



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 having a global outreach, supporting members from all countries and cultures in an effort to better understand our international members. Our community is composed of individuals with different cultures, ethnicities, gender identities, disabilities, neurodiversity, religions, sizes, ages, and intersecting identities. We strive to be able to accurately center diversity through our education, awareness campaigns, advocacy, community-building, care initiatives, staff, and board composition.

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 strives to listen to the community to better understand needs, stigma, and barriers around care. We invite community feedback through multiple streams of surveys and polls, such as our [Let's Chat Virtual Support Group Community Survey](#). We also encourage 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 community member, caregiver, and provider perspectives whenever able, which is reflected within programs such as [The International Consortium](#) and [Community Coalition](#).

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 2021.

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.
- The Society has created new priorities to diversify medical imagery, research, and outreach efforts through initiatives such as the "Breaking Down Barriers: Diversifying Medical Imagery" Project.

Education:

Promoting diversity and increasing accessibility in education.

Professionals

- Within [Project ECHO](#), we encourage presenters to consider community diversity factors and how that may have impacted conceptualization/treatment.
- We have expanded our scientific days to include poster presentations, creating more access and allowing a larger pool of professionals to share their research with the community.
- We are creating new accessibility guidelines for professionals who provide conference presentations from 2021-2022 and forward.

Community

- Community members requested an increased focus on resources aimed towards quality of life, which has shaped our projects over 2021 and will as we move into 2022.
- To increase access, we offer a collection of translated [materials](#), which includes [conference videos](#) and medical articles. We have begun to explore translation processes that will allow for more fluid translation material and access for community members.
- When sharing content, we are committed to providing alternative text, transcriptions, and/or close captioning whenever possible.
- We are intentional about recognizing acknowledgment and awareness days from a lens of empowerment through our messaging.

Awareness

- We are intentionally elevating others' lived experiences through [Community Voices](#), [Our Stories](#), and 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).

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 continue to create community and support through the [Let's Chat Virtual Support Groups](#), and host 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 see HSD/EDS community members.

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

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