



[www.gpac-porphyrria.org](http://www.gpac-porphyrria.org)

### Accurate Information Statement

*This statement has been produced by GPAC with the support of patient advocacy organisations from around the world and with approval from international clinical and research networks*

The global porphyria community is aware of potentially dangerous information being circulated across social media platforms and on various websites regarding the diagnosis, management, and treatment of the porphyrias. Unfortunately, some of the information is inaccurate, misquoted or taken out of context. Such information could be medically dangerous if taken as advice or guidance without input from a porphyria expert or qualified healthcare professional.

If you have concerns about your care, testing or general porphyria management, please connect with a recognised porphyria specialist/expert centre or your national porphyria patient organisation. These organisations will be best equipped to guide you toward appropriate testing and safe management/treatment for your porphyria.

**This statement is endorsed by the following porphyria networks and patient advocacy organisations:**



<https://porphyria.eu/>  
European Porphyria Network



[www.porphyrria.uct.ac.za/](http://www.porphyrria.uct.ac.za/)



[www.bipnet.org.uk](http://www.bipnet.org.uk)



[www.porphyrriafoundation.org](http://www.porphyrriafoundation.org)



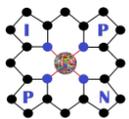
[www.porphyrria-australia.org/](http://www.porphyrria-australia.org/)



[www.porfirria.org.br](http://www.porfirria.org.br)



[www.porphyrria.org.uk](http://www.porphyrria.org.uk)



[www.porphyrria.network](http://www.porphyrria.network)



[www.porphyrries-patients.org](http://www.porphyrries-patients.org)



[www.porfyrri.se](http://www.porfyrri.se)



[www.porphyrria.ch](http://www.porphyrria.ch)



[www.epp-deutschland.de](http://www.epp-deutschland.de)



<https://spiporz.ru/>



[www.epp.info](http://www.epp.info)



[www.porfirria.org](http://www.porfirria.org)



[www.smporfirria.org.mx](http://www.smporfirria.org.mx)



<https://porfyriforeningen.dk/>



Canadian Association for Porphyria

Association Canadienne de Porphyrie

[www.canadianassociationforporphyria.ca/](http://www.canadianassociationforporphyria.ca/)

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### Background

The global porphyria community is aware of potentially dangerous information being circulated across social media platforms and on various websites regarding the diagnosis, management, and treatment of the porphyrias. Unfortunately, some of the information is inaccurate, misquoted or taken out of context. Such information could be medically dangerous if taken as advice or guidance without input from a porphyria expert or qualified healthcare professional.

The porphyria community encourages all patients to continually learn about their condition in order to pursue wellness and optimal health outcomes. This statement offers important precautions so that patients can evaluate research and various information as safely as possible and without the dangers of misinformation. The following guidance supports individuals seeking to educate themselves about the porphyrias.

### Guidance

Please treat all information sourced online, and especially on social media platforms, with caution and remember to perform due diligence when checking the safety and accuracy of information. Things to consider:

**When was it published?** Information that was accurate a few years or even months ago might now be out of date. Check with your healthcare provider or a porphyria expert if you have a question about the reliability of information.

**Who has written or published it?** Is it medical information offered by a layperson who is not medically qualified? Do they have an agenda in sharing the information? Are they trying to promote or sell something? Can you find contact details and/or documents that prove the legitimacy of the organisation or person's qualifications?

**Is the information well written and complete?** Snippets of information may be confusing or taken out of context.

**How reliable is the information?** High-quality information and strong research will be peer-reviewed, meaning that other scientists and researchers have reviewed the study, assessed its strengths and weaknesses, and agree with its findings. Please check that you are referring to well-researched information, usually from established scientific journals, that has been peer-reviewed and is deemed to be scientifically reliable.

For research, what sort of research was it and how was it conducted? How large was the study? Was it published in a national or international medical or research journal? Generally (but not always), the more participants, the stronger the findings. However, a large study for a common condition may have thousands of participants, whereas a rare condition like porphyria will have a small sample. A single case study presented in research is simply that, it could be an anomaly and should not be used to draw large correlations, conclusions or guidance to a wider cohort of patients without further evidence to confirm the results.

**An entire global network of porphyria specialists and patient organisations are working collectively to support and care for patients.** This community has developed over many years. They meet biennially at the International Congress on Porphyrins and Porphyrias (ICPP) and regularly share their knowledge and experience of caring for the complex needs of patients affected by porphyria.

The porphyrias have a dedicated and experienced network of physicians and medical scientists that endeavour to research and develop best practices/guidelines for patient care, including diagnosis. These health care professionals come from countries across the world and are collectively well-respected, they provide an exceptional scientific body, and cover varying national public health contexts and practices.

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