
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 296 Session of
2024

INTRODUCED BY MARTIN, TARTAGLIONE, BROWN, FONTANA, PHILLIPS-HILL
AND HAYWOOD, MAY 28, 2024

REFERRED TO RULES AND EXECUTIVE NOMINATIONS, MAY 28, 2024

A RESOLUTION

1 Designating the month of May 2024 as "Ehlers-Danlos Syndrome
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Ehlers-Danlos syndrome (EDS) is a group of genetic
4 disorders affecting connective tissue in the body, characterized
5 by looseness, instability and dislocations of the joints, and
6 fragile and often hyper-elastic skin that bruises, scars and
7 tears easily; and

8 WHEREAS, In extreme cases, EDS can cause unpredictable
9 arterial and organ rupture that can lead to acute pain,
10 excessive internal bleeding, shock, stroke and premature death;
11 and

12 WHEREAS, In 1936, EDS was named after the medical research
13 and contributions of Edvard Ehlers in 1901 and Henri-Alexandre
14 Danlos in 1908; and

15 WHEREAS, According to the National Institutes of Health, it
16 is estimated that the combined prevalence of all types of EDS is
17 1 in 5,000 individuals worldwide, however it is likely that this
18 is an underestimation; and

1 WHEREAS, There is no routine screening or cure for EDS, and
2 individuals must seek a diagnosis from a health care provider
3 who is knowledgeable in the symptoms of EDS; and

4 WHEREAS, EDS is frequently misdiagnosed or undiagnosed,
5 resulting in great frustration and discomfort for affected
6 individuals and their families; and

7 WHEREAS, The symbol of EDS is the zebra because no two zebras
8 are the same, just as no two patients with EDS are the same; and

9 WHEREAS, Lack of knowledge of EDS, combined with varying
10 symptoms that can be different in each individual, has hampered
11 diagnosis and treatment efforts for those affected; and

12 WHEREAS, While limited modern research on EDS exists
13 currently, there is hope that research will be increased in the
14 near future; and

15 WHEREAS, Treatment is limited to drugs that manage or
16 minimize symptoms, physical therapy and surgical intervention in
17 some cases; and

18 WHEREAS, Collaboration among nurses, social workers,
19 pediatricians, physical therapists, orthopedists, surgeons,
20 rheumatologists, neurologists, dermatologists, pain control
21 specialists, cardiologists, dentists and a genetics team is key
22 as the management of EDS requires the use of a multidisciplinary
23 approach; and

24 WHEREAS, A network of EDS support groups further connects
25 affected individuals and caregivers, raises public awareness and
26 promotes related research and funding within the medical
27 community; therefore be it

28 RESOLVED, That the Senate designate the month of May 2024 as
29 "Ehlers-Danlos Syndrome Awareness Month" in Pennsylvania.