



The Ehlers-Danlos Society Diversity & Inclusion Statement

Breaking Down Barriers, Together.

Disparities in healthcare are very real. Many face barriers to diagnosis and care, which impacts quality of life. The Ehlers-Danlos Society (hereby referred to as The Society) is committed to dismantling inequality and inequity as we continue to strive in our mission to give hope to and improve the lives of people affected by EDS and HSD. We recognize our community's experiences of inequality and desire to use our platforms to highlight these historically underrepresented narratives.

How Do We Hope To Do That?

Representation:

The Society's goal is to amplify community voices. We recognize that at this time, much of our community engagement comes from parts of North America, Europe, Australia, and New Zealand which does not fully represent the breadth and depth of diversity within the EDS and HSD community. We are committed to have a global outreach, supporting members from all countries and cultures in an effort to better understand our international tribe. Our community is composed of individuals with different cultures, ethnicities, gender identities, disabilities, neurodiversities, religions, sizes, ages, and more. We strive to be able to accurately represent this diversity through our education, awareness campaigns, advocacy, community-building, and care initiatives.

Equal Employment Opportunity:

The Society is an equal opportunities employer. We embrace and encourage our employees' differences in race, nationality, ethnicity, gender, marital or civil partner status, caring responsibilities, disability, gender identity, age, social class, sexual orientation or religion/belief. Employment decisions are based on merit, economic feasibility, and business needs. To learn more, please visit our [Hiring policy](#).

Communication:

Our staff strive to listen to the community to better understand needs, stigma, and barriers to care. We invite community feedback through surveys and polls, such as our [Let's Chat Virtual Support Group Community Survey](#). We also seek community engagement through our [Breaking Down Barriers Initiative](#), which allows individuals to share their personal experiences, needs, and feedback to the Society. We are intentional about including patient, caregiver, and provider perspectives whenever able, which is reflected within programs such as [The International Consortium](#) and [Community Coalition](#).

To share your thoughts or ask questions related to diversity and inclusion, contact our Diversity and Inclusion Coordinator at Marisa.Bergfield@Ehlers-Danlos.com. We also have a [Feedback](#) and [Third Party Complaint Policy](#) that can be reviewed for more information.

Affirmative Action:

As a Society, we strive to create policies and practices that are representative and respectful of the EDS and HSD community. However, we recognize the size and significance of this task and are creating a program of work to break down barriers for the community. Below you will find some examples of our diversity and inclusion efforts from 2020.

Research:

Encouraging inclusion in the research we do, share, and fund.

- Studies that are shared through the Society require researchers to discuss how they have addressed diversity considerations within their study design.
- Through Breaking Down Barriers, we are building a community focus group to inform future research guidelines to ensure more inclusive and representative research.

Education:

Promoting diversity and increasing accessibility in education.

Professionals

- Within [Project ECHO](#), we encourage presenters to consider patient diversity factors and how that may have impacted conceptualization/treatment.
- We have expanded our scientific days to include poster presentations, allowing a larger pool of professionals to share their research with the community.

Community

- Community members requested an increased focus on resources aimed towards quality of life, which has shaped our projects over 2020 and into 2021.
- To increase access, we offer a collection of translated [materials](#), which includes [conference videos](#) and medical articles.
- When sharing content, we are committed to providing alternative text, transcriptions, and/or close captioning whenever possible.

Awareness:

- We are intentionally elevating others' lived experiences through [Community Voices](#), [Our Stories](#), and the new Conversations With webinar.
- We are committed to continuing relationships with [Online Communities](#), [Affiliates](#), [Support Groups](#), and [other Charities](#), while also creating new relationships by joining the Rare Disease Diversity Coalition (RDDC) and sponsoring events such as [The TRUE Project](#).

Advocacy and Support:

- The [Mental Health Resources page](#) was created and continues to be edited by community collaboration through our Breaking Down Barriers initiative.
- We created the [Let's Chat Virtual Support Groups](#), and introduced specialty groups, including Young Adult, LGBTQ+, Mens, vEDS, and more.
- We continue to build and share the [Healthcare Professional Directory](#), increasing ease of finding providers who are desire to see HSD/EDS patients

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 Diversity & Inclusion Policy, please do not hesitate to contact us.

Email us at: info@ehlers-danlos.com

Diversity and Inclusion Coordinator email: Marisa.Bergfield@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