**EUPATI SWITZERLAND** 

# Annual Report 2024

















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## PRESIDENT'S MESSAGE

Dear Members Dear Sponsors and Donors Dear Friends of EUPATI CH



2024 was an intense year of growth and consolidation for EUPATI CH. We expanded patient engagement initiatives, strengthened collaborations, and launched new training programs. We had the opportunity to present and teach at various events. EUPATI CH becomes a well-recognized stakeholder in the Swiss patient engagement arena. Our commitment to empower patients by becoming true patient partners in all aspects of research and development of health care solutions remains unwavering. Thank you for your continuous support.

## ACKNOWLEDGEMENTS

We sincerely thank all members of the Executive Board, our EUPATI Fellows, our membership community as well as all friends and supporters for their collaboration, and precious contributions. Their dedication is essential in advancing patient involvement in research and healthcare.

A special thanks goes to Dr. Barbara Peters and Dr. Daniel Hammes from the Department of Clinical Research at the University Hospital Basel for their key role in organizing the second EUPATI CH Patient Expert Training. We also extend our gratitude to Sabine Berger and Christine Aeschlimann for their invaluable collaboration in co-organizing the PPIE Symposium and Swiss Patient Forum.

Lastly, we deeply appreciate the support of our Supporting Members, whose financial contributions have enabled us to launch and sustain impactful projects: AstraZeneca, Bayer Switzerland, BeiGene, Biogen, Gilead, Sensile, Takeda, and Vertex. Their partnership is important in strengthening patient engagement and education.



## **EUPATI CH ACTIVITIES 2024**

## Swiss Training Module for Patients

In 2024, EUPATI CH, in partnership with the Department of Clinical Research (DKF) at University Hospital Basel, launched the second Swiss Patient Expert Training Course, funded by the Swiss National Science Foundation (<u>SNSF</u>) and Swiss Academy of Medical Sciences (<u>SAMS</u>). The eight-month blended learning program (both online and in-class) began in April, with 18 participants graduating in November. The course provided in-depth knowledge of clinical research and patient engagement and was enriched by expert insights, best practices, and direct exchanges with researchers. We look forward to seeing this dedicated group contribute to the EUPATI CH community.



#### **Online Course on Patient Involvement**

In collaboration with the Department of Clinical Research at the University Hospital Basel, EUPATI CH launched Switzerland's first online self-paced course on patient involvement in medical research.

The free course, which is available in German, French, and Italian, consists of six modules covering essential aspects of medical research, from ethical and legal foundations to translating research into practice. By providing structured and accessible knowledge, the course serves as an ideal introduction to clinical research for those interested in engaging more actively in the field. To complete the course, participants are able to take a knowledge test and obtain a certificate for a CHF 100 administrative fee.



## **EUPATI Fellows**

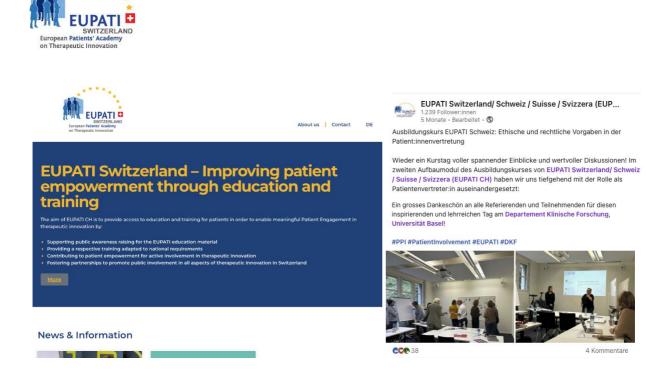
The EUPATI Expert Training Course provides patients and patient advocates with advanced training in therapeutic innovation. Originally a 14-month blended learning program, the course is now available on-demand via the EUPATI Open Classroom. In 2024, three patient representatives from Switzerland successfully graduated as EUPATI Fellows—congratulations to all! As of 2024, 27 patient representatives from Switzerland have completed the European EUPATI course.



#### Communication activities

In 2024, EUPATI CH engaged with members and the wider public through various communication channels. A new, Swiss-specific <u>website</u> was launched to improve accessibility, allow direct course and event registration, and better meet the needs of different target groups. The existing EUPATI CH webpage which is run by EUPATI Foundation's platform remains active.

In 2024, our social media channels (<u>Facebook</u>, <u>X</u>, <u>LinkedIn</u>) were used to share news, relevant activities, events, and training opportunities, contributing to a steady growth in followers. Additionally, our newsletter remains an essential tool for reaching our community and keeping them informed of ongoing EUPATI courses and engagements.



