

2023 -- S 1022

LC002964

STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2023

SENATE RESOLUTION

PROCLAIMING MAY OF 2023, TO BE "EHLERS-DANLOS SYNDROMES AND HYPERMOBILITY SPECTRUM DISORDERS AWARENESS MONTH" IN THE STATE OF RHODE ISLAND

Introduced By: Senators Lawson, Lauria, Britto, Cano, F. Lombardi, Felag, Ujifusa, Lombardo, Mack, and Bell

Date Introduced: May 16, 2023

Referred To: Recommended for Immediate Consideration

1 WHEREAS, Ehlers-Danlos syndromes (EDS) are a group of genetic connective tissue
2 disorders caused by different underlying abnormalities in collagen that together affect 1 in 5,000
3 people of every age and race; and

4 WHEREAS, Each type of EDS has its own set of symptoms, but some features seen
5 across all types of EDS include joint hypermobility and dislocation, fragile, hyperextensible skin
6 that bruises and scars easily, and tissue fragility; and

7 WHEREAS, EDS is often inherited and can affect multiple generations within a family;
8 and

9 WHEREAS, There is neither routine screening nor a cure for EDS, and treatment focuses
10 on managing symptoms and preventing dangerous complications; and

11 WHEREAS, Severe cases can be associated with unpredictable tearing of blood vessels
12 and organs, leading to internal bleeding and other potentially life-threatening complications; and

13 WHEREAS, Hypermobility Spectrum Disorders (HSD) are connective tissue disorders
14 that cause joint hypermobility, instability, injury, pain, fatigue, headaches, GI problems, and
15 autonomic dysfunction; and

16 WHEREAS, HSD is diagnosed when the musculoskeletal complications of joint
17 hypermobility and joint stability, such as joint movement beyond the normal range, joint pain,
18 and dislocations, arise in a person who does not have the defining features of an underlying
19 syndrome such as EDS or other heritable disorders of connective tissue; and

1 WHEREAS, In addition, several related disorders are observed in a number of people of
2 EDS and with HSD, which can add complexity to the presentation of their condition and its
3 management; and

4 WHEREAS, There is no cure for any type of EDS or HSD and conditions are managed
5 by addressing a person's individual symptoms; and

6 WHEREAS, EDS and HSD can cause a variety of symptoms in many different areas of
7 the body, so people with these conditions often require multiple providers in different specialties
8 to manage their care; and

9 WHEREAS, Access to professionals who are knowledgeable about EDS and HSD is
10 limited not only in Rhode Island, but across the world; and

11 WHEREAS, Individuals with EDS and HSD can sometimes remain undiagnosed for
12 decades, while their symptoms progress and become more difficult to treat; and

13 WHEREAS, Improved knowledge and recognition of EDS and HSD will lead to earlier
14 detection and medical management, thereby reducing the burden of disease and its negative
15 impact on families; and

16 WHEREAS, Continued research is needed to better understand EDS and HSD and
17 encouraging further studies can lead to breakthroughs in genetic testing, treatments, and other
18 medical interventions, generating growth in the knowledge base and bringing hope for a cure;
19 now, therefore be it

20 RESOLVED, That this Senate of the State of Rhode Island hereby proclaims May of
21 2023, to be "Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders Awareness
22 Month" in the State of Rhode Island; and be it further

23 RESOLVED, That the Secretary of State be and hereby is authorized and directed to
24 transmit a duly certified copy of this resolution to Ms. Susan Hawkins, Chair, The Ehlers-Danlos
25 Society.

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