

THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 336 Session of
2018

INTRODUCED BY MARTIN, GREENLEAF, EICHELBERGER, BARTOLOTTA,
FONTANA, DINNIMAN, VULAKOVICH, BROWNE, HUGHES, SABATINA,
HUTCHINSON, KILLION, SCHWANK, MENSCH, AUMENT, RAFFERTY,
SCAVELLO, COSTA AND BREWSTER, APRIL 24, 2018

INTRODUCED AND ADOPTED, APRIL 24, 2018

A RESOLUTION

1 Designating the month of May 2018 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 hyperelastic 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 2,500
16 to 1 in 5,000 people with fewer than 200,000 cases diagnosed in
17 the United States each year; 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 that 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 and a genetics team is key; and

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

26 RESOLVED, That the Senate designate the month of May 2018 as
27 "Ehlers-Danlos Syndrome Awareness Month" in Pennsylvania.