## The Swiss Patient Forum 2024

On November 16, 2024, EUPATI CH hosted the Swiss Patient Forum in Bern under the theme "Patient Preparedness: Shaping Our Roles Across All Levels?". The event, which was embedded in the first Swiss PPIE Symposium, brought together patients, experts, and stakeholders to explore strategies for enhancing patient participation in decision-making.

An interactive workshop focused on empowering patient representatives through training, support, and collaboration with industry and authorities. In the afternoon, panel discussions addressed key challenges and structural changes needed for equal patient involvement in healthcare governance. The forum highlighted the importance of patients as equal stakeholders and provided valuable insights to shape future initiatives.





## Update from the EUPATI CH Executive Board Association members

In 2024, EUPATI CH experienced significant growth, reaching 104 members — a 44% increase compared to the previous year. Most of our members are patient representatives (78%) and academic representatives (20%), with two members from the industry sector (2%).

#### Membership fees

At the 2024 General Assembly, EUPATI CH members agreed to maintain the membership fee of CHF 30 for individual members and representatives of non-profit organizations as well as for industry representatives.

#### Executive Board 2024

In 2024, EUPATI CH held five hybrid Executive Board meetings, with the General Assembly taking place in person at the University of Bern. The leadership positions of President, Vice President and Secretary remain the same until 2026, as they were elected in 2023 for a three-year term. The Executive Board consists of:

- Ivo Schauwecker, President
- Cristiana Sessa, Vice President
- Larisa Aragon
- Chantal Britt
- Ghada Ibrahim
- Rosine Mucklow
- Rosmarie Pfau
- Stephan Schobinger
- Hansruedi Voelkle

Caecilia Schmid stepped down from her position as a board member in 2024. EUPATI CH recognizes the exceptional and long lasting engagement of Caecilia with a very warm thank you.

#### Administrative activities

At the end of 2023, the Swiss Clinical Trial Organisation (SCTO) concluded its role in hosting and managing the EUPATI CH secretariat. We extend our gratitude to SCTO for its valuable support over the years.

From 2024 onwards, the PR- and marketing agency Life Science Communication (LSC) in Zurich has taken over EUPATI CH's office administration. With this transition, the official address and bank details have also moved to Zurich. Since 2024, LSC supports the association in its operations and administrative tasks, including the administration of the EUPATI Switzerland Patient Expert training course and the planning of the Swiss Patient Forum.



## EUPATI CH participation and contribution activities in 2024

Throughout 2024, EUPATI CH actively contributed to key discussions, panels, and initiatives on patient involvement in research and healthcare. Highlights include:

- Policy & Regulatory Engagement: Swissmedic Working Group on Patient & Consumer Organizations (March).
- Academic Contributions: Lectures at ETH Zurich, University of Basel, ECPM Seminar, and Kantonsspital Aarau.
- National & International Events: SCTO Symposium, HRA 10th Anniversary Symposium, ENP AGM in Brussels.
- Publications & Outreach: Article in H+ Magazine and Competence 4/2024.
- Federal Event Participation: Involvement in the 10-year anniversary celebration of the Swiss Federal Act on Research involving Human Beings (HFG) hosted by the Federal Office of Public Health (FOPH).

EUPATI CH continues to strengthen patient engagement by sharing expertise, fostering dialogue, and shaping best practices across diverse platforms.

## **EUPATI INTERNATIONAL ACTIVITIES IN 2024**

## **EUPATI** Foundation

The EUPATI Patient Expert Training Programme, initiated in 2015, has successfully trained over 415 individuals across seven cohorts. In October 2024, 85 new EUPATI Fellows graduated from the EUPATI Patient Expert Training Programme Cohort 7. These graduates, now EUPATI Fellows, are recognized as expert patients and actively contribute to medicines research and development. https://oife.orghttps://learning.eupati.eu

The EUPATI Toolbox continues to be a valuable resource and has reached over 7.9 million users in 14 languages. The Open Classroom platform has also seen significant engagement, with over 533,000 new visitors accessing the learning materials. These milestones highlight the increasing demand for patient-friendly educational resources in medicines R&D. Also, the EUPATI Impact Study confirmed that such training enhances the capacity of patients and their representatives to engage effectively with various stakeholders.

For more detailed insights into EUPATI's activities and achievements, please refer to their annual report available on the <u>EUPATI website</u>.



#### EUPATI national Platforms network (ENPs)

The 24 national EUPATI platforms (ENPs) form one body in EUPATI's governance (sustaining partners). The ENPs under the lead of EUPATI secretariat meet regularly throughout the year and exchange on experiences, lessons learnt and share their latest news.

## **Financing EUPATI CH**

In 2024, EUPATI CH successfully leveraged the funding instruments introduced in the previous year, securing sustainable resources for our work. While our 104 members provide an important foundation, the financial impact of individual memberships remains limited. In contrast, the eight Supporting Members have significantly contributed to our financial stability, demonstrating the value of targeted partnerships.

