



The  
**Ehlers  
Danlos**  
Society™



# GET INVOLVED WITH RESEARCH & HELP US CHANGE THE LANDSCAPE FOR EDS & HSD!

## Join the Global EDS/HSD Registry

Help us with research and understanding the true prevalence of the Ehlers-Danlos syndromes and hypermobility spectrum disorders worldwide.

We need as much data as possible to better understand the different sub-types and their varying, multi-systemic impact on patients. The global EDS and HSD registry collects a wide range of data from people living with all types of Ehlers-Danlos syndrome and those living with hypermobility spectrum disorders.

Given the different ways in which the Ehlers-Danlos syndromes and hypermobility spectrum disorders can present, it will also help us to raise awareness and support clinicians to recognize signs and symptoms more effectively. The registry will also provide new opportunities for research, including identifying links between EDS/HSD and other conditions. Without this understanding, patients will continue to be mistakenly or undiagnosed.

To join the registry, visit:



[www.ehlers-danlos.com/eds-global-registry](http://www.ehlers-danlos.com/eds-global-registry)



H E D S O C I E T Y

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# HELP US FIND THE GENETIC MARKERS FOR HYPERMOBILE EHLERS-DANLOS SYNDROME

The Ehlers-Danlos Society has started recruitment for participants in the HEDGE (Hypermobile Ehlers-Danlos Genetic Evaluation) Study, devoted to finding the underlying genetic markers for hypermobile EDS (hEDS).

The Ehlers-Danlos Society will **recruit, screen, and genetically sequence** 1,000 individuals who have been diagnosed with hypermobile EDS according to the most recent clinical criteria established in 2017.

Interested participants must be diagnosed with hypermobile EDS, complete the Ehlers-Danlos and Related Disorders Global Registry, the HEDGE study participant application, and agree to provide a blood sample during the recruitment event. Applicants accepted by the HEDGE research team will be contacted to schedule an appointment for the study.

Visit: [www.ehlers-danlos.com/hedge](http://www.ehlers-danlos.com/hedge)



- ✓ | RECRUIT
- ✓ | SCREEN
- ✓ | GENETIC SEQUENCE

## The Ehlers-Danlos Society

 [www.ehlers-danlos.com](http://www.ehlers-danlos.com) Follow us on:     

**The Ehlers-Danlos Society is a global community of patients, caregivers, health care professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes.**

Headquartered in New York, NY, The Ehlers-Danlos Society is a registered 501c3 nonprofit organization in the United States and a registered charity in the United Kingdom. The Ehlers-Danlos Society is 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.

H E D G E