
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 201 Session of
2015

INTRODUCED BY D. COSTA, KIM, COHEN, YOUNGBLOOD, DeLUCA, BAKER,
READSHAW, BISHOP, THOMAS, DONATUCCI, HEFFLEY, CALTAGIRONE,
HARHART, SONNEY, DUSH, WHEELAND, MILLARD, LONGIETTI, ACOSTA,
SCHWEYER, KINSEY, DiGIROLAMO, HENNESSEY, McNEILL, MARSICO,
ROSS, O'NEILL, FARINA, BROWNLEE, MAJOR, MAHONEY, GINGRICH,
KIRKLAND, MURT AND GILLEN, MARCH 26, 2015

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
MARCH 26, 2015

A RESOLUTION

1 Designating the month of May 2015 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, caused by various defects in the synthesis of collagen
6 which provides support to many body parts such as the skin,
7 muscles and ligaments; and

8 WHEREAS, EDS is characterized by looseness, instability and
9 dislocations of the joints and fragile and often hyperelastic
10 skin that bruises, scars and tears easily; and

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

15 WHEREAS, There are six types of EDS, defined according to the

1 signs and systems that are manifested in a set of major and
2 minor diagnostic criteria for each type; and

3 WHEREAS, Though the first possible description of EDS was
4 made by Hippocrates in 400 B.C., Edvard Ehlers defined it in
5 1901 as a nameless, distinct disorder in a case history that
6 included lax joints, hyperextensible skin and a tendency to
7 bruise; and

8 WHEREAS, In 1908, Henri-Alexandre Danlos published a second
9 case history on the disorder and in 1936, it was suggested that
10 the disorder be named Ehlers-Danlos Syndrome to honor the
11 previous research on the disorder; and

12 WHEREAS, It is estimated that EDS is prevalent in 1 in 2,500
13 to 1 in 5,000 people; and

14 WHEREAS, The significant risk of injury associated with EDS
15 prevents those affected from enjoying activities many of us take
16 for granted, such as contact sports and weightlifting; and

17 WHEREAS, There is no routine screening or cure for EDS, and
18 individuals must seek a diagnosis from a health care provider
19 that is knowledgeable in the symptoms of EDS as all individual
20 symptoms must be evaluated and cared for appropriately; and

21 WHEREAS, Early diagnosis and screening is key to properly
22 managing the symptoms of EDS and improving the quality of life
23 for affected individuals; and

24 WHEREAS, EDS is frequently misdiagnosed or undiagnosed,
25 resulting in great frustration and discomfort for affected
26 individuals and their families; and

27 WHEREAS, The prognosis for an individual with EDS depends on
28 the type of EDS and the individual as life expectancy can be
29 shortened for those with the vascular type of EDS due to the
30 possibility of organ and vessel rupture; and

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

4 WHEREAS, While limited modern research on EDS exists
5 currently, there is hope that genetic testing and research will
6 be increased in the near future; therefore be it

7 RESOLVED, That the House of Representatives designate the
8 month of May 2015 as "Ehlers-Danlos Syndrome Awareness Month" in
9 Pennsylvania.