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SENATE JOINT RESOLUTION NO. 254

Offered January 8, 2025

Prefiled January 6, 2025

Designating May, in 2025 and in each succeeding year, as Ehlers-Danlos Syndromes Awareness Month in Virginia.

Patron—Perry

Referred to Committee on Rules

WHEREAS, Ehlers-Danlos syndromes (EDS) are a group of heritable disorders that affect the body's connective tissues, which provide support, protection, and structure to various parts of the body, including the skin, tendons, ligaments, blood vessels, internal organs, and bones; and

WHEREAS, EDS was first described in the early twentieth century by Dr. Edvard Lauritz Ehlers and Dr. Henri-Alexandre Danlos, and the classifications of EDS have evolved over time, with 14 types of EDS recognized today; and

WHEREAS, the different types of EDS are hypermobile EDS, classical EDS, classical-like-2 EDS, vascular EDS, periodontal EDS, kyphoscoliotic EDS, spondylodysplastic EDS, brittle cornea syndrome, arthrochalasia EDS, musculocontractural EDS, classical-like EDS, dermatosparaxis EDS, myopathic EDS, and cardiac-valvular EDS; and

WHEREAS, the different types of EDS are caused by variants in specific genes that affect the way the body produces collagen, the primary component of connective tissue, and other related proteins; and

WHEREAS, each type of EDS is unique and has its own signs and symptoms, although these disorders are most commonly associated with excessively flexible joints and stretchy, fragile skin; and

WHEREAS, in addition to the variability across types of EDS, different individuals with the same type of EDS may experience different signs and symptoms, complicating diagnosis and treatment and often requiring patients to see multiple providers across different specialties; and

WHEREAS, the most common type of EDS, hypermobile EDS, is believed to affect at least one in 3,100–5,000 people, although the true prevalence is not known and may be greater; and

WHEREAS, certain types of EDS may be identified through genetic testing; however, there is currently no such test for hypermobile EDS; and

WHEREAS, EDS shares similarities with hypermobility spectrum disorders, which are connective tissue disorders that cause symptomatic joint hypermobility and joint instability and which cannot be explained by other conditions; they are referred to as spectrum disorders because people experience a wide range of types and severities of symptoms; and

WHEREAS, EDS can greatly impact one's quality of life depending on its severity and is often associated with comorbidities such as dysautonomia, mast cell diseases, and postural orthostatic tachycardia syndrome; and

WHEREAS, there is currently no known cure for EDS, and greater medical research is necessary to offer aid and relief to those coping with this disorder; and

WHEREAS, by bringing greater awareness and understanding to EDS, an untold number of individuals and families may hope to lead healthier and more fulfilling lives; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the General Assembly designate May, in 2025 and in each succeeding year, as Ehlers-Danlos Syndromes Awareness Month in Virginia; and, be it

RESOLVED FURTHER, That the Clerk of the Senate transmit a copy of this resolution to the Ehlers-Danlos Society so that members of the organization may be apprised of the sense of the General Assembly of Virginia in this matter; and, be it

RESOLVED FINALLY, That the Clerk of the Senate post the designation of this month on the General Assembly's website.

INTRODUCED

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