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2022 Volunteer's Report

This year I have been lucky enough to continue working as the association's Patient Liaison Officer in a volunteer capacity.

Throughout 2022 I have noticed some substantial developments in the organisation's outreach. Since the launch of the new website, the number of telephone and email enquiries have increased.

This has allowed us to provide support to the community more actively and has exposed me to a variety of different perspectives and experiences. Anecdotally, I have been told on more than one occasion that our website was the first time that new members have been exposed to support resources for porphyria; this demonstrates the success of our project from last year and shows the value of our services. I hope to continue to work with the association to develop resources for the community to further raise national awareness and reach more of our community.

I have spoken to a range of community members this year and have seen the various ways in which we can provide support. Many people contact us for help with getting tested, however some cases require more active and specific support. This variety of cases has only increased in 2022 and indicates the need for tailored support beyond information packages. I hope the organisation will be able to develop its capacity to provide tailored support throughout 2023, and I hope to help provide this as the Patient Liaison Officer.

This year, I began as a student in the Master of Genetic Counselling program, and recently concluded my first year of learning. Much of my studies have involved developing the skills and knowledge to communicate health information in an empathetic and understandable manner. I hope that my continued academic and professional development within the program will be useful for the association and its members, as I shall be able to fulfil my role as Patient Liaison Officer in a more expert manner.

I would like to thank our president Jessica and the entire board once again for their guidance and expertise. It is a privilege to work collaboratively with such a dedicated and innovative group of people. In the same manner, I would like to express my appreciation

for the national and international porphyria community. It is a pleasure to be able to work closely with you all, and I hope to be able to continue to provide support throughout 2023.

Kind regards,

James Clark
Patient Liaison Officer