
EUPATI CH Newsletter 10



Bern, September 2020

Welcome

Welcome to the **EUPATI CH** newsletter. We hope you enjoy the following updates and news about our association, current activities, and the lives of our stakeholders and members. Please tell us about your stories, successes, and resources, so we can share them with our readers.

Newsletter highlights

- New members and news from the Executive Board
- The Swiss Patient Forum
- EUPATI CH participation at events – DayOne hackathon
- Swiss regulatory news and recommended readings

EUPATI CH welcoming new members

We wish to warmly welcome our newest members as individual member Beatrice Heim and as institutional representatives Nicole Gusset (SMA Schweiz, EUPATI Fellow) and Caroline Hyde (Clinical Trials Centre, University Hospital Zürich). Browse the full list of members on our [webpage](#).

Follow us on our social media

Join us on our social media ([Facebook](#), [Twitter](#), [LinkedIn](#)) for serious news, updates, events, and calls for participation relating to patient engagement, in Switzerland and beyond.

News from the EUPATI CH Executive Board

The EUPATI CH Executive Board convened twice since its election in April 2020. Due to the current health situation, the meetings were held via video conferencing. In these board meetings, we confirmed the key activities and projects of EUPATI CH for the coming years. These are:

- **Swiss Patient Forum** - The annual training event of EUPATI CH (more details below)
- **Swiss training module** - The development of a Swiss module to educate patients in clinical research with a focus on Swiss aspects: the concept was approved and as a next step, potential collaboration partners will be contacted to plan the development and roll-out of the Swiss Module.
- **Networking and fundraising** - The multiple networking activities will be consolidated and pursued. A valuable source is our stakeholder analysis that has been finalised and will be published soon. A new focus will be on fundraising with an objective to secure financial resources for specific projects but also to provide a continuous and sustainable back-office support.
- **EUPATI central collaboration** - The good collaboration with EUPATI central (the European umbrella organisation, now a foundation) is an ongoing activity and will be ensured also in the future. This will allow us learning from others and sharing of expertise and tools.

The Swiss Patient Forum 2021

“patients in pandemic”



The **Swiss Patient Forum** of EUPATI CH has already been carried out since 2017. Each of the events was a great success and extremely motivating for all the participants. Twice it took place in German (Olten and Bern) and once in French (Lausanne). It enabled a constructive exchange between patients, their representatives on the one hand, and health professionals, healthcare providers and the pharmaceutical industry on the other.

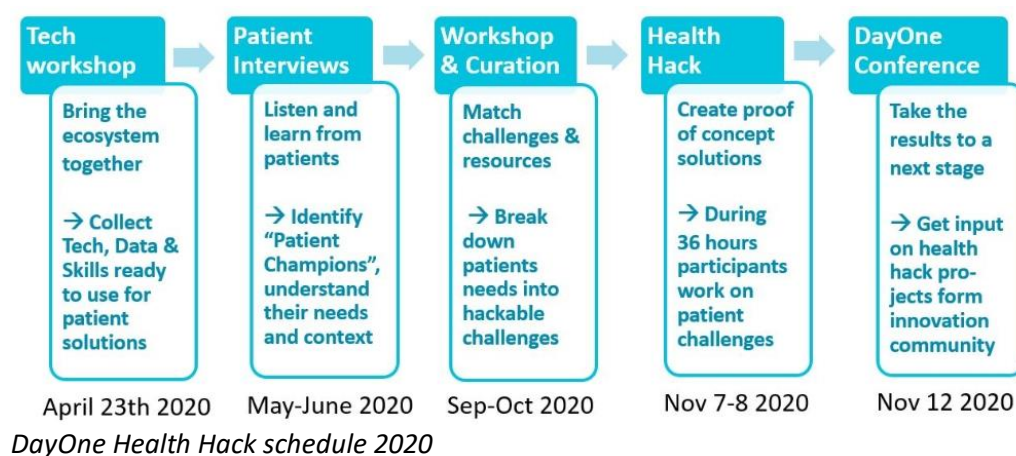
The format was retained since the beginning: a workshop (20-30 participants) only for patients in the morning and oral presentations followed by a discussion in the afternoon (50-60 participants). The treated topics were: [“Patient information”](#), [“Quality of life”](#), and [“The digital patient”](#).

The Swiss Patient Forum 2020 of EUPATI CH was postponed to 2021 and will be devoted to *“patients in pandemic – lessons learnt”*. The event will most likely be held virtually but the format of a workshop for patients and an open plenary session will be maintained. The date will be announced as soon as the planning group has kick-started the organisation of the event.

