



The Ehlers Danlos Society (hereby referred to as The Society) is committed to making decisions that are in the best interests of the charity but ultimately in the best interests of our community. This policy ensures that we do not compromise our mission and values when it comes to raising funds.

This policy governs the acceptance and refusal of donations by The Society where there is a perceived risk to our mission, staff, reputation, or financial position in accepting the donation. By implementing this policy, we have a robust and informed decision-making process for all donations/partnerships/opportunities that are deemed high risk. This policy is reviewed regularly internally and by our Board of Directors/Trustees.

The Society shall seek legal counsel in matters relating to acceptance of donations/gifts when appropriate.

Our Mission

The Ehlers-Danlos Society is a global community of individuals, caregivers, healthcare professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and related conditions.

We are proudly working to provide global learning conferences, collaborative research and education initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD population: Giving HOPE to all those whose lives are affected by EDS and HSD.

How We Accept & Refuse Donations

When choosing to accept or refuse a donation/gift The Society will consider the following factors:

- *Values*. Whether the acceptance of the donation/gift compromises any of the core values of The Society
- *Compatibility*. Whether there is compatibility between the intent of the donor and The Society's use of the donation/gift
- *Public Relations*. Whether acceptance of the donation/gift could damage the reputation of The Society
- *Primary Benefit*. Whether the primary benefit is to The Society versus the donor
- *Consistency*. Whether the acceptance of the donation/gift is consistent with prior practice
- *For of Donation/Gift*. Whether the donation/gift is in a form The Society can use without incurring substantial difficulties or expense

- *Effect on Future Giving.* Whether the donation/gift will encourage or discourage future donations/gifts

All decisions to accept/refuse donations/gifts will be made by The Society's Governance Committee, the committee is made up of members of our Board of Directors/Trustees. On a day-to-day basis, the committee delegates the responsibility to accept or refuse donations to the Chief Executive Officer and Development Director. These judgments must not promote any personal moral agenda or interest and must not allow individual or collective personal, political or ethical issues, which are not directly related to the interests of The Society, to affect judgment. The committee must not derive any personal benefit (individually or collectively) from donations, loans or other material support offered to The Society.

In the first instance, the Development Director is responsible for ensuring any potential corporate or individual donors are supporting The Society in accordance with this policy. If any element of the policy is contravened the Development Director will make recommendations to the Chief Executive Officer on the acceptance or refusal of suggested donations. The Chief Executive Officer will ensure that the committee is informed on any donation that they judge could potentially raise questions as to why The Society rejected it or accepted it. The Chief Executive Officer, assisted by the Development Director will present the case, any evidence and share the key decision points and procedure that was followed in that particular case in order for the committee to make a recommendation of acceptance or refusal.

The Society will refuse donations in the following circumstances:

- Where the activities of a donor are directly contrary to the objectives or agreed policies of The Society or The Society suspects that the gift has been donated to facilitate money laundering or other criminal activity
- Where it can be clearly shown that the cost to The Society of accepting a donation will be greater than the value of the donation itself, and that acceptance of the donation will directly lead to a net decline in the assets of The Society
- Where the offer of support is dependent upon the fulfillment of certain conditions placed upon The Society and any condition:
 - is in itself contrary to the objectives of The Society
 - is regarded as needing an unreasonable level of support from The Society especially in relation to the size or impact the donation will have on The Society's charitable activities
 - will divert The Society from pursuing its current objectives, policies, or work priorities as a necessary result of the fulfillment of the conditions alone
- Where companies are currently part of any research study in which The Society is involved

The committee will take great care and consideration in deciding whether to accept/refuse a donation:

- Where an offer of support is dependent upon The Society first spending its own money or resources in order to facilitate the conditions of the donation, as this might place The Society's assets under

undue and inappropriate risk. Donations should preferably be given in full up-front or alternatively in installments linked to an agreed contract and work plan

- Where the support, whilst reflecting The Society's objectives, is untenable. For example, if The Society does not have the resources to maintain the running costs associated with the donation
- Where the support consists of goods, services, or property which The Society cannot lawfully use, convert, exchange or sell in direct support of its charitable objectives

In the event that an accepted donation which has been assigned to a specific project/program of work is more than is required, remaining funds will be used to support the most closely related project/program of work as determined by The Society's Donation/Gift Acceptance Committee, unless specified otherwise by the donor at the time of the donation. In any such case, the donor will be informed by The Society.

Return of Donations

Under charity law, and in common with all registered charities, The Society is only able to return/refund donations in certain circumstances:

- If the terms and conditions of the gift provide for it to be returned in particular circumstances
- Where the law specifically provides for the gift to be returned in particular circumstances
- By way of an ex-gratia 'out of kindness' payment (except for Scotland where this is not allowed, as the distribution of charitable funds for non-charitable purposes is prohibited)
- If after accepting the donation, information comes to light that contradicts this policy

Depending on the circumstances, there may be restrictions on whether a donation can be returned, and the relevant charity regulator may need to allow such returns by issuing a specific order

Policy Concerning Specific Industries

Pharmaceutical Companies

Working in conjunction with pharmaceutical and broader health care industry is one component of fulfilling our mission at The Society. It is crucial to build research partnerships with the industry to accelerate the development of new therapies. We seek financial support from the industry to support our educational and patient support programs and services. The Society is committed to maintaining the highest standards of compliance and transparency regarding the financial support we receive from the healthcare industry. Corporate donors do not have any influence on educational, research or public policy positions, and we follow strict guidelines for accepting corporate support.

CBD Companies

The Ehlers-Danlos Society holds a 501c3 tax status under the federal designation with the Internal Revenue Service. As of now the cannabis industry is denied tax benefits for making donations, and by accepting those donations The Ehlers-Danlos Society could jeopardize our filing status and or be denied funding from others. At this time we are unable to accept donations from the cannabis industry but will monitor and update this policy as laws change.

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 Donation & Gift Acceptance 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