

EUPATI Schweiz / Suisse / Svizzera / Switzerland

EUPATI CH Association

(European Patients' Academy on Therapeutic Innovation)

Annual Activities Report of 2018



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Authors Secretariat (Dr Caecilia Schmid and Rosine Mucklow), Communications officer (Estelle Jobson), and President (Dr Hansruedi Völkle) EUPATI CH.

PRESIDENT'S MESSAGE

Dear Members

Dear Sponsors and Donors

Dear Friends of EUPATI CH



2018 was, after the official founding of EUPATI CH as an association on 4 October 2016, the second full and busy year of operation. This successful year was only possible thanks to the voluntary engagement from our members and EUPATI expert patients and also thanks to the professional support by our secretariat at the Swiss Clinical Trial Organisation (SCTO) as well as the Positivrat Schweiz (Positive Council).

This report provides all the details, serving as a report for 2018. The EUPATI CH strategy and workplan were further implemented in 2018, including the EUPATI CH communication plan. All our events and projects were only made possible thanks to the efficient fundraising by SCTO and in particular thanks to our generous sponsors.

Through 2018, EUPATI CH increased its communication activities and organised the second patient-centred public event, the Swiss Patient Forum in French in Lausanne, on the topic of "Quality of Life of patients" with an amazing participation full of enthusiasm.

Also, in 2018 EUPATI CH increased the number of its association members and newsletter subscribers.

During 2018, four new Swiss fellows completed successfully the EUPATI Expert training course thanks to several months of intense e-learning and two Face-to-Face Meetings in Madrid. We congratulate them all and look forward to their future active participation in EUPATI CH.

The website (<https://ch.eupati.eu>) was further developed and populated with content in English, French, German, and Italian. Our social media are increasingly active, too.

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 and Advisory Experts 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); Rosmarie Pfau (Lymphoma); Liz Isler (Forum Lungenkrebs Schweiz); Caecilia Schmid, Rosine Mucklow, and Annette Magnin (SCTO, Secretariat); Marie Mi Bonde Hansen (University Hospital Basel); Cristiana Sessa (Ente Ospedaliero Cantonale Ticino).

Advising Experts: David Haerry (patvocates); Cordula Landgraf (Swissmedic); Heiner Sandmeier (Interpharma); Stephanie Ludwig (Takeda Pharma AG); Steven Bourke (Member); Matthew May (Member).

EUPATI Fellows: Estelle Jobson (Endometriosis); Rosmarie Pfau (Lymphoma); Florian Klett (Rheumatic diseases), Peter Lack (Paediatric cancer); Hansruedi Völkle (HIV/AIDS); Malena Vetterli (Autoinflammatory diseases), Nicole Gusset (Spinal Muscular Atrophy (SMA)); Max Lippuner (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 2019 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 2018

- EUPATI CH engaged in a wide range of events and activities and in differing roles.
- EUPATI CH 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 capacity training for expert patients, organised by the European Patients' Forum (EPF).
- EUPATI CH held its second Swiss Patient Forum, this time on quality of life of patients. 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 increased its communication activities considerably through numerous channels and to a wider audience.

EUPATI CH ANNUAL ACTIVITIES REPORT OF 2018

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 provides the president.

In 2018, 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.

Furthermore, the SCTO appointed a EUPATI fellow and patient expert, Estelle Jobson, as communications manager at its organisation, strengthening a more targeted communication with the public.



The EUPATI CH secretariat was introduced in the [December](#) edition of our newsletter. Without them, EUPATI CH could not have been so active this year, so EUPATI CH wishes to thank Caecilia Schmid, Rosine Mucklow, and Estelle Jobson for their unwavering commitment.

Association members

During 2018, the association's membership further increased to a total of 29 members. Of those, 16 are representatives of patients or patient organisations, 10 are from academia, and 3 from industry. The members are publicly listed on our website (<https://ch.eupati.eu/eupati-ch-association>).

The membership fees were agreed by the General Assembly for 2018 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.

Association meetings

EUPATI CH held several internal meetings and teleconferences, three Executive Board meetings (26 March, 9 August, and 18 October 2018), and the General Assembly (26 April 2018).

A glimpse from the General Assembly, including some photos, was published in the [May edition](#) of our newsletter.



The "Swiss Patient Forum" on 28 September 2018 in Lausanne



What is quality of life for patients? How do we define it, we who struggle with it? And what do we need to improve it, practically?

At the **Swiss Patient Forum** held on 28 September 2018, EUPATI CH brought together a vibrant group of 20 patients, representatives, and their caretakers to brainstorm these burning questions in a welcoming atmosphere. We discussed family life, persisting pain and fatigue, social integration, access to medication and reimbursement, emotional and physical challenges, peer-to-peer support, information sharing... and more.

