

EUPATI Schweiz / Suisse / Svizzera / Switzerland

EUPATI CH Association

(European Patients' Academy on Therapeutic Innovation)

Annual Activities Report of 2019



Report date 07.04.2020

Authors Secretariat (Dr Caecilia Schmid) and President (Dr Hansruedi Völkle) EUPATI CH.

PRESIDENT'S MESSAGE

Dear Members
Dear Sponsors and Donors
Dear Friends of EUPATI CH



2019 was again a busy year and only possible thanks to the voluntary engagement from our members and EUPATI expert patients, but also thanks to the professional support by our secretariat at the Swiss Clinical Trial Organisation (SCTO) as well as the Positivrat Schweiz (Positive Council). All our events and projects were only made possible thanks to the efficient fundraising by SCTO and in particular thanks to our generous sponsors.

This report provides all the details, serving as a report for 2019.

The EUPATI CH strategy and workplan were further implemented in 2019, including the EUPATI CH communication plan. Work in progress or brain storming is on the way on the following topics: A Swiss Data Base on patient organisations; the implementation of a Swiss module for the EUPATI Expert training course (focused on the specificities of our national health care system, in particular on development, testing and licensing of medicines in our country); a closer cooperation between the three German speaking EUPATI National platforms of Germany, Austria and Switzerland.

Through 2019, EUPATI CH increased its communication activities and organised the 3rd patient-centred public event, the Swiss Patient Forum on the topic of "The digital patient". The 2019 Swiss Patient Forum, held in Bern in German, was again an amazing event of great participation and full of enthusiasm. As digitalisation is challenging our national health system but also us as patients, the forum workshop and the presentations by health care specialists were focused on the new electronic patient record in Switzerland (the so called EPD, to be launched officially in April 2020), on the wide and confusing variety of health Apps, on the use of patient data and biological samples for research, on e-health from the point of view of patient and on the general consent.

Also, in 2019 the number members of our association and the subscribers of our newsletter increased further. The website (<https://ch.eupati.eu>) was further developed and populated with content in English, French, German, and Italian.

Objectives of EUPATI CH

EUPATI CH has two main goals: First, to establish itself as a sustainable partner in the development and discussion of relevant health and medicinal research and development (R&D) topics in politics and practice, by promoting the EUPATI educational material, organising events for education and training of patients and members of patient organisations. And second, to build an efficient network amongst the (more than 100) patient organisations in our country in order to improve the communication throughout the Swiss health 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. Patient 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. Our Advisory Board, made up of independent representatives from the Swiss healthcare sector, helps us to maintain this independence and impartiality and to mediate in conflict situations.

ACKNOWLEDGEMENTS

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

Executive Board: Hansruedi Völkle (Positivrat Schweiz, President); Estelle Jobson (Endometriosis, Communications Officer, until October); Rosmarie Pfau (Lymphome); Liz Isler (Forum Lungenkrebs Schweiz, until October); Caecilia Schmid and Rosine Mucklow (SCTO, Secretariat, until December); Annette Magnin (SCTO); Marie Mi Bonde Hansen (University Hospital Basel); Cristiana Sessa (Ente Ospedaliero Cantonale Ticino).

Advising Experts, members and EUPATI Fellows: David Haerry (patvocates); Cordula Landgraf (Swissmedic, until September 2019); Stephanie Ludwig (Takeda Pharma AG, until October 2019); Olivia Walther (Janssen); Matthew May (EUPATI Coordinator, member); Steven Bourke (member); Judith Safford (rheumatic diseases, member); Catherine Bates (member); Rosmarie Pfau (Fellow, Lymphoma); Florian Klett (Fellow, Rheumatic diseases), Peter Lack (Fellow, Paediatric cancer); Hansruedi Völkle (Fellow, HIV/AIDS); Malena Vetterli (Fellow, Autoinflammatory diseases), Nicole Gusset (Fellow, Spinal Muscular Atrophy (SMA)); Max Lippuner (Fellow, Prostate cancer).

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 also thank the Positivrat Schweiz for their valuable advice and accepting the presidency of the association. We gratefully acknowledge the pharmaceutical companies (Janssen-Cilag AG, Takeda Pharma AG, Roche Pharma (Schweiz) AG, Pfizer AG and Amgen AG) who support us financially in setting up our communication network and activities, in carrying out the Swiss Patient Forum and in further EUPATI CH projects.

We look forward to seeing our association grow from strength to strength, through 2020 and beyond.



Dr Hansruedi Völkle
President EUPATI CH

THE EUPATI MOVEMENT

EUPATI (European Patients' Academy on Therapeutic Innovation) aims to build competencies and expert capacity among patients and thereby facilitates patient engagement in medicines R&D. Over the course of this pan-European umbrella project (2012-2017), EUPATI has provided scientifically reliable, objective, comprehensive information and trainings for patients. This information was built for three audiences, at increasing levels of complexity: 1. the lay public, 2. patient advocates and, 3. expert patients. Read the closing report for this five-year project period [here](#).

All the training and educational material to date can be accessed through the [EUPATI website](#).

To support the wider dissemination of these resources and multiply the effect of EUPATI, national platforms in more than 19 European countries were subsequently established. These platforms are predominantly led by patients and are composed of representatives of patient organisations, academia, and industry and they usually work in partnership with regulators or other relevant stakeholders. The EUPATI national platforms are the main hubs for implementing the EUPATI training at the national levels.

After considerable work to lay the foundations, the Swiss national platform transformed its legal status into an association, according to Swiss law, on 4 October 2016: [EUPATI CH](#).

EUPATI CH HIGHLIGHTS OF 2019

- EUPATI CH engaged in a wide range of events and activities and in differing roles and made a great effort to ensure that there was substantial representation, participation and presentation at numerous events, conferences, patient seminars, public debates, patient advisory boards, in addition to patient peer reviewing for scientific journals.
- EUPATI CH also attended the annual general meeting (AGM ENP) of national EUPATI platforms around Europe and joined forces with the German speaking platforms (EFO EUPATI region 2).
- EUPATI CH held its third Swiss Patient Forum, this time on the digital patient. The Swiss Patient Forum is an annual event to build the skills of patient representatives and patient organisations regarding selected topics of current or national interest.
- EUPATI CH continued its communication activities through numerous channels and to a wide audience.

EUPATI CH ANNUAL ACTIVITIES REPORT OF 2019

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. The [Positive Council](#) Switzerland provided the president.

In 2019, 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.

Association members

During 2019, the association's membership further increased to a total of 35 members. Of those, 20 are representatives of patients or patient organisations, 12 are from academia, and 3 from industry. The members are listed on our website (<https://ch.eupati.eu/eupati-ch-association>).

The membership fees were agreed by the General Assembly for 2019 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.

Association meetings

EUPATI CH held several internal meetings and teleconferences, and the General Assembly on 25 April 2019.

One successful Swiss applicant for the fourth EUPATI expert patient training

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 Course is a mixture of independent e-learning coursework and face-to-face training events over a 14-month period.

The first Course cycle kicked off in October 2014 and ran until December 2015. The second course started in September 2015 and ended in November 2016. The third expert patient course with 56 participants ended in December 2018.

The fourth course has finished recruiting on 28 October 2019 and amongst all applicants there was only one successful Swiss candidate. We will introduce and portray the person shortly, as soon as the information is public.

All EUPATI Expert Fellows ([Alumni](#)) are listed on the EUPATI website. They are now numbering almost 150 and cover more than 80 disease areas.

The “Swiss Patient Forum” on 25 October 2019 in Bern

“The digital patient” – Are patients sufficiently competent in the increasing digitalisation in healthcare? What hopes and fears are associated with this? What wishes and demands can be derived from this?



