

## Additional minutes meeting Scientific Panel Epilepsy June 28<sup>th</sup>, 2022, 08:00 – 09:30 CEST

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### Participants:

Whole MG and many SP Epilepsy Panel Members either in person or by Web (Hybrid Meeting)

Excused: Ettore Beghi (EB), Ronan McGinty (RMG; RRFS representative) for health problem.

Most of the content is summarized in the meeting pdf. attached also to this e-mail.

Therefore, we mention only some few additional points of discussion:

### - Regarding the proposals:

- as much as possible !
- **submissions still possible – but be fast to submit! (best before July 7<sup>th</sup>, so we have still 2 weeks to streamline and finalize everything!)**
  - o case based seminar on genetic epilepsies/ syndromal epilepsies
  - o symposium: no longer on big data, but on how genetic profile can help in personalized medicine for the care of patients with complex to diagnose and treat epilepsies
  - o case based seminar on driving and epilepsy
  - o for political reasons: one symposium should deal with the approval of the Global Action Plan on Epilepsy (and other Neurological Diseases) approved by the WHO/ WHA; this is clearly a political move because the IGAP, for which epilepsy organizations fiercely fought during 25 years) had been clearly “absorbed” by the EAN. Thus, so we might be able to, at least, “in the frame”.
- the overarching theme of Budapest 2023 “**neurology beyond big data**” has been somewhat misleading, as many proposals suggest topics of big data/ AI/ ML etc., **but the theme focuses on personalized and precision medicine**

Thus, it would be important that the SP Epilepsy, together with the ERN-EpiCARE has at least one proposal demonstrating the role model of epileptology when it comes to personalized medical care (genetic epilepsies and encephalopathies, everolimus in TSC usf.)

- Guidelines: Regarding the Guideline on presurgical evaluation and epilepsy surgery prioritized by the EAN Guideline Committee, Eugen Trinkla clarifies that already 39 experts (chosen ex officio, by expertise, specialty, and interest) have been already assigned, thus the panel is already quite large, but may be happy to accept a few (3-4) additional members.

Thanks to the efforts of the Epilepsy Alliance Europe (led by Philippe Ryvlin) which has been reconstituted in the last months, an extensive body of analyses important during the production of guidelines is already available and will be merged to this guideline.

- collaboration with ILAE: well underway

ERN EpiCARE: well underway

EAE: very important on the political level for negotiations with the EU (research funding, societal issues, public awareness, health system improvements for patients with epilepsy)

- EFNA: regarding one representative on the SP Epilepsy: could be one solution.

However, Reetta Kälviäinen correctly intervened and suggested that the patient organization of the epilepsy patients, i.e., the International Bureau of Epilepsy (IBE), specifically, its chair, Francesca SOFIA, should be addressed. Would be great, when she could become a member of our panel.

Next meeting dates:

- 4<sup>th</sup> Meeting Management Group for discussion (and ev. submission) of congress proposals for Budapest 2023: **Thursday, June 30<sup>th</sup>, 18:00 – 20:00 CEST**
  
- 5<sup>th</sup> Meeting of the Management Group of the SP Epilepsy: **Thursday, September 22<sup>th</sup>, 18:00 – 20:00 CEST**  
**(alternative dates: Thursday September 15<sup>th</sup> or September 29<sup>th</sup>)**
  
- next Meeting Management Group with whole SP Epilepsy:  
**Thursday, November 24<sup>th</sup>, 18:00 – 20:00 CEST**

Basel, June 28<sup>th</sup>, 2022

Responsible for the minutes: Stephan Rüegg