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## EUPATI CH Newsletter 1/2018



Bern, 10 May 2018

### Welcome

Welcome to the 1/2018 edition of the **EUPATI CH** newsletter. We're bringing you updates and news about the association, our activities, and the life of our stakeholders and members. Please tell us about your stories, successes, and resources, so we can share them with our readers.

#### Newsletter highlights

- A snapshot from our General Assembly (Bern, 26 April)
- Announcing the Swiss Patient Forum 2018, autumn in Lausanne
- Meet our Swiss fellows in training
- Training and participation opportunities

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### A snapshot from our General Assembly (Bern, 26 April 2018)

We held our General Assembly on Thursday 26 April 2018, in Bern. EUPATI CH has grown over the past year to a total of 26 members: representatives of patient organisations, academic institutions, and the pharmaceutical industry. Our [Annual Report](#) was approved and is now online in English and three national languages. The EUPATI CH workplan 2018 was presented to the members and the plans for [communication activities](#) of the association were approved. EUPATI CH was able to secure funds for 2018 to expand these communication activities, organise the Swiss Patient Forum, and receive support for the long-term strategic planning. Our sponsors will be publicly disclosed on our website once the agreements are signed.

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## SWISS PATIENT FORUM

**Save the date: Swiss Patient Forum in Lausanne, 28 September or 5 October 2018**

The 2018 Swiss Patient Forum will be held in French in the Romandie, in Lausanne. Save the date to share your views, experiences, and vision on *quality of life*.

We will retain the format of the event, with an interactive workshop in the morning for patient representatives and a plenary session in the afternoon open to a wider audience.

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### EUPATI CH welcoming new members

We warmly welcome our new members, representing their institutions: Olivia Walther for Janssen-Cilag AG, Andrea Schäfer for Nierenpatienten Schweiz, and as individual members: Max Lippuner and Steven Bourke. The full list of members is viewable on our [webpage](#). Please join forces with us!

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### Meet our Swiss fellows in training

In our 2018 newsletters, we'll be introducing you to our third group of Swiss-based fellows undergoing the EUPATI course for patient experts, starting with **Dr Hansruedi Völkle (Positivrat)**. You will know him as our EUPATI CH President, but through this training, he is switching from being a teacher of students, to a student himself.



Hansruedi originally studied physics and radiation protection, obtained his PhD, and became *Professeur Titulaire* at Fribourg University. He then worked for many years at the Swiss Federal Office of Public Health in the domain of environmental radioactivity and radiation protection. He was a longstanding member of the the board of the Swiss Aids Federation (Aids-Hilfe Schweiz) and ran as its president from 2008 to 2011, as well as being member of the Swiss Federal AIDS Commission. He is currently member of the Positive Council Switzerland and has been our EUPATI CH President since 2016.

In February, for his training, Hansruedi met 53 fellow participants from 27 European countries, with their teachers and monitors in Madrid.

*“The three-day meeting was intense and motivating, but demanding. It was well-structured and balanced between teaching and interactive working. The cultural and linguistic diversity of Europe and the way we are able to cooperate, notwithstanding, is amazing.”* Read the full article [on our website](#).

In forthcoming newsletters, you'll meet the other Swiss-based fellows in training: **Nicole Gusset** (SMA Schweiz), **Malena Vetterli** (FMF & AID Global Association), and **Max Lippuner** (Europa Uomo Schweiz).

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## EUPATI CH participation opportunities (much done and more ahead)

### *Ways we have been active and participating*

So far, 2018 has brought us an abundance of opportunities to participate, contribute, and share our expertise and experiences. Opportunities have included: being invited onto a **community advisory board**; **joining a patient working group** with e-health Suisse; **advising** the academic community, researchers and students, clinical trial units and their staff, by offering a perspective on the relevance of patient engagement (generally and relating to paediatrics); as **panellists**, engaging with science journalists; and **taking part** in and circulating several Europe-wide and international **surveys** – including for Cochrane Crowd, the European Medicines Agency (EMA), the Clinical Research Initiative for Global Health ([CRIGH](#)), and [Pain Alliance Europe](#).

### *Seminar for science journalists*

On 21 March 2018, the Swiss Academy of Medical Sciences, the Swiss Clinical Trial Organisation, and Interpharma jointly held a seminar about personalised health and Big Data in Zurich. It reached over 70 attendants: science journalists, actors in the scientific area, representatives from the authorities and from health insurance providers. Dr Deborah Mascalon, Centre for Research Ethics & Bioethics, Uppsala University, showcased two positive, highly successful models of informed and dynamic consent for patients in her [presentation](#). Representing EUPATI CH, Estelle Jobson offered the patient perspective, proposing engaging patients in steps of increasing complexity and in different formats, so they can grow into their new knowledge.

