117TH CONGRESS 1ST SESSION

H. RES. 335

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

April 20, 2021

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 sears;

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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