
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 296 Session of
2022

INTRODUCED BY MARTIN, BROWNE, MENSCH, SCAVELLO, FONTANA, COSTA,
BARTOLOTTA, J. WARD AND STEFANO, MAY 18, 2022

REFERRED TO RULES AND EXECUTIVE NOMINATIONS, MAY 18, 2022

A RESOLUTION

1 Designating the month of May 2022 as "Ehlers-Danlos Syndrome
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Ehlers-Danlos syndrome, also known as EDS, is a
4 group of genetic disorders affecting connective tissue in the
5 body, characterized by looseness, instability and dislocations
6 of the joints and fragile, and often hyper-elastic, skin that
7 bruises, scars and 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, It is estimated that EDS is prevalent in 1 in 3,500
16 to 1 in 5,000 individuals, with fewer than 200,000 cases
17 diagnosed in the United States each year; 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 2022 as
26 "Ehlers-Danlos Syndrome Awareness Month" in Pennsylvania.