnostic



### Ocugen

Therapy focuses on modulating the retinal environment to promote cell survival and function.



### Nanoscope

Optogenetic therapy to deliver light-sensitive proteins to the surviving retinal cells to restore vision.



### Endogena

Small molecules that activate endogenous stem and progenitor cells to regenerate retinal cells, aiming to slow down or stop the degenerative process.



### Kiora pharmaceuticals

Developing small molecule drugs that aim to improve visual function in patients with RP. Their therapies are designed to enhance retinal cell survival and function



### Ray Therapeutics

Developing optogenetic therapy that aims to restore vision by using light-sensitive proteins delivered via viral vectors to retinal cells. They work on the surviving retinal cells to restore their light-sensing ability.



### Sparing Vision

Therapy to deliver a neurotrophic factor to the retina, which can protect and preserve the function of photoreceptors.



### IOB

Pioneering optogenetic therapies to restore vision. Their approach involves introducing light-sensitive proteins into the retinal cells that survive the degeneration process. By using these proteins, they aim to convert the remaining retinal cells into new photoreceptors, enabling them to respond to light and potentially restore vision in patients with RP.



# **Activities and Fundraising**

# Fundraising Initiatives

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:

We raise funds in a variety of ways: by applying for research grants, through fundraising campaigns led by the Spanish Foundation and the Swiss Association, and through Usher events we organize or that are promoted by families and friends.

We work to ensure that the Usher community pushes forward—strongly and united—toward what can become a reality.

**SAVE  
SIGHT  
NOW.**

### SOIRÉE À FRIBOURG

Fundraising Concert Dinner and Awareness Event for Usher Syndrome and the Newly Established Swiss Association – September 2022



### COURSE DE L'ESCALADE

L'Escalade 2022 – Running Together with the Wyss Center

**GENERALI  
GENÈVE  
MARATHON**

### GENEVA MARATHON

We had the opportunity to take part with a team of runners in the 2023 and 2024 editions of the Generali Geneva Marathon.



### LA SAINT NICOLAS

Solidarity Fondues – Saint Nicholas Event in Fribourg



### TRAM'DRAMES

Onboard Performance Aboard Geneva's Historic Boats with La Mouette – Fundraising for Research, September 2023



### (MIS)COMMUNICATION

One-Act Comedies for Charity. A theatre performance by Geneva's GEDS group to raise funds to help defeat Usher syndrome.





# Initiatives in Spain:



## LA NIT DE LA VISIÓ

La Nit de la Visió (The Night of Vision) Official Presentation of the Foundation in Spain



## THE USHER RACE

First Edition of the Solidarity Race to Defeat Usher Syndrome June 2023, Les Franqueses del Vallès



## SOLIDARITY RUN – INSTITUT DELTEBRE

Solidarity Run Organized by the School of One of the Children Affected by Usher Syndrome



## WAKEBOARD FUNDRAISER

Tardeo Wakeboard, T-Toms Wakepark, Deltebre, Cataloia



## T-SHIRT RAFFLE

Raffle of an FC Barcelona Women's Football Jersey



## ‘CAMÍ DE NADAL’

Christmas Trail: La Xarxa Matadepera and Cia La Bleda



## FESTIVAL ‘MENUTS’

Awareness and fundraising for research, organized by the nursery school of a young child affected by Usher syndrome.



## REBEL GENETICS

Rebel Genetics: Solidarity Bracelets and More



## ROSES FIGHTING USHER SYNDROME

Roses and Pencils to Fight and Rewrite the Future of All Children Living with USH1B Awareness and fundraising action during Sant Jordi Day 2024 in Barcelona.



## DONES DESMUNTADES

Somni'ts Theatre and La Lira joined forces to stage this play in support of Usher 1B research.



## LA MESCLA

Gastronomic Event in Terres de l'Ebre. Awareness and fundraising stand to support research.



