

111TH CONGRESS
1ST SESSION

H. RES. 536

Expressing support for the HHT Foundation International's designation of a "National Hereditary Hemorrhagic Telangiectasia (HHT) Month" and supporting efforts to educate the public about HHT.

IN THE HOUSE OF REPRESENTATIVES

JUNE 11, 2009

Mr. NEAL of Massachusetts (for himself and Mr. WILSON of South Carolina) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for the HHT Foundation International's designation of a "National Hereditary Hemