

EPU Annual General Meeting 2018 minutes

Rheinsberg (Germany), June 16, 2018

Participants: see the list of attendees (a total of 47 EPU member organisations including Prof. Arzu On, TR, and Dr. Peter Brauer, DE, attended the AGM)

Apologies: Ireland, Norway and the Czech Republic sent apologies, Poland did not show. John McFarlane (IRL) was unable to attend for health reasons, but submitted his message by Skype.

Agenda:

1. Welcome & Registration of EPU Member Organisations & Guest Delegates
2. Apologies
3. Minutes of 2017 Annual General Meeting – Lobbach, Germany
4. 2017 Annual Report – EPU President
5. 2017 Annual Accounts – EPU Treasurer
6. 2018 Annual Budget – EPU Treasurer
7. Motions & Resolutions
 - a) To adopt and accept the minutes of the Annual General Meeting held in Lobbach, Germany in June 2017
 - b) To receive and adopt the Audited Accounts of the European Polio Union for year ending 31/12/2017
 - c) To receive and adopt the 2018 budget of the European Polio Union
 - d) EPU Director Nominations and Appointments
8. Any Other Business
9. Place & Date of 2019 EPU AGM

Opening by Gurli Nielsen, EPU President, at 9:30 am:

- Welcome to delegates and to our guest speaker Dr. med. Peter Brauer
- Paul Neuhaus, DE, is now an official EPU board member – confirmed by the Bundesverband Poliomyelitis e. V.
- Confirmation renewal of previous board members: John McFarlane, Daniel Peltzer, Margret Embry, and Erika Gehrig for the next 3 years. (Globally elected)

Minutes of the AGM 2017 in Lobbach (June 24, 2017) – approved.

Gurli Nielsen, EPU President, read the annual report (see Annex 1).

Daniel Peltzer, EPU treasurer, presented the official approved annual statements of accounts (see Annex 2).

Daniel Peltzer then presented the actual updated budget (see Annex 3) and explained that due to reduced mobility of board and EPU members the charges for the EPU meetings are going up; he also pointed at a lack of funds, and expressed our hopes that PoPSyCLE will support us in the future. Daniel Peltzer has a good contact with EURORDIS in Bruxelles and they will once again support us for the translation costs after presenting the bill.

Motions and resolutions:

All motions and resolutions as mentioned above (Minutes of the AGM 2017 in Lobbach; Audited Accounts of the EPU for year ending 31/12/2017; EPU Budget for the year 2018; EPU Director Nominations and Appointments) were unanimously approved by AGM participants.

Varia:

- Stefan Grajcar, EPU Board Member, informed about the recent EURORDIS Rare Disease Europe conference held in Vienna on May 10-12, 2018, that he attended together with Paul Neuhaus. 850 participants from 58 countries attended the conference. EPU is a full member of EURORDIS.
- Stefan Grajcar shortly informed also about the Annual General Assembly of the European Disability Forum held in Vilnius, Lithuania, on May 26-27, 2018, where he participated as an official delegate of the Slovak Disability Council. More information on both international events will be presented in the autumn issue of the EPU Newsletter.
- The next AGM of the EPU will take place in London 21-22/06/2019. David Mitchell offered to organize the meeting as the British Polio Fellowship celebrates its 80th jubilee in 2019.
- Mario Feijo Anakabe of Spain announced that Pablo Cervantes, a Rotary International member, will arrive to Rheinsberg to inform about the purpose to organise a 2019 International Conference on polio and PPS in Spain in close cooperation with Rotary International.

Prof. Arzu-On, Izmir - Turkey (EPU member)

Before the lunch break, Prof. Arzu On from Turkey gave us full details on their planned World Polio/PPS Eurasian Conference in Antalya in 2020. She showed us wonderful photos of Antalya and adapted hotels for handicapped persons. She talked about her work at the hospital in Izmir. Turkey has still many polio survivors. The older survivors start having PPS. She further mentioned that one has to pay special attention to other neurological diseases like Fibromyalgia, Chronic-Fatigue-Syndrom and PPS. These groups of survivors have no lobby, therefore it is important to support them in the future.

John Mc Farlane - former EPU-President - Message by Video

Daniel Peltzer organised the video message, immediately after lunch. John McFarlane apologized for not being able to have joined us in Rheinsberg.

He informed about his PoPSyCLE work and mentioned that the funds have been spoken, but not released yet because of money-laundering laws. However it should be solved during the summer. He further mentioned that at the actual competence centers in Ireland and England the training of Doctors with respect of PPS has started.

He will keep us informed of further progress.

Dr. Peter Brauer – Germany

Dr. Peter Brauer impressed us with his lecture on PPS Pain Therapy “Pharmacological Aspect of an Urgent Problem”. He mentioned that unfortunately many old rumours are circulating regarding PPS (Physicians give medicines, knowing little about these, in human bodies, knowing even less, too, about these, to treat illnesses, knowing nothing about these.) He explained the Post-Polio-Syndrome, types of pain, acute pain and chronic pain. He has a great knowledge regarding chronic PPS pain and knows that CANNABIS could be the solution. In Germany, Austria, and Switzerland it is still tough to get to it. But slowly one can see that it is more and more recognized. The Netherlands are very open in this respect.

One of the conclusions with therapeutic Cannabis is: The medical effect of cannabis is not reduced to the effect of THC and not to the use for pain relief. Cannabis, with careful attention given to its various ingredients, offers the reasonable possibility of a complex PPS therapy in terms of anti-inflammatory action, pain relief, nerve protection, muscle spasm inhibition, attention, memory and concentration promotion and stress inhibition under medical supervision.

Dr. Brauer pointed out that the medical supervision is indispensable.

At the end of his lecture he answered many, many questions. He pointed out that we all should read his article: "Verbreitete Irrtümer zum Post-Polio-Syndrom".

In recognition of his outstanding and long-term efforts to raising awareness of the needs and health care for poliosurvivors in Europe EPU decided to award Dr. Peter Brauer the **HONORARY MEMBERSHIP OF THE EUROPEAN POLIO UNION**. The award was warmly applauded by the audience.

Video shown by representatives of Vitoria Gasteiz – Spain

Pablo Cervantes showed a wonderful film about Vitoria Gasteiz. Together with Mario they gave us a lot of information on this interesting city in Spain. They informed about the Congress in Vitoria which will be organized by the Rotary Club in Vitoria. The Danish organisation (Merete Bertelsen) has informed the Rotary in Vitoria in the past year. There are still a lot of questions to be solved during next few months.

EPU offered that Merete could support them in person but the travel costs, her salary, etc., would have to be covered by Rotary.

EPU will most certainly support Spanish organisers in relation to questions with PPS, etc. It was appreciated very much that Mr. Cervantes came to Rheinsberg to provide us with information we required.

By this presentation the Annual General Meeting of the EPU was officially concluded and Mrs. Gurli Nielsen thanked all for their active participation.

Prepared by Erika Gehrig & Stefan Grajcar, EPU Board Members

Gattikon & Bratislava, August 2018