

EUPATI Schweiz / Suisse / Svizzera / Switzerland

EUPATI CH Association

(European Patients' Academy on Therapeutic Innovation)

Annual Activities Report of 2023



EUPATI Switzerland – #patientsinvolved, the missing puzzle piece in better medicines

Our vision for the future is informed and empowered patients and persons concerned, actively involved in health care research and development.

Report date 04.04.2024

Authors Office, Member of the Executive Board (Dr Caecilia Schmid) and President (Ivo Schauwecker)



PRESIDENT'S MESSAGE

Dear Members
 Dear Sponsors and Donors
 Dear Friends of EUPATI CH

2023 - our journey continues

For all of us and for EUPATI CH, 2023 continued to be a challenging and important year. And we at EUPATI CH are proud to also look back on a successful year.

We have reached an important milestone in the history of our association and implemented the [first Swiss specific patient training](#) in collaboration with the Department of Clinical Research (DKF) at the University Hospital Basel. 23 participants successfully graduated on December 1 and we are happy to have contributed to the growing EUPATI family. French and Italian courses are in planning and the organisation for the 2024 edition of the German course are underway.

On European level, seven new [Swiss Fellows](#) graduated from the EUPATI Expert Patient training in 2023 and 32 [new members](#) joined EUPATI CH this year, bringing the number of members to 72.

To consolidate our financial backbone we have launched the Supporting Membership. This is targeted to companies who want to support the vision and mission of EUPATI CH with a minimal annual contribution of CHF 2,000.- First companies have already signed up for 2023 and 2024. In addition, we have launched the EUPATI CH Education Fund and the EUPATI CH Research Fund. These funds offer a possibility to donate targeted support and will be advertised widely in 2024.

Last but not least, we have established a contract with Life Science Communication AG, Zurich to take over our office support as of 1 January 2024. And a great thank you to SCTO and Caecilia Schmid who have supported EUPATI CH through all these years since its foundation. Without this support, EUPATI CH never would have reached all the milestones of success.

With many other activities of all our board members and members, EUPATI CH indeed contributed substantially to bring valuable health care solutions forward in Switzerland! Let's continue this journey with joy and enthusiasm.

Ivo Schauwecker

President EUPATI CH



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ACKNOWLEDGEMENTS

We wish to sincerely thank all our colleagues of the Executive Board and members for supporting us as well as our EUPATI Fellows for their valuable and constructive cooperation and voluntary contributions.

Very special thanks go to the SCTO who hosted and ran our secretariat for years and gave us much needed professional support, without which our work would not be possible.

The social media activities of EUPATI CH were supported by some of our members and we owe a huge thank to Steven Bourke for channelling his health communications expertise into creatively and diligently maintaining our profile on [LinkedIn](#).

We would also like to thank the team of Dr Barbara Peters and Dr Daniel Hammes, department of clinical research at the University Hospital Basel for pushing forward the development of the EUPATI CH patient training tailored to the national landscape.

Financing EUPATI CH

Becoming more successful goes along with growing and becoming a more complex association. With our new office support, we will ensure continued and improved financial and administrative management. To secure a sustainable funding of EUPATI CH, we prepared the following tools to be fully launched in 2024:

Supporting membership: Supporting members are organisations or individuals who want to support EUPATI CH with a donation. In addition to an ordinary donation, the Supporting Membership donation may express a motivation for recurring (e.g. annual) support and it can be used as a label by the Supporting Member. Supporting Members (or their delegate(s)) do not have any voting rights and do not influence the activities of EUPATI CH. However, employees of supporting member can become individual regular member of EUPATI CH.

EUPATI CH Education Fund: Donations can be targeted into this fund to support individuals who are interested and willing to educate themselves in the field of patient and persons concerned engagement, but are not capable of covering enrolment fees etc. In addition, the development of educational offers will be supported through this fund.

EUPATI CH Education Fund: Donations can be targeted into this fund to support scientific research activities which are in the scope of EUPATI CH vision and mission.

The funds are governed by governance documents developed and approved by the EUPATI CH board.

Besides financial contributions, the most important resource for EUPATI CH remains the substantial work by its board members and other members contributing their time as volunteers.



