



European Foundation for SATB2-Associated Syndrome (SATB2 Europe)

Evropska fundacija SATB2, ustanova za SATB2 sindrom

Šentjošt nad Horjulom 54A,

1354 Horjul

Slovenia

erika.stariha@satb2europe.org

ANNUAL REPORT OF THE FOUNDATION for the financial year 2025

(1 January 2025 – 31 December 2025)

I. BUSINESS REPORT

1. INTRODUCTION

1.1. Presentation of the Foundation

The Foundation is a non-profit, charitable organization operating in the field of healthcare, specifically in the area of rare diseases.

Its purpose is of general public benefit and permanent in nature, aimed at improving the quality of life of individuals with SATB2 syndrome and their families by enabling research for the discovery and development of targeted treatment for the syndrome and by ensuring better healthcare and rehabilitation services within the European healthcare system.

1.2. Development of the Foundation

The idea for the Foundation was conceived in January 2021 at the first virtual meeting of three families who have a child with SATB2 syndrome. This was followed by the preparation of a strategic plan and all necessary documentation for establishing the foundation at the competent ministry – the Ministry of Health – and registration in the Register of Foundations on 21 July 2021.

At the same time, we informed European families about our vision and held meetings with representatives from 18 European countries as well as the USA and Australia. We created a (temporary) website and all necessary infrastructure to begin operations.

1.3. Management

The Management Board consists of the founders (officially, the founder is the President of the Board, who is the only member from Slovenia), namely:



- Erika Stariha (President of the Board)
- Jenny Li Örsell (Board Member, Sweden)
- Paul Maksys (Board Member, Austria)

The Foundation is managed in accordance with its internal rules. Currently, the President, with the assistance of Board Member Paul Maksys, is also responsible for financial matters, administrative tasks, and communication with the target audience.

All board members and other collaborators performed their work voluntarily and without remuneration.

1.4. Committees – Initiatives

The Foundation has two main initiatives:

- **CareSATB2**, aimed at improving healthcare and rehabilitation services within the European healthcare system.
 - **CureSATB2**, aimed at encouraging and enabling research in the field of understanding and treating SATB2 syndrome.
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Overview of Activities

The Foundation operates in four main areas:

- Promoting and enabling research into understanding and treating SATB2 syndrome.
- Improving rehabilitation and healthcare services and health protection for individuals with SATB2 syndrome within the European healthcare system.
- Providing assistance and support to families of children or adults with SATB2 syndrome.
- Raising awareness among the scientific, medical, rehabilitation, educational, and general public about SATB2 syndrome.

In accordance with the above, we carry out the following activities:

- Organizing professional events, meetings, and preparing other educational content.
- Networking among researchers, physicians, parents, and other organizations or companies in the field.
- Networking among physicians and clinics in Europe and encouraging the establishment of reference center for SATB2 syndrome patients, as well as clinical guidelines for diagnosis and treatment.



- Assisting and supporting families of children or adults with SATB2 syndrome, primarily by raising awareness and providing information about activities and developments in this field.
- Raising awareness among the scientific, medical, rehabilitation, educational, and general public about SATB2 syndrome.
- Fundraising, particularly obtaining donations from individuals and legal entities to support the Foundation's mission.

1.5. Environmental Impact

SATB2 syndrome belongs to the group of rare diseases, specifically rare neurodevelopmental syndromes. Currently, there are approximately 700 diagnosed individuals worldwide (about half of them in Europe). In Slovenia, according to our knowledge, there are four patients.

These facts demonstrate that international action is essential if we are to successfully achieve our goals.

In 2021, there were only five national associations in Europe (two of them established in 2021), while other countries had no formal associations. Therefore, we established a European foundation to help those without national associations and to serve as a strong partner in discussions with organizations outside Europe.

2. PROGRAM

2.1. Achievement of the 2025 Plan

We set realistic goals and successfully achieved them.

2.1.1. Core Operations

- **Establishment of advisory bodies and executive team**

We established two new advisory bodies and an Executive Management Team:

- Medical Advisory Board, composed of six distinguished physicians from various specialties, a clinical psychologist, and a speech therapist.
- Scientific Advisory Board, composed of nine researchers from fields relevant to our mission.
- Executive Management Team (EMT), consisting of four members – the board members plus one additional member.

The EMT performs tasks and represents the organization within assigned competences, adopts work and development programs, monitors their implementation, and participates in decision-making processes.



• Awareness Raising

The President was invited as a speaker:

- At a round table marking Rare Disease Day in Brdo pri Kranju (February 2025).
- At a Public Forum on Rare Diseases (April 2025).

We participated in the International Conference of Clinical Geneticists Alpe Adria in Bled (October 2025) and the annual ERN ITHACA meeting in Norway.

Through our social media posts (primarily LinkedIn), we achieved significant engagement and reach, contributing to awareness of rare diseases in Slovenia and beyond.

