
EUPATI CH Newsletter 2/2018



Bern, August 2018

Welcome

Welcome to the 2/2018 edition of the **EUPATI CH** newsletter. We hope you enjoy the following updates and news about our association, 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

- You're invited: Swiss Patient Forum 2018, Friday, 28 September, Lausanne
- Meet our Swiss fellow in training, Malena Vetterli
- EUPATI's Europe-wide news
- Training and participation opportunities



You're invited to the Swiss Patient Forum 2018!

On Friday, 28 September 2018, from 9h00–17h00, we're holding our second ever Swiss Patient Forum, this time on the topic of **quality of life for patients**. The daylong Forum will be held in Lausanne in French to serve the region's community, and will be moderated by science journalist, Elisabeth Gordon.

The morning session is devoted to *patients only* and will enable them to explore the topic of quality of life according to their perceptions, experiences, and needs. The afternoon, *a public plenary*, will focus on how quality of life links to the patient's working life. You'll hear speakers offering views and insights from different perspectives and moderated discussions.

Attendance is free, but registration is mandatory. Please register via this [link](#) or per email to secretariat@ch.eupati.eu by **10 September** latest.

EUPATI CH welcoming new members

We warmly welcome our new member, Debra De Silva-Sun. The full list of members is viewable on our [webpage](#). Please join forces with us!

Meet our Swiss fellows in training

In our 2018 newsletters, we're introducing you to our third group of Swiss-based fellows undergoing the EUPATI course for patient experts. Meet our member **Malena Vetterli**, founder and president of [FMF & AID Global Association](#): Familial Mediterranean Fever and Autoinflammatory Diseases, established in Zurich in 2017. The association has been elected into the European Reference Networks (ERN) Patient Advocacy Group, to actively represent patients. Malena is also a member of the Novartis Autoinflammatory Council and has been asked to represent the patient voice at EULAR and in an EU financed project.



About the training course, Malena commented: *"The few gaps I had are being well addressed through the EUPATI course. After completing this course, I will be a recognised patient expert. What's more, I expect to be much more actively involved in determining the course of future research into medicines for Familial Mediterranean Fever and other auto-inflammatory diseases."*

Like many patient representatives, Malena faced numerous obstacles and mounting difficulties seeking diagnosis and treatment, when her son developed serious health issues. Since there was little information or help available, Malena turned to the internet and social media in search of answers and there she found many patients and carers in a similar situation. In 2011, she heard for the first time about FMF and AID, causing inflammation of the internal organs. Having finally found a name for her son's condition, she reached out to connect with many other patients.

In the next newsletter, you'll meet the other Swiss-based fellow in training: Dr **Nicole Gusset** (President SMA Schweiz).

EUPATI CH participation opportunities (much done and more ahead)

Ways we have been active and participating

2018 has brought us yet further opportunities to participate, contribute, and share our expertise and experiences. Opportunities have included: joining a **patient working group** with [eHealth Suisse](#) on the implementation of the nationwide electronic patient dossier; joining a **patient advisory board** with the Swiss Transplant Cohort Study ([STCS](#)); **advising** the academic community and researchers on a proposal preparation for funding application for a patient advisory board in personalised health projects; holding a **booth and presentation** at the trination German-language [DACH Symposium](#) on clinical research, and doing **patient peer review** for the [British Medical Journal](#).

EUPATI CH new promotional material

Are you enjoying the new, clean layout of this newsletter? We've made it more reader-friendly. Please share it with others.

Additionally, we have developed new postcards, flyers, and a give-away (a nifty pillbox-pillcutter combined) to spread the word about EUPATI and our goals. We're passing on the motif that patients are the missing puzzle piece in better medicines.

Please get in touch with us if you wish to distribute some material at events or among your network. You're also welcome to join us on [twitter](#) and [facebook](#).

DACH Symposium, 11–12 June 2018, Zurich

Our secretariat held a booth over two days of the trination DACH Symposium “Klinische Prüfungen”, a German-language conference on clinical research. The Symposium was attended by more than 500 participants, including researchers, study nurses, and other clinical study staff. There was also strong interest in the EUPATI toolbox, as a way to train up patients to become more informed potential participants.

Patient engagement was on the agenda at the Symposium. There were dedicated sessions, with presentations from patient advocate David Haerry, academia, and pharma discussing the pressing challenge of patients' responsibilities in clinical research.



Would you like to hold a EUPATI stand at an event you are attending? Please get in touch with us.