Donate to EUPATI CH

EUPATI CH continues to increase the educational activities for patients and persons concerned. Additionally, EUPATI CH wants to support research done to keep evolving meaningful and effective engagement of patients and persons concerned in health care research.

With the new funds established, donors can support activities more specifically and targeted.

Thanks to major donations, EUPATI CH achieved important milestones in 2023. However, EUPATI CH has concrete plans to have even more impact in the evolution of health care research in Switzerland. This will be possible only with future substantial donations and supporting members who continue to support EUPATI CH on a regular base.

EUPATI CH IBAN: CH 84 0900 0000 8956 5298 4

Postfinance AG, 3030 Bern

Please note, if you donate into a specific fund.

Update from the EUPATI CH Executive Board

Association meetings

EUPATI CH held six Executive Board meetings in 2023, mostly as hybrid meetings. The General Assembly 2023 was also held in person at the University of Bern.

Association members

In 2023, we continued growing and count 72 members, the majority being patient representatives (71%) and academic representatives (22%), and we have two representatives of for profit organisations. Two members resigned from the association. To comply with data protection standards, the members are no longer listed on our [website](#).

Executive Board 2023



Ivo Schauwecker, Positive Council, President



Rosmarie Pfau, Lymphome.ch, EUPATI Fellow



Stephan Schobinger, MPN



Cristiana Sessa, EOC, Vice-president



Ghada Ibrahim, PACRT



Chantal Britt, Long COVID Schweiz, EUPATI Fellow



Rosine Mucklow, EUPATI Fellow



Hansruedi Völkle, Positivrat, EUPATI Fellow



Caecilia Schmid, SCTO, Secretariat



Cordula Landgraf, SCTO



Larisa Aragon, Europa Donna, EUPATI Fellow in training

In 2023, the General Assembly elected the Executive Board for the term 2023 – 2026, confirmed the president, vice-president and secretary. Cordula Landgraf resigned from the Executive Board.

Membership fees

The membership fees were agreed by the General Assembly for 2024 to be CHF 30 for individual members as well as for representatives of not-for-profit organisations and min CHF 2'000 for supporting membership. A hardship clause, mentioned in the statutes, is available for individuals who cannot pay this amount.



Administrative activities

The [SCTO](#) continued to support the activities of EUPATI CH at the national level by hosting and running the secretariat and fostering networking with the relevant stakeholders in Switzerland. In 2023 too, EUPATI CH and SCTO have increasingly been involved in identifying expert patients for presentations at events, representing EUPATI CH at diverse occasions and contributing to patient advisory boards. As announced in due time, SCTO has terminated this collaboration by end 2023.

A contract was established with Life Science Communication AG, Zurich and we look forward to a fruitful collaboration with our new office support team. Hand over activities have been initiated end 2023.

Statutes and associated documents

The Executive Board revised the association's statutes to accommodate the request of the Bernese cantonal financial department for tax exemption, the respective clause was adapted and written approval by the General Assembly received.

Tax exemption

EUPATI CH filed the tax exemption request by the end of 2022 and received the approval in October 2023 and is now considered a tax exempted non-profit organisation in the canton of Bern and many other cantons.

EUPATI CH ACTIVITIES 2023

Swiss Training Module for Patients

EUPATI CH in a joint venture with Department of Clinical Research at the University Hospital Basel ([DKF USB](#)) have rolled out the first Swiss patient expert training. This first edition of the course started in May and concluded in December 2023. It was held in German as a blended learning (mix of online and in class teaching). Funding was received from the public sector through the Swiss National Science Foundation ([SNSF](#)) and the Swiss Academy of Medical Sciences ([SAMS](#)).

The course has received quite some attention and was promoted in diverse media throughout the year (see [website](#)):

- [SAEZ article](#) (D)
- [Bulletin des Médecins suisses](#) (F)
- [Medinside](#) (D)
- [Radio RTS](#) (F, starting at min 2)
- [Tagesanzeiger](#) (D)
- [24Heures](#) (F)



The program can unquestionably be deemed a success. The first course was attended by 23 interested participants who all graduated on 1st December. Over the course of 8 months, the participants completed various modules, gaining targeted insights into the functioning of clinical research operations in Switzerland and identifying effective areas for their contribution. The program emphasized practical relevance, showcasing a range of best practices from diverse institutions, often presented by patient representatives.

