

## **EUPATI Schweiz / Suisse / Svizzera / Switzerland**

### **EUPATI CH Association**

*(European Patients' Academy on Therapeutic Innovation)*

### **Annual Activities Report of 2021**



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

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

Report date 06.04.2022

Authors Secretariat (Dr Caecilia Schmid) and President (Ivo Schauwecker)

## PRESIDENT'S MESSAGE

Dear Members

Dear Sponsors and Donors

Dear Friends of EUPATI CH



### 2021- our journey continues

For all of us and for EUPATI CH, 2021 continued to be a challenging year. We have longed to meet face-to-face again – and yet, it was still not possible. We have waited, and partly been able, to work in the office again and interact with our colleagues not only through zoom – and yet, we have been kept in our home-offices. And most importantly, we have also managed to establish efficient ways to perform and to deliver in the new settings as well. 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.

In retrospective for 2021, I concretely want to highlight the Swiss Patient Forum "Patients in a pandemic" bringing together experts and participants in a virtual format. The event was very well prepared, and it was a big success with excellent feedback received.

The other highlight is the now well-established collaboration with the Department of Clinical Research (DKF) of the University Hospital Basel to develop the Swiss Training Module for EUPATI CH. The fundraising was not completed yet, but promising leads have enabled us to take the risk and start the development before end of 2022.

Finally, I warmly recommend the lecture of the Swiss Clinical Trial Organisation ([SCTO](#)) Regulatory Affairs Watch ([RA Watch](#)) issue 6 with its focus on Patient and Public Involvement in Switzerland. EUPATI CH board members have been actively contributing.

I hope you enjoy reading the detailed reports on these and on the many other activities performed by members of EUPATI CH in 2021 in this annual report.

The journey continues indeed, and we keep working on our priority projects also in 2022.

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.

We gratefully acknowledge the pharmaceutical companies (Janssen-Cilag AG, Takeda Pharma AG, and Bayer (Schweiz) AG) who support us financially in carrying out the Swiss Patient Forum.

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 setting up and maintaining our profile on [LinkedIn](#).

We would also like to thank our member Marie Hansen from the University Hospital Basel for her longstanding support, who stepped down at the end of the year to pursue new horizons. In particular, we would like to thank Marie for her tireless promotion of the Swiss Patient Training Module.

## 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.

## Power to the patient: How EUPATI (CH) is changing the face of patient education

*EUPATI CH article in the [SCTO RA Watch Issue 6](#) on Patient and Public Involvement (PPI), published on October 28, 2021*

Involving patients in research can provide a significant benefit to the medicines development process. Patients can contribute to developing better treatments for themselves and others by sharing their priorities and perspectives. Experience has shown that greater patient involvement in R&D increases the efficacy and safety of new treatments and increases public support for medical research.

### ***EUPATI: Empowering patients through education***

[EUPATI](#) was launched as a flagship project of the Innovative Medicines Initiative (IMI) in early 2012. The project aims to trigger a major rethink in the way patients and the public understand medicines development and their own involvement in the medicines development process. Equipped with a deeper understanding of this process, patient experts are empowered to work effectively with relevant authorities, healthcare professionals, and industry partners to influence medicines development for the benefit of patients and the public. The main goal of the EUPATI project is to develop and disseminate accessible, well-structured, comprehensive, scientifically reliable, and user-friendly educational material to patients.

The EUPATI project provides [educational resources](#) in key areas of medicines research and development that have been translated into several languages under Creative

Commons licenses. The educational resources are aimed at two main audiences: the EUPATI [Open Classroom](#) (a newly designed version of its [Patient Expert Training Programme](#)) is intended for expert-level patients who are already experienced, knowledgeable advocates, and the EUPATI [Toolbox](#) is intended for education-level patients with little or no prior knowledge of the topic.

Following the huge impact of the pioneering and well-recognised EUPATI Patient Expert Training Programme, which has been conducted in four cohorts since its start in 2015, EUPATI recently launched a new format called Open Classroom. This new format enables participants to take courses online or on-demand at their own pace and in their preferred sequence.

### ***EUPATI CH: Promoting patient involvement in Switzerland***

In parallel with its international activities, EUPATI has established [National Platforms](#) in more than twenty countries, including Switzerland, with the aim of bringing patient, academic, and industry partners together to foster patient education and involvement in medicines R&D at a national level.