• New Website

We continued redesigning and upgrading our website, which was successfully completed **and published in December 2025**.

• Networking and Development of the Rare Disease Field in Europe

In December 2025, the President attended the annual ERN ITHACA General Assembly and actively contributed by leading a workshop on Natural History Studies (NHS).

We maintained contact and actively collaborated with SATB2 organizations in the USA, Australia, France, Italy, Spain, England, and the Netherlands & Belgium.

We actively participated in ERN ITHACA Patient Council meetings and attended the annual meeting of all ERN ITHACA members in Bergen, Norway.

We remained founding members of Genetic Alliance, members of EURORDIS, the Association of Patient Organizations of Slovenia (Rare Disease Section), and members of the “patient and citizen pillar” at BBMRI-ERIC – the international biobank network.

• PUBLIC INTEREST STATUS

In December 2025, **we obtained public interest status from the Ministry of Health of Slovenia for the first time**.



2.1.2. CareSATB2 Initiative

Guidelines

In 2025, we continued one of our main projects: preparing the FIRST global guidelines for the care and treatment of SATB2 syndrome.

The project is methodologically supported by ERN ITHACA. We independently established a network of interested clinicians worldwide through information obtained from parents. This represents an important milestone for the field and required significant effort and advocacy.

Based on a survey of 270 respondents, we prioritized 22 clinical questions divided into 10 overarching areas and formed 10 working groups comprising 60 physicians and 16 parents worldwide. The entire project is led by the President of the Foundation.

We **applied for ERDERA funding to organize a Consensus Meeting in October 2026 in Ljubljana.**

European Reference Center for SATB2 Syndrome

We successfully agreed on the establishment of an Expert/Reference Center in the Netherlands. In June 2025, the President and an EMT member visited the newly established reference center for SATB2 syndrome in Radboud Nijmegen. Further agreements are needed regarding logistics and service provision for patients from other European countries.

Contacts for New Families - Local Ambassadors

We obtained **contacts of parents in most European countries** who will serve as local ambassadors and support new families with SATB2 syndrome in their respective countries.

This network did not previously exist.

2.1.3. CureSATB2 Initiative

In 2025, we successfully established and confirmed both the Scientific Advisory Board and the Medical Advisory Board.

We initiated new projects in cooperation with the Faculty of Pharmacy in Ljubljana and laid the foundations for collaboration with a laboratory in Madrid and a center in the Czech Republic in the field of translational science related to our syndrome.

We wrote four letters of support to different research groups, held meetings with several research groups, and were successful in a call for proposals for a SATB2 syndrome mouse model.



We held meetings with the American and Australian foundations to coordinate a joint research strategy in the field of SATB2 syndrome and to share our knowledge.

II. FINANCIAL STATEMENTS

1. Notes to the Financial Statements

The Annual Report of the European SATB2 Foundation is based on the Accounting Act, referring to Slovenian Accounting Standards (2016), particularly Standard 34 – Accounting Solutions in Non-Profit Organizations – Private Law Legal Entities.

Accounting records are kept according to the double-entry bookkeeping principle. Financial statements are prepared for the financial year corresponding to the calendar year.

The deadline for submission of the annual report is the last day of February of the current year for the previous calendar year.

2. Balance Sheet

Text	Assets	Liabilities
Cash and cash equivalents	2,861.91	
Founding contribution		1,200
Surplus of income over expenses – current year		224.79
Surplus of income over expenses – previous years		1,437.12
Total	2,861.91	2,861.91

3. Notes to the Balance Sheet

Cash and cash equivalents represent funds in the transaction account at UniCredit Bank and the PayPal account in the total amount of EUR 2,861.91.

The founding contribution amounts to EUR 1,200.

The surplus of income over expenses for the current year amounts to EUR 224.79. The accumulated surplus from previous years amounts to EUR 1,437.12.



4. Statement of Income and Expenses

	2025	2024	2023	2022
Income	386.97	1,103.10	150.01	445.80
Expenses	162.18	126.17	127.04	663.40
Surplus of income	224.79	976.93	22.97	
Excess of expenses				217.60

5. Notes to the Statement of Income and Expenses

Income and expenses are recognized on an accrual basis.

Income consists of donations in the amount of EUR 386.97.

Expenses include costs of goods, services, and payment and banking transaction fees in the amount of EUR 162.18.

Since income exceeded expenses, a surplus of EUR 224.79 was recorded for the accounting period.

All income derives from non-profit activities; therefore, all expenses are also related to non-profit activities.

III. CONCLUSION

The report was prepared by the President of the Board and presented at the virtual board meeting on 18 February 2026, where it was unanimously adopted.

The signatory is the official representative of the Foundation and President of the Board, Erika Stariha.

Šentjošt nad Horjulom, 24th February 2026