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**EPNET is a non-profit association of
European Centres for Porphyria
Expertise**

The association is registered
in 2018 in the Brønnøysund
Register Centre, Norway
Organization number: 919 181 508

www.porphyria.eu



EUROPEAN PORPHYRIA NETWORK

GENERAL ASSEMBLY MEETING

EPNET ASSOCIATION

Aula Magna, University of Milan

September 9th, 2019

MINUTES

Opening and Welcome

The President of the Executive Board, Sverre Sandberg welcomed the members of EPNET to the second General Assembly Meeting of EPNET.

The minutes from the GA Meeting October 26th, 2018 were approved.

Sverre Sandberg gave an update on EPNET First Year Achievements.

EPNET has now 64 members; 23 Full members, 30 Associate members, 5 Corporate Members and 6 Honorary members. After the first GA Meeting in 2018 a survey was sent to all members asking for the member prioritized areas on which EPNET should focus. From the 36 responses coming from 19 different countries it was concluded that EPNET should organize Working Groups focusing on Laboratory Guidelines, Clinical Guidelines for Acute and Cutaneous Porphyrias, Research and Development and the EPNET Webpage. The Working Groups are open for all members and consists of core members and corresponding members.

EPNET has agreed to have regular meetings with the American Porphyria Consortium and to facilitate cooperation between our organizations.

EPNET has had meetings with the corporate members to develop future cooperation.

EPNET has on-going discussions on how to collaborate with MetabERN, primarily regarding clinical guidelines and registries.

EPNET will organize the third GA Meeting in November 2020.

Financial information

EPNET treasurer Janneke Langendonk presented the financial report for 2019. The report had been reviewed by EPNET's external reviewers; Felicity Stewart from Salford Royal NHS Foundation Trust, Salford, UK and Ylva Floderus from the Swedish Porphyria Centre, Stockholm Sweden.

The GA approved the accounts for 2019.

The two external auditors were unanimously elected to continue as auditors of EPNET finances.

Report from Working Group Chairs

The Laboratory Working Group was presented by chair Aasne Aarsand.

The Clinical Working Group for Cutaneous Porphyrrias was presented by chair Mike Badminton.

The Clinical Working Group for Acute Porphyrrias was presented by chair Penny Stein.

The Research and Development Working Group was presented by chair Laurent Gouya.

The Webpage Working Group was presented by chair Caroline Schmitt.

Voting for the ICPP 2021

There were two candidates applying for ICPP 2021; Aneta Ivanova, representing the University of Sofia, Bulgaria and Peter Meissner representing the University of Cape Town, South Africa.

The respective candidates presented their applications.

The closed voting procedure elected Aneta Ivanova from the University of Sofia, Bulgaria to host ICPP 2021.

Conclusions and closure

Sverre Sandberg concluded the meeting and closed the second GA meeting of the EPNET Association.

Sverre Sandberg
EPNET President

Eliane Sardh
EPNET Secretary