For the first time, this event was held in the Swiss-French region, reaching the local francophone community.

In the afternoon, open to the public with more than 50 participants, debates zoomed in on a crucial aspect of quality of life: patients' access to the working world. Handpicked speakers gave their engaging and expert perspective on pertinent considerations: the patient–doctor relationship, the employer, legal and psycho-social factors, the view of the pharmaceutical industry, and [EUPATI's patient training opportunities](#).

The event was kindly sponsored by Takeda Pharma AG and Janssen-Cilag AG. More about the 2018 Swiss Patient Forum, inspiring pictures, and the workshop report appear in our [website coverage](#).



Four Swiss patient advocates completed the third EUPATI expert patient training

For the third year running, applicants from Switzerland were selected to undergo the training for patient experts on medicines R&D. Out of 170 applications, the selection committee chose a group of 60, from 28 countries, 40 illnesses and disease areas, of whom 16 were men and 44 women. Four Swiss participants were selected. The successful candidates started their studies in September 2017 and graduated in January 2019.

Join EUPATI CH in congratulating this third group of Swiss-based participants and new EUPATI Fellows, who are portrayed on our website: EUPATI CH president [Hansruedi Völkle](#) (Positivrat), [Nicole Gusset](#) (SMA Schweiz), [Malena Vetterli](#) (FMF & AID Global Association), and Max Lippuner (Europa Uomo Schweiz). May they become more active in EUPATI CH, in time.

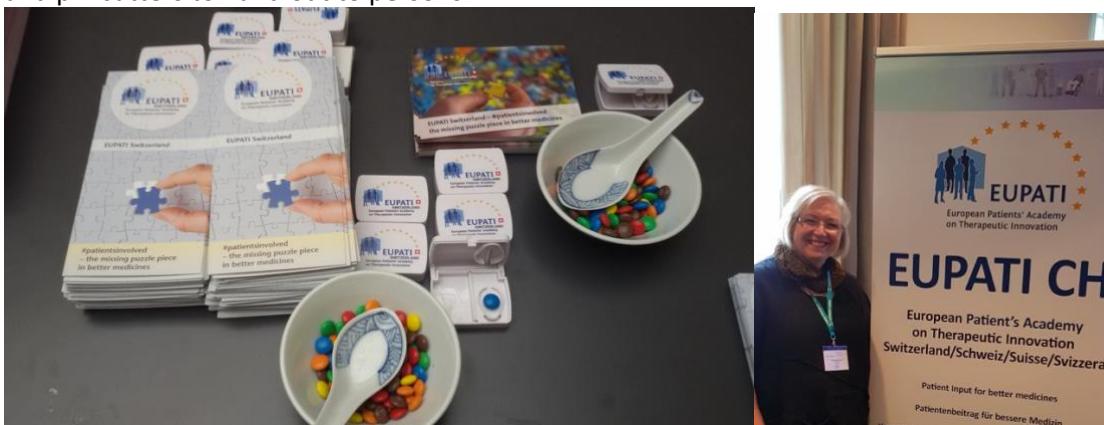
The EUPATI Cohort 3 Trainees' Virtual Graduation Ceremony took place on [EUPATI Facebook](#) on 31 January 2019, from 17h00 to 18h30 (CET).

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

Communication activities in 2018

Thanks to external sponsorship from Pfizer AG and Roche Pharma Schweiz AG, EUPATI CH was able to boost its communications activities, channels, and audience reach considerably.

Through 2018 EUPATI CH was able to prepare **various communication (promotion) materials**, such as a PowerPoint presentation template to provide an overview of EUPATI CH, a roll-up banner to mount at events, a flyer and key-messages postcard in four languages (English, German, French and Italian), and pill-cutters to hand out to persons.



Newsletter and mailing campaigns

The EUPATI CH newsletter and mailing campaigns gained a new, fresh look. A total of 19 mail campaigns were sent out throughout the year, including the three substantial 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 are prepared by the secretariat with support from members and external contributors, and sent to 520 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 [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. In addition, EUPATI CH has been introducing all the EUPATI Fellows and the secretariat. Additionally, “advocacy resources” page was added to share and make available relevant and interesting publications, videos, tutorials, and other educational resources.

