



The Ehlers-Danlos Society Third Party Complaints Policy

The following is guidance as to how The Ehlers-Danlos Society (referred to here as the Society) handles complaints received from the public and professionals that is directed at the Society. This is not a policy for handling staff work-related complaints, or the process for the Society raising a complaint.

In order to ensure our organization and programs remain at a high and improving standard, we have a procedure to follow should you not be satisfied with your dealings with the organization.

Definition of a Complaint

A complaint is any expression of dissatisfaction or statement of something unsatisfactory, whether justified or not, about any aspect of The Society and the work of its mission globally.

If the complaint is about an individual(s) professional practice or the Society considers the complaint should be directed to that individual(s) principal organisation or governing authority, the Society will not instigate an investigation. The Society will recommend that the complainant consider passing their complaint to the individual concerned, or the service lead, relevant organization, or over-seeing governing authority.

Formal Complaints Related to the Actions of The Society

- We accept complaints by post, email, and/or telephone
- All postal/emailed complaints should be addressed to the President and Chief Executive Officer of the Society, and include details of the individual(s) and/or event(s) to which the complaint applies. The correspondence should include the address, telephone number, and preferably also the email address of the person to whom the Society should respond.
- If the complaint is about the President and Chief Executive Officer of the Society, this should be addressed to the Chair of the Board of Directors of the Society.
- Complaints may be sent by post to the Society 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
UK

E-mail to info@ehlers-danlos.com

Verbal complaints may be given by phone to:

Headquarters: +1 410-670-7577

Europe Office: +44 203 887 6132

The Society will not accept or use social media to respond to formal complaints.

- The Executive of the Society (or the Chair, as above) will determine who should lead on the investigation and based on the nature of the complaint.
- A notification will be sent to the complainant acknowledging receipt of their correspondence and informing them of the lead for the investigation; unless it is determined at the above stage that this is not a matter for the Society, in which case a notification letter or email will be sent explaining this.
- The lead will undertake the appropriate investigation, consider reasonable actions and report back to the President and Chief Executive.
- The President and Chief Executive will consider the actions and determine whether the complaint is i. not upheld; ii. upheld and managed by the Executive accordingly; iii. referred to the Board
- In either outcome of i. or ii. above, a notification with the outcome of the investigation will be sent to the complainant with the invitation to reply if there are further concerns. If further concerns are received the process will be reinstated.
- In the event of referral to the Board, the President and Chief Executive may first raise the concern with the Chair of the Board for Chairs' action or seek to have this raised with the Board. Notification will be sent to the complainant to inform them of the action, and then again of the outcome, with the invitation to reply if there are further concerns. If further concerns are received, these will be reviewed by the Board.
- In the event a complaint cannot be resolved by this process, the Board will consider whether a third independent party with the relevant investigative experience should be invited to review the case.

External Stage

As The Society is a registered charity in England, the complainant can complain to the Charity Commission or fundraising regulator. Information about the kind of complaints the Charity Commission and fundraising regulator can involve itself in can be found here <https://www.gov.uk/complain-about-charity>. In addition, US complainants may send information that raises questions about an exempt organization's compliance with the Internal Revenue Code by submitting [Form 13909](#), Tax-Exempt Organization Complaint (Referral) Form to eoclass@irs.gov.

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 Third Party Complaints 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