



The Ehlers-Danlos Society **Social Media and Community Standards Policy**

This policy outlines information about The Ehlers-Danlos Society's (hereby referred to as The Society) social media accounts and how they are managed.

Our Social Media Accounts

We use social media to provide regular updates about the work of The Society and share relevant information for the Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and related conditions.

[Facebook](#)

[Instagram](#)

[YouTube](#)

[Twitter](#)

[LinkedIn](#)

TikTok

Social Media Content

If you follow our accounts you can expect regular content such as:

- Inclusive stories and experiences from the EDS and HSD communities.
- News stories and press releases from the Society.
- Global news stories that are relevant to EDS, HSD, and related symptoms and conditions.
- Research updates and grant announcements.
- Research surveys that have IRB approval.
- Society events and educational initiatives
- Awareness, advocacy, and fundraising campaign messages.
- Content of interest to health professionals and researchers.
- Retweets of announcements by our global partners, affiliates, health care, and research institutions, and relevant tips and advice from other organizations relevant to rare diseases and chronic conditions.

If we follow a social media account or refer to existing hashtags it does not imply any kind of endorsement.

If we share information from other websites and sources it does not imply any kind of endorsement.

The sharing of survey opportunities does not serve as an endorsement from The Society of the research taking place.

Moderation Policy

Being part of The Society community is a commitment to respect. We value community voices, but hatred is not welcome in our herd. We respect each other, the experiences of others, ourselves, Society staff and volunteers, and the rules.

Please:

- stay on-topic
- respect other comments and individuals' experiences as they may not necessarily be similar to your own, and medical advice given to one person may vary from another (comments should not be malicious or offensive in nature, and should not constitute a personal attack on a person's character). Be mindful that we are an international community, and access to healthcare, medicines, and advice differs geographically in many different ways. Treat your fellow community members with kindness and respect.

Do not:

- ⊘ reveal personal details, such as private addresses, phone numbers, email addresses, or other online contact details or personal financial information.
- ⊘ break the law. This includes libel: a published false statement that is damaging to a person's reputation; a written defamation.
- ⊘ condone illegal activity
- ⊘ swear, make malicious or offensive comments
- ⊘ incite hatred on the basis of race, religion, gender, nationality or sexuality, or other personal characteristics
- ⊘ impersonate or falsely claim to represent a person or organization, including falsely claiming to represent The Society
- ⊘ post messages that are unrelated to the topic of the original post
- ⊘ break copyright
- ⊘ Share false news stories or unsubstantiated information

We reserve the right to remove comments at any time. For serious or persistent breaches of our moderation policy, we reserve the right to stop people from posting further comments and to block them from our social media profiles.

Social Media Management

Our social media accounts are managed and moderated by the Communications team.

Replies and Direct Messages

We welcome feedback and ideas from our communities. We will help with inquiries where possible by referring to relevant guidance, resources from the Society, or other affiliates. To best direct your inquiry, we

may reference contact channels within the Society, such as our dedicated Helpline, as well as external relevant organizations/institutions.

We endeavor to reply to all messages in a timely manner according to Monday-Friday working hours, however, in the instance of staff absence, we will respond as soon as possible. In the instance of technical difficulties both internal and with the social media platforms, messages can be delayed or remain unseen, and we will make every effort to manage inquiries as soon as we are notified.

To contact the Society about this social media policy or a social media posting visit <https://www.ehlers-danlos.com/about-us/contact-us/>

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 The Society and its community.

How to Contact Us

If you have any questions about The Society's Social Media & Community Standards Policy, please do not hesitate to contact us.

Email us at: info@ehlers-danlos.com

Call us: +1 410-670-7577 or +44 203 887 6132

Or write to us at: The Ehlers-Danlos Society Headquarters, 1732 1st Ave. #20373, New York, NY 10128, USA or The Ehlers-Danlos Society Europe Office, Office 7, 35-37 Ludgate Hill, London, EC4M 7JN, United Kingdom