



Poster no: 85
Theme 3: Share, Care, Rare: Transforming care for rare disease by 2030
Title: EDS ECHO: Worldwide, Case-based Learning And Support For Clinicians Managing Ehlers-Danlos Syndromes
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Background

The Ehlers-Danlos syndromes (EDS) are a group of rare heritable disorders of connective tissue (1). Surveys demonstrate globally that people with EDS have considerable difficulty accessing specialist care primarily due to limited numbers of experts in the field.

Project ECHO™ is a non-profit promoting multidisciplinary care through video conferencing where clinicians share knowledge using case-based learning (2). Recognizing the opportunity to support clinicians internationally, the Ehlers-Danlos Society joined Project ECHO in 2018 and launched EDS ECHO in April 2019; the first world-wide network in EDS, and the first advocacy training using the ECHO model (3).

EDS ECHO Structure

EDS ECHO is managed by staff from the Ehlers-Danlos Society with expert support from clinician colleagues across the breadth of the relevant medical, surgical, mental health, and allied health professional fields of care. The portfolio is funded by donations.

Programs are run virtually using the ZOOM video conference platform.

Currently EDS ECHO runs 7 programs, free to participants, including 2 in all areas of health concern pertinent to EDS and hypermobility spectrum disorders (HSD); 1 for vascular EDS; 3 for allied health care; and 1 patient advocacy program.

In 2020/21 the portfolio expands to include Pediatrics, Orthopedics, and other EDS rare variants. The portfolio is managed from 3 regions (USA, Europe, and Australia), with the desire to expand in 2020/21 to cover South America, India, and South East Asia.

EDS ECHO is also exploring the ‘upskilling’ of clinicians on the programs through formal research reviewing experience at baseline, 6, 12 and 24 months from joining. Preliminary data will be available later in 2020.

Outcomes

Since inception EDS ECHO has welcomed 300 clinicians to its alumni network, and, aspires to achieve 1000 by 2021. Clinicians have come from North America (including 24 US States), South America, Europe, the Middle East, Australia, and New Zealand. Over 20 specialties across medical, surgical, and allied health fields have been represented.

Feedback on all EDS ECHO programs has been highly supportive, specifically the opportunity to share experience through case-based learning in multi-disciplinary discussions that promote the philosophy of ‘all teach, all learn’

Conclusion

The Ehlers-Danlos Society’s experience is that this approach to supporting clinicians is highly valued, and we commend this model to other rare disease groups.

References:

1. Malfait F, Francomano C, Byers P, et al. The 2017 international classification of the Ehlers-Danlos syndromes. *Am J Med Genet C Semin Med Genet.* 2017 Mar;175(1):8-26.
2. <https://echo.unm.edu>
3. <https://www.ehlers-danlos.com/echo/>