The Swiss National Platform EUPATI CH was formed as an association in November 2016. As stated in its statutes, the association is fully committed to acting as a central point for inquiries and as a cooperation platform

for patient empowerment and involvement in medicines R&D in Switzerland. The [EUPATI CH association](#) consists of a steadily growing number of members who form the General Assembly, an Executive Committee that oversees strategic operations, and an Advisory Board, which is currently in the planning phase.

Since its inception, EUPATI CH has promoted awareness of EUPATI and its educational resources by actively participating in various public events and conferences throughout Switzerland. In 2017, EUPATI CH successfully launched the [Swiss Patient Forum](#), an increasingly popular annual event whose programme is co-developed by EUPATI CH members and external experts; the event is sponsored by industry.

### ***Swiss training module: Training patients to become clinical research partners***

More recently, EUPATI CH decided to create a Swiss training module, its own national training programme to empower Swiss patients and patient representatives to contribute as partners in the design, planning, and conduct of clinical research through patient engagement. In contrast to the EUPATI Patient Expert Training course, the Swiss training module will offer an introduction to clinical research and patient engagement for Swiss patients in a national language (German) and will be adapted to the Swiss legal framework and regulatory environment for research involving human subjects.

Similar to the Open Classroom programme, the Swiss training module will accommodate the special needs and often challenging schedules of prospective participants. To do this, it will offer a blended learning format

and modular structure, thereby allowing for greater flexibility as to when and where content can be completed. The course will consist of three basic mandatory modules that will introduce the topic of research, including ethical and legal aspects, and will consider why the latter aspects are important for improving healthcare. In addition, four voluntary advanced modules will be offered that focus on specific aspects of clinical trials and how patients can become involved in them. Generally, each module will last 12–15 hours and will be available online; each module will also include virtual Q&A sessions and face-to-face training sessions. At the end of each module, participants can either take a short test or complete written assignments in order to obtain a certificate of completion.

The Swiss training module is currently being developed in close collaboration with the Department of Clinical Research (**DKF**), which is an integral part of the University Hospital Basel. EUPATI CH plans to launch the programme in early 2022; the exact date will be confirmed once sufficient funding has been secured. The Swiss training module will allow EUPATI CH to train patients for the ever-increasing number of opportunities for patient involvement in Switzerland. Looking ahead, EUPATI CH continually seeks interesting initiatives related to patient education and remains grateful for input from the public.

Authors: Rosine Mucklow and Caecilia Schmid with input from members of the EUPATI CH Executive Board.

Full RA Watch 6 Issue can be downloaded from [here](#).

## The Role of EUPATI CH in Promoting Patient Involvement in Clinical Research: A Multi-Stakeholder Research Project

**EUPATI CH stakeholder analysis published in Frontiers in Medicine on December 24, 2021**

By Cristiana Sessa, Caecilia Schmid, Angela Tolotti, Annette Magnin, David Haerry, Loris Bonetti, and Ingrid Klingmann

### **Abstract**

**Background:** The European Patients' Academy on Therapeutic Innovation Switzerland (EUPATI CH) was established as an association in 2016 with the mission to improve patient empowerment in Switzerland, raise public awareness of EUPATI's education material, and foster multi-stakeholder partnerships in order to promote public involvement in all aspects of medicines research and development (R&D). In order to achieve its goal of improving patient involvement (PI) in all processes of medicines R&D in Switzerland and to obtain guidance and recommendations for future activities, EUPATI CH initiated a multi-stakeholder survey on PI experiences, hurdles, and best practices. The survey enabled EUPATI CH to obtain and analyse the views of various stakeholders and shape its workplan.

**Methods:** Data collection occurred between January and July 2019 using a survey and semi-structured interviews with individual stakeholders from different groups. The online survey responses were analysed using quantitative methods and the interviews were analysed using qualitative methods.

