FOWLER'S SYNDROME UK

Social Media and Community Standards Policy

This Policy outlines important information about Fowler's Syndrome UK's social media accounts and how these are managed.

Definitions

- References to "**FSUK**", "**us**", "**we**" or "**our**" refers to Fowler's Syndrome UK (registered charity number 1196903);
- References to "**you**", "**your**", or "**user**" refers to the person visiting and/or using our social media accounts and Website;
- References to **"Policy"** means this Social Media and Community Standards Policy; and
- References to "**Website**" means to www.fowlerssyndrome.co.uk.

About this Policy

- We have put this Policy in place to minimise the risks to us as a registered charity through our use of social media accounts, and to establish standards of behaviour that we expect all users to follow. This includes users of our social media accounts and our Website, and individuals that are members of our support or focus groups, or that attend our webinars, roundtables, or any targeted sessions we may host.
- This Policy relates to our use of social media, including without limitation, Facebook, Google+, Instagram, LinkedIn, Wikipedia, X, and any other social media platforms or networking sites that we may choose to have a presence on (both now or in the future), in addition to other sources such as internet postings and blogs.
- This Policy applies to all users of our social media accounts and our Website (including both individuals and businesses), any interactions between users and all groups that FSUK may organise. By using our social media accounts and our Website, you confirm that you accept this Policy. This Policy must also be read in conjunction with our Website Terms and Conditions, and our Privacy Policy and Cookies Policy.
- This Policy will be reviewed annually to ensure that it continues to meet the needs of FSUK and our community and was last updated on [19.09.24].

Our social media accounts

We use social media for many purposes, including without limitation, to raise awareness of Fowler's Syndrome and promote our community, to provide regular updates about the important work that we are doing and to share relevant information for the wider Fowler's Syndrome community.

If you follow any of our social media accounts, you can expect regular content from us such as:

- inclusive stories and experiences from us and members of our community;
- news stories and press releases from us;
- global news stories from third parties that related to Fowler's Syndrome and any linked symptoms or conditions;
- research updates and grant announcements;

- research surveys;
- events and educational initiatives;
- awareness, advocacy, and fundraising campaign messages;
- content that we consider really helpful and which we are sharing as it may be of interest to individuals or health professionals or researchers;
- reposts of announcements by third parties, including without limitation, our partners, affiliates, or healthcare, and research institutions, and other tips and advice from related organizations relevant to rare diseases and/or chronic conditions;
- and much more!

Actions by us, including without limitation, following a third party's social media account, referring to existing hashtags, sharing information from third party websites or other third party sources, or sharing details of survey opportunities, does not imply any kind of endorsement or approval by us of the third party, the content more generally, or any specific research being undertaken.

Social media moderation guidelines and management

Our aim is to provide a safe space for members of our community, which means that all users of any of our social media accounts and Website must accept and be fully committed to the values set out in this Policy. If you are a user of any of our social media accounts or Website, you are personally responsible for all communications which will be published on the internet for anyone to see.

We are grateful for our community voices, but ask that everyone is kind as hatred, discrimination or bullying are not welcome on our social media accounts, Website, forums, support groups or any other similar settings. We ask that you always show respect for each other, the unique experiences of others, our staff and volunteers, and these guidelines.

Please do:

- show respect and support. This includes respecting other users' comments and showing support for individual experiences (which may not necessarily be similar to your own), and appreciate that medical advice may vary person to person;
- observe the privacy of others. Do not share any information relating to others if you do not have their permission;
- be mindful that access to healthcare, medicines, information and advice differs geographically in a variety of ways;
- stay on-topic. Please don't post unrelated content, or content that may be deemed spam or advertising for other products or services; and
- always treat your fellow community members with kindness and respect; and
- show support and consideration for other users and their individual experiences.

Please do not:

- break the law by participating in or condoning any illegal activity. For example, this may include without limitation, publishing false statements that are damaging to a person's reputation (known as 'libel') or any other written defamation, or sharing medications or prescriptions;
- share false stories about a medical condition;
- swear or make malicious or offensive comments;
- incite hatred on the basis of race, religion, gender, nationality or sexuality, or any other personal characteristics;
- discriminate against or bully any other individual;
- take any action which may constitute a personal attack on an individual’s character;
- impersonate or falsely claim to represent a person or organization, including without limitation, falsely claiming to represent us;

- post messages or comments that are unrelated to the topic of the original post;
- infringe our, or any third party's, trade marks or copyright, which may include actions that have not been permitted such as sharing any articles, documents, websites or images (including logos) which are not otherwise available for public use without the content owner's written permission;
- provide medical advice to others (even if you are qualified); and
- share false or unsubstantiated news stories or any other similar information.

All of our social media accounts, including any comments or interactions from our users, are managed and moderated by our Communications Team. We take this Policy seriously and reserve the right to remove comments at any time acting in our sole discretion or that do not fulfil our guidelines above.

For serious or persistent breaches by users of these guidelines, we reserve the right acting in our sole discretion to stop the individual user(s) from posting further comments and/or to block the user from our social media accounts on any platform.

If you have any issues relating to our social media accounts or experience any problems when using these, please contact us at hello@fowlerssyndrome.co.uk.

Information sharing by users

We understand that users of our social media accounts and our Website often share their personal experiences which may include sharing details of their medications, prescriptions and/or effectiveness of any of these. We are not responsible for any of our users choosing to share details of their medications or prescriptions or any other sharing of similar information which may be discussed on our social media accounts or Website, or occur via any of our events, support groups, forums, or other similar groups. Any sharing of such information relating to their medications or prescriptions is shared wholly at our users' own risk and we wholly exclude our liability in relation to this. Medication or prescription sharing is illegal, and we do not condone or encourage this and our social media accounts, our Website and all of the services which we provide our users are not intended to encourage or facilitate any such sharing of medications or prescriptions.

Replies and direct messages

- We welcome feedback and ideas from our communities, including you.
- We will help with enquiries where possible by referring to relevant guidance, our resources, or resources from other affiliates or third parties (where applicable). To best direct your enquiry, we may include our contact details but also contact details for other relevant third party organisations or institutions.
- We will try our best to reply to any messages that we receive in a timely manner according to our usual working hours (Monday to Friday during UK business hours, excluding UK bank holidays). However, there may be times where our replies are slightly delayed, for example in the instance of staff absence, We will make every reasonable effort try to respond as soon as possible.
- Additionally, there may also sometimes be technical difficulties (both internally at FSUK and with third party social media platforms) which may mean that messages and responses are delayed or remain unseen. We will make every reasonable effort to manage enquiries as soon as we are notified.

Policy Review and Amendments: This policy will be reviewed annually, by the end of the first quarter (Q1), to ensure that it continues to meet the needs of FSUK and its community.

FSUK
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Last reviewed on [02/03/26]
Reviewed and agreed by [IH, HE]