
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 123 Session of
2023

INTRODUCED BY MARTIN, BARTOLOTTA, LAUGHLIN AND COSTA,
MAY 31, 2023

REFERRED TO RULES AND EXECUTIVE NOMINATIONS, MAY 31, 2023

A RESOLUTION

1 Designating the month of May 2023 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; and

18 WHEREAS, There is no routine screening or cure for EDS, and

1 individuals must seek a diagnosis from a health care provider
2 that is knowledgeable in the symptoms of EDS; and

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

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

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

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

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

17 WHEREAS, Collaboration among nurses, social workers,
18 pediatricians, physical therapists, orthopedists, surgeons,
19 rheumatologists, neurologists, dermatologists, pain control
20 specialists, cardiologists and a genetics team is key; and

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

25 RESOLVED, That the Senate designate the month of May 2023 as
26 "Ehlers-Danlos Syndrome Awareness Month" in Pennsylvania.