
EUPATI CH Newsletter 7



Bern, June 2019

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

- General Assembly 2019 and Annual Activity Report 2018
- Swiss Patient Forum 2019, save the date 25.10.2019
- Portrait of our fellow, Max Lippuner
- EUPATI CH participation activities

General Assembly 2019 and Annual Activity Report 2018

We held our General Assembly on 25 April 2019 in Bern, which was attended by members of the association as well as the members of the independent Advisory Board and invited guests. The General Assembly approved the annual activity report as well as gave green light to the planned activities in 2019.

The [annual report](#) 2018 is ready and online for download in English, German, French and Italian! 2018 was the second full and busy year of operation of EUPATI CH. And this was only possible thanks to the voluntary engagement from our members, the EUPATI Fellows and the professional support by our secretariat. All our activities were only made possible thanks to our generous sponsors.



Save the date: Swiss Patient Forum 2019 on 25 October in Bern

The **Swiss Patient Forum** 2019 will take place on 25 October in Bern in German with the title “Der digitale Patient”.

Please save the date, an invitation and programme will follow shortly as well as on our [webpage](#).

EUPATI CH welcoming new members

We warmly welcome our latest member, Judith Safford as an individual member. To date we have 31 members, 16 of those are representatives of patients or patient organisations, 10 are from academia, and 4 individual members and 1 from industry. Browse the full list of members on our [webpage](#). Please join forces with us!

Introducing Max Lippuner, our fourth 2018 Swiss fellow

Throughout 2018, we’ve been continuously introducing you to our third cohort of Swiss-based fellows undergoing the EUPATI training as patient experts: [Hansruedi Völkle](#), [Malena Vetterli](#), [Dr Nicole Gusset](#) and presently, [Max Lippuner](#). The third trainee [cohort](#) successfully graduated in January 2019, forming a total of **more than 150 EUPATI alumni Europe-wide, covering at least 80 disease areas.**



Max Lippuner, founder and president of [Europa Uomo Switzerland](#) (EUS, umbrella organisation for men’s cancer, in particular prostate, testicles, bladder and urethra cancer) is a prostate cancer patient since 2007.

As president of EUS, he mainly engages in public awareness on risks, early detection and treatment of men’s cancer and promotes specific prostate-cancer rehabilitation in Switzerland. [Read more](#)

“The EUPATI Patient expert training gave me a huge basic education for my work in patient-advocacy and as a patient advocate. I understand now how the R&D processes of the Swiss health system are working, as well as what is done on the European level”.

EUPATI CH activities (much done and more ahead)

Stakeholder analysis – preliminary results

Our member Prof. Cristiana Sessa is currently performing a stakeholder analysis of and for EUPATI Switzerland within the framework of her [ECPM](#) Master in Medicines Development, supervised by David Haerry (Patvocates), Caecilia Schmid and Annette Magnin (both SCTO). In an online survey, she gathered the opinion of 55 different people, a representative sample of our stakeholders with responders from patient organisations, academia and industry, whereas 30% of the responders are members of EUPATI CH. At the General Assembly, Cristiana Sessa presented some preliminary results which will lead to in-depth interviews with selected stakeholders.

The stakeholder analysis will inform EUPATI CH of the needs and expectations of our stakeholders and thus help us shape the future strategy and workplan of our association. The results will be published in an open access journal towards the end of the year.

Healthcare Business Women Association 21 March, Zurich

Our member [Debra De Silva-Sun](#) had the great opportunity to represent and share information on EUPATI CH at the **Healthcare Businesswomen Association** event, organised by Roche Schweiz AG at the University Hospital Zurich. Experts shared their vision and understanding of the value of precision medicine, how it will shape future cancer treatment and change the lives of cancer patients. During the panel discussion, the participants gained insights into how this academic-industry collaboration started, how it works and how it may also offer learnings for other disease areas where personalised patient care is becoming a reality. [Event information](#).

Ticino Breast Cancer group 5 April, Ticino

On April 5th, we had the first informative meeting of EUPATI CH with a group of [breast cancer patients](#) of Ticino. After an introduction on the EUPATI CH mission, objectives and current activities, the Italian version of the EUPATI Toolbox was demonstrated.

The patients were very interested in the glossary, which provides written explanations to words or expressions. They wish to further explore the EUPATI Toolbox in a guided manner with health care professionals.



IMI Paradigm Workshop 27 March, Berlin

On 27 March 2019, our EUPATI Fellow [Estelle Jobson](#) took part as a patient representative in the [IMI-PARADIGM's Workshop](#) in Berlin. The workshop “Towards Consensus on a Monitoring and Evaluation Framework”, explored this framework and compiled ideas on how to apply it. This is one piece of the puzzle towards realising a sharable, online tool to help clarify return on engagement (not return on investment) for projects that include patients. The exchange was rich and interactive.

