

Annual General Meeting – Agenda

- Apologies for absence
- Minutes of the last AGM
- Chairman's Report
- Treasurer's Report
- Election of Officers
- 2024 meetings
- AOB

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Annual General Meeting

- Apologies for absence
- Minutes of last AGM
- Full Chairman's and Treasurer's Reports available at porphyria.org.uk/policies-and-procedures
- The slides will also be available



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Chairman's Report

2022 Summary

- May 2022 – back to face-to-face in Dundee
 - 40 people in person and more online
- Sept 22 – International Congress – Sofia
 - New research and updates
- October 2022 – First Alfresco event in Leeds – great success
 - 55 people and more than 13 families affected by EPP
 - Predominantly funded by National Lottery Community Fund grant of £9,500
 - Funds from Disc Medicines enabled two families from Ireland to attend
- Business as usual for other patient support – helplines, website, social media

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Chairman's Report

2023 Strategic aims

- Added Advocacy to our aims of Education, Support & Research to reflect what we do more accurately
- Continue supporting patients through themes of **UNDERSTAND**, **CONNECT**, **TAKE CONTROL** and **SHARE***
- Face-to-face patient meeting – June 2023: Tamworth
- Connect Alfresco (residential) – Thetford – postponed until 2024
- Continued focus on engagement and accessibility for young people
 - Seeking funds to support the event
 - Launching a fundraising campaign with a target of £20,000

*Share was added as a new theme in 2023

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Chairman's Report

2023 Updates

- Demonstrated the patient experience in the Scenesse appraisal process
 - disappointingly still not approved for patients in England, Wales or Ireland
- Seeking a new Volunteer Treasurer after Danil resigned
- Enlisted support from two administrators (one paid, one volunteer)
- Continued focus on bringing in volunteers with specific skills
- Encourage and support research and continue to develop international networks

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Chairman's Report

2023 Updates

- Sunscreen feedback
 - CYACELLE products kindly donated by Clinuvel
 - Light protection funds used to secure La Roche Posay Anthelios Mineral One products
 - Obtaining patient feedback on how useful, how used etc.
 - Results to be shared in early 2024

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CLINUVEL

Treasurer's Report

For 2022-23 Year

- Income: £43,549
- Expenditure: £48,132

Account name	31 Mar 2023	28 Sep 2023
BPA General Funds	£20,274	£11,830
Helen Gibbs Fund (restricted to research into acute <u>porphyrias</u>)	£16,885	£16,964
BPA Light Protection Fund (restricted)	£1,022	£1,204
Festival 2019 (restricted)	£1,200	£913

- We are expecting a grant of £10,000 from Alnylam soon

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Election of Officers

Treasurer position

- Acting Treasurer – Anne Newton

Other officers – happy to continue

- Chairman – John Chamberlayne
- Secretary – Richard Bennett

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Thank you to our Working Groups and our corporate supporters

Fundraising & Awareness

Sue Burrell
Victoria Harrold
Natassja Chadwick
Alicia Cawthorne
Karen Harris
Anne Newton

Events

Antony Fearn
Richard Bennett
Sue Burrell
Liz Gill
Victoria Harrold
Vicky McGuire

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Date of next meetings

Dublin

Sunday 3 March 10:00- 17:00

Ashling Hotel, Dublin

Thetford

Saturday & Sunday 12-13 October 2024

Alfresco residential designed for young people with EPP

ICPP

Pamplona, Spain

21-25 September 2024

Any other business?

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