



## British Porphyria Association

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Charity No: 1089609  
[www.porphyrria.org.uk](http://www.porphyrria.org.uk)

### Social Media Guidelines

The British Porphyria Association is a charity which provides support, education and research to those with and/or affected by porphyria. The BPA encourages the responsible use of social media and believes that such applications provide great forums to connect with others. Informative and supportive social media groups aim to raise awareness and improve the lives of porphyria patients through member stories and sharing experiences, but, please be aware that the opinions, feelings and beliefs expressed on our pages have resulted from open discussions. The BPA have only limited control over posts and cannot, therefore, be held responsible for the content expressed.

The BPA will not tolerate abusive behaviour of any nature, this includes bullying, foul language or arguments. If you experience anything on this group that is offensive, please make one of the admins or moderators aware, so that we can attempt to resolve the matter.

#### Notes of caution for users

1. Remember that social media is never private. Please do not publish personal or sensitive information about yourself or others.
2. Porphyria patients are often the best experts, however, do remember that any advice given by others should be treated with caution (most patients are not medically trained and may have multiple/complex medical circumstances that are very different to you).
3. There is considerable inaccurate and outdated information across the internet, but the BPA admins and moderators work hard to ensure that the information provided reflects that given by NAPS (National Acute Porphyria Service) and EpNet (European Porphyria Network). If you are concerned about your porphyria healthcare, please contact your porphyria specialist, GP, or the BPA for further advice: [helpline@porphyria.org.uk](mailto:helpline@porphyria.org.uk) or 0300 30 200 30.
4. Patients may not always be at their best when they post, please be respectful of feelings.

#### Disclaimer

**The opinions, feelings and beliefs expressed on this page have resulted from an open discussion forum. While we will try to control offensive and inflammatory comments, views and opinions expressed herein do not necessarily represent the opinions, values or beliefs of the BPA. The BPA cannot be held responsible for the accuracy or reliability of information posted by external parties.**

**The BPA reserves the right to remove any unacceptable posts, and remove users if they post offensive or medically dangerous content or may in any way put others at risk from confusing or conflicting information.**