

General Assembly 2025

Agenda

General Assembly 2025
Save Sight Now Europe Switzerland
Monday, October 6, 2025
6:00 PM – 7:00 PM (approx. 1 hour)
Online session (mainly in English)

1. Opening and welcome
2. Approval of annual accounts
3. Election of the Presidency**
4. Update on research supported by SSNEU (CH) (Ongoing projects and roadmap)
5. Building an informed and engaged community (Participation and communication strategies)
6. Open floor for members' input
7. Closing remarks

***According to the Statutes, the Presidency has a three-year term and may be renewed only once. At this General Assembly, we will therefore proceed with the election of the Presidency for the next term. The current President, Berta Adell, is standing for renewal. Members who wish may also present their candidacy before or during the Assembly.*

Minutes of the General Assembly 2025

Save Sight Now Europe – Switzerland
Monday, October 6, 2025
Online Session – 6:00 PM to 7:05 PM

1. Opening of the Meeting and Welcome

The session opened at 18:00.

The meeting was chaired by Berta Adell, President of Save Sight Now Europe (SSNEU), with the participation of: (founders) Arnau Espinosa, Júlia Espinosa, and Hermes Solé.

Several messages were sent to confirm the attendance of members at the General Assembly. No members were ultimately able to join the session.

However, it should be noted that one person had expressed interest in attending, but their email was unfortunately not seen in time, which prevented them from joining the meeting. The Board subsequently contacted this person, explained the oversight, and shared all information related to the General Assembly so that they could provide any comments or input if desired. This person expressed full confidence in the team and in the resolutions adopted on each item of the agenda.

The Board apologises for this error in email handling.

The President welcomed the attendees and recalled the mission of SSNEU: to ensure that Usher syndrome type 1B becomes fully treatable—in vision, hearing, and balance—and that no child should ever lose their sight due to this disease.

The dual legal and operational structure (Swiss Association + Spanish Foundation) was reiterated as a strength, enabling strong local anchoring and international impact, while also requiring significant coordination and workload.

The President highlighted SSNEU's growing engagement and recognition in the scientific community, following active participation at ARVO, EURETINA, and the USH2025 Congress in Nijmegen (summer 2025), which strengthened relationships with researchers, institutions, and companies working on inherited retinal dystrophies and helped shape the research programmes for the coming year.

Two new volunteers were welcomed. The President underlined the urgent need for additional volunteer support, given the increasing operational load of running two active organizations and multiple research partnerships. She emphasised the importance of involving members in communication, administration, fundraising, and event support, and invited those interested to collaborate.

2. Approval of Annual Accounts 2024

The annual accounts for fiscal year 2024, previously circulated and uploaded on the Save Sight Now Europe website, were presented to the members.

It was noted that:

- All funds raised were allocated to research projects (in particular the programme of Dr Elvir Becirovic at the University of Zurich) and to visibility and awareness activities, including the partnership with the sailing boat Adrenaline.
- Financial statements continue to be issued in French, in accordance with the requirements of the Canton of Geneva, with English summaries provided for accessibility.

No objections were raised. The accounts for 2024 were unanimously approved.

3. Election of the Presidency

According to the Statutes (three-year term, renewable once), the Assembly proceeded with the election of the Presidency.

The current President, Berta Adell, having completed her first mandate, declared her intention to continue and stand for renewal. No additional candidacies were presented before or during the Assembly.

The Assembly unanimously approved the renewal of the Presidency of Berta Adell for a second and final term.

****Note on the 2024 General Assembly decision – “Golden List” of distinguished donors***

The Board reminded members that, at the previous General Assembly, the creation of a Golden List of distinguished donors had been approved. However, implementation has been delayed, as SSNEU must first contact each individual or company concerned to obtain consent and verify their inclusion.

Due to limited resources and a high operational workload, this process has not yet been completed. The Board apologized for the delay and committed to finalising the first version of the Golden List during 2026.

4. Update on Research Supported by SSNEU (CH)

A comprehensive update was provided by Arnau Espinosa and Berta Adell.

Global scientific landscape

The field is advancing rapidly, with several therapeutic lines evolving in parallel:

Advanced-stage therapies and antioxidants (Nacuity – NPI-001): SSNEU remains in direct contact with the Nacuity team. FDA approval is pending for the start of Phase 3. SSNEU is exploring mechanisms to support future European market access, advised by Paola Valinotti, an expert in rare-disease pricing, reimbursement and regulatory pathways. Her guidance is expected to be key to ensuring equitable access for European families once treatments become available.

Gene therapy – LUCE clinical trial (dual AAV MYO7A): SSNEU remains in contact with the AAVantgarde Bio team as the only Usher 1B-specific organization in Europe, supporting awareness, patient contact and advocacy around the LUCE-1 programme.

Additional therapeutic projects:

Beyond LUCE and Nacuity, SSNEU continues proactive engagement with different biotech actors to keep Usher 1B visible and scientifically attractive as a disease area worth investing in and pursuing.

Two programme discussions are currently at an advanced stage. As no agreement has yet been signed, details cannot be disclosed at this time.

SSNEU CH – Funded research programmes 2025

University of Zurich – Dr Elvir Becirovic: two therapeutic directions continue to be pursued: dual AAV supplementation and MYO7B activation. Recent pig injections with a modified vector did not replicate previous positive expression results, underlining the complexity of vector design and optimisation. GMP-like production of new MYO7A vectors is being planned, with the aim of enabling further injections in 2026, subject to securing the necessary funding. MYO7B vectors are expected in the coming weeks.

