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European
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Committee

Meeting of the European Regional Committee held on 15 September 2016 at Prague Conference Centre.

Present:

ALEXA, Michael Vice Chair, EREC	Austria	michi19691@yahoo.de
ANDERSSON, Margaretha Member, EREC	Sweden	maggan-peter@comhem.se
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In attendance:

Name	Association	Country	Email
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Ann Little	Exec Director, IBE		IBEexecdir@eircom.net
Sari Tervonen	Secretary General, IBE	Finland	sari.tervonen@epilepsia.fi
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1. **Opening and Welcome.**
   On behalf of the European Regional Executive Committee (EREC), Anastasia Vassou warmly welcomed everyone to Prague and to the meeting of EREC.

2. **Minutes of the EREC meeting held in Istanbul, 8 September 2015.**
   The minutes were accepted as an accurate record of the meeting. Proposed by Michael Alexa and seconded by Janet Mifsud.

3. **Review of activities in Europe 2015 – 2016.**

   i. **International Epilepsy Day 2016**

   Sari Tervonen reminded the meeting that International Epilepsy Day provides a framework for IBE chapters to lobby and campaign for epilepsy. On International Epilepsy Day 2016, 35 meetings with MEPs and an evening reception were held at the European Parliament. There are now 45 MEPs on the Epilepsy Advocacy Europe. Forty three countries across the world took part in International Epilepsy Day this year, each in their own way. Planning is underway for International Epilepsy Day on 13 February 2017. The theme will again be "epilepsy is more than seizures" and the intention is to hold another event at the European Parliament. More news will follow regarding the art event / competition already announced.
   In the meantime, Sari invited everyone to meet Campi, the International Epilepsy Day mascot at http://epilepsy.org/campi/

   ii. **Epifocus**

   Ljubica Vrba reported that it had not been possible to produce any issues of Epifocus this year due to lack of contributions, and asked for suggestions to stimulate input. **Conference delegates were invited to submit their feedback on the conference experience for publication in the next EpiFocus.**

   iii. **European Medicines Agency**

   Janet Mifsud reported that IBE is working to synergise with other organisations including the European Medicines Agency, the European Patients Forum and the European Federation of Neurological Alliances as an additional means of ensuring the voice of epilepsy is heard in Europe.
   The European Medicines Agency, based in London, regulates medicines in Europe. IBE has "observer status" as a result of which EREC is invited to contribute to initiatives, meetings and projects from time to time. Recently EREC representatives have contributed to discussions on how digital technology might be used to enable straightforward reporting of side effects of medication, and on how patient information leaflets about sodium valproate might be improved to better convey advice to women of childbearing potential.
   Janet urged conference delegates to contact their local medicines agency and seek ways of getting involved at national level.

   iv. **Pictorial Guide to Epilepsy**

   Shirley Maxwell reminded the meeting that the suggestion for a pictorial guide to epilepsy had been made by Caroline Morton of SEIN in her response to a survey of IBE members. The target audiences are adults in Europe with low levels of literacy, including new arrivals with limited local language skills. Extensive review of available resources has indicated that there is no shortage of cartoons, videos etc but that these are largely targeted at children. However, a possible model had recently been suggested, and a small working group were looking at Erasmus Plus funding with a view to taking the project forward. **Shirley invited interested parties to contact her if they wished to get involved.**

v. Update from Epilepsy Alliance Europe

Thanos Covanis briefly outlined the background to and development of Epilepsy Alliance Europe, a not-for-profit body formed under the auspices of the IBE and ILAE with aim of stimulating and supporting research that will improve the quality of life of people with epilepsy. Examples of research include the ESBACE programme, a population-based study of prevalence, cost and stigma of epilepsy, and of the organization and quality of epilepsy care in Europe. Other programmes are looking at how to raise awareness of and accessibility to epilepsy surgery, and the potential of wearable technology to improve the wellbeing of people with epilepsy.

vi. European Patients Forum

Michael Alexa noted that the European Patients Forum (EPF) offers a range of opportunities for engagement in surveys and events, and advised chapters to register with EPF via their IBE membership to receive newsletters and surveys.

4. Membership Update

Maggan Anderson reported that membership was unchanged since her last report in September 2015, with 38 full chapters and 22 associate chapters in Europe.

5. Any other business

Mickey Nashke expressed his pleasure to be at the meeting, noting the number of European members of IBE and querying the low numbers of American members. Mickey called for unity and inclusion. Ann Little noted that the IBE’s European region has the highest membership and America the lowest, and that this is in large part due to the way in which lay organisations are structured in these regions.

After the formal proceedings were completed, Dominika Hondlíková and Petra Stehlíková made a short presentation on the work of local chapter Spolecnost E, covering the challenges faced by people with epilepsy in the Czech Republic, particularly in relation to employment, and the services Spolecnost E provide, including a social enterprise offering training and employment.

There followed a number of short personal presentations on a range of topics including:

- The role of cannabidiols in the treatment of epilepsy.
- Living with and raising awareness of epilepsy in Prague.
- The work of the Bulgarian Epilepsy Association to raise awareness of epilepsy in schools.
- The importance of support offered by epilepsy associations: “Support helps as much as the medicine, sometimes even more”.
- Self-management – an holistic approach to living with epilepsy.