

Who **WE ARE**

OUR MISSION

The Ehlers-Danlos Society is dedicated to advancing and accelerating research and education in the Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD).

We support the development of effective and equitable EDS and HSD therapies and work collaboratively to improve the lives of individuals affected by EDS and HSD.

OUR VISION

To create a world in which each person living with the Ehlers-Danlos syndromes and hypermobility spectrum disorders has the right treatment and care at the right time for their specific needs.



The
**Ehlers
Danlos**
Society

WHO WE ARE & WHAT WE DO

Our Strength Begins
With Hope



We CARE For **vEDS**

Care

HELPLINE

Offering support, guidance, and advice to all who need it. Our dedicated helpline team supports individuals, families, carers, and health professionals worldwide through a telephone helpline and email support.

VIRTUAL SUPPORT GROUPS

Providing monthly virtual Let's Chat groups for individuals who have vEDS and parents who have vEDS or children with vEDS to speak with others who understand.

Access

CENTERS & NETWORKS OF EXCELLENCE

Working to increase the availability of clinical services for people with vEDS, decreasing the diagnostic odyssey, and standardizing communication and care.

COMMUNITY

Bringing together and uniting our vEDS community, providing annual conferences globally, Junior Zebras programs, and family camps.

Research

RESEARCH GRANT PROGRAM

Bringing together and funding clinicians and researchers from all over the world to work on groundbreaking research, management, and care in vEDS.

MEDICAL & SCIENTIFIC SYMPOSIUMS

Examining the latest research, facilitating networking, and updating guidelines for management and care.

Education

RESOURCES & EDUCATION

Guiding both people with vEDS and medical professionals to the most up-to-date information, resources, and education through our website, collaborations, EDS ECHO program, and annual conferences.



What is **vEDS?**

vEDS // VASCULAR EHLERS-DANLOS SYNDROME

vEDS is a genetic connective tissue disorder that causes the blood vessels and organs to be fragile and prone to tearing.

The complications of vEDS can be life-threatening and include aneurysm, dissection, and rupture of the arteries and rupture of organs. vEDS may also cause a variety of other symptoms, including extensive bruising and spontaneous pneumothorax. vEDS can cause symptoms in many different areas of the body, so people with vEDS may require multiple providers in different specialties to manage their care.

Key aspects of care focus on monitoring and managing arterial and organ fragility. It is recommended that people with vEDS have an emergency plan in place and make lifestyle modifications to minimize the risk of complications.

GET IN TOUCH

For more information on The Ehlers-Danlos Society's work, to get involved, or to donate, please visit:

www.ehlers-danlos.com

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