One participant in the course remarked, “Switzerland has really lacked such a program until now.” She, along with other attendees, emphasized the enriching exchanges within the group and with researchers. Regular discussions were particularly beneficial for all attendees. Furthermore, another participant expressed appreciation for the option of online forum interaction, stating, “Our Q&A sessions were consistently stimulating, and the ability to revisit online content ensured the course remained engaging, avoiding a dull, static lecture format.”

At the graduation ceremony, the president of EUPATI CH Ivo Schauwecker mentioned how deeply impressed he was to feel the motivation of all course participants when he was attending some of the onsite course days. Also, the commitment of the lecturers and the content of the program was outstanding. He said: “Attending, listening, and participating in the onsite part of this course has changed my way to teach like nothing before. To allow emotions while delivering state-of-the-art content and to tell a personal story is a game changer in medical education. Patients and persons concerned – namely you, the participants of this course – show us and guide the way, how this can be achieved.”

The program also served as a bridge between researchers and patients, providing avenues for networking and imparting concrete ways for patients to engage in research initiatives, thus enabling them to make tangible contributions.

Several participants subsequently became involved in research projects. One such individual, Jennifer Woods, completed the course and now serves as a patient representative in clinical research at the Swiss Academy of Medical Sciences.

Insights from the EUPATI CH training course and feedback from participants contributed a lot in the process of planning the 2024 course. To broaden accessibility, online courses, offered in slightly modified formats, will be available as standalone options. This allows interested individuals to engage with the material independently before committing to the full program. Furthermore, these standalone courses will also be offered in French and Italian to cater to a wider audience.

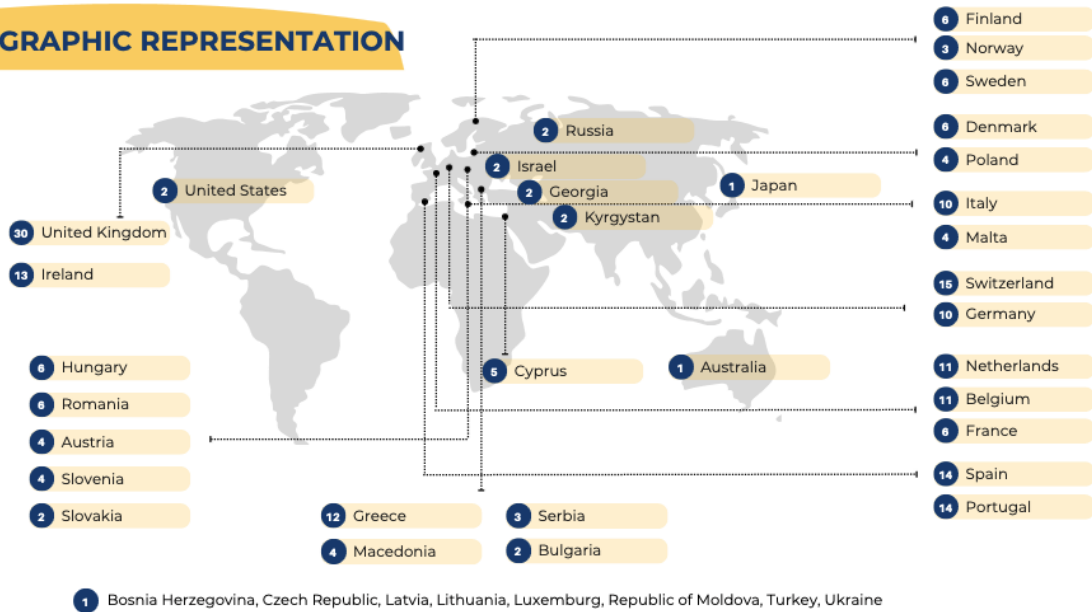


EUPATI Fellows

The EUPATI Expert Training Course is an exciting and unique opportunity offering patients and patient advocates expert-level training in therapeutic innovation. The first editions of the course were a mixture of independent e-learning coursework and face-to-face training events over a 14-month period. Now, the complete course is offered as on-demand in the [Open Classroom](#).

