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EDS Awareness in collaboration with EDS Wellness is hosting *LEAD EDS --* a first of its kind EDS Leadership Conference on May 17th during Ehlers-Danlos Awareness Month.

Mason, Ohio - EDS Awareness (a.k.a. Chronic Pain Partners) is teaming up with EDS Wellness, based in Maryland, to host *LEAD EDS* – the 1st EDS Leadership Conference. The inaugural LEAD EDS event will be held on May 17, 2019 in Mason, Ohio and will feature Mandy Harvey as the special guest entertainer. Mandy Harvey, an America's Got Talent golden buzzer winner, suffers from hearing loss due to Ehlers-Danlos syndromes (EDS).

This partnership was formed out of the need to provide education and training for support, advocacy, and social media group leaders for EDS and related conditions.

May is recognized as Ehlers-Danlos Awareness Month; each May brings to light thousands of patients struggling with symptoms of EDS and hypermobility spectrum disorders (HSD). Most of these individuals are looking for connection, support, and education related to their condition. EDS Awareness and EDS Wellness created the EDS Leadership Program, including the conference on May 17th, 2019, to train leaders of local, virtual, and social media-based support groups to answer this need.

The conference will be live-streamed for those interested. Please visit <u>www.leadeds.com</u> for additional information and to register to attend either in person or virtually via live stream.

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2019 EDS Leadership Conference Speakers:

John Ferman - President and founder of Chronic Pain Partners, an international EDS Awareness organization. Their programs have helped to form over 120 EDS Support Groups, provided over 85 patient-oriented live monthly educational webinars, and launched the first Online EDS Physician CME program.

Kendra Neilsen Myles, CHES, BCPA - Executive Director & Founder of EDS Wellness, Inc., a global public health and wellness-focused organization. EDS Wellness' work includes: Wellapalooza Integrative

Wellness Conferences (and Retreats!), the 2017 Physicians Learning Conference, EDS Ride for a Cause, the 'Mind-Body Strategies for Hypermobility with Chronic Pain' program, Integrative Healing for EDS brochure, and the 2018 and 2019 'Integrative Strategies for Managing Hypermobility Disorders & Related Conditions, Restoring Function & Living Well' video webinar series and education program.

Dr. Linda Bluestein - Founder of *Wisconsin Integrative Pain Specialists, S.C.* and a volunteer medical consultant to several non-profit organizations including Chronic Pain Partners and EDS Wellness.

Maria Dastur, M.B.A.- Executive Director of the Rocky Mountain Chapter of the Scleroderma Foundation. Maria's work in the rare disease field began with the Ben's Friends (BF) AVM Patient Community. Initially serving as a group moderator, she quickly graduated to the new BF's Facebook development team.

Amanda Aikulola - Founder and President of the Dysautonomia Support Network.

Andrea Julian - Director of the Dayton Ohio Zebras. Functional Training Specialist and Youth Mentor.

Cathy Rouhier - Teen group leader for the Dayton Ohio group

Chronic Pain Partners aka EDS Awareness is a non-profit organization founded by John Ferman as a resource for the Ehlers-Danlos Syndromes community: individuals suffering with EDS and their caregivers. https://www.chronicpainpartners.com/

EDS Wellness is a 501(c)(3) non-profit organization founded by Kendra Neilsen Myles to promote health education, integrative healthcare, and wellness strategies for individuals suffering from hypermobility disorders, such as Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and related conditions. https://edswellness.org