

### Welcome

Welcome to the **EUPATI CH** newsletter. **EUPATI CH** association will be offering you updates and information about the association, our activities and stories from the everyday life of our stakeholders and members. If you wish to contribute your story or news, please share it with us.

If you know patient advocates or representatives who are getting involved in exciting ways, let's share their stories. One story we're sharing is that of our founding representative, the EUPATI fellow [Florian Klett](#), who successfully completed the European Patients' Academy Expert Training Course and became the **EUPATI Fellow Alumni coordinator**.

### Highlights in this newsletter:

- Announcing the Swiss Patient Forum
- EUPATI CH association news
- Our strategy and workplan has gone public
- EUPATI national platforms annual meeting report
- EUPATI events and publications

### EUPATI CH Invitation to the “*The Swiss Patient Forum*” on 27 October 2017

Our flagship event will be the annual “Swiss Patient Forum”, a full-day event including several lectures and a workshop, designed to train patient advocates and empower them to become active and meaningfully engaged. Each year, a different topic of current interest will be chosen. The first event is planned to take place in northwest Switzerland, the next one in Romandie and then in Ticino.



This year, the “**Swiss Patient Forum**” will take place on 27 October in Olten and will be held in German on the topic of “Patienteninformation – Was Patienten wissen wollen und sollen” (Patient information: What patients want and need to know).

For more information and registration, follow the link [here](#).

We are extremely happy to receive information about any upcoming events and trainings, as well as participation opportunities to present at a booth or to introduce EUPATI CH to an interested audience. Please get in contact with us via the [secretariat by email](#).

### EUPATI CH association - New members

We warmly welcome our new members, representing their institutions: Peter Lack of Kinderkrebs Schweiz, Bruno Raffa of SMCC, Karl Ehrenbaum of Gesundheitsbildung Schweiz, Peter Durrer of SAKK and as individual members: Mr. Stephane Charbon, Mr Matthew May, Ms. Emilie Berger and Prof Uyen Huynh-Do.

The full list of members is public on our [webpage](#).



## SAVE the date: General Assembly 26 October 2017

The General Assembly of the EUPATI CH association is set to take place on 26 October 2017, from 14:30–16:30 in Basel, followed by a meet-and-greet aperitif. Please save this date for this important event. You will receive details on the location, the meeting agenda, and its related documents, approximately 2 weeks before the meeting.

## EUPATI CH association – Strategy- and workplan is online

We are happy to share our strategy and workplan with you, summarising our core activities. The workplan is available in English and can be downloaded [here](#).

## Annual meeting of EUPATI national platforms – Switzerland participated on 28-29 June in Berlin

The **EUPATI Network of National Platforms** held its first general meeting in Berlin on 28 June 2017. Fifteen of the 18 national platforms were represented and two delegates from **EUPATI Switzerland** participated, Estelle Jobson and Caecilia Schmid, both members of the EUPATI CH Executive Board. A full report and pictures are available [here](#).

National platforms serve to bring patient, academic and industry partners together to discuss patient education and patient involvement in medicines research and development. Although each country has a unique profile and features, with its specific constraints and opportunities, they share one key goal: to raise awareness about the important role of patients and to identify challenges and opportunities for collaborative action.

The meeting provided an excellent opportunity for the different platforms to present themselves. Some showcased their achievements to date. Together, the platforms discussed and shared challenges, opportunities and good practices.

Crucial for the participants was the debate on how the platforms can and should collaborate more across the geographical or language regions in Europe. In this spirit, the German-speaking platforms (Austria, Germany and Switzerland) have set up an exchange group and will share with one another essential documents, such as training materials and translations. Similarly, the French-speaking and Italian-speaking regions will set up such exchange opportunities. All the platforms face the challenge of sourcing funding and being run on the scarce time of volunteers. Read more [here](#) about the synergies explored and how platforms can overcome challenges they face by working together.

The second day of the meeting, “Train the Trainers”, was attended by over 40 EUPATI Fellows. The purpose of the meeting was to train and empower participants to share and multiply the knowledge and skills gained from the [EUPATI Expert Training Course](#) and the [EUPATI Toolbox](#) with their own patient groups and constituencies. Representing Switzerland were EUPATI Fellow Estelle Jobson and EUPATI Program Coordinator [Matthew May](#). The day was full, rich and stimulating, with practical exercises and many useful tools and templates to use as resources. Participants left Berlin encouraged to take their learning forward and equipped with the tools to do it, view a report and photos [here](#).

Patient groups wanting short training courses on various aspects of medical R&D are welcome to approach [EUPATI CH](#) with their proposals or requests.

## EUPATI training for Swiss patient experts

The [third EUPATI Patient Expert Training Course](#) started on 4 of September 2017 and will run for 15 months. We wish the four Swiss trainees all the success for their studies and we will soon introduce them to you on our [website](#).



Moreover, we are happy to share stories from former students who have successfully managed to bring in their expertise in their line of work.

### All EUPATI guidance webinars in one place

EUPATI guidance webinars explaining and discussing the patient involvement in regulatory processes, in health technology assessment (HTA) work, in ethical review of clinical trials, and in industry-led medicine research are now collected [in one place](#), as well as on the [website](#).

The EUPATI guidance documents aim to support the integration of patient involvement across the entire process of medicines research and development, including regulatory agencies, HTA bodies, ethics committees and the pharmaceutical industry.

### Publications, events and good to know

An article about EUPATI CH (in German) appeared in the first 2017 edition of *the ho/noho* newsletter, issued by the ho/noho, Schweizerische Patientenorganisation für Lymphombetroffene und Angehörige (the Swiss patient organisation for those affected by lymphoma and their relatives). Read the article [here](#). Please let us know if you would like to include us in your organisation's newsletter or website.

### SAMS general consent

The Swiss Academy for Medical Sciences (SAMS) and swissethics prepared a template for a general consent form, press release and templates can be accessed [here](#). The customisable general consent form is available in German, French, Italian, and English.

### SPHN Public Information event

On Monday 28 August 2017 (14h00-19h00) the first public information event of SPHN (Swiss Personalised Health Network) took place in Bern. The SPHN informed about what is needed to facilitate research projects in personalised health (or precision medicine) in Switzerland, such as a system for a nationwide exchange of health-related data. Karin Holm and David Haerry presented the patients' views. Find the agenda and the presentations of all the speakers [here](#).

### EMA annual report 2016

EMA's annual report (2016) on interactions with patients, consumers, healthcare professionals and their organisations is now available [here](#).

### Membership applications

*EUPATI CH is open for membership to anyone interested and is currently free of charge. You are welcome to apply as either an individual member or as a representative of your organisation. Please find the application form and more details on our [webpage](#).*