



Porphyria Association Inc. (Australia)
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2022 President's Report

2022 has been another successful year at the Porphyria Association. With the easing of lockdown and other COVID-19 related restrictions this year we started to enjoy our new normal with a semblance of pre covid activities.

This year at the association we started the year off with a rebranding campaign launching our new logo on Rare Disease Day 2022. With the help of our medical advisory board and the committee our website received a major update and refresh. Our website serves as a first point of contact for the public, and we receive most of our enquiries through this channel. Since the launching of our new platform enquiries to the association have doubled and we are observing more targeted queries rather than general questions which has been positive. We were thrilled to work with local graphic design artists Jazmyn and Liam Wellington who were very thoughtful and respectful to our previous branding. We will continue to update our website periodically throughout the year as new research is released.

In September this year I had the great privilege to attend the International Congress of Porphyrins and Porphyria's in Sofia, Bulgaria. This conference was very informative and was a fantastic opportunity to learn about the work of other patient organisations globally. I also took to opportunity to connect with our international colleagues to work on some collaborative projects that are being championed through the work of GPAC.

During the conference we learned about the latest in clinical understanding of the porphyria's. New and emerging treatments for Acute and Cutaneous Porphyria's were also presented and discussed with promising treatments being developed and trialed in the pharmaceutical pipeline.

In the coming year we look forward to continuing our peer support work as well as our educational awareness programs. With the easing of COVID-19 travel restrictions the committee will be accessing the viability of an Australian and New Zealand Patient Day in the coming year.

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 2023 and continuing to engage with our community locally and abroad.

Kind Regards,

A handwritten signature in black ink, appearing to be 'J. Betteridge', with a horizontal line above it.

Jessica Betteridge
President