

**The Ehlers-Danlos Society**

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FOR IMMEDIATE RELEASE

May is Ehlers-Danlos Awareness Month

The Ehlers-Danlos Society kicks off Ehlers-Danlos Awareness Month on Monday, May 1. This month-long observance of awareness, education, outreach, and fundraising for the Ehlers-Danlos syndromes and related disorders first began in 2006.

“More awareness is needed for these often misdiagnosed and misunderstood conditions,” said Lara Bloom, International Executive Director of The Ehlers-Danlos Society and an EDS patient herself. “For too long, patients have had to wait years, even decades, for a diagnosis. Until an accurate diagnosis is made, patients cannot get the proper care they need to handle the many debilitating manifestations of their condition. Our goal is to make the Ehlers-Danlos syndromes so widely recognized that these patients get the care they need as soon as they present with symptoms.”

The Ehlers-Danlos syndromes are a collection of thirteen multi-systemic, heritable disorders affecting connective tissue, the most abundant tissues in the body. With the exception of the hypermobile Ehlers-Danlos syndrome, each type is a distinct entity defined by mutations in a single or small set of genes. Common features among the types include joint hypermobility, skin fragility, chronic pain, and fatigue. More severe types, such as Vascular Ehlers-Danlos syndrome, can be life-threatening, as fragile blood vessels and internal organs can spontaneously rupture.

This is the first May Awareness Month since the Ehlers-Danlos syndromes received a major classification update in March of this year with the release of 18 new papers in the *American Journal of Medical Genetics*. The Ehlers-Danlos Society, representing a recently formed international consortium of over 90 experts on the Ehlers-Danlos syndromes, released the culmination of two years of review on March 15. This publication clarified the bases for the diagnosis of and the descriptions of more than a dozen different types of the Ehlers-Danlos syndromes. This long-awaited review updated the diagnostic criteria for the first time in 20 years, and provided management and care guidelines. It also introduced the newly-described hypermobility spectrum disorders.

The theme for The Ehlers-Danlos Society's 2017 Ehlers-Danlos Awareness Month is #DazzleTogether. Patients with Ehlers-Danlos syndromes are often referred to as “zebras,” which references a popular medical school mantra, “When you hear hoof beats, think horses, not zebras,” equating zebras with rare diseases. In the wild, a group of zebras is called a dazzle. The #DazzleTogether campaign encourages the community to work together as a “dazzle” to raise awareness and funds for research throughout the month of May.

The Ehlers-Danlos Society is a global community of patients, caregivers, healthcare professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes and related disorders. It is a 501(c)(3) nonprofit organization. More information about the Society can be found at ehlers-danlos.com.

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