The third **Swiss Patient Forum 2019** of EUPATI CH took place at the end of October in Bern and was followed with great interest: representatives of over 30 patient organisations exchanged opinions and information with experts about «the digital patient» on present and future aspects of the digitisation in health care. During the workshops they debated on current topics concerning the introduction of the electronic patient dossier (EPD), the consequences of research with patient data, and the effects of digital health apps. The program, presentations, the subsequent report and media releases, and pictures are available [here](#).

The event was kindly sponsored by Takeda Pharma AG and Janssen-Cilag AG.



Communication activities in 2019

Thanks to external sponsorship from Pfizer AG and Roche Pharma Schweiz AG, EUPATI CH was able to maintain its communications activities, feed all the channels, and reach a considerable audience.

Through 2019 EUPATI CH was able to use its **various communication (promotion) materials developed in 2018**, such as PowerPoint presentation template, a roll-up banner to mount at events, a flyer and key-messages postcard in four languages (English, German, French and Italian).



Newsletter and mailing campaigns

The EUPATI CH newsletter and mailing campaigns gained a new, fresh look in 2018 and is much appreciated. A total of 10 mail campaigns were sent out throughout 2019, including the two comprehensive newsletters with information about the association's activities, events, training opportunities, European EUPATI updates and selected publications worth reading, as well as videos and tutorials on patient involvement.

The newsletters were prepared by the secretariat with support from members and external contributors, and sent to over 560 subscribers of which 40% represent patients, 38% academia, 15% the pharmaceutical industry, 5% the authorities, and 2% the press or media. All newsletters are available on the [EUPATI CH website](#).

Website

The EUPATI CH [website](#) was further populated with content and is available in four languages. All the essential documents and activities are reported there. Additionally, "advocacy resources" page was added to share and make available relevant and interesting publications, videos, tutorials, and other educational resources.

The website contains currently about 46,000 words, requiring a huge effort to translate this in German, French, and Italian. Because this translation is provisionally being conducted by auto-translation software, it is unfortunately prone to errors and nonsensical expressions. EUPATI CH looks forward to ameliorating the translations and to finding a better solution (which will only be implemented during late 2020).

Social media presence

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](#).

As in the past, the most followed posts during 2019 on [facebook](#) were the about the Swiss Patient Forum, reaching more than 550 people. [Twitter](#) followers increased from 350 to 434.

Join in the debates and share your news on [Twitter](#), [Facebook](#) and [LinkedIn](#).

EUPATI CH participation and contribution activities in 2019

The year 2019 brought an abundance of opportunities to participate, contribute, and share EUPATI CH members expertise and experiences, most of them were reported in our newsletters. Opportunities have included:

- **attending events** by invitation (e.g. SCTO Forum of Clinical Research, STCS annual scientific meeting);
- being invited onto a **community advisory board** (CIOMS);
- joining a **patient working group and scientific advisory board**, with [eHealth Suisse](#) on the implementation of the nationwide electronic patient dossier, the Basel Breast Cancer group, and the Swiss Transplant Cohort Study ([STCS](#)), respectively;

- **advising** the academic community, researchers and students, clinical trial units and their staff, by offering a perspective on the relevance of patient engagement (generally and relating to paediatrics) and in the support of grant application proposal development;
- **presenting EUPATI CH or the patient view** (see details in [our newsletters](#)) at the breast cancer group Ticino, the SGES (Swiss Green Economy Symposium), the DayOne Conference (Shaping the Future of Health), the All.Can (Nachhaltige Krebsversorgung), the EUPATI D Sommerschule, the SAKK Patientensymposium, the HBA Precision Medicine in Oncology, and the NZZ future health.

INTERNATIONAL ACTIVITIES IN 2019

EFO EUPATI

Ensuring the future of EUPATI, the IMI-EFOEUPATI project was launched in 2018 and will run until 2020 with the main aim to ensure optimal exploitation and sustainability of the core achievements of the previous IMI funded EUPATI Project (2012-2017): Patient Expert Training Course, public Toolbox, and the EUPATI National Platforms Network.

Within this project, EUPATI CH collaborates in the work package WP4, strengthening the existing national platforms through knowledge/experience exchange and sharing.