## CHRISTMAS SALE

Institut Escola Gavà Mar – Solidarity Sale at an affected kid's School, Catalonia



## DEMONIETS DE DELTEBRE

Solidarity Morning with Demoniets del Delta in Terres de l'Ebre



## CHARITY GIFT BASKETS



## LA CARA B

La Cara B (Temps de Terra) A cultural and musical day in Amposta



## CHARITY DONATION BOXES

You can visit our [events page](#), including [past events](#), to see our fundraising activities and also access the collaborators section to learn about the commitment and transparency we uphold.

## Visibility Campaigns:



### ROGER FREIXES AND THE PURITO RACE

An adult living with Usher 1B who cycles competitively and supports Save Sight Now Europe in its mission to raise funds and provide scientific support to defeat Usher syndrome.



### MARIO RAÚL MARTÍNEZ & BCN MARATÓN

Zurich Barcelona Marathon with Save Sight Now Europe (Usher Syndrome Foundation).



### COURSE DE L'ESCALADE

L'escalade 2022, running together with Wyss Center



### GENEVA MARATHON

SSNEU proudly participated in the Geneva Marathon, fielding a dedicated team of runners committed to raising awareness and funds to support research

## In the Media:



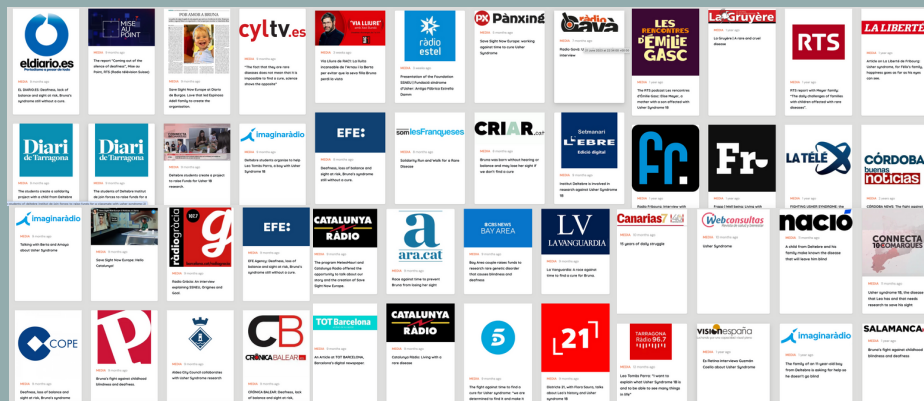
### LES BONES CAUSES MORNING SHOW ON CATALUNYA RÀDIO

Awareness Spots on “El Matí” of Catalunya Ràdio during Prime Time Featuring voices of prominent figures from the Catalan cultural sector.



### PLEASE VISIT OUR MEDIA SECTION ON THE WEBSITE.

We have been featured in television and radio interviews, as well as across social media platforms, actively promoting awareness of Usher syndrome type 1 and our efforts 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.





# 5

**Key  
Figures**

01.01.23 - 31.12.23

## Interim Report

### Bilan intermédiaire

Actif			Précédent
1	Actifs	88'557.22	48'906.03
10	Actifs circulants	88'557.22	48'906.03
100	Trésorerie	88'557.22	48'906.03
1020	Compte courant UBS IBAN CH21 002	88'557.22	48'906.03
		88'557.22	48'906.03

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

## Profit and Loss

### Pertes et Profits

Charges			Précédent
4	Charges directes d'exploitation	508.95	
460	Charges de la formation	508.95	
4660	Publicité	508.95	
6	Autres charges d'exploitation, amortisse	11'803.74	65.10
67	Autres charges d'exploitation	11'648.94	
6720	Dons	11'648.94	
69	Charges et produits financiers	154.80	65.10
6940	Autres charges financières (frais banca	154.80	65.10
	Différence (bénéfice)	39'651.19	
	Différence précédente (bénéfice)		48'906.03
		51'963.88	48'971.13

Produits			Précédent
3	Produits nets des ventes de biens et de	51'963.88	48'971.13
301	Dons	51'963.88	48'971.13
3010	Produits de donateurs	51'963.88	48'971.13
		51'963.88	48'971.13