These funding mechanisms have now proven effective, enabling us to continue offering high-quality education for patients and stakeholders. The EUPATI CH Education Funds have also gained traction:

The Education Fund for Individuals supports participants facing financial barriers to patient engagement training. The Education Fund for Research fosters scientific projects on patient involvement. So far, CHF 8,000 has already been allocated to the Education Fund, marking a meaningful start for this initiative. Additionally, the dedicated voluntary work of our members and board remains a cornerstone of our organization. Their commitment is crucial in achieving our mission.

EUPATI CH is committed to transparent and sustainable financing, ensuring that collaborations with external partners follow clear principles to maintain our independence.

#### **FINANCIAL REPORT 2024**

EUPATI CH annual financial report 2024 Account 01.01.2024 - 31.12.2024 Balance sheet

1. Income	2024
Membership fees	1'750.00
Income from teaching	1'400.00
Income Sponsoring Swiss Patient Forum	12'000.00
Income from Swiss patient training (course fees)	18'100.00
Income from Donations and Sponsoring	23'300.00
Total income	56'550.00
2. Expenses	
Compensation office LSC	26'008.85
Compensation course administration LSC	6'486.00
Swiss Patient Forum	2'000.00
Postfinance account fees	63.15
Hosting Webseite	73.80
	800.00
Return course fees	
Return course fees Other (travel, fees, rent, meetings)	595.05

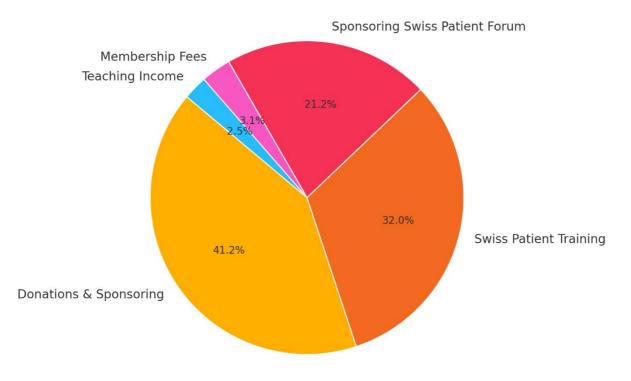


## EUPATI CH revenue by origin 2024

In 2024, EUPATI CH generated a total income of CHF 56'550, sourced from various activities and funding streams:

- 41.2% from donations and sponsorships, ensuring financial stability for our projects.
- 32.0% from the Swiss Patient Expert Training Course, covering part of the program's costs.
- 21.2% from sponsoring the Swiss Patient Forum, supporting this key event.
- 3.1% from membership fees, reflecting the community's commitment.
- 2.5% from teaching activities, demonstrating our growing role in education.

While these funds are essential for running EUPATI CH, volunteer contributions remain a cornerstone of our work. Board members and engaged patient representatives continue to invest their time and expertise in stakeholder management, education, and patient engagement—a commitment that cannot be quantified financially and is invaluable to our mission.



#### EUPATI CH Revenue by Origin 2024



## AUDITOR'S REPORT 2024

I hereby confirm, to the best of my knowledge, that the 2024 annual financial statement accurately reflects the EUPATI CH account at PostFinance and its bookkeeping. The Auditor proposes the discharge of the members of the Executive Board and the secretary of EUPATI CH for their activities during the financial year 2024.

16<sup>th</sup> March 2025

the Franke- Right Dr med Brigitte Franke-Bray FFPM GFMD Specialist in Pharmaceutical Medicine FMH Independent Consultant

## **Donate to EUPATI CH**

EUPATI CH has been dedicated to strengthening the role of patients as equal partners in clinical research for over 10 years. In the past year, we have made significant strides, but this is just the beginning.

This year, we aim to expand our membership base and reach patients from all language regions of Switzerland with our educational programs. To achieve these ambitious goals, we rely on the support of our donors.

Your donations are vital in helping us continue our work and increase the impact of patient engagement in healthcare research. With the generous contributions we have already received, we have reached key milestones, but to accomplish even more, we need your ongoing support.

# EUPATI CH IBAN: CH 84 0900 0000 8956 5298 4

Postfinance AG, 3030 Bern

If you would like your donation to go to a specific initiative, please specify "Education Fund" or "Research Fund" when making the payment. More information on our donation options and purpose-driven funds is available at: www.eupati.ch/spenden

We sincerely thank all our donors and supporters for their commitment to strengthening patient engagement in research and healthcare. Your contributions truly make a lasting impact!

Report date20.04.2025AuthorsOffice (Enrique Heer) and President (Ivo Schauwecker)