SwissPALS event, 5 June 2018, Zurich

Rosmarie Pfau and Hansruedi Voelkle represented EUPATI CH at SwissPALS (Swiss Patient Advocacy Leadership Summit), a meeting organised by the pharmaceutical companies of Pfizer, Novartis, and GSK. The topic of the day was “Information exchange with policy-makers – how can patient organisations gain a voice in Bern?”. The numerous representatives from patient organisations who attended received valuable information on the ABCs of political work and lobbying and on the importance of networking and pooling synergies and energies. Unfortunately, no health politics representative was present to answer the many questions the participants had.

EUPATI National Platforms annual assembly, 8–9 May 2018, Berlin

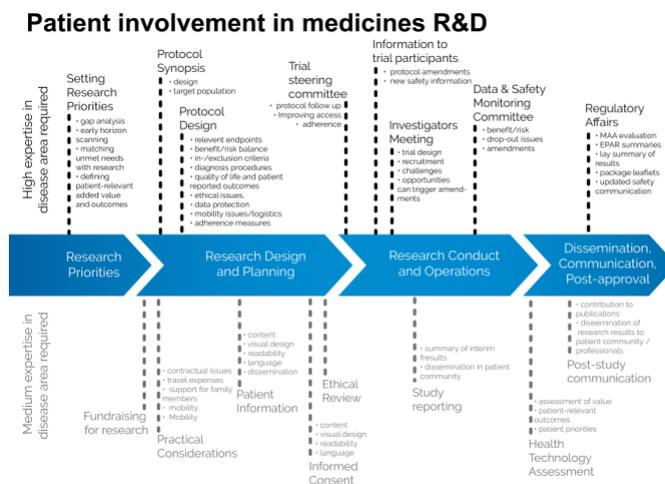
Once a year, many of the EUPATI national platforms (ENPs) active across Europe come together to share experiences, lessons learned, and refine their vision for the future. Representing the Swiss platform, Rosmarie Pfau and Caecilia Schmid attended the meeting together with delegates from 18 different national platforms and received an update on EUPATI’s Europe-wide plans. The national platforms then informed one another of the challenges they have encountered, and held discussions and workshops on how best to shape the future of EUPATI and to further patient education and engagement. The learning gleaned from this meeting will be channelled into the newly funded IMI project, [PARADIGM](#).

EUPATI European updates

“Author of the year” award for founding EUPATI roadmap

Hearty congratulations to the pioneering author team of Jan Geissler, Bettina Ryll, Mary Uhlenhopp, and Susanna Leto on winning an exceptional [award](#) for their [article](#), "Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap". The article was first published in *Therapeutic Innovation & Regulatory Science* in 2017. The four co-authors were awarded “Author of the year” by the Drug Information Association (DIA), since this article has become one of the most popular in the journal, downloaded in full text over 1,800 times.

The [roadmap](#) featured has become a widely used practical guide on how to involve patients in a meaningful way along the four key stages of the medicines R&D life cycle.



Training opportunities

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

EUPATI training opportunities

- A new EUPATI webinar on [Community advisory boards \(CABs\)](#) is up online. A CAB is an effective and increasingly widely used structure to create neutral and scientifically framed platforms for all stakeholders involved in medicines R&D to interact on an equal footing. CABs are run and controlled by the patient community, and focus on adding patient input into the research and policy processes, in a structured and unbiased way.
- The vast [EUPATI toolbox](#) is now available in 9 (!) different languages. It encompasses a variety of learning and teaching materials, from graphics, simple fact sheets, and publications, to complex training modules. Note the toolbox material in [French](#), [German](#) and [Italian](#).
- You can always draw upon the ever-expanding repertoire of EUPATI [webinars](#) and other video resources on [vimeo](#).

Other local and international training opportunities

- Uppsala Monitoring Centre has a wealth of online training material on [YouTube](#), such as this lecture on [communicating pharmacovigilance](#).
- The Global Health Training Centre has a rich collection of training resources, for patients and professionals of all skill levels, offering an international perspective. Their [video seminar archives](#) is a good section to explore.

New, open-access reads and nuggets of interest

- “What do stakeholders expect from patient engagement: Are these expectations being met?”, by M. Boudes *et al.* in [Health Expectations. 2018, 1–11](#).
 - “Inverting the patient involvement paradigm: defining patient led research”, by L. Mader *et al.* in [Research and Engagement. 2018, 4-21](#).
 - The award-winning article mentioned above: “Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap”, by J. Geissler *et al.* in [Patient Engagement. 2017, Vol. 51\(5\), 612-619](#).
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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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