CIOMS Open Meeting on Patient Involvement 30 April, Geneva

Our members [Estelle Jobson](#) and [Matthew May](#) attended the **CIOMS Open Meeting on Patient Involvement in Development and Safe Use of Medicines** in Geneva, representing EUPATI CH and EUPATI overall coordination. The aim of the meeting was to seek wider input from various stakeholders through an open pre-meeting to the CIOMS working group, developing a report on patient initiatives globally. This pre-meeting also marked the 70th Anniversary of CIOMS. Watch the [press briefing video](#).

Estelle and Matthew were both briefly on panels and pleased to see numerous mentions of EUPATI throughout the day made by several parties. The reputation of EUPATI has obviously grown since its foundation in 2012.

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.

EUPATI Europe-wide updates

New EUPATI platform: EUPATI Luxembourg has been established

On April 5, 2019, EUPATI Luxembourg has signed its statutes as an association. Read more on their [Twitter Feed](#).

EUPATI National Platforms annual assembly, 20 May, Copenhagen

Once a year, the EUPATI national platforms (ENPs) active across Europe come together to share experiences, lessons learned, and refine their collaboration for the future ([EUPATI Newsflash June 2019](#)). Representing the Swiss platform, our members Estelle Jobson, Caecilia Schmid and Olivia Walther attended the meeting together with delegates from 23 different countries. This year's focus was on “*developing a common national platform message*” to support the national platforms to better articulate what we do and stand for. The delegates also developed several tools (poster, slide deck, animated movie) to support the dissemination of our common message.

European platform on Rare Diseases Registration

On 28 February 2019, at the occasion of the Rare Disease Day, the European Commission announced a new EU platform to support better diagnosis and treatment for more than 30 million Europeans living with a rare disease. The goal of the [European Platform on Rare](#)

[Diseases Registration](#) is to collect patient data scattered all over Europe. Read the [press release](#) for more information.

EU Roadmap Initiative to Good Lay Summary Practices: Meeting with strong EUPATI Presence, 11 March, Brussels

The Clinical Trial Regulation [EU 536/2014](#) will come into effect in the second half of 2020. The regulation requires the dissemination of a Lay Summary within 12 months after the end of the study. This will give patients better, understandable, and reliable access to the results of clinical trials that might change their lives and allow them to disseminate this information within their communities. A group of concerned stakeholders met to create a “Roadmap Initiative to Good Lay Summary Practices” to find a systematic approach which supports the development of such a lay summary. This initiative will help to provide our community with concrete recommendations to implement the Lay Summary process. Members of the extended EUPATI network are also contributing to the working groups’ representatives from EFGCP, EFPIA, EPF, ECRIN, EORTC, EATG, AGAH, Boehringer Ingelheim, and AstraZeneca. ([Read more](#))

New, open-access reads

- “Co-creation of patient engagement quality guidance for medicines development: an international multi-stakeholder initiative”, by K. Deane et al. in [BMJ Innovations](#).

In this article, the authors described the methodological four-step approach towards the co-creation of a pilot meta-framework for patient engagement: this requires multi-stakeholder, long-term investment in a global and collaborative venture.

- “Patient involvement in clinical trials: motivation and expectations differ between patients and researchers involved in a trial on urinary tract infections” by I. Schilling *et al.* in [Research Involvement and Engagement](#).

Patient involvement in clinical trials is a reality. There are different expectations and motivations from both researchers and patients which can hamper the involvement. Discussing the roles and tasks of involved patients and researchers in the beginning is necessary to develop a common understanding of PPI and to address patients’ insecurities.

- “Patient Preference Studies During Early Drug Development: Aligning Stakeholders to Ensure Development Plans Meet Patient Needs” by N. Cook *et al.* in [Frontiers in Medicine](#).

In this publication, the authors provide three hypotheses in support of input from patient preference studies early in the development of therapeutics. In addition, the relevance of assisting in the development of treatments and products that are relevant to patient needs is described.

- “Meet the researchers: an alternative method of engaging patients with research in mesothelioma” by K. Hill *et al.* in [Research Involvement and Engagement](#).

This article describes a method of public engagement called “Meet the Researchers” which enables patients and all interested parties to find out more about current trends in research in a face to face setting, together with the researchers planning or conducting it.

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, Rosine Mucklow and Estelle Jobson

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, Account No: PC 89-565298-4