
EUPATI CH Newsletter 8



Bern, December 2019

Seasonal Greetings!

Welcome to this year's last edition of the **EUPATI CH** newsletter in 2019. We hope you will enjoy the following updates and news about our association, current activities, and the lives of our stakeholders and members. Please continue to tell us your stories, successes, and resources, so we can share them with our readers. We look forward to sharing 2020 with you, a year rich in interesting patient-centred projects and initiatives.

Newsletter highlights

- New members
- Swiss Patient Forum 2019, a success
- EUPATI CH activities
- EUPATI Europe news

EUPATI CH welcoming new members and information from the boards

We wish to warmly welcome our newest members as individual members: Larisa Aragon Castro, Catherine Bates, Anne-Lise Ducournau Lichtenberg, Ayomi Gunawardhana, Lucie Hofmann, Rosine Mucklow, Ivo Schauwecker, and as representative of her organisation: Nuriye Vanggaard from Bristol-Myers Squibb. Browse the full list of members on our [webpage](#).

EUPATI CH will run (re-)elections at the upcoming general assembly in April 2020 and we are therefore calling for your interest for an active engagement in the association, as executive board member and also for the main charges within it. Please send your nomination in writing to the [secretariat](#), along with a statement of your motivation and a short biography (see [statutes 10.5 and 11.1](#)) no later than mid-March 2020.



SWISS PATIENT FORUM

Swiss Patient Forum 2019 - “The digital patient”



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](#).

EUPATI CH participation activities (much done and more ahead)

EUPATI Germany Summer School 17 July 2019, Munich

EUPATI CH was invited together with our Austrian equivalents to attend the summer school of the German node of EUPATI. Our president Hansruedi Völkle presented our association, its

aims and values and further explored with the other national nodes on how potential collaboration, exchange and making use of synergies can be increased. We also convened to share resources such as guidelines, documents, presentations and training modules. Read the summer school report [here](#).

DayOne Conference – Shaping the Future of Health, 9 September 2019, Basel

EUPATI CH was invited to the DayOne Conference 2019, which took place in Basel. The event attracted approximately 400 participants who followed an inspiring and extensive full-day program.

Our member Judith Safford participated in the opening patient panel discussion and later in the ethics panel together with other patient representatives. The perspectives of the three patients, who gave insights into their lives at the beginning of the event were perceived as very refreshing. This patient panel also laid an optimal foundation for subsequent discussions later on. [Read](#) more about the conference.

Reatch event: Patient*in im Fokus, 16 September, Bern

[Reatch](#) is an independent think tank for young researchers with over 250 members across Switzerland. The group invited researchers as well as EUPATI CH to one of their events entitled "Patient im Fokus".

After the presentations on the topic "Patient in Focus", the speakers Prof. Dr. Milo Puhan (University of Zurich), Annette Magnin (Swiss Clinical Trial Organisation) and Dr. Nicole Gusset (SMA Switzerland and EUPATI Fellow) jointly discussed about the role of patients in human research and how the dialogue between researchers and patients can be promoted. [Read](#) more about the event.

Call for your contribution: Survey Swiss National Clinical Trials Portal (SNCTP)

The Human Research division at the Federal Office of Public Health (FOPH) is seeking your opinion and experience which it is collecting through an online survey on the Swiss National Clinical Trials Portal (SNCTP), in order to explore the portal's intended purpose and user-friendliness. You are kindly invited to take part in this survey and share your experience, so that the FOPH can obtain meaningful results that can be used to improve the website, and thus **help to improve transparency in human research!** [Go to the survey](#).

For more information on the SNCTP studies portal and on the Coordination Office for Human Research (kofam), visit www.kofam.ch.

Active EUPATI CH engagements as patient stakeholder group

EUPATI CH is engaging as patient stakeholder group and is represented by our members in diverse initiatives, projects and studies such as the Swiss Transplant Cohort Study ([STCS](#)), [eHealth Suisse](#) patient working group, [cancer screening committee](#), and studies initiated by University Hospitals (SPITEX study, breast cancer board).

Ehealthsuisse EPD training kit

eHealth Suisse is in the pilot test phase of the training kit for the electronic patient dossier (EPD), containing a comprehensive compilation of diverse materials: guidelines, workshop material, presentation slides, quiz, group work, graphics, poster, brochures, and video clips. A glimpse of the video clips can already be taken on their [youtube channel](#).

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.

Upcoming events:

- 28 January 2020, Future Health Basel, Redesigning healthcare. Me, myself and algorithms. More information [here](#).
- 30 January 2020, Gesundheitsförderung Schweiz, Nationale Gesundheitsförderungs-Konferenz. More information [here](#).
- 23 April 2020, EUPATI CH association general assembly.

EUPATI Europe-wide updates

IMI Paradigm Patient Engagement Open Forum, 18/19 September, Brussels

The aim of the two-day [patient engagement open forum](#) was to provide a comprehensive overview of Patient Engagement (PE) from the perspectives of the different stakeholders (health care industry, patients advocates, patient organisations, regulatory representatives) and to foster collaborations and development of future joint projects. The Forum was organised by the three initiatives IMI [Paradigm](#), Patient Focused Medicine Development ([PFMD](#)) and [EUPATI](#).

EUPATI CH was also participating and represented by our members Cristiana Sessa and Ann-Lise Ducournau and followed with interest the interactive sessions as e.g. “compensation of patient engagement”, “legal contracts”, “plain language summaries”.

EUPATI Training for academia and industry professionals

There is currently no standardised training for professionals working in patient relations and engagement leading to too much on the job learning, diverse approaches and lack of knowledge transfer both institutional as well as experiential. This training on Patient Engagement is necessary to address the gap preventing effective patient engagement and is not intended for patient advocates and patient organisations. Next training will take place on 11 February 2020 in Brussels, more information and registration [here](#).

Cohort 4 - EUPATI Patient Expert Course

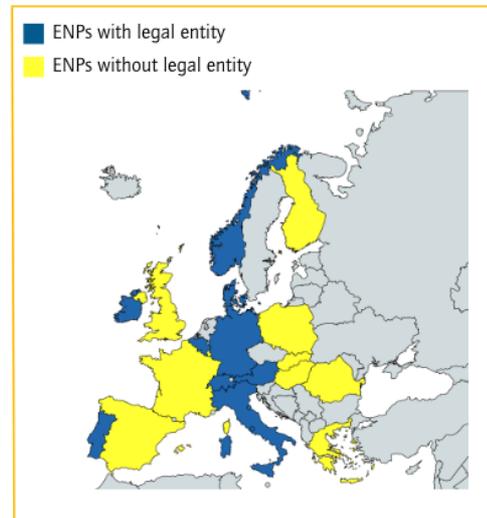
Applications are now closed for Cohort 4 of the EUPATI Patient Expert Course. With 117 applications from 33 countries it is wonderful to see the continued growth and interest in patient education. Review of applications is currently underway. Applicants will be notified whether or not they have been successful in their applications by 16 December 2019. The Cohort 4 kick-off webinar will be held on Thursday 19 December 2019.

New EUPATI 2020 Brochure

EUPATI is proud to announce that the new EUPATI 2020 [brochure](#) and [one pager](#), outlining the key facts and figures, are now available. Please feel free to use and share widely.

BY 2018, EUPATI ESTABLISHED PLATFORMS IN 19 COUNTRIES

Austria	Malta
Belgium	Norway
Denmark	Poland
France	Portugal
Finland	Romania
Germany	Slovakia
Greece	Spain
Ireland	Switzerland
Italy	United Kingdom
Luxembourg	



New, open-access reads

- “*What’s in a name? From ‘subject’ to ‘participant’*” by E. Jobson in the special supplement of the Advisor 445, ISSN 2041-3661, Canary Ltd, UK, www.canarybooks.com. Those who take part in clinical trials are usually called “subjects”, the term most commonly found in the legal documentation framing trials. Some of these people are keen to see a change from “subject” to “participants”. Read more about the debate on the [SCTO website](#).
- “*Including the patient voice in the development and implementation of patient-reported outcomes in cancer clinical trials*” by Bonnie Addario *et al.* in [Health Expectations](#). Jan Geissler, Ananda Plate and Kathy Oliver of EUPATI fame wrote this article on patient engagement in the cancer field - a brilliant example for co-creation of scientific evidence literature for advocacy.
- “*Patient empowerment and access to medicines: Insights from a scientist-patient suffering from erythropoietic protoporphyria*” by Jasmin Barman-Aksözen in [Medicine Access @ Point of Care](#). Patient representation during the evaluation of medicines by key decision makers such as regulatory agencies, Health Technology Assessment bodies, and healthcare payers is increasingly considered to add value to the appraisals and empowers patients, which means that they gain a more powerful voice over decisions and actions affecting their own health.
- “*The Patient Perspective: A Matter of Minutes*” by Rocco Falchetto in [The Patient](#). How patient input can contribute to medical product research and development processes, and raising awareness on the urgent need for a full integration of the perspective of patients in decisions affecting their health and well-being.

- “Evaluating the “return on patient engagement initiatives” in medicines research and development: A literature review”, by Lidewij Eva Vat K *et al.* in [Health Expectations](#). Currently available indicators and methods are of some use in measuring impact but are not sufficient to understand the pathway to impact, nor whether interaction between researchers and patients leads to change. The authors suggest that the impacts of patient engagement can best be determined not by applying single indicators, but a coherent set of measures.
- “Patient views on research use of clinical data without consent: Legal, but also acceptable?” by G. Richter *et al.* in [European Journal of Human Genetics](#). The authors examined whether abolishing consent for secondary data use would be acceptable to patients and conducted a survey among 700 outpatients of a hospital to assess their attitude towards use of clinical data for scientific research without consent.
- “Effective involvement: a report on the evaluation of a research awareness training package for public involvement in health research” by C. Richardson *et al.* in [Research Involvement and Engagement](#). This evaluation validated a training package and demonstrated the value and impact of Public Involvement at all levels in research.

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.

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