



**Porphyria Association Inc. (Australia)**  
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## **2023 President's Report**

2023 has been a very productive year for the Porphyria Association. The Association this year has been focusing on business-as-usual activities. We have been working with the community and the porphyria community to offer information and support services.

The Association this year has also been heavily involved in developing a research study in conjunction with the medical advisory board that explores the diagnosis of acute porphyria patients in emergency departments. We all look forward to progressing this study in 2024 pending ethics approval.

In addition to the research the Association has been focusing on working with healthcare teams and the pharmaceutical industry to advocate for the access of new treatment options for both Acute and Cutaneous Porphyria's. We will continue to let our members know of any new developments in the space and if new clinical trials are available to participate in.

In the next year we are looking forward to attending the 2024 International Congress of Porphyrins and Porphyria's which will continue to assist in educating our team to provide the most up to date research and learning for the porphyria's to bring back to our Australian and New Zealand communities.

We are also exploring some new educational and awareness campaigns and we look forward to sharing that with our members in the coming months.

I would like to take this opportunity to thank our committee, Sean, Wolfgang, Amy, James, and Brad for all their hard work during this year. I would also like to sincerely thank Prof Edward Janus, Dr Gayle Ross, and the rest of our medical advisory board for all your work over the year helping our committee with advice and guidance.

We look forward to 2024 and continuing to engage with our community locally and abroad.

Kind regards,

Jessica Betteridge  
President