

Porphyria Association Inc. (Australia) – Annual General Meeting Minutes

Date: 8/12/2022

Attendees: Jessica B, James C, Brad P, Wolfgang H, Aiko M, Liz D, Danielle C, Petula R.

Apologies: Sean H, Edward J, Gayle R, Amy S.

Minutes documented by James Clark

Commencement at 7:05pm

Agenda Item	Action(s) and notes if necessary
1. Acknowledgment of country.	No necessary notes or actions.
2. Welcome address.	President Jessica Betteridge performed the welcome address. Introductions from board members Wolfgang H, James C, and Brad P. Introductions from other attendees.
3. Present and apologies.	Attendance from Jessica B, James C, Brad P, Wolfgang H, Aiko M, Liz D, Danielle C, Petula R. Apologies from Sean H, Edward J, Gayle R.
4. Confirmation of minutes from previous AGM.	No objections to the previous meeting minutes. Accuracy of previous minutes confirmed by James Clark.
5. Matters arising from minutes.	Website development and logo was voted on and implemented as per the correspondence from the previous AGM.
6. Correspondence.	No necessary notes or actions.
7. President's annual report.	President's report relayed to present members verbally by Jessica Betteridge and via email to all members. Contained overview of website development success, ICPP conference report, and ongoing projects (Australasian Porphyria patient day and continual website improvement). Volunteer report also relayed to present members verbally by James Clark and via email to all members.
8. Treasurer's annual report.	Treasurer Amy Schneider is an apology for this AGM. President Jessica Betteridge relayed treasurer's report verbally to attending AGM members, and report is made available via email to all members. No objections or further discussions.
9. Election of committee and office bearers.	Jessica Betteridge elected as president, seconded by Brad Pearson. Sean Hegarty elected as vice-president, seconded by James Clark. Amy Schneider elected as treasurer, seconded by Jessica Betteridge. Wolfgang Haehr elected as secretary, seconded by James Clark. Brad Pearson elected as board member, seconded by James Clark.
10. Membership fees.	No change to membership fees. Notion to remove agenda item for membership fees in future AGMs approved (proposed by Jessica Betteridge and seconded by Wolfgang Haehr). Agenda item can be re-introduced should the need arise.
11. Porphyria treatment and clinical update.	Clinical trial for Bitopertin use for EPP management discussed. Letter written by pharmaceutical company was emailed to members, though the association does not officially support it. Givosiran clinical trial has yet to result in approval in Australia. Relevant of availability and experiences with Givosiran due to number of clinical enquiries.

	Clinical trial for Scenesse use for EPP management discussed. Has been approved for use in Australia however is currently inaccessible due to price.
12. Updates on clinical trials and porphyria treatments.	No further formal updates on treatments for various porphyrias. Case studies presented at ICPP discussed. Porphyria Worldwide Patient Experience Research study results discussed (vice-president Sean Hegarty is a co-author).
13. Any other business.	Availability of RMH Porphyria clinic for interstate patients discussed, Potential developments in biochemical testing discussed.
14. Date of next meeting.	Next AGM is to be tentatively scheduled in November 2023 and announced within six weeks of it scheduled date.
15. Close AGM.	AGM closed at 8:06pm