### *Calls for participation in public consultation currently open*

You're invited to participate, too! The Federal Office of Public Health (FOPH) is revising some legislation, of particular relevance, the [Swiss Human Research Act](#). Proposed revisions include making it mandatory to have a patient on an ethics committee. Accordingly, the FOPH is inviting the public to comment. At EUPATI CH, we wish to collect and combine feedback from you, individuals and organisations, to create a stronger voice. **The deadline for your feedback is 4 June 2018**. Please send us your comments by email to our [Secretariat](#).

### *Contribute to Patient Focused Medicines Development*

In the spirit of committing concretely to meaningful patient engagement, Patient Focused Medicines Development (PFMD) aims to establish a systematic and consistent approach to patient involvement at a global level – a worldwide, accepted standard for how and when patient engagement should occur. PFMD would like to hear from patients, patient groups, the pharmaceutical industry, and regulators. Please share your goals, plans, and work with them. Register and find peers at [PFMD](#).

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## EUPATI European updates

### ***EFO-EUPATI***

Looking to build longer-term sustainability, EUPATI central responded to a call from the Innovative Medicines Initiative (IMI) in October 2017. It submitted a proposal of three main themes (EUPATI sustainability, IT infrastructure, and the national platform network), called EFO EUPATI. We are delighted to say that this proposal has passed the first threshold of evaluation and is now in negotiation for final approval. We will let you know after the final stages have evolved and a decision is made. To see how far we have come, read this [interview](#) with Jan Geissler reflecting on the origins, development, and importance of EUPATI in patient education, together with this [EUPATI factsheet](#) and timeline.

### ***PARADIGM***

On 10 April, our [EUPATI peers across Europe](#) attended the first meeting following the launch of Patients Active in Research and Dialogues for an Improved Generation of Medicines ([PARADIGM](#)). PARADIGM's mission is "to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement and demonstrates the 'return on the engagement' for all players. It is calling for all stakeholders to make a "Made with patients" pledge to patients. Watch this short [video](#) to find out more about this exciting initiative.

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## Training opportunities

Share these inspiring and enriching training opportunities with your peers and with patients you know.

### ***EUPATI training opportunities***

- EUPATI Italy is undertaking the translation of the entire expert training course into [Italian](#). To express your interest, please get in touch with Silvia Starita on [s.starita@accademiadeipazienti.it](mailto:s.starita@accademiadeipazienti.it)
- The vast EUPATI Toolbox has new, topical training material. A recent addition is a [starter kit](#) on taking part in community advisory boards. Community advisory boards are patient, community-led, neutral spaces where stakeholders in medical R&D and clinical trials can meet to discuss scientific (or policy) matters and questions. To discover how helpful users find the Toolbox to be, read these [published survey results](#).
- You can always draw upon the ever-expanding repertoire of EUPATI [webinars](#) and other video resources on [vimeo](#).

### ***Other local and international training opportunities***

- [Bénévolat-Vaud](#) offers training and workshops in the French part of Switzerland yearlong to [volunteers](#), [associations](#), and [support groups](#).

- The European Patient Ambassador Programme ([EPAP](#)) is offering a free, online learning programme introducing patients and carers to the essential skills and knowledge they need to interact with healthcare professionals, policymakers, researchers, and journalists. It is currently available in English and Dutch. To find out more, browse the [EPAP course overview](#).
- European Communication on Research Awareness Needs ([ECRAN](#)) has launched a series of videos explaining the process of clinical trials in six languages, including three Swiss national ones.
- The Global Health Training Centre has a rich collection of training resources, for patients and professionals of all skill levels, offering an international perspective. Start by exploring their e-learning [short courses](#).

### *New, open-access reads and nuggets of interest*

- “Early-career researchers’ views on ethical dimensions of patient engagement in research”, published in [BMC Medical Ethics](#).
- “Advancing patient engagement: youth and family participation in health research communities of practice”, in [Research Involvement and Engagement](#).
- “Enhancing the incorporation of the patient’s voice in drug development and evaluation”, in [Research Involvement and Engagement](#).

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## **Membership applications**

EUPATI CH is open for membership to anyone interested. You are welcome to join as an individual, an organisation, or a member of academia or industry. Please find the application form and more details on our [webpage](#).

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## **Contact**

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