

## EPNET EXECUTIVE BOARD

### President

Sverre SANDBERG

Norwegian Porphyria Centre  
Bergen - Norway  
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### Secretary

Eliane SARDH

Porphyria Centre Sweden  
Stockholm - Sweden  
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### Treasurer

Janneke LANGENDONK

Porphyria Center Rotterdam  
Rotterdam - The Netherlands  
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### Member at Large

Michael BADMINTON

Cardiff SAS Porphyria  
Cardiff - United Kingdom  
Mike.Badminton@wales.nhs.uk

### Member at Large

Maria Domenica CAPPELLINI

Rare Disease Center  
Milan - Italy  
maria.cappellini@unimi.it

### Member at Large

David CASSIMAN

Metabolic Centre Leuven  
Leuven - Belgium  
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### Member at Large

Laurent GOUYA

Centre Français des Porphyries  
Paris - France  
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### Patient Representative

Liz GILL

British Porphyria Association  
Bishop Auckland - United Kingdom  
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### EPNET OFFICE

epnetoffice@helse-bergen.no

### BANK INFORMATION

DNB Bank ASA

Postboks 1600 Sentrum,  
NO-0021 Oslo, Norway

IBAN code: NO95 1506 0535 423  
SWIFT/BIC code: DNBANOKK

**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](http://www.porphyria.eu)



EUROPEAN PORPHYRIA NETWORK

## GENERAL ASSEMBLY MEETING

## EPNET ASSOCIATION

September 5<sup>th</sup>, 2022

Sofia, Bulgaria

## MINUTES

### Opening and Welcome

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

**The minutes from the GA Meeting December 4<sup>th</sup>, 2020, were approved.**

**President Sverre Sandberg gave a report on Epnnet activities 2021 – September 2022**

### Financial information

EPNET treasurer Janneke Langendonk presented the Epnnet budget for 2021 which was approved and closed. The accounts had been approved by auditors by Felicity Stewart from Salford Royal NHS Foundation Trust, Salford, UK and Ylva Floderus from the Swedish Porphyria Centre, Stockholm Sweden.

An overview of anticipated revenues for 2022 was presented.

Felicity Stewart agreed to continue as auditor for 2023-2024 while Ylva Floderus announced that she was not available for a further period. Peter Meissner, Cape Town South Africa has agreed to be an auditor for 2023-2024 and will be officially appointed during 2023.

**The new Executive Board for Epnnet 2023-2024 was elected by the full members of Epnnet:**

President: Sverre Sandberg

Secretary: Eliane Sardh

Treasurer: Janneke Langendonk

Members at Large:

Mike Badminton

Maria Cappellini

Laurent Gouya

Jordi To-Figueras

**The General Assembly decided by vote in favor by 14 Yes and 1 No to transform Epnnet to an International organisation.**

The statutes for an international organisation had been circulated to Epnnet members prior to the GA, the transformation to an international organisation including the name change will be handled by Epnnet EB during the next term.

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## Report from Working Group Chairs

The Laboratory Working Group was presented by chair Aasne Aarsand.

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

The Clinical Working Group for Acute Porphyrias 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.

The PECC Working Group was presented by member Maria Cappillini.

## Conclusion and Closure

Sverre Sandberg concluded the meeting and closed the fourth GA meeting of the Epnet Association.

Sverre Sandberg  
EPNET President

Eliane Sardh  
EPNET Secretary