

118TH CONGRESS
1ST SESSION

H. RES. 419

Expressing support for the designation of May as Ehlers-Danlos Syndrome Awareness Month to increase the knowledge of this little-known, potentially fatal, genetic disease.

IN THE HOUSE OF REPRESENTATIVES

MAY 17, 2023

Mr. RUPPERSBERGER submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for the designation of May as Ehlers-Danlos Syndrome Awareness Month to increase the knowledge of this little-known, potentially fatal, genetic disease.

Whereas Ehlers-Danlos Syndrome represents multiple genetic disorders involving mutations in connective tissue that are characterized by looseness, instability, and dislocation of the joints and fragile skin that easily bruises and scars;

Whereas there are 13 types of Ehlers-Danlos Syndrome caused by genetic defects in collagen, one of the major structural components of the body;

Whereas it is estimated that the prevalence of all types of the syndrome affect at least 1 in 5,000 people worldwide;

Whereas a network of Ehlers-Danlos Syndrome support groups can help connect those managing life with the disease as well as better inform the health care community and the public;

Whereas early and accurate diagnosis can provide the opportunity to create lifesaving medical plans and ensure the quality of life;

Whereas there is currently no treatment for Ehlers-Danlos Syndrome and no known cure;

Whereas further medical research and awareness bring hope for treatment and a cure; and

Whereas the month of May would be an appropriate month to designate as Ehlers-Danlos Syndrome Awareness Month: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the designation of Ehlers-Danlos
3 Syndrome Awareness Month;

4 (2) honors those bravely suffering from Ehlers-
5 Danlos Syndrome; and

6 (3) encourages scientific research and funding
7 to find a cure for Ehlers-Danlos Syndrome.

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