In 2023, seven patient representatives from Switzerland graduated as EUPATI Fellows, our heartfelt congratulations! All the Swiss Fellows are listed and portrayed on our dedicated [website](#) and the majority of them are actively engaging with us be it as board member or acting as EUPATI CH representative in patient involvement activities. EUPATI Foundation has a dedicated website for and about the fellows: [EUPATI fellows](#). The geographic representation of EUPATI fellows in 2023 is summarised in the graph below.

GEOGRAPHIC REPRESENTATION



Communication activities



Through 2023 EUPATI CH continued to communicate through diverse channels to the members and the interested public in general. EUPATI CH maintains its website, a subsite of the EUPATI Foundation: [EUPATI CH website](#). Through the social media channels we continued to actively spread news, relevant activities, events and trainings of interest and continuously grow our follower community ([Facebook](#), [Twitter](#), [LinkedIn](#)).

The Swiss Patient Forum 2023 was not held due to resource constraints

The Swiss Patient Forum of EUPATI CH did not take place in 2022 & 2023 as EUPATI CH experienced human resources restrictions. In 2024, we plan to hold the forum in a cooperation format and will again bring together the most important stakeholders to debate about a topic of actual importance and offer the patient representatives a related training and opportunity to network with the stakeholders.



EUPATI CH participation and contribution activities in 2023

During 2023 we had several opportunities to actively engage and participate by contributing and sharing EUPATI CH members' expertise and experiences, here we report some highlights:

- **SCTO PPI in academic clinical research:** participation in the SCTO PPI working group and contributing to the development of templates supporting researchers and contributors in their PPI activities. The PPI templates are for the agreement, planning, participation request, and evaluation of PPI activities. ([link to templates](#)).
- EUPATI CH members **participated** or attended several invited **events** and workshops: SCTO Forum, SCTO Symposium
- EUPATI CH **presented** or contributed in discussion **panels** at several occasions: Swissmedic, University Hospital Zurich, ETH Zurich, ECRIN, ERA PerMed, Pharma 2023, DIA 2023, MPP2023, SGPM, Bangkok Hospital, WLAD Patientensymposium,
- EUPATI CH was part of the Swiss expert patient course faculty, **teaching** several sessions.
- EUPATI CH Board members and Fellows **participated** as patient representative in **projects** and clinical trials, e.g., in the SPOTnat study ([publication](#)).
- EUPATI CH delegated patient representatives provided valuable **review** to improving the six modules of the new [Swiss Training Course](#).

EUPATI INTERNATIONAL ACTIVITIES IN 2023

EUPATI Foundation

EUPATI reached a record-wide audience in 2023. The EUPATI Toolbox reached 1 million new users (7 million since its launch) and the Open Classroom was accessed by over 160,000 new learners. EUPATI's Patient Expert Training Programme had the highest number of registrations of all time and 81 new Fellows graduated, which is the largest cohort since the launch of the Programme in 2015 (bringing the total number of Fellows to 330+).

These figures demonstrate the important and growing need for patient-friendly information & educational resources on medicines R&D and patients' role in this process – and the EUPATI Impact Study shows that training makes a difference in how patients and patient representatives engage with other stakeholders.

For more details on their activities see their annual report on the [website](#).



EUPATI website and Training portfolio

EUPATI has redesigned its website to accommodate the integration of the EUPATI website with the diverse trainings, the toolbox, and the national platforms' websites into one site. The look comes clean and fresh, have a peak at the [EUPATI website](#).

The EUPATI Patient Expert Programme has been transformed into an online, on-demand learning opportunity on the [EUPATI Open Classroom](#) platform. The EUPATI Open Classroom is freely accessible and can be explored and browsed for the content without registering.

EUPATI also offers [patient engagement trainings](#) for various stakeholder groups as EUPATI Fundamentals, EUPATI Essentials and In-House trainings.

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.

OUTLOOK

In 2024, EUPATI CH will persist in promoting awareness of the overarching EUPATI objectives, with a specific focus on educational materials and other supportive tools. Additionally, EUPATI CH will maintain its provision of the [Swiss training course](#) to patient representatives, empowering them for active involvement in clinical research.

