



**The Ehlers-Danlos Society**  
**Donor Support Policy**

The Ehlers-Danlos Society (hereby referred to as The Society) is a 501(c)(3) not for profit organization. Contributions made to The Society are tax-deductible to the extent that is permitted by law and will be used solely for the purpose of furthering the organization's mission. Donors may designate contributions to specific projects. The use of those funds will be used with the donor intent and won't be used elsewhere unless agreed upon with the donor after further discussions.

In accordance with IRS regulations, acknowledgement letters will be issued to all donors for all donations received unless otherwise specified (i.e third party donations where the donor makes a donations through their work company. The company claims the tax benefit from those so a donor will receive and acknowledgment letter but not for the specific amount of the donation). If an item or service is exchanged for a donation, an acknowledgment letter will be issued stating what portion of the donation is tax deductible. All in-kind gifts will be documented and acknowledged for the portion of the donation that is tax deductible.

**Our Commitment to you**

As a supporter of The Society you are at the core of everything we do and we hope to provide you with a positive and rewarding experience. Below is our promise to you:

- Personal information provided by the donor will not be shared for any reason unless the donor grants permission.
- The Society will never sell or trade donor information.
- The Society will always honor a donor's request to remain anonymous.
- All donors will be contacted at times through mail, email, and phone solicitations regarding upcoming events and opportunities unless the donor has specifically opted out of communications.
- Donors can opt out of mail, email, or phone solicitations by emailing [giving@ehlers-danlos.com](mailto:giving@ehlers-danlos.com).
- The Society will always be clear in who we are, what we do, and how money is being used.
- We will treat each third party fundraiser as a relationship and the financial arrangement will be transparent.
- The Society will never under any circumstance put pressure on a donor to make a gift. If you choose to cease giving, we will respect your decision always.
- The Society promises to be sensitive in all giving situations as we are aware some donations are made through memorials, estate planning, and other difficult situations.
- The Society will do all we can to ensure that our fundraisers, volunteers and third party agencies working with us comply with all fundraising regulations.

- If a donor is unhappy with anything we have done, you can contact us to make us aware of a concern. If we make a mistake, we will apologize and do everything in our power to make the situation right. However, if we cannot resolve the situation we accept the authority of the fundraising regulator to make a final adjudication.

### **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 Donor Support Policy, please do not hesitate to contact us.

Email us at: [info@ehlers-danlos.com](mailto: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