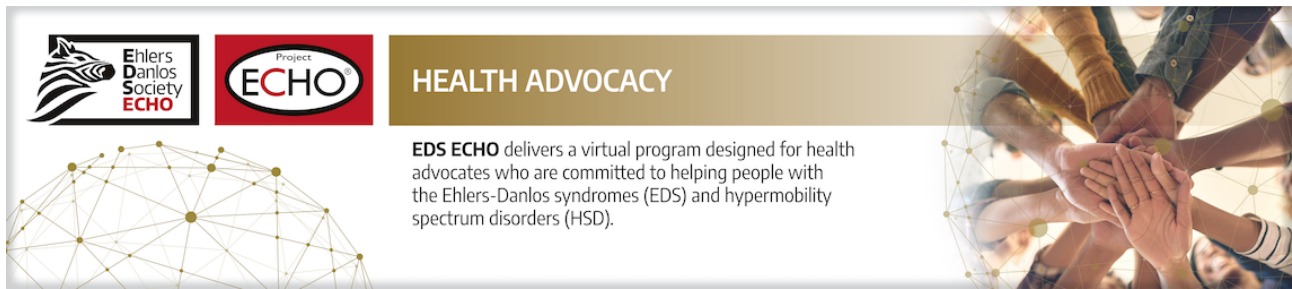


EDS ECHO Health Advocacy

Certificate Supplement and Program Summary

Table of Contents

Program Title:	2
Program Overview:	2
Educational Aims:	2
Program Structure & Curriculum:	2
Program Schedule:	3
Faculty:	4
Participation Requirements:	4
Provider Information:	4
CPD Self-Reporting Disclaimer:	5
Contact:	5



Program Title:

Program Title: EDS ECHO Health Advocacy

Program Code: HADV3

Program Overview:

EDS ECHO Health Advocacy program is a virtual program designed for health advocates who are committed to helping people with the Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). This program equips participants with essential skills, tools, and experience, allowing them to support others in effectively navigating the healthcare system and life, and advocating for better care of people with EDS and HSD.

Health advocates play a crucial role in guiding people through the healthcare system. They educate and support patients to make informed healthcare decisions, improve communication with healthcare providers, manage administrative tasks like scheduling and dealing with insurance, and direct individuals to helpful resources for financial, legal, and social support. Advocates might also identify roles in commenting on or the development of local or national policies that affect the care of people in their community.

This program is designed for a diverse group of health advocates who are dedicated to enhancing support for people with EDS and HSD. The program is open to adults (18+) worldwide who speak English. We aim to identify individuals who are eager to learn, engage, and actively contribute to the program's network and subsequent activities.

Educational Aims:

Learn how to better support people with EDS and HSD

Gain knowledge and skills to support you in helping people navigate life with EDS and HSD. This includes learning how to effectively communicate about EDS and HSD, understanding how the healthcare system works, and consider your role as a health advocate.

Provide helpful resources to people with EDS and HSD

Learn how to address common concerns and challenges faced by the EDS and HSD community. Provide tailored support by identifying and sharing helpful resources relevant to each person's individual needs.

Engage in a supportive advocacy community

Connect with a global community of health advocates who share your dedication to supporting those with EDS and HSD. Collaborate with fellow advocates to strengthen support for people with EDS and HSD.

Program Structure & Curriculum:

The program is composed of 10 sessions, with a short break between session 5 and 6. A drop-in session will be held during the break for any further discussion and networking. Each session includes presentations from community leaders and interactive discussions about applying what was learned. Sessions are co-facilitated

by Caroline Kim and Marty Miller. Please see the Program Schedule table below for information of session topics and dates.

Each 90-minute session is delivered virtually through the Zoom platform in English. Captions will be available during the sessions for accessibility purposes.

Participants can expect to receive assignments and surveys before, during, and after the program to assess engagement, understanding, and progress.