# Balance Sheet 2023

## Association Save Sight Now Europe

Genève

### Bilan au 31.12.2023

Actifs	Note	2023	2022
<b>Actifs circulants</b>			
Trésorerie		88 557	48 906
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)			
<b>Total actif circulant</b>		<b>88 557</b>	<b>48 906</b>
<b>Actifs immobilisés</b>			
Immobilisations financières			
Participations			
Immobilisations corporelles meubles	3.3		
Immobilisations corporelles immeubles			
Immobilisations incorporelles			
Capital social (ou capital de fondation) non libéré			
<b>Total actif immobilisé</b>		<b>0</b>	<b>0</b>
<b>Total actif</b>		<b>88 557</b>	<b>48 906</b>
<b>Passifs</b>			
<b>Capitaux étrangers à court terme</b>			
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			
<b>Total capitaux étrangers à court terme</b>		<b>0</b>	<b>0</b>
<b>Capitaux étrangers à long terme</b>			
Dettes à long terme portant intérêt			
Autres dettes à long terme			
Provisions et postes analogues prévus par la loi	3.6		
Prêts postposés			
<b>Total capitaux étrangers à long terme</b>		<b>0</b>	<b>0</b>
<b>Total capitaux étrangers</b>		<b>0</b>	<b>0</b>
<b>Capital de l'organisation</b>			
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		48 906	
Bénéfice ou perte de l'exercice		39 651	48 906
Propres actions, parts sociales, droits de participations (poste négatif)			
<b>Total capitaux propres</b>		<b>88 557</b>	<b>48 906</b>
<b>Total passif</b>		<b>88 557</b>	<b>48 906</b>

# Income Statement for 2023 Fiscal Year

## Association Save Sight Now Europe

Genève

### Compte de résultat pour l'exercice clôturé au 31.12.2023

	Note	2023	2022
Produits nets des ventes de biens et de prestations de services		51 964	48 971
Variations des stocks et variation des prestations de services non facturés			
Charges directes des projets		-509	
<b>Résultat brut après charges directes</b>		<b>51 455</b>	<b>48 971</b>
Charges de personnel			
Autres charges administratives	3.8	-11 649	
<b>Résultat d'exploitation avant amortissements et corrections de valeur, résultat financier et impôts (EBIDTA)</b>		<b>39 806</b>	<b>48 971</b>
Amortissements et corrections de la valeur des immobilisations			
<b>Résultat d'exploitation avant résultat financier et impôts (EBIT)</b>		<b>39 806</b>	<b>48 971</b>
Charges financières		-155	-65
Produits financiers			
<b>Résultat d'exploitation avant impôts (EBT)</b>		<b>39 651</b>	<b>48 906</b>
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 >			
<b>Resultat annuel avant impôts</b>		<b>39 651</b>	<b>48 906</b>
Impôts directs			
<b>Resultat annuel sans resultat des fonds</b>		<b>39 651</b>	<b>48 906</b>

### Key Figures for 2023

Total Income: CHF 51,963.88

Total Expenses: CHF 12,467.69

Net Result: CHF +39,651.19

Cash Assets as of 31.12.2023: CHF 88,557.22



**Our Thanks**



# Closing of the 2023 Fiscal Year

## Our Thanks

2023 marked a year of beginnings and consolidation for the Save Sight Now Europe Association in Switzerland. With strength, commitment, and deep personal involvement, we helped raise awareness about Usher syndrome type 1B and directed resources toward biomedical research aimed at stopping, slowing, or even reversing vision loss in affected children.

This balance sheet transparently reflects the first steps of our activity as an association, which complements and reinforces the global work of the foundation. Thanks to the support of every donor, collaborator, and volunteer, we have moved forward toward a shared goal: to ensure a future with more hope and opportunity for all families affected by Usher 1B.

We will continue working with the same determination and transparency to keep building bridges between the community, science, and institutions.

Thank you for being part of this journey.

Arnau Espinosa and Berta Adell  
Co-founders of Save Sight Now Europe



Arnau Espinosa  
cofundador y secretario



Berta Adell  
cofundadora y presidenta