EUPATI CH will enhance stakeholder networking and targeted fundraising efforts, particularly by assisting members in securing sustainable financing for its office and the Swiss training course. Concurrently, EUPATI CH aims to uphold the standard and quality of communication activities conducted by the Executive Board and the office. We look forward to the active involvement and support of our fellows and association members in commitment, knowledge, and experience sharing.

On the international level we will continue the collaboration and contribution to the EUPATI Foundation and regional group activities (German and French speaking platforms' activities) which will not only strengthen the network of the national platforms, but also provide us with a unique opportunity to learn and profit from others.



FINANCIAL REPORT 2023

EUPATI CH annual financial report 2023

Account 01.01.2023 - 31.12.2023

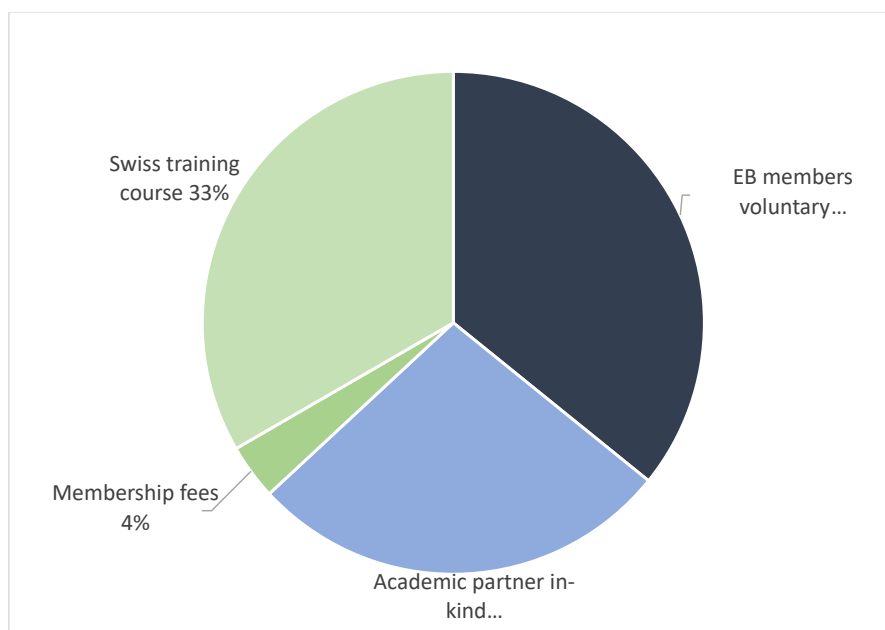
Balance sheet

| 1. Income | 2023 |
|--|-------------------------|
| Membership fees | 1'472.50 |
| Income from teaching (FHBE) | 646.00 |
| Income from Swiss patient training (IS lecture fees) | 1'000.00 |
| Income from Swiss patient training (course fees) | 14'300.00 |
| Income from Donation | 7'269.75 |
| <i>Total income</i> | <u>24'688.25</u> |
| 2. Expenses | |
| LSC media campaign | 7'269.75 |
| Postfinance account fees | 60.00 |
| Patient reviewers | 3'400.00 |
| Return course fees | 1'800.00 |
| Compensation backoffice (LSC) | 4'308.00 |
| Other (travel, fees, rent, meetings) | 915.59 |
| <i>Total expenses</i> | <u>17'753.34</u> |
| Balance as per 31.12.2023 | |
| Account balance PC 89-565298-4 | 16'956.25 |

EUPATI CH revenue by origin 2023

EUPATI CH runs primarily on great personal commitment and considerable volunteer work from those involved. To transparently disclose our revenue, we also include the volunteer activities in the financial reporting, these comprise time provided of EUPATI CH members and Executive Board members for meetings, representation in committees, conferences, presentations, administrative support, stakeholder management, liaison with Stichting EUPATI Foundation and the national platforms' network, and collaboration in working groups.

Graph, Sources of revenue (including human resources in-kind contributions)





AUDITOR'S REPORT 2023

I hereby confirm, to the best of my knowledge, that the 2023 annual financial statements accurately reflect 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 association and financial year 2023.

28th February 2024

Dr med Brigitte Franke-Bray FFPM GFMD
Independent Consultant