



British Porphyria Association

136 Devonshire Rd
Durham City
County Durham
DH1 2BL
Charity No: 1089609
www.porphyria.org.uk

Social Media Policy

The British Porphyria Association (BPA) have a presence on Facebook, Twitter, Instagram and Rare Connect, as well as having our own website. The BPA believes that social media applications provide a great forum to connect with others affected by porphyria. Such sites encourage conversations and the formation of collaborative relationships.

This BPA Social Media Policy aims to encourage the responsible use of social media while reminding users that social media is never really private. This policy aims to safeguard against any problems or inappropriate behaviours from group members and ensure that occurrences are dealt with in an appropriate, consistent and timely manner by the BPA. Finally, this policy provides guidance to make certain that website and social media posts have the correct permissions for re-use.

Confidentiality

Moderators or admins may be privy to names or personal information about group members or patients and are bound by a duty of confidentiality. All social media information will be handled sensitively, telling only those who need to know and following any relevant data protection requirements.

Responsibility

Overall responsibility for this policy and its implementation lies with the board of trustees and the executive committee.

Review

This policy is reviewed regularly and updated as required.

Adopted on: May 2020

Last reviewed: May 2020

Signed: *J Chamberlayne* NameJohn Chamberlayne.....

Position:BPA Chair.....

Social Media and Website Procedures

1. BPA presence on social media

Website: www.porphyria.org.uk

Facebook: www.facebook.com/groups/110926852272162/

Limited involvement in other Facebook groups: Porphyria UK, Erythropoietic Protoporphyrinuria, EPP - Erythropoietic Protoporphyrinuria, American Porphyria Foundation

Twitter: Brit_Porphyrin_Assoc
twitter.com/BPA_Porphyrin
@BPA_Porphyrin

Instagram: british_porphyrin_association

Rare Connect: www.rareconnect.org/en/community/porphyria

2. Responsibilities

Moderators and admins of BPA social media and websites have a responsibility to be professional and responsible in their responses and maintain the BPA principles as outlined in the **Committee Information Pack**.

3. Creating BPA posts

Before creating any social media post that includes music, film or images, it is important to make sure that the BPA has the appropriate permissions. This applies to permission for media content use and permission from individuals too. Types of questions to consider:

- Do we have copyright to include a film clip, music or image?
- Do I have permission to upload an image of event participants onto Twitter?
- By posting a picture online and tagging it with a location / person's name am I breaching any restrictions?
- Have I asked permission from parents or carers before posting pictures of children or vulnerable adults online?

Suggested places to find free images that are available to use for commercial and non-commercial purposes.

- <https://unsplash.com>
- <https://pixabay.com>
- www.canva.com great for creating images with text
- www.shutterstock.com or www.istockphoto.com/gb (subscription usually needed for images, but often have free trial periods or small free image banks)

4. Social Media Guidelines

The BPA publish **Social Media Guidelines** (Appendix 1) on their website and social media outlets to try to keep members safe and to help them to feel comfortable in reporting activities to the BPA that are unacceptable.

5. What group member behaviour is considered to be unacceptable or inappropriate?

The BPA will not take part in or allow content that is inappropriate or unacceptable. This includes foul language or content that is defamatory, abusive, aggressive, bullying, pornographic or otherwise hostile. BPA social media outlets are not a forum for advertising or for sales companies to use.

To protect members, individuals posting unacceptable material will receive only one warning. Further unacceptable behaviour will lead to the individual being blocked from access to the BPA's social media site(s). At least two BPA volunteers will be involved with the decision to block a user.

Example scenarios and suggested actions are listed below.

Example actions for unacceptable behaviour

Inappropriate behaviour	Action: first instance	Action: repeat behaviour
Selling, unrelated or inappropriate links	<ul style="list-style-type: none"> Remove post Advise individual not appropriate Include a warning that repeat behaviour will result in being removed from the group 	<ul style="list-style-type: none"> Remove post Remove individual from group Message to advise why
Abusive or aggressive posts, arguments, bullying or foul language	<ul style="list-style-type: none"> Remove post Advise individual not appropriate Include a warning that repeat behaviour will result in being removed from the group 	<ul style="list-style-type: none"> Remove post Remove individual from group Message to advise why
<p>Providing prescriptive/ill-advised medical advice</p> <p>E.g. ... you must... ... you should....</p> <p>... followed by medical advice or treatment that sounds contradictory to UK guidelines, etc.</p> <p>Including posts that could simply contain confusing or conflicting information.</p>	<ol style="list-style-type: none"> Moderator: Flag to an admin using a comment and tagging Liz Gill and Sue Burrell. Sample words: Please remember this is a patient viewpoint. This post has been flagged with BPA administrators so that they can help to provide further advice. Admin: create response to go within the post Advise individual why behaviour is inappropriate Include a warning that repeat behaviour will result in being removed from the group 	<ul style="list-style-type: none"> Remove post Remove individual from group Message to advise why

Providing dangerous advice or an inflammatory comment	<ul style="list-style-type: none"> • Immediate action: Remove post • Turn on 'post approval for author' • Notify other admins as to why removed • Advise individual why behaviour inappropriate 	<ul style="list-style-type: none"> • Remove post • Remove individual from group • Message to advise why
Posting detailed personal information, e.g. telephone numbers, addresses, health details about themselves or others	<ul style="list-style-type: none"> • If relating to others: immediately remove the post • If relating to the person making the post: remind the user about the risks in posting personal information 	

6. Distinguishing personal accounts from professional accounts

Personal/private accounts of volunteers/committee should not include the BPA's name.

The use of the BPA's logo is not permitted on personal accounts, except where frames might be used as part of awareness campaigns.

7. Timely responses

Posts on Facebook and Twitter should be responded to, where possible and relevant, within 72 hours.



British Porphyria Association

136 Devonshire Rd
Durham City
County Durham
DH1 2BL
Charity No: 1089609
www.porphyria.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 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.