

IPNET EXECUTIVE BOARD

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IPNET is a non-profit association of International Centres for Porphyria Expertise

The association is registered
in 2018 in the Brønnøysund
Register Centre, Norway

Organization number: 919 181 508

porphyrianet.org



INTERNATIONAL PORPHYRIA NETWORK

GENERAL ASSEMBLY MEETING

IPNET ASSOCIATION

September 23rd, 2024

Pamplona, Spain

MINUTES

Opening and Welcome

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

The minutes from the GA Meeting September 4th, 2022, were approved.

President Sverre Sandberg gave a report on Ipnet activities September 2022-September 2024.

During 2022-2024, the Ipnet Board has been working to transform Ipnet into an international organisation and this work is now complete.

Ipnet's membership has grown steadily since we became an international organisation. We now have a total of 114 members, compared to 79 in 2022.

Important work carried out during the period includes the publication of definitions for acute porphyria and the forthcoming publication of evidence-based guidelines for acute porphyria.

The Acute Porphyria International Support working Group (WG-APIS) has been established with the aim to provide acute porphyria support to healthcare professionals looking after patients in countries where specialist care is not available.

A popular initiative established for members is the Ipnet newsletter.

Financial information

Ipnet Treasurer Janneke Langendonk presented the expenses and revenues for Ipnet fiscal years 2022 and 2023, which had been approved by the auditors Peter Meissner (Cape Town, South Africa) and Danja Schulenburg-Brand (Cardiff, United Kingdom). An overview of anticipated revenues for 2024 was presented, along with the Ipnet savings account. The 2022 and 2023 financial years were closed after tacit approval by the General Assembly.

Membership fees have remained unchanged since 2019 and an increase was proposed to the General Assembly, which approved the proposed new fees:

- Full member € 230
- Associate member € 115
- Individual member € 25
- Corporate member € 12.000

The new Executive Board for Ipnet 2025-2026 was elected by the full members of Ipnet:

President:	Eliane Sardh (Sweden)
Past president (only 2025):	Sverre Sandberg (Norway)
Secretary:	Penelope Stein (England)
Treasurer:	Vicky McGuire (Scotland)
Members at Large:	Edith Friesema (The Netherlands) Jordi To-Figueras (Spain) Paolo Ventura (Italy) Staffan Wahlin (Sweden)
Patient representative:	Nadezda Pejovic (Serbia)

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 Working Group for Porphyria Expert Clinical Centers was presented by chair David Cassiman
- The Webpage Working Group was presented by chair Caroline Schmitt
- The Working Group for The safety of drugs for Porphyria Patients was presented by chair Janneke Langendonk
- The Working Group for The gene variant classification was presented by chair Michela Barbaro.

The venue for ICPP 2026 will be organised by: The Turkish Porphyria Association in Istanbul during September 24 – 27, 2026.

The following Honorary Members of Ipnet was appointed:

Felix de Rooij (The Netherlands), Peter Meissner (South Africa) and Desiree Lyon (USA)

Conclusion and Closure

Sverre Sandberg concluded the meeting and closed the fifth GA meeting of the Ipnet Association.

Sverre Sandberg
Ipnet President

Eliane Sardh
Ipnet Secretary