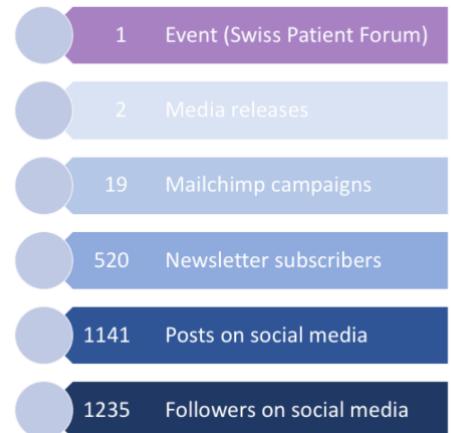
The website contains currently about 27,000 words, requiring a huge effort to translate this in German, French, and Italian. Because this translation is provisionally being conducted by auto-translation software, it is unfortunately prone to errors and nonsensical expressions. EUPATI CH looks forward to ameliorating the translations and to finding a better solution (which will likely only be implemented in 2020).

Social media presence

The social media activities are soaring! EUPATI CH owes a huge thanks to its member, Steven Bourke, for channelling his health communications expertise into creatively and diligently setting up a new professional profile on [LinkedIn](#).

In a record-breaking moment, a [post](#) on Facebook, announcing the success of the Swiss Patient Forum, reached 880+ people. One of the [Twitter tweets](#), commenting on patient perspectives shared at the *British Medical Journal* ([BMJ](#)), garnered an astonishing 7,000 impressions (meaning the number of times users saw the tweet).

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



Participation and contribution activities in 2018

The year 2018 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. SwissPALS; SCTO Forum of Clinical Research, Patient partnership at the Geneva University Hospitals);
- being invited onto a **community advisory board** (Novartis);
- joining a **patient working group and scientific advisory board**, with [eHealth Suisse](#) on the implementation of the nationwide electronic patient dossier 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 the patient view** at the [Seminar for science journalists](#) about personalised health and Big Data attended by over 70 participants, and at the [IEEE Blockchain](#) for Clinical Trials event.
- **giving a lecture** at the University of Lucerne on the patients' voice in clinical research from an academic point of view, to more than 100 health science students;
- **presenting** EUPATI CH to the [AO Foundation](#), the [BIHAM](#), the [SAKK patient advisory group](#), and at the Hospitals Clinical Research days of [EOC Ticino](#) and the [USB](#).
- holding a **booth and presentation** at the tri-nation German-language [DACH Symposium](#) on clinical research attended by more than 500 participants;
- **taking part** in and circulating several Europe-wide and international **surveys** – including for Cochrane Crowd, the European Medicines Agency (EMA), the Clinical Research Initiative for Global Health ([CRIGH](#)), [WECAN](#), and [Pain Alliance Europe](#).
- doing **patient peer review** and writing an Opinion piece for the [British Medical Journal](#).

INTERNATIONAL ACTIVITIES IN 2018



EUPATI celebrated its one millionth visitor to the toolbox on 8 October 2018

In less than three years, the EUPATI website and its [Toolbox](#) have reached the milestone of one million individual users! A competition was held to guess the magical date of achievement. The winners, who won a rare EUPATI mug, were avidly engaged EUPATI people, Kay Warner and Caecilia Schmid.

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 by the elected delegates, Estelle Jobson and Caecilia Schmid.

Within this context EUPATI CH attends and contributes 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 2019, EUPATI CH will continue raising awareness, including for the education material, and to promote membership of the EUPATI CH association.

EUPATI CH will also adapt the long-term **strategy** for the association based on the findings of a stakeholder analysis that will be available by the end of 2019.

The **stakeholder analysis** will be 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 2019, EUPATI CH will hold the **Swiss Patient Forum** in Q3.

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 association members and propose ways for them to get more involved and support the EB and secretariat (our forthcoming **Member involvement** proposal).

Continuing the collaboration and contribution to the **IMI-EFOEUPATI** will not only strengthen the network of the national platforms, but also provide us with a unique opportunity to learn and profit from others.

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.

FINANCIAL REPORT 2018

Income 2018	Date	in CHF
Membership fees 2018	31.12.2018	1'140.00
Sponsoring Swiss Patient Forum 2018	31.10.2018	17'000.00
Sponsoring Communication	31.05.2018	21'200.00
Sponsoring Stakeholder Analysis	31.07.2018	8'000.00
Overall income	31.12.2018	47'340.00
Expenses 2018	Date	in CHF
The Swiss Patient Forum 2018 (excl. Overheads)	31.12.2018	12'890.30
Communications activities (excl. Overheads)	31.12.2018	16'722.65
Stakeholder analysis (excl. Overheads)	31.12.2018	2'122.00
Overheads use EUPATI CH (travel, fees, rent, meetings)	31.12.2018	4'246.55
Overall expenses	31.12.2018	35'981.50
Projected Balance	31.12.2018	in CHF
Balance EUPATI CH	31.12.2018	11'358.50
<i>Thereof earmarked: carry-over for The Swiss Patient Forum & Communication & Stakeholder analysis</i>	31.12.2018	9'150.71