

EUPATI Schweiz / Suisse / Svizzera / Switzerland

EUPATI CH Association

(European Patients' Academy on Therapeutic Innovation)

Annual Activities Report of 2022



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

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

Report date draft 17.03.2023

Authors Secretariat, 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



2022- our journey continues

For all of us and for EUPATI CH, 2022 continued to be a challenging year. Nevertheless, we look back to an important year for EUPATI CH.

We were able to develop the [Swiss specific patient training](#) after having secured the funding and establishing a joint venture with an academic partner for the development of the course content over the year. The first course was announced in January 2023 and will take off in May 2023.

Despite of EUPATI CH not being a lobbying organisation we decided to join forces and engage in the national initiative and vote to the ban of experiments on animals and humans and produced a position statement ([German](#) and [French](#)). At the same time, we also boosted our social media activity which brought us many new followers. Fortunately, the initiative was rejected by the people, so medical progress and therapeutic innovation in Switzerland is not at risk.

Nine new [Swiss Fellows](#) graduated from the EUPATI Expert Patient training in 2022 and eight [new members](#) joined EUPATI CH this year, bringing the number of members to 42.

EUPATI CH will strive to consolidate and integrate what we have learned in the past years and to keep open for change also in the future. Finally, we would like to thank you all for your continuing support in all that we do. Together we are changing the role patients play in health care R&D, empowering their voice through education. Together we can take patient education to the next level!

The journey continues indeed, and we keep working on our priority projects also in 2023.

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 hosts and runs our secretariat and gives 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, department of clinical research at the University Hospital Basel for pushing forward the development of a EUPATI CH patient training tailored to the national landscape.

Financing EUPATI CH

Full transparency of our work and how we are funded and what we are doing with the money we get from our sponsors is my personal concern as president. Not for profit organisations run primarily on great personal commitment and considerable volunteer work from those involved. However, for an organisation like EUPATI CH to be optimally professional and efficient, some funding is necessary. In order to ensure the integrity and independence fitting for EUPATI CH and to avoid adverse influence from third parties, we have established a “Code of Conduct” to regulate cooperation with external sponsors.

Donate to EUPATI CH

We focus on dissemination of the EUPATI training material and are working on the provision of a [Swiss adapted education and training course](#) for patients in clinical research to increase the capacity and capability of patients to be knowledgeable contributors to clinical research.

Your donation will help to achieve our mission and to reach more patients with our training courses and the [EUPATI](#) education materials.

Much of this work has been done with YOUR support. However, there is still some need to support the operational work of EUPATI CH.

EUPATI CH Postfinance

IBAN No: CH 84 0900 0000 8956 5298 4

Account No: PC 89-565298-4

Update from the EUPATI CH Executive Board

Association meetings

EUPATI CH held seven Executive Board meetings in 2022, five short video calls and two hybrid meetings in Bern. The General Assembly 2022 was also held as video call conference.

Association members

In 2022, we continued growing and count 42 members, the majority being patient representatives (64%) and academic representatives (31%), and we have one industry member. Two members resigned from the association. The members are listed on our [website](#).

Executive Board 2022



From left to right: Ivo Schauwecker, Hansruedi Völkle, Rosmarie Pfau, Cristiana Sessa, Rosine Mucklow, Cordula Landgraf, Caecilia Schmid, Larisa Aragon, Catherine Bates, Stephan Schobinger

In 2020, the General Assembly elected the Executive Board for the term 2020 – 2023, the portraits of each of the members were introduced in the [EUPATI CH annual report 2020](#). Marie Mi Bonde Hansen (Department of Clinical Research, University Hospital of Basel) and Annette Magnin (SCTO) have resigned from the Executive Board in 2021 and Catherine Bates during 2022. We wish to express our sincere thanks to them who contributed with much insight and competent advice to the association since its foundation in 2016. For the remaining board members their election term ends in 2023. Re-elections are foreseen at the General Assembly 27 on April 2023.

Membership fees

The membership fees were agreed by the General Assembly for 2022 to be CHF 30 for individual members and at least CHF 50 for organisations. A hardship clause, mentioned in the statutes, is available for individuals who cannot pay this amount.



