
EUPATI CH Newsletter 3/2018



Bern, December 2018

Happy festive season!

Welcome to the 3/2018 edition of the **EUPATI CH** newsletter, bringing the year to a close. 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. We look forward to sharing 2019 with you, a year rich in interesting patient-centred projects.

Newsletter highlights

- Meet our Secretariat
- Portrait of our fellow in training, Nicole Gusset
- Swiss Patient Forum 2018, a success
- Social media highlights

Introducing the EUPATI CH Secretariat



Behind the scenes of EUPATI Switzerland, plenty of work gets done. Meet our small, yet industrious Secretariat (from left to right): Rosine Mucklow, Caecilia Schmid, and Estelle Jobson. The Swiss Clinical Trial Organisation ([SCTO](#)), where we are based, hosts the Secretariat

to support patient engagement in the country. In every newsletter, we'll be profiling our people, members, and fellows, introducing you to one other. We're stronger together.



Successful Swiss Patient Forum 2018!

At the **Swiss Patient Forum** held on 28 September 2018, EUPATI CH brought together a vibrant group of patients, representatives, and their caretakers to brainstorm burning questions about the "*quality of life of patients*", in a welcoming atmosphere.

The workshop report, presentations, and wonderful photos capturing the spirit of the day are now [online](#).

EUPATI CH welcoming new members

We warmly welcome our new members, Alice Grosjean Espinosa representing the Association Romande du Syndrome de Sjögren ([ARSYS](#)) and Vanya Lorocho as an individual member. Browse the full list of members on our [webpage](#). Please join forces with us!

Introducing Nicole Gusset, our third 2018 Swiss fellow in training

Through 2018, we've been introducing you to our third group of Swiss-based fellows taking the EUPATI training for patient experts: [Hansruedi Völkle](#), [Malena Vetterli](#) and now, [Dr Nicole Gusset](#). She and her peers in the third trainee [cohort](#) will be graduating in early 2019, following on 15 months of intense study. Altogether these graduates will form a total of **more than 150 EUPATI alumni Europe-wide, covering at least 80 disease areas**.

Nicole is founder and president of [SMA Schweiz](#), an organisation aiming to recognise and encourage promising research approaches in spinal muscular atrophy ([SMA](#)) and to bring these therapies to the patients. SMA is a rare genetic neuromuscular disease characterised by muscular atrophy and weakness.

Ever since her firstborn daughter, Victoria, was diagnosed in 2011 with SMA Type II, Nicole has been investing her time in patient advocacy.



“The EUPATI patient expert training provided me with tools to advocate in an even more effective and goal-orientated way for the needs of patients,” said Nicole about the training.

“The face-to-face meetings were especially inspiring. They provided us with a wealth of information that cannot be read in books, but can only be learned by talking to others and exchanging our experiences.”

EUPATI CH activities (much done and more ahead)

Social media activities, on the up and up!

Our social media activities are soaring! We owe a huge thanks to our member, Steven Bourke, for channelling his health communications expertise into creatively and diligently setting up a new professional profile for us on [Linkedin](#). Join us there for serious news, updates, and calls for participation relating to patient engagement, in Switzerland and beyond.

In a record-breaking moment, a [post](#) of ours on Facebook, announcing the success of our Swiss Patient Forum, reached 880+ people. One of our [tweets](#), commenting on patient perspectives shared at the *British Medical Journal* ([BMJ](#)), garnered an astonishing 7,000 impressions (meaning the number of times users saw the tweet).



EUPATI_CH @EUPATI_CH · Nov 19

7,011

Thank you to [@bmj_latest](#) for putting together interesting, insightful blogs, opinion pieces, and getting [#patientsinvolved](#), such as this one with input from a Eupati [@eupatients](#) trained patient expert. Patients, make your voices heard. [twitter.com/bmj_latest/sta...](https://twitter.com/bmj_latest/status/1041111111)

[View Tweet activity](#)

Join in the debates and share your news on [twitter](#), [facebook](#) and [Linkedin](#).

EUPATI Europe-wide updates

EUPATI celebrates its one millionth visitor to the toolbox

Who wants to be a millionaire? The EUPATI websites do! At least, in reaching millions of people. In less than three years, the EUPATI website and its [Toolbox](#) have reached the milestone of 1,000,000 (yes, one million individual users have visited the site)! A competition was held to guess the magical date of achievement. The winners, who won a EUPATI mug, were avidly engaged EUPATI people, Kay Warner and Caecilia Schmid.



WE HAVE A WINNER!
(actually two)

Caecilia Schmid, the Coordinator of Eupati Schweiz / Suisse / Svizzera, and Kay Warner of GSK came closest when guessing the date when the EUPATI Toolbox would reach 1,000,000 individual visitors. It happened on the 8th October, and there has been an exponential growth in the number since then! Congratulations to our two colleagues who are now happy owners of an EUPATI mug.

Tag photo Add location Edit

371 People reached 63 Engagements Boost Post

18 2 shares

Announcing the publication of pioneering EUPATI guidances

Throughout 2018, many excellent articles and resources were released. A crowning feature of the six years of EUPATI is a four-part series of EUPATI guidances, co-written by EUPATI consortium partners and collaborators, and published in as peer-reviewed articles in an open-access journal, *Frontiers in Medicine*. The series encompasses patient involvement in R&D, specifically: in [regulatory processes](#), in Health Technology Assessment ([HTA](#)), in the [ethical review](#) of clinical trials, and in [pharmaceutical industry-led medicines R&D](#).

You can find these guidances, along with other valuable publications, on our [Advocacy Resources](#) webpage.

Getting to grips with the GDPR

The EU's new General Data Protection Regulation (GDPR) is here and there is no escaping it, not even behind the Swiss Alps. The ever-growing library of EUPATI webinars now includes one about the impact of GDPR on clinical trials. Find out how GDPR influences the organisation of and recruitment for trials. Two legal experts discuss these consequences and what they foresee, from the perspective of medicines R&D. You can watch the webinar and view the presentations [here](#).

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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