Seven MYO7A Q181* homozygous pigs are currently available for natural history and intervention studies. An update from Zdenka was shared with the members during the Assembly.

Institut de la Vision, Paris (Isabelle Audo, Aziz El-Amraoui, Deniz Dalkara and team): work continues on genotype–phenotype correlations, Light4Deaf natural history studies and the development of new gene therapy approaches. The planned AI partnership to accelerate data analysis remains of high strategic interest but requires further administrative and contractual steps before it can be formally launched.

Retina AI: SSNEU is preparing a collaboration with Retina AI in the field of AI-assisted data processing for natural history studies and clinical trial readiness. The company specialises in high-performance retinal image analysis and biomarker identification, with the objective of helping to better characterise disease progression and define meaningful endpoints for future trials.

University of Wisconsin–Madison – Dr David Gamm: the lentiviral MYO7A supplementation programme has been successfully completed, demonstrating expression in patient-derived cells. This work provides a valuable foundation and additional knowledge for future therapeutic strategies targeting MYO7A.

University of Mainz – Uwe and Kerstin Wolfrum: ongoing work continues with the natural Usher 1B pig model and retinal organoids. New piglets are expected in 2026, which will further strengthen the preclinical platform available for natural history and therapeutic studies.

Vestibular research

While SSNEU's primary priority remains vision, the organisation also continues its collaboration with vestibular researchers. The HUG vestibular implant team recently secured a national grant, for which SSNEU provided supporting arguments on the impact of balance disorders on the quality of life of children with Usher syndrome.

The team underlined the importance of SSNEU's community survey on vestibular function, and SSNEU is now preparing additional questionnaires to better document the needs and expectations of families in view of possible future vestibular trials. This work aims to further support the case for dedicated treatments and to ensure that trial designs are aligned with what matters most to affected individuals.

This demonstrates how crucial it is for the community to share lived experiences: everyday reality can open doors to science and help researchers design the most relevant and effective interventions. SSNEU will continue working and exploring possible collaborations in this area.

Roadmap summary for research

The coming two years will focus on:

- Advancing MYO7A gene therapy programmes

- Establishing AI infrastructure for clinical and imaging data
- Supporting clinical trial pipelines
- Working to ensure future therapeutic access for European families

5. Building an Informed and Engaged Community

The Board emphasized that an informed and engaged community is essential for accelerating the development of treatments.

Despite significant efforts in 2024 (newsletters, media appearances, social media and in-person events), it was noted that the community is still not as engaged in research and in the activities that could help accelerate research as the organisation would wish. In a constructive and respectful way, the Board underlined that many families may not yet fully see how they can contribute to shaping research and speeding up the path toward treatments.

SSNEU will therefore continue – and, where possible, reinforce – its efforts to communicate clearly, share understandable scientific updates and explain concrete ways in which families and affected individuals can participate and help.

A key example discussed was that current outcome measures in Usher 1B clinical research are not always aligned with what patients consider most meaningful. Only those living with Usher can indicate which changes really matter in daily life (for example night vision, balance and stability, fatigue or autonomy). Engaged families are therefore essential partners in redefining and prioritising appropriate endpoints.

Community Collaboration Model & Volunteer Network

SSNEU's structured system for grassroots initiatives – combining a collaboration charter with an event form – has proven extremely effective. When this model is presented to external organisations, banks and companies, they consistently highlight its clarity, professionalism and added value.

At the same time, the organisation stressed the ongoing need for volunteers. To sustain and expand this collaboration model, SSNEU intends to invest effort in building a broader volunteer network, so that more tasks can be shared with individuals who are interested in contributing. This will help strengthen the internal structure and ensure that opportunities are not lost simply because of limited capacity.

Future Engagement Strategy

The Board shared the idea – still at an early stage – of organising a “Families and Affected Individuals Day”, to bring families together, share knowledge and empower them to engage more directly in research-related discussions and priorities. There was an extended discussion about the possibilities that such an initiative could open, and about the potential impact it could have on the objectives of the organisation.

In the short term, the organisation will remain focused on:

- The ongoing research collaborations
- searching for grants and sponsors
- The preparation of the solidarity auction
- The preparation of La Nit de la Visió 2025

while keeping community engagement as a central theme for 2026.

As part of this engagement strategy, a survey will be launched to better understand the interests, expectations, and priorities of the community.

Fundraising and future editions of La Nit de la Visió

In relation to fundraising, the Board also noted that, after three years of experience organising La Nit de la Visió in Spain, it may now be the right moment to explore bringing this event to Switzerland, where there could be significant opportunities for sponsorship and institutional support. The Board will therefore begin to explore the feasibility and possible formats of a future edition of La Nit de la Visió in Switzerland.

6. Open Floor for Members' Input

Other members and founders were invited to express suggestions and comments.

The discussion reflected a shared interest in:

- strengthening community information and education tools, to improve community engagement
- exploring different fundraising models and partnerships
- identifying opportunities for new collaborations with research groups, institutions, and supportive organisations

7. Closing Remarks

The President thanked all founders for their attendance and support, and expressed her gratitude to the members, volunteers, families, and donors for their continued trust and involvement.

She reaffirmed that 2026 will be a decisive year for SSNEU's scientific partnerships and community strategy, with the same mission guiding all efforts: to protect the vision, autonomy, and quality of life of children with Usher syndrome type 1B.

The next General Assembly is scheduled for September or early October 2026.

The session was formally closed at 19:05.



Berta Adell

President and Co-founder SSNEU Switzerland

10th October 2025 Genève