An additional category of “Supporting Members” was introduced with an annual contribution of CHF 2000 and no voting rights.

Administrative activities

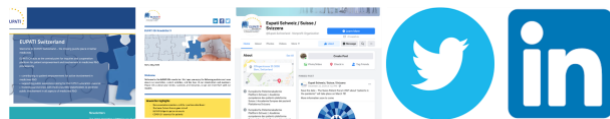
The [SCTO](#) continued to support the activities of EUPATI CH at the national level by hosting and running the secretariat and fostering networking with the relevant stakeholders in Switzerland. In 2022 too, EUPATI CH and SCTO have increasingly been involved in identifying expert patients for presentations at events, representing EUPATI CH at diverse occasions and contributing to patient advisory boards.

Statutes and associated documents

The Executive Board revised the association’s statutes to accommodate them to the current landscape and especially to strengthen the association’s purpose, which is awareness raising of the EUPATI training material and support the **provision of training** to patients. Also, the membership categories were precised and some administrative corrections done. The revised statutes will be endorsed by the General Assembly.

EUPATI CH ACTIVITIES 2022

Communication activities



Through 2022 EUPATI CH continued to communicate through diverse channels to the members and the interested public in general. EUPATI CH issued a statement on a national population initiative jeopardising therapeutic innovation, details see below. 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 and relevant activities and events and trainings of interest ([Facebook](#), [Twitter](#), [LinkedIn](#)).

EUPATI CH statement on the popular initiative "Yes to the ban on experiments on animals and humans"

Despite of EUPATI CH not being a lobbying organisation we decided to join forces and engage in the national initiative and vote to the ban experiments on animals and humans. Without animal and human research progress in medical research would not be possible and thus endanger the well-being of patients.

The public statement of EUPATI CH can be accessed on our website in [German](#) and [French](#). At the same time, we also boosted our social media activity which brought us many new followers.

The initiative was rejected by the people, so medical progress and therapeutic innovation in Switzerland is not at risk.

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 2022, nine patient representatives from Switzerland graduated as EUPATI Fellows, our heartfelt congratulations! All the Swiss Fellows are listed and portrayed on our dedicated [website](#): Rosmarie Pfau, Florian Klett, Hansruedi Völkle, Malena Vetterli, Nicole Gusset, Max Lippuner, Rosine Mucklow, Chantal Britt, Mercy Berger, Gloria Macia, Sanda Velic, Laure-Isabelle Chapoutier, Christel Naujoks, Caridad Rodriguez, and Steven Bourke.



The Swiss Patient Forum 2022 was cancelled due to resource constraints

The Swiss Patient Forum of EUPATI CH did not take place in 2022 as EUPATI CH experienced human resources restrictions. In 2023 however, we plan to hold the forum 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.



Swiss Training Module for Patients

EUPATI CH has initiated with a small working group the development of a Swiss Training Course to educate patients in clinical research based on the EUPATI training but adapted to Swiss specific aspects and in national languages.

A concept was developed and approved by the Executive Board. As a next step, collaboration partners were determined, and a collaboration agreement signed with the Department of Clinical Research at the University Hospital Basel ([DKF USB](#)). Funding was received from the public sector through the Swiss National Science Foundation ([SNSF](#)) and the Swiss Academy of Medical Sciences ([SAMS](#)).

Throughout 2022, the DKF developed the course modules composed of two basic and four advanced modules which received very valuable patient representatives' review. The first edition of the course will be offered early 2023 as a blended learning (mix of online and in class teaching) and will held in German. The course was announced and registrations opened, more information is available on the [website](#).

EUPATI CH participation and contribution activities in 2021

During 2022 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 monitoring. (CS represented EUPATI CH).
- EUPATI CH members **participated** or attended several invited events and workshops: FOPH Steering Group "Medical Profession of the Future», Salon Santé organised by Interpharma
- EUPATI CH and the EUPATI mission was **presented** at several occasions by members of EUPATI CH: Sitem Insel learn@lunch, Roche Clinical Trials Innovation Summit 2022, Bangkok Hospital in Bangkok, WLAD Patientensymposium, this includes also **teaching** at the World Cancer Congress in Geneva.
- EUPATI CH Board member and Fellow participated as patient representative in the defunding application preparation of a new clinical trial in stroke, the [EMINENT](#) study of the University Hospital Basel.
- EUPATI CH delegated patient representatives provided valuable review to improving the six modules of the new [Swiss Training Course](#).