EUPATI CH participation activities (much done and more ahead)

DayOne Health Hack collaboration

EUPATI CH in partnership with DayOne Basel Area.Swiss continued to help shape the DayOne Health Hack and contributed to the workshop to develop patient needs into hackable challenges. The workshop brought together more than 50 experts, patients, technology enthusiasts, healthcare innovators, and industry partners. The hackathon is planned to take place on November 6-7, 2020 and the results will be presented at the DayOne Conference on November 12, 2020.



The hackathons' strength comes from bringing together a unique group of partners. Including patient champions from several disease areas, Innovation-horizon.ch, Roche, Experientia, Novartis, Microsoft, Takeda, Helsana and Google, University Hospital of Basel, the Health Hacking Lab and EUPATI CH, Swiss Center for Electronics and Microtechnology and Swiss Made Software.

[More information](#) on the Health Hack. Watch the [recording of the Tech for Patient Kick-off](#).

COVID-19 resources for patients

In response to the COVID-19 pandemic, patient organisations and EUPATI have provided content and resources related to medicines research and development, patient education, and other relevant topics, here is just a selection:

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

Swiss regulatory environment

Further development of the portal for clinical trials in Switzerland

The **Swiss National Clinical Trials Portal** (SNCTP) operated by the Federal Office of Public Health (FOPH) lists all clinical trials conducted in Switzerland and neighbouring countries.

The portal is being continuously developed (link to [portal](#)). The following improvements were recently introduced:

- Display of clinical trial results
- New filter options for children, adolescents and healthy volunteers
- Notification of the authorising ethics committee

“No” to the Limitation Initiative

Our member SCTO and other academic institutions say "NO" to the Limitation Initiative and join the Swiss Science Council, the Swiss National Science Foundation and the Swiss Academies of Arts and Sciences in their opposition to the initiative. If passed, this initiative would negatively impact Switzerland as a place to conduct clinical research and thus jeopardise the development of new therapeutic innovations and access to those in Switzerland.

Read their full position statement [here](#).

Revision of “Pharma Cooperation Code”

The pharmaceutical industry has revised the so-called [Pharma Code](#) (Code of Conduct of the Pharmaceutical Industry in Switzerland) that will be applied as of 1 January 2021. The changes concern **formal changes**, **additional definitions** and **rules of cooperation** with health care professionals (HCP), health care organisations (HCO) and patient organisations (PO).

These recent developments have shown that also a adaptation of the SAMS guideline "[Cooperation between the medical profession and industry](#)" is necessary and will go into revision.

EUPATI Europe-wide updates

New EUPATI website

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: <https://www.eupati.eu/>.

Please note that that some of the national platforms are still finalising their websites and the [links](#) may not be working properly. By end of September 2020, all of the links should be working correctly.

EUPATI turned into a foundation

EUPATI has become a foundation under Dutch law, the “EUPATI Stichting Foundation”, and is currently developing its business model as well as associated strategy and workplan. The national platforms will become [members](#) in the Foundation and the first General Assembly be held on September 17, 2020.

Recommended readings

- “Designing a tool to support patient and public involvement in research projects: The Involvement Matrix” by Dirk-Wouter Smits, University Medical Center in Research Involvement and Engagement (2020) 6:30 (<https://doi.org/10.1186/s40900-020-00188-4>)
- The involvement matrix and other helpful tools to promote and facilitate patient involvement are accessible through the [UMC Utrecht website](#).
- Kaisler, R. E. & Missbach, B. 2019. Patient and Public Involvement and Engagement: A ‘How To’ Guide for Researchers. [DOI: 10.5281/zenodo.3515811](https://doi.org/10.5281/zenodo.3515811)

Membership applications

EUPATI CH is open for membership to anyone interested. You are welcome to join as an individual or as a representative of an organisation, or a member of academia or industry. Please find the application form and more details on our [webpage](#). Membership fees are in line with other non-profit associations in Switzerland: CHF30 for individuals and CHF50 for professional organisations.

Contact

EUPATI Switzerland Secretariat
Caecilia Schmid
email: secretariat@ch.eupati.eu
<https://ch.eupati.eu/>

EUPATI CH, c/o SCTO
Effingerstrasse 35, 3008 Bern, Switzerland
IBAN No: CH 84 0900 0000 8956 5298 4