**Results:** The online survey was completed by 55 respondents (10%), and the semi-structured interviews were conducted with 14 stakeholders. Respondents to the online survey were patient representatives (45%), researchers from academia (25%), individuals from the pharmaceutical industry (9%), healthcare professionals (23%), and representatives from government agencies (6%). Some respondents were also members of EUPATI CH. Thirty-eight percent of respondents consider PI in Switzerland to be limited or absent. They identified the main barriers to PI as, first and foremost, a lack of funds and human resources (65%), followed by a lack of information and a lack of education on how to become a patient advocate (21%), a lack of collaboration with other stakeholders (16%), and a lack of adequate resources. Respondents' expectations of EUPATI CH's role in supporting PI were to provide education for active PI and improve networking and collaboration among stakeholders.

**Conclusions:** EUPATI CH's multi-stakeholder research identified some of the difficulties in promoting PI in medicines R&D in Switzerland, in particular the complex collaboration among stakeholders and a lack of funds, human resources, and knowledge. To respond to these difficulties, EUPATI CH has begun preparing a basic training course for patients that is adapted to Switzerland.

Sessa C, Schmid C, Tolotti A, Magnin A, Haerry D, Bonetti L and Klingmann I (2021) The Role of EUPATI CH in Promoting Patient Involvement in Clinical Research: A Multi-Stakeholder Research Project. *Front. Med.* 8:795659. [doi: 10.3389/fmed.2021.795659](https://doi.org/10.3389/fmed.2021.795659)

## UPDATE FROM THE EUPATI CH EXECUTIVE BOARD

### *Association meetings*

EUPATI CH held six Executive Board meetings in 2021, three short and three long video calls. The General Assembly 2021 was also held as video call conference.

### *Executive Board*

The General Assembly 2020 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. We wish to express our sincere thanks to both who contributed with much insight and competent advice to the association since its foundation in 2016.

At the EUPATI CH General Assembly on May 6, 2021, three new Executive Board Members were elected: Cordula Landgraf, Rosine Mucklow and Caecilia Schmid.

#### Executive Board 2021:

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



## UPDATE FROM THE EUPATI CH SECRETARIAT

### *Association members*

In 2021, we continued growing and count 40 members, the majority being patient representatives (58%) and academic representatives (31%), and we have one industry member. Two members resigned from the association. The members are listed on our [website](#).

## **Membership fees**

The membership fees were agreed by the General Assembly for 2021 to be CHF 30 for individual members and at least CHF 50 for organisations as well as an additional category of “supporters” was introduced. A hardship clause, mentioned in the statutes, is available for individuals who cannot pay this amount.

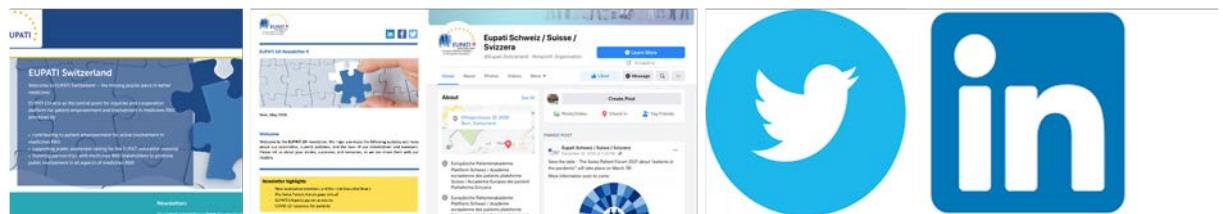
## **Administrative activities**

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 2021 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.

## **Communication activities**

Through 2021 EUPATI CH continued to communicate through diverse channels to the members and the interested public in general. EUPATI CH issued two publications, accessible through the EUPATI [CH website](#), and several internal newsletters. Through the social media channels we continued to actively spread news and relevant activities and events and training of interest ([Facebook](#), [twitter](#)).



## **EUPATI Fellows**

The EUPATI Expert Training Course is an exciting and unique opportunity offering patients and patient advocates expert-level training in medicines research and development. 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](#).

The Swiss Fellows are: Rosmarie Pfau (Lymphoma); Florian Klett (Rheumatic diseases), Hansruedi Völkle (HIV/AIDS); Malena Vetterli (Autoinflammatory diseases), Nicole Gusset (Spinal Muscular Atrophy (SMA)); Max Lippuner (Prostate cancer). They are all portrayed on our dedicated page of our [website](#).

### **EUPATI CH and the COVID-19 restrictions**

As many other teams around the world EUPATI CH also faced major restrictions to physical activities. Our members were absorbed by the workload posed by the coronavirus crisis and thus not able to pursue EUPATI CH projects and trainings for the time being.