EUPATI INTERNATIONAL ACTIVITIES IN 2022

EUPATI Foundation

In 2022, the EUPATI foundation continued its mission to improve patient education, this includes development of new training modules (e.g., [Medical Devices](#)), upgrading the Open Classroom, continuing support to the 24 [national platforms](#), and expanding its [partnerships](#) (e.g., new member ECRIN).

Also in 2022, EUPATI celebrated its [10th anniversary](#) on May 19/20 in Brussels, bringing together EUPATI partners, national platform representatives, EUPATI Fellows, and key individuals who have contributed to EUPATI's success story over the years.

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.

OUTLOOK

In 2023, EUPATI CH will continue raising awareness, including for the education material, and provide a [national training](#) to patient representatives to empower them for active engagements in clinical research.

EUPATI CH will work on the stakeholder networking and targeted fundraising by supporting members for a sustainable financing of its back office and the Swiss Training Module.

At the same time, EUPATI CH strives to maintain the level and quality of the communication activities and build on the commitment, knowledge, and experience of our fellows and association members proposing ways for them to get more involved and support the Executive Board and secretariat.

On an 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 2022

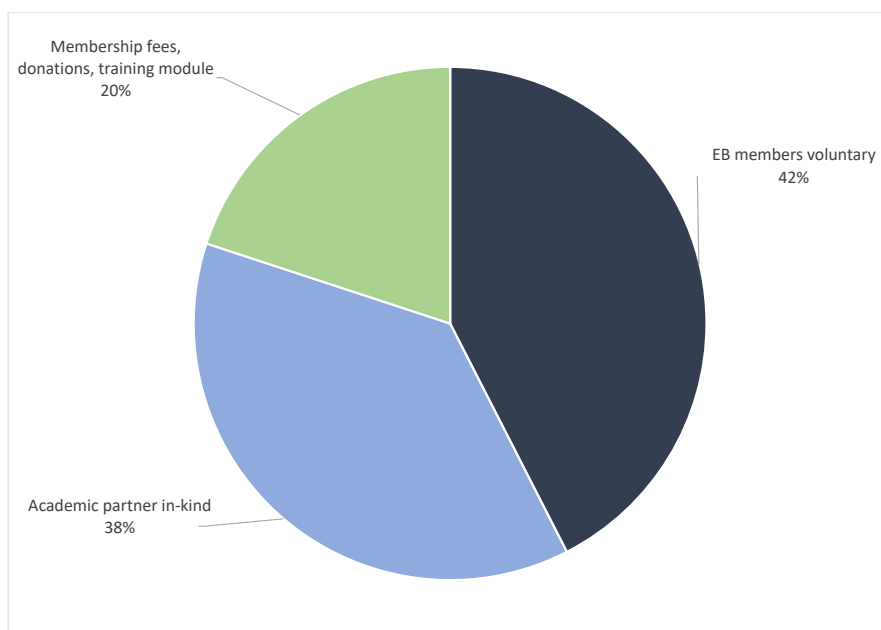
Financial report 2022

Income	in CHF
Membership fees	1'400.00
Sponsoring SPF (2019)	0.00
Donations and other income	4'256.00
Overall income	5'656.00
Expenses	in CHF
Communication activities	3'444.90
Stakeholder analysis	0.00
Overhead (travel, fees, meetings)	1'141.70
Swiss Patient Forum	0.00
Overall expenses	4'586.60
Balance	in CHF
Account balance Postfinance EUPATI CH (31.12.2022)	10'021.34

EUPATI CH revenue by origin 2022

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 2022

I hereby confirm, to the best of my knowledge, that the 2022 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 2022.

27th January 2023

Dr med Brigitte Franke-Bray FFPM GFMD
Independent Consultant