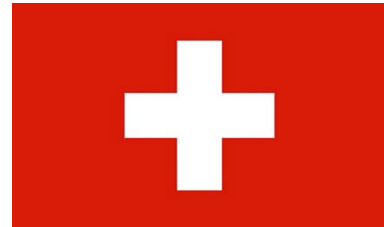


Swiss League Against Epilepsy 2021-2022 Report

CHAPTER OFFICERS

Prof. Dr. med. Barbara Tettenborn, President
PD Dr. med. Lukas Imbach, Vice President
Urs Sennhauser, Treasurer
Julia Franke, Managing Director
Prof. Dr. med. Georgia Ramantani, PhD
PD Dr. med. Fabienne Picard
PD Dr. med. Jan Novy
Dr. med. Pamela Agazzi
PD Dr. med. Martinus Hauf
Ms. Noëlle Mercier
Prof. Dr. med. Johannes Sarnthein
PD Dr. Dr. med. Frédéric Zubler.
PD Dr. med. Martin E. Hardmeie
Dr. med. Judith Kalser



Retired: Prof. Dr. med. Stephan Rüegg, past-president; Prof. Dr. med. Andrea Rossetti, vice-president; Mr. Marco Beng, treasurer; PD Dr. med. Alexandre Datta; Prof. Dr. med. Martin Kurthen; Prof. Dr. med. Margitta Seeck.

Officer Election Date: Spring 2024

ACTIVITIES AND ACCOMPLISHMENTS

2021

- The German-Austrian-Swiss Epilepsy Congress in Berlin had to be postponed until 2023.
- We cooperated with Prof. Stephan Rüegg for his biannual “Basel Epilepsy Day” as our annual meeting. The theme was “Fitness to drive – important not only for people with epilepsy”. The meeting took place on 19 August 2021 as a face-to-face event with special restrictions (more space, COVID certificate check), 225 persons were registered.
- The Annual General Meeting in May had to take place virtually.

2022

- The ILAE European Epilepsy Congress took place in Geneva, 9-13 July 2022. Former board member Prof. Margitta Seeck co-chaired it, and many League members were intensely involved in the scientific programme. The Swiss League organized a drinks reception (“Swiss Aperò”) for its members and friends on the terrace of a nearby Italian restaurant.
- For the first time since the start of the pandemic, the Annual General Meeting in May was held as a hybrid event, with most of the old and new board members attending in person in Olten.

Summary of other activities in 2021 and 2022

- 10 short, animated videos in 10 languages, including English, explain the most important facts about epilepsy: <https://www.epi.ch/en/simple-videos-explain-epilepsy/>
- Annual Research Recognition Award (CHF 25'000) for the most promising research study in Switzerland in the field of epileptology: <https://www.epi.ch/en/awards-go-to-three-swiss-research-projects/> and <https://www.epi.ch/en/award-for-epilepsy-research-better-diagnoses-will-lead-to-improved-care/>
- Biannual Alfred Hauptmann Award in 2021 (€10'000) in cooperation with the German and Austrian chapter
- In future, the Hauptmann award will be funded by four different sponsors; the prize money is now €20,000, divided between basic and clinical research.
- Swiss Epilepsy Research Network "SERENE": <https://www.epi.ch/en/research/serene/>
- In 2021, for the first time, the Tissot Medal (honorary prize for special services to Swiss epileptology) was awarded to a woman. The recipient, Anne Beaumanoir, died in 2022 <https://www.epi.ch/en/in-memoriam-anne-beaumanoir/>
- Since the beginning of the pandemic, many events for people with epilepsy have been successfully organized online, together with the IBE chapter Epi-Suisse. Some events took place face-to-face or hybrid. Total attendance 2021-22: in-person 299; online 423.
- In 2022, most professional events were hybrid. In 2021, 195 people attended our face-to-face events including the annual meeting in Basel; in 2022, our professional events had 41 in-person and 90 online participants.
- Our website www.epi.ch is updated constantly, for example it now contains information about riding a bicycle with epilepsy, about hormones and bone fractures.
- Answers to medical questions, about 200 questions a year. Important new topics were the new coronavirus and vaccinations.
- Media activities resulting in several articles, radio and TV features; cooperation with "BrainMag"
- Donation of anti-seizure drugs to Ukraine soon after the Russian invasion; personal contacts to the Ukrainian ILAE chapter at the European Epilepsy Congress in Geneva
- We submitted a request for health insurance to cover the cost of regular osteoporosis screening for patients who have been taking "old" anti-seizure medication for more than 10 years.
- We got involved so that people with epilepsy could also donate blood - so far without success.
- Sponsorship rules: We have set out rules governing our engagement with industry, including our independence, transparency, data protection and the ban on mono-sponsorship.
- The League has become an official partner of the Swiss Neurological Society.
- Passing of our long-standing board member Markus Schmutz (1947-2021) <https://www.epi.ch/en/in-memoriam-markus-schmutz/>

RESEARCH AND PUBLISHED ARTICLES

Regular Publications:

- Journal “Zeitschrift für Epileptologie”: trinational journal with the German and Austrian ILAE chapters, in German and English; published as joint publication since 2022, after long preparations and negotiations. Future name of the journal: “[Clinical Epileptology](#)”.
- Annual report (German, French)
- Continuing presence on Facebook (over 1,500 followers) and LinkedIn (250 followers)
- Monthly e-newsletter with about 8,900 German-speaking and 2,500 French-speaking recipients
- e-Newsletter for doctors, mainly in English (about 5-6 times per year)
- Pocket calendar for donors

New information leaflets/brochures, both printed and online:

- Updated leaflet “Types of seizures” (German, French, Italian)
- Updated leaflet “Seizure observation” (German, French, Italian)
- New leaflet “Seizures in the hospital – information for nursing staff” (German, French)
- New leaflet “Dental treatment and epilepsy” (German, French, Italian)
- New leaflet “Status epilepticus” (German, French, Italian)
- New leaflet “More than seizures” (German, French, Italian)
- Flyers newly available in Turkish, for example “What are epileptic seizures and epilepsies” and “First aid during epileptic seizures” <https://www.epi.ch/tr/>
- Updated E-book (PDF/epub file containing all leaflets for tablet computers, German/French)
- New brochure on testaments and provisions, due to new legislation in Switzerland (German, French, Italian)

More New Publications:

- First aid poster in 2 versions, for children and for adults, with IBE chapter Epi-Suisse (German, French, Italian)
- Letter template for health insurance companies so that medications are not substituted by cheaper ones (German, French)
- Plan how to proceed in case of drug shortage (“5 point plan”)

CHALLENGES FACED IN 2021 AND 2022

- The coronavirus pandemic had only a limited impact due to liberal regulations in Switzerland. However, planning events and finding partners (hospitals) had become more difficult, partly due to staff shortages. Also, the return of face-to-face participants was slow, as many people had become accustomed to online events. Our office also suffered from several medical absences. This meant that some projects had to be delayed.

- At the end of 2021, applications for our awards were slow to come in, so we decided to extend the deadlines. Increased communication, including by post, was successful and at the end we were pleased with the number of entries.
- Finances remain a challenge. Despite increasing success in fundraising, regular income continues to fall short of expenditure.

FUTURE PLANS FOR 2023

- Updated leaflet “Anti-seizure medication” for people with epilepsy
- Project “Epilepsy Nurses”
- We will be a guest association at the annual meeting of the Swiss Neurological Society in 2024.

Epilepsy Videos

		
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Report submitted by Julia Franke, Dr. phil.