



Everyone affected by the
Ehlers-Danlos syndromes and
hypermobility spectrum disorders
deserves great care.

At **EDS ECHO** we are supporting:

doctors, nurses, therapists, midwives, pharmacists, health and social care administrators, and community leaders and educators, worldwide, to be better informed and confident in the diagnosis and management of the Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD), and to provide care locally.



STEP 1

People need
easier access to
speciality care



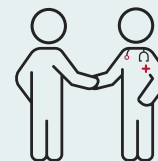
STEP 2

There aren't enough
clinicians knowledgeable
about EDS and HSD
to treat everyone



STEP 3

EDS ECHO uses
specialists to train and
support healthcare
professionals remotely



STEP 4

Now more healthcare
professionals can
provide speciality
care to their patients



In 2025 **EDS ECHO** will cost **\$280,000**
to deliver our wide portfolio of programs
free to participants around the world.

We cannot do this
without your support.

Everything we do supports people suffering today and helps prevent their symptoms from progressing tomorrow, **ensuring a better future** for every child and adult diagnosed with these conditions.



HERE IS HOW **YOU** CAN HELP

\$14,000

| supports the provision of **Continuing Education Credits** for all healthcare professionals who participate in our programs.

\$4,500

| provides a **6-week program for clinicians** from multiple disciplines to come together and learn, share and grow their knowledge and confidence.

\$2,300

| brings our **Allied Health Professionals** together from around the world for a 4-week module on a specialist aspect of therapy care.

\$100

| covers the average cost of a participant attending a program.

TO DONATE TODAY [CLICK HERE](#)



WHY **EDS ECHO** IS SO IMPORTANT

Across community and hospital settings, many healthcare professionals will attend to people with EDS or HSD. Yet too often the journey to diagnosis and treatment is challenging for patients, who may receive no diagnosis, or misdiagnoses, and delays of over 10 years in receiving the right care.

There are many health concerns that can arise in EDS and HSD. Care requires a holistic and multi-disciplinary approach. Yet such care is lacking for EDS and HSD internationally. There are small numbers of expert clinics, centres, and networks. Access to care is profoundly limited.

However, most generalists can manage many of the common concerns if given the right support. EDS ECHO supports healthcare professionals and community advocates, helping them to be better informed and confident in the diagnosis and management of EDS and HSD.





Hakim AJ, Tinkle BT, Francomano CA. Ehlers-Danlos syndromes, hypermobility spectrum disorders, and associated co-morbidities: Reports from EDS ECHO. Am J Med Genet C Semin Med Genet. 2021; 187(4).

2,600

**PARTICIPANTS
HAVE
ALREADY
JOINED
EDS **ECHO****



EDS **ECHO PROGRAMS:**

-  Clinicians
-  Fundamentals of the Integral Movement Method (IMM)
-  Health Advocacy
-  Allied Health Professionals
-  Pediatrics
-  Genetics & Genomics
-  Finding Functional Foundations (FFF)
-  Multidisciplinary Team Practice
-  Healthcare Students Program

“

The interdisciplinary model of EDS ECHO has allowed me to **build a massive network to help my patients** and to learn more about each specific system involved in the healthcare of my EDS patients.

”

“

I think as important as the EDS diagnosis itself, it was **very valuable to identify the many comorbidities that this population has**. More in-depth screening for specific comorbidities associated with EDS will be something to implement in my assessments.

”

“

Absolutely loved this experience. It was inspiring, engaging, and wonderful. **A rare opportunity to learn from leaders in the field.**

”

EDS **ECHO** PROGRAMS HELP PARTICIPANTS TO:



GAIN KNOWLEDGE

With programs in **adult and pediatric care**, our medical, therapies, and advocacy experts have already worked with over **2,200** healthcare professionals and **400** community advocates to support their learning and understanding of EDS and HSD.



NETWORK WORLDWIDE

EDS ECHO runs programs around the world. Clinicians network across multiple disciplines to support them in the care of their patients. Leaders and educators network across international communities. All can access advice from experienced colleagues worldwide.

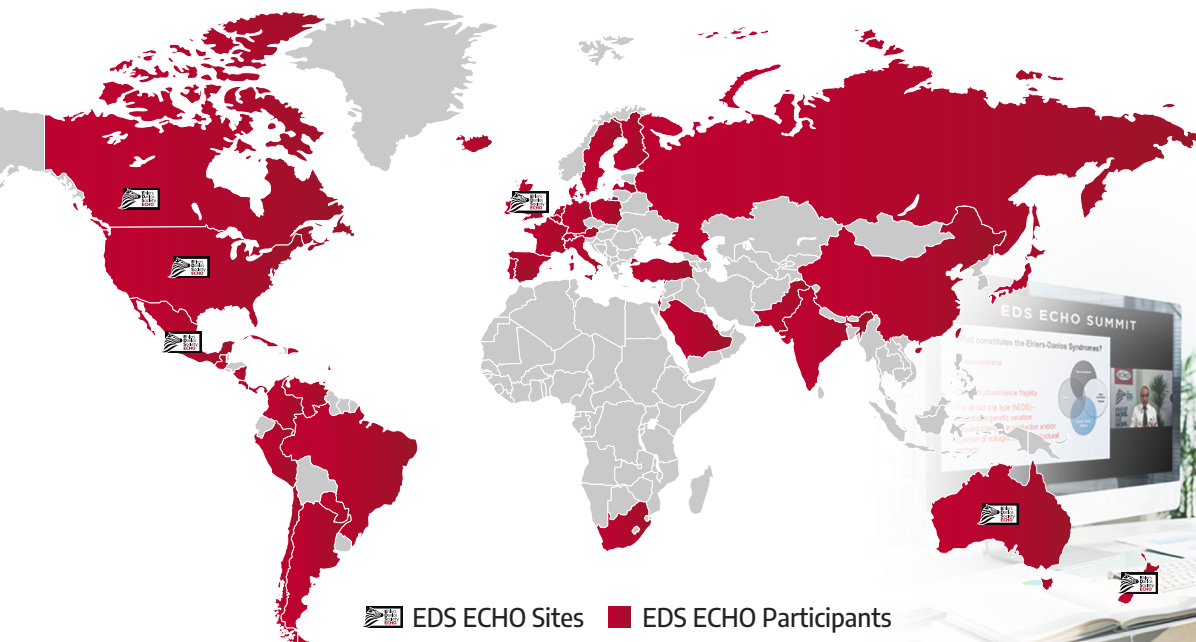


BECOME MORE CONFIDENT

Bringing their own experiences and patient case studies to sessions, participants learn from others and become more familiar with best practices and how to care for and support people living with these conditions.

Schubart JR, Bascom R, Francomano CA, Bloom L, Hakim AJ. Initial description and evaluation of EDS ECHO: An international effort to improve care for people with the Ehlers-Danlos syndromes and hypermobility spectrum disorders. *Am J Med Genet C Semin Med Genet.* 2021;187(4):609-615.

EDS **ECHO** SITES & PARTICIPANTS SO FAR



CHANGING FUTURES

In 2023, we launched an international **EDS ECHO Genetics & Genomics** program and an **EDS ECHO Nutrition** program to our portfolio. In 2024, we launched an **EDS ECHO Health Advocacy** program for our community members, and in 2025, we will be introducing a program for **caregivers**.

Our aim is to develop our network and reach of programs worldwide, increasing the languages the program is delivered in, and improving care and quality of life for people worldwide living with the complexities of EDS and HSD.

WHO WE ARE

EDS ECHO is run by The Ehlers-Danlos Society, an international non-profit. The organization supports people with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD).

EDS ECHO is an affiliate of Project ECHO®. Project ECHO's philosophies include "all teach, all learn" and "move knowledge, not people." Our model follows these principles, seeking to increase access to care.

We run several programs for healthcare professionals and community leaders and advocates in EDS and HSD across the world. Participation is free. All can then access a large repository of teaching material and support from a truly multidisciplinary and international network of peers.

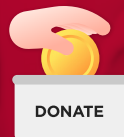
Over the last 6 years, **EDS ECHO** has worked with over 2,600 participants across all its programs.

Participants gain both knowledge and confidence in managing EDS and HSD, and increase their network of support, helping them help their patients and communities.

Hakim AJ, Tinkle BT, Francomano CA. Ehlers-Danlos syndromes, hypermobility spectrum disorders, and associated co-morbidities: Reports from EDS ECHO. Am J Med Genet C Semin Med Genet. 2021; 187(4).

 ehlers-danos.com

 echo@ehlers-danos.com



Every gift counts.

Together, we can advance education and care for people and families living with EDS and HSD, worldwide.



ALL TEACH ALL LEARN



GIVE TODAY



An **online donation** is easy to make

Visit: www.ehlers-danlos.com/donate/



Donate by **check**

United States: As a 501c3 organization, your donation is a tax-deductible charitable contribution. EIN# 38-2813140. To donate by mail, send a check (payable to The Ehlers-Danlos Society) to 447 Broadway, 2nd Fl #670; New York, NY 10013; USA.

Please reference your donation with "EDS ECHO" to confirm its designation.

United Kingdom: As a registered charity in England and Wales (1180984), your donation is eligible for Gift Aid. To donate by mail, send a check (payable to The Ehlers-Danlos Society) to Office 7; 35-37 Ludgate Hill; London, EC4M 7JN; UK.

Please reference your donation with "EDS ECHO" to confirm its designation.



Contact us to discuss **making a gift**

To arrange a call with us to discuss how you can help email us at: echo@ehlers-danlos.com

Platinum
Transparency
2025

Candid.

United States:

As a 501c3 organization, your donation is a tax-deductible charitable contribution to the extent allowed by the law, EIN# 38-2813140. Certain states require written disclosures for nonprofit organizations soliciting contributions. Please click here for individual state disclosures.

United Kingdom

As a registered charity in England and Wales (1180984), your donation is eligible for the Gift Aid scheme to the extent allowed by law. The Ehlers-Danlos Society's Companies House Number is 10722868. To include Gift Aid in your donation please download, fill out, and return the gift aid form to giving@ehlers-danlos.com.