Program Schedule:

Session	Session Topic	Date and Time: Wednesdays at 3:00pm–4:30pm Eastern Time (US and Canada)
1	Opportunities in Health Advocacy Guest Speakers: Maggie Buckley	April 22, 2026
2	Understanding EDS & HSD Guest Speaker: Dr. Dacre Knight	April 29, 2026
3	Life Planning Guest Speaker: Caroline Kim	May 6, 2026
4	Navigating the Healthcare System Guest Speaker: Dr. Dacre Knight	May 13, 2026
5	Communicating as a Health Advocate Guest Speaker: Marty Miller	May 20, 2026
6	Healthcare Troubleshooting Guest Speaker: Dr. Akilah Cadet	June 3, 2026
7	Accessing Accommodations Guest Speaker: Emily Thorpe	June 10, 2026
8	Applying for Benefits Guest Speaker: Emily Thorpe	June 17, 2026
9	Providing Helpful Resources Guest Speaker: Caroline Kim	June 24, 2026
10	Supporting Health and Wellbeing Guest Speaker: Dr. Chad Shepherd	July 1, 2026

Faculty:

Program Facilitator: Caroline Kim

Caroline Kim opened her own independent advocacy practice, Norbella Health Advocates after becoming a Board Certified Patient Advocate in 2024. Having lived with multiple chronic conditions and Ehlers Danlos for the past 2 decades, she's passionate about advocating for others and ensuring people have access to quality healthcare.

Caroline's a member of various organizations, including Bay Area Health Care Advocates, Greater National Advocates, the Alliance of Professional Health Advocates, and the Ehlers Danlos Society, where she's obtained their ECHO certification for advocacy.

With an undergraduate and master's degree in journalism, Caroline's worked in media and tech industries prior to opening her own practice and has a patient advocacy certificate from UCLA. She has spoken on panels and mentors advocates who are newer to the field. Her unique experience and expertise have helped others learn how to advocate for themselves and facilitate communication with providers while encouraging efficient healthcare management.

Program Facilitator: Marty Miller

Marty is a board-certified patient advocate and graduate student at Case Western Reserve University. Their primary focuses are barriers to marginalized communities and chronic conditions with mental health comorbidities. They have three years of experience working in case management and program development for Q+ youth and young adults.

Guest Speakers:

Guest speakers are experienced clinicians and health advocates with specialist expertise relevant to each session topic.

Participation Requirements:

Participants are encouraged to attend the full program to support continuity of learning and achievement of all educational outcomes. Partial attendance will qualify for a Certificate of Attendance, which will reflect the number of sessions attended. Session recordings do not count toward program completion or certificate eligibility.

Program Certificates:

- A **Certificate of Attendance** will be issued to participants who complete the post-program evaluation. A link to the evaluation will be provided following the conclusion of the course.
- A **Certificate of Completion** will be issued to participants who meet the attendance requirement of 8/10 sessions attended live.

Provider Information:

The Ehlers-Danlos Society is a global organization dedicated to advancing and accelerating research and education in [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.

By bridging geographic and systemic barriers, The Ehlers-Danlos Society is committed to driving meaningful change in EDS and HSD management and care delivery through educational programming.

EDS ECHO is a global program for practicing health care professionals across all disciplines who want to improve their ability to care for people with EDS, HSD and associated symptoms and conditions.

Project ECHO® addresses population health in a scalable way — moving knowledge instead of patients via telementoring and collaborative care. The heart of the ECHO model™ is its hub-and-spoke knowledge-

sharing networks, led by expert specialist teams. The ECHO model is not “telemedicine” where specialists assume the care of the patient; it is a guided model aimed at practice improvement, in which providers retain responsibility for patients, and gain increasing independence as skills, confidence, and self-efficacy grow.

CPD Self-Reporting Disclaimer:

This activity is not formally accredited for CME/CPD points. Participants may be able to self-report this activity to their professional body in accordance with local CPD requirements.

Contact:

If you have any questions or would like further clarification, please contact us at echo@ehlers-danlos.com