



**The Ehlers-Danlos Society
Partnerships & Affiliates Policy**

The Ehlers-Danlos Society (hereby referred to as The Society) strives to increase awareness, improve care, and grow community support for those around the world living with Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and related disorders. Hundreds of local support groups and charities are working hard to help those with EDS and HSD in their communities throughout the world. The Society will identify, pursue, engage in, and evaluate strategic partnerships and affiliates consistent with our vision and mission.

The Society believes in the importance and value of partnerships and affiliates. We know that our community benefits from engaging with and learning from a broad range of resources – and as an organization, we too are strengthened by collaborating with others.

Our partnerships and Affiliates are free to join and no financial compensation is given to or required of any of its members.

Partnerships

The Society forms our partnerships with organizations and individuals with whom we share a vision and long-term goals, combining knowledge and resources to achieve advancements for our shared global communities. The Society also ensures we are a part of external partnership programs with international organizations to further this mission.

Our current partnerships include:

- Bobby Jones CSF
- EURORDIS-Rare Diseases Europe
- Genetic Alliance
- IndoUSrare
- National Organization for Rare Disorders
- IAPO
- Society for Hereditary Diseases of Connective Tissue (Singapore)
- Creative Healing for Youth in Pain (chyp)
- UK Genetic Disorders Partnership Network
- Everylife Foundation's Community Congress
- VASCERN
- Rare Disease Diversity Coalition (RDDC)
- Rare Disease International (RDI)
- GenTAC Alliance

Aortic Dissection Collaborative
The Long Covid Alliance
WHO Collaborative Global Network for Rare Diseases
Rare Disease Legislative Advocates (RDLA)
Global Genes
LiveOn.Org (to launch in spring 2022)

Partnership Membership

- The Society will identify, through research and recommendations, potential partnerships through strategic planning, program evaluation processes, and environmental scanning
- Identified potential members will be discussed with existing members of each partnership to ensure a collaborative fit
- A formal invite will be extended outlining the works and commitments required for each group, along with an official membership application form
- Membership terms are determined per partnership, dependent on their program of work and longevity of projects
- Membership is reliant upon continued commitment and involvement, which is continually reviewed by The Society
- Membership includes shared commitment to upholding business and community values.

Affiliates

The Society also collaborates through our [Global Affiliation Network](#) to expand outreach, programming, and collaborative efforts with outstanding regional and local support groups, charities, and societies. These affiliates work toward a future where everyone living with EDS, HSD, and related disorders can receive the care and support they need through wider awareness in the medical and general communities, expanded research efforts, and improved medical care.

Affiliate Membership

- Affiliates must be a formal support group or a nonprofit organization
- Facebook-only support groups, and ones on similar social media and forum platforms, are not permitted to be listed on our website or join our Global Affiliate Program.
- Support groups and nonprofit organizations are invited to apply for membership [here](#), applications are reviewed and approved/declined by our Community & Advocacy Director
- Membership is reliant on continued community support according to their individual mission statements
- Membership will be terminated of any group/organization that engages in activities in direct conflict with The Society's mission or ethos (harassing, bullying, etc)
- Termination confirmation and the reasons for this termination will be provided by a formal letter to the group/organization. Termination will be with immediate effect

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 Partnerships & Affiliates 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