Switzerland is grouped with Germany, Austria, Romania, Slovakia, and Poland in the Regional Group 2, and EUPATI CH is represented in this group through delegates (in 2019: Estelle Jobson (patient representative), Caecilia Schmid (academic) and Olivia Walther (pharmaceutical industry)).

Within this context EUPATI CH attended and contributed to the annual general assembly of the EUPATI national platforms (**AGM ENP**). The German-speaking countries agreed to set measures to share via appropriate channels various important resources, such as guidance and governance documents and education material, so as to learn from each other, benefit from existing work, and prevent unnecessary duplication. Regular exchange TCs are held within this sub-group.

A mid-term goal is also to develop a mini training course in German on a topic of common interest, e.g. patient involvement in ethics committees.

OUTLOOK

In 2020, 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 re-elect the existing members and add new members to its executive board at the general assembly in April 2020.

EUPATI CH will also adapt the long-term **strategy** for the association based on the findings of the stakeholder analysis that will be available by the end of 2020.

The **stakeholder analysis** has been done by a [ECPM Master](#) student with the goal of supporting EUPATI CH to define and strengthen its role in the Swiss R&D and healthcare landscape and to secure funding in a sustainable manner. Part of this stakeholder project is kindly sponsored by Amgen AG.

EUPATI CH strives to maintain the level and quality of the **communications** activities and expects that a continuing sponsoring can be secured.

Also, in 2020, EUPATI CH will hold the **Swiss Patient Forum** in Q3.

At the time of writing this report and planning the activities for 2020 and beyond, we temporarily suspended all activities due to the Corona virus pandemic lockdown. Several projects are anticipated for which extensive fundraising is needed as well as identification of national competent partners to support us e.g. in the development of a database of nation-wide patient experts and **patient organisations, plus a mini training course**. 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 EB and secretariat.

EUPATI CH will continue to support the national debate about patient rights and participation and create opportunities for patient engagement in medicinal R&D processes in Switzerland. We look forward to fostering a stronger, vibrant network of patients to bring their voices to the Swiss debates.

On an international level we will continue the collaboration and contribution to the **IMI-EFOEUPATI** 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 2019

EUPATI CH annual financial report 2019

Accounts 01.01.2019 - 31.12.2019

Balance sheet 10.03.2020

1. Income	2018	2019
Membership fees	1'140.00	1'230.00
Sponsoring Swiss Patient Forum	17'000.00	6'000.00
Sponsoring Communication	21'200.00	10'000.00
Donation (Roche)	0.00	850.00
Sponsoring Stakeholder analysis	8'000.00	0.00
<i>Total income</i>	47'340.00	18'080.00

2. Expenses		
The Swiss Patient Forum (excl. Overheads)	12'890.30	12'347.75
Communcations activities (excl. Overheads)	16'722.56	4'547.60
Stakeholder analysis (excl. Overheads)	2'122.00	0.00
Overheads use EUPATI CH (travel, fees, rent, meetings)	4'246.55	6'389.08
<i>Total expenses</i>	35'981.41	23'284.43

Total income	47'340.00	18'080.00
Total expenses	35'981.41	23'284.43
<i>Total profit margin/ loss of profits:</i>	11'358.59	-5'204.43

Balance as per 31.12.2019	Liabilities	
Account balance PC 89-565298-4	13'488.81	
Deferred charges to income	0.00	
Deferred charges to expenses		0.00
Capital of the association		13'488.81
	13'488.81	13'488.81

4. Association assets	CHF
Asset as per 30.12.2018	18'693.24
Asset as per 30.12.2019	13'488.81
<i>profit margin / loss of profits:</i>	-5'204.43

Auditor's report extract: "I hereby confirm, to the best of my knowledge, that the annual financial statements convey an accurate image of the EUPATI CH account and its bookkeeping. The Auditor proposes the discharge of the members of the Executive Board and the secretary of EUPATI CH for their activity during the association and financial year 2019."