The academic representatives are overwhelmed by the vast and uncoordinated amount of new clinical research projects popping up and they strongly promoted the involvement of patients in such projects and undertakings. The patient organisations in turn are overrun with questions and requests from their communities and work on guidelines and tips on how to cope in the current situation, they became a main and reliable source of information.

There is a great deal of conflicting information about the virus and the actions people should take. EUPATI provides a reliable resource designed to provide evidence-based information and tools available to anyone who is interested in combatting the spread of the virus, links to the COVID-19 resources:

- European Patients' Academy ([EUPATI\) COVID-19 resources](#)
- European Patient Forum ([EPF\) resource hub](#)
- Patient focused medicine development ([PFMD\) resource hub](#)
- EURORDIS [COVID-19 Information resource centre](#)

## **EUPATI CH ACTIVITIES 2021**

### ***The Swiss Patient Forum 2021 on «Patients in a pandemic»***

Virtual meeting 19 March 2021

The fourth Swiss Patient Forum of EUPATI CH on the topic of "*Patients in a Pandemic*" took place in the form of an online exchange. Representatives of Swiss patient organisations discussed the topic with representatives of various health care sectors. There was consensus that care in the COVID-19 crisis has worked well, but that the pandemic has not yet been overcome and there is much potential for improvement in the future.



The format of the event consisted of a workshop for patients and their representatives, as well as a plenary session that was open to the public where an exchange with health professionals took place. Further information and a report are available on our [website](#).

### ***Swiss Training Module for Patients***

EUPATI CH has initiated with a small working group the development of a Swiss Module to educate patients in clinical research with a focus on Swiss specific aspects and national language. 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

applications were submitted, and we are currently awaiting the results. Next steps will be to plan the development and roll-out of the Swiss Module which is based on the available [EUPATI training material](#).

### ***EUPATI CH participation and contribution activities in 2021***

During 2021 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 research:** workshop on 19.01.2021 to collect the current initiatives of PPI in CH (CS represented EUPATI CH).
- **Davos digital health:** IS did present EUPATI CH on the topic of patient (and public) engagement on 28.01.2021. The Forum is open and more information (including the link to registration is here: <https://davosdigitalforum.ch/>)
- RP attended the **SwissPALS** event that was organised by Pfizer, GSK and Novartis on the Swiss health care system and its actors
- Advisory role in consortium of **Digital drug design & development** (CTU Uni Bern call to NTN Innovation Booster)
- **BaselAreaSwiss DayOne health hackathon**, EUPATI CH was represented by several members and actively shaped and contributed the health hackathon ([Link](#) to event and information of health hack)
- **SCTO Regulatory Affairs Watch (RA Watch)** issue 6 with focus on PPI. EUPATI CH contributed with an article (copied in the beginning of this annual report).
- **EBMT Nurses Group** with a EUPATI CH presentation on 08.10.2021 held by CL.
- **BAG Steuerungsgruppe "Arztberuf der Zukunft"**: IS attended as EUPATI CH representative in workshop 28.10.2021
- **Stakeholder analysis publication** in Frontiers in medicine on 23.12.2021 (abstract and link to publication given at the beginning of the annual report)
- **eHealth Suisse** working group "patient organisations and health leagues" on the electronic health record, HV represented EUPATI CH

## **EUPATI INTERNATIONAL ACTIVITIES IN 2021**

### ***EUPATI Foundation***

EUPATI has become a foundation under Dutch law, the "Stichting EUPATI Foundation", and has published its business model as well as the new governance structure and associated strategy and workplan.

The national platforms are [members](#) of the Foundation and the annual General Assembly was held on September 23, 2021. Each national platform has delegated three representatives to

attend. Working together, national platforms raise awareness about the important role of patients, and members identify challenges and opportunities for joint action.

### ***EUPATI website and Open Classroom training***

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.

## **OUTLOOK**

In 2022, EUPATI CH will continue raising awareness, including for the education material, and to promote training of patient representatives to empower them for active engagements.

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

EUPATI CH will develop and deliver a Swiss Training Module.

At the same time, we strive to maintain the level and quality of the communications activities and expect that a continuing sponsoring can be secured.

In addition, we want to build on the commitment, knowledge, and experience of our fellows and association members and propose ways for them to get more involved and support the Executive Board and secretariat.

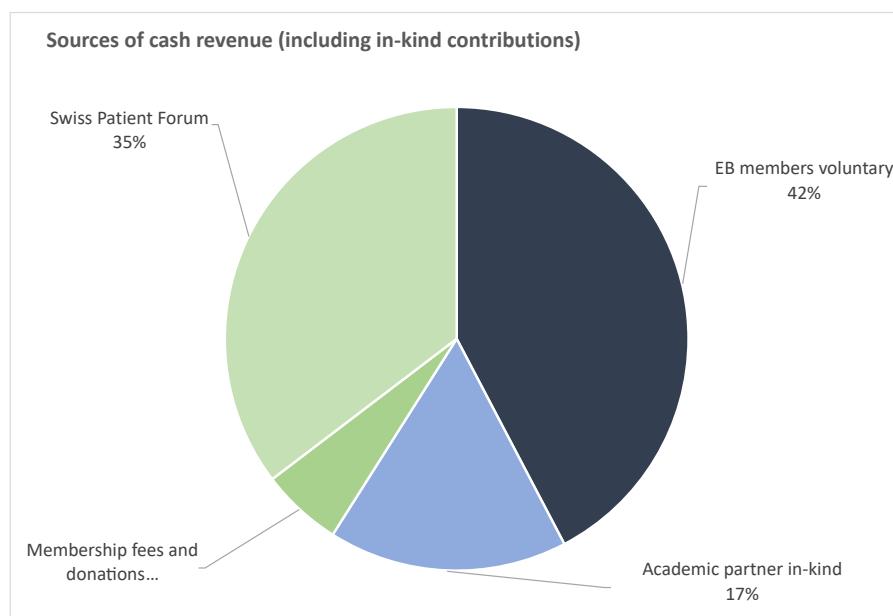
On an international level we will continue the collaboration and contribution to the EUPATI Foundation and regional group activities (German and French speaking platforms' activities) which will not only strengthen the network of the national platforms, but also provide us with a unique opportunity to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

## FINANCIAL REPORT 2021

<b>EUPATI CH annual financial report 2021</b>			
Account 01.01.2021 - 31.12.2021			
Balance sheet 10.02.2022			
<b>1. Income</b>	<b>2019</b>	<b>2020</b>	<b>2021</b>
Membership fees	1'230.00	1'452.47	1'270.00
Sponsoring Swiss Patient Forum	6'000.00	6'000.00	14'100.00
Sponsoring Communication	10'000.00	0.00	0.00
Donations	850.00	0.00	990.00
Sponsoring Stakeholder analysis	0.00	0.00	0.00
<i>Total income</i>	<b>18'080.00</b>	<b>7'452.47</b>	<b>16'360.00</b>
<b>2. Expenses</b>			
The Swiss Patient Forum (excl. Overheads)	12'347.75	0.00	11'518.70
Communications activities (excl. Overheads)	4'547.60	3'372.20	701.71
Stakeholder analysis (excl. Overheads)	0.00	1'667.00	3'532.54
Overheads use EUPATI CH (travel, fees, rent, meetings)	6'389.08	520.85	6'401.35
<i>Total expenses</i>	<b>23'284.43</b>	<b>5'560.05</b>	<b>22'154.30</b>
Total income	18'080.00	7'452.47	16'360.00
Total expenses	23'284.43	5'560.05	22'154.30
<i>Total profit margin/loss of profits:</i>	<b>-5'204.43</b>	<b>1'892.42</b>	<b>-5'794.30</b>
<b>Balance as per 31.12.2021</b>			
Account balance PC 89-565298-4			8'951.94
Income previous period			-240.00
Deferred charges to income			316.00
Deferred charges to expenses			3'241.11
			<b>12'749.05</b>
<b>4. Association assets</b>		<b>CHF</b>	
Asset as per 31.12.2020	14'746.24		
Asset as per 31.12.2021	8'951.94		
<i>profit margin / loss of profits:</i>	<b>-5'794.30</b>		

## EUPATI CH revenue by origin 2021

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.



## AUDITOR's REPORT 2021

I hereby confirm, to the best of my knowledge, that the 2021 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 2021.

Date: April 6, 2021

Brigitte Franke-Bray

Treasurer IFAPP