

Welcome

Welcome to the 03/2017 edition of the **EUPATI CH** newsletter dealing with updates and information about the association, our activities, and the everyday life of our stakeholders and members.

If you know patient advocates who are getting involved in exciting ways, let's share their stories. One example is that of [Estelle Jobson's](#) career step. Thanks to her 2016 training as a **EUPATI patient expert**, she was elected communications officer of the EUPATI CH association and hired as communications manager at the Swiss Clinical Trial Organisation (SCTO) from October 2017. This merges her prior professional experience with her newly acquired knowledge of medicines R&D and background in patient advocacy, putting it all under one roof.

Highlights in this newsletter:

- Successful Swiss Patient Forum 2017
- EUPATI CH association news
- Publication, events, and good to know

Successful EUPATI CH “Swiss Patient Forum” on 27 October 2017



On 27 October 2017, EUPATI CH hosted the “**Swiss Patient Forum**” on *patient information – what patients want and need to know*. During the workshop morning, patient representatives elaborated on key criteria for patient information and discussed in what ways these criteria should be reflected in the diverse forms of patient information.

During the plenary sessions in the afternoon, the results of the workshop were presented together with views of the other stakeholders attending. These included academia, the pharmaceutical industry, and the authorities.

As EUPATI CH's annual flagship event, the “**Swiss Patient Forum**”, is a full-day event including several lectures and a workshop. It is designed to train patient advocates and empower them to become active and meaningfully engaged. The forum was initiated by Janssen-Cilag AG and transferred to EUPATI CH, which is now co-sponsored by Janssen and Takeda AG. This year, the event was held in German in north-western Switzerland, so the next ones will be held in the Romandie and then in the Ticino.

EUPATI CH association news

EUPATI CH welcoming new members

We warmly welcome our new members, representing their institutions: Karin Holm of Patient Advocates for Cancer Research and Therapy (PACRT), and as individual members: Julia Amann and Thomas Lanzewizki. Please join forces with us! The full list of members is viewable on our [webpage](#).

EUPATI CH, General Assembly (Basel, 26 October)

EUPATI CH held its General Assembly on Thursday 26 October, 2017 in the Wildt'sche Haus in Basel. The members of the Executive Board and its bodies were confirmed and we congratulate: Hansruedi Voelkle as president, Caecilia Schmid & Rosine Mucklow as secretaries, and Estelle Jobson as communications officer.

The positions of the vice-president and treasurer are still vacant.



The strategy and workplan of EUPATI CH were presented to the members (also [on our website](#)) and the plans for communication activities of the association discussed. EUPATI CH was able to secure funds for 2018 to increase communication activities and implement this through several channels. The sponsors of the communication projects will be publicly disclosed on our website once the agreements are signed.

Follow us on [facebook](#) or twitter ([@EUPATI_CH](#)), share our newsletter, or visit our [website](#).

EUPATI CH visibility and participation

Semi-annual meeting of SAKK and its patient forum (Zurich, 23-24 November)

EUPATI CH was represented by members of the association at the [SAKK semi-annual meeting](#) and given the opportunity to present our roll-up banner and distribute the poster to the SAKK patient forum.

EUPATI CH at ESGO ENGAGE (Vienna, 4-5 November)

EUPATI CH attended the Patient Seminar of the European Network of Gynaecological Cancer Advocacy Groups ([ESGO](#)) in Vienna, Austria on 4-5 November 2017. There were about 40 European Network of Gynaecological Cancer Advocacy Groups ([ENGAGE](#)) present at this two-day event. Oncologist Prof Cristiana Sessa, from EUPATI CH, also one of the chairs of the seminar, did a presentation for the patient advocates on "What is a clinical trial?". The experience was a rich mix of roundtable input from experts, updates on developments in treatments, and supportive exchange among patient groups. Estelle Jobson represented EUPATI CH as patient advocate.

Events, publications and good to know

Public debate in Lausanne: Personalised health and society

You are invited by the SantéPerSo Platform to a public debate (in French) on "Predictive Medicine: Shall we dream or be apprehensive?", planned for 8 February 2018. To consult the programme and reserve your place, view the [relevant information](#).

Public access to the Swiss portal for clinical trials (SNCTP)

Each clinical trial in Switzerland must be registered in an appropriate registry. Switzerland has setup an online portal which is operated by the Federal Office for Public Health (FOPH) and contains all relevant trial information for trials run in the country. Information about these trials can be publicly accessed on the website of the [portal for human research](#). You can find more information on the [FOPH website](#).

EMA's unparalleled access to clinical data - one year on

One year ago, the European Medicines Agency (EMA) became the first regulatory authority to give open access to clinical data submitted by companies in support of their marketing authorisation applications. EMA's initiative resulted in over 3,000 clinical documents published, 3,600 registered users, and positive stakeholder feedback. Read more about the initiative under www.ema.europa.eu.

What is the added value of patient organisations?

The European Patients' Forum (EPF) has just launched its new publication (36 pages in English), [The Added Value of Patient Organisations](#) – comprehensive, accessible and attractive. Watch this [video](#) interviewing one of the authors, Dorota Sienkiewicz, discussing the value of this publication.



Partnering with patients at the HUG, Geneva

As part of its Vision 2020 strategic plan, the University Hospitals of Geneva (HUG) are running a programme to partner with patients. “As recipients of services, patients are indeed in a good position to assess their quality and their suggestions are crucial to identify areas for improvement.”

To find out more or join the [HUG patient partners](#), contact patients.partenaires@hcuge.ch or visit their website.

Interesting reads about patient and public involvement in healthcare and medicinal R&D

- Network methods to support user involvement in qualitative data analyses. [Trials 2017](#)
- Extent, quality, and impact of patient and public involvement in antimicrobial drug development research. [Health Expectations 2017](#)
- Patient involvement in the development of patient-reported outcome measures. [Health Expectations, 20](#)
- GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. [Research Involvement and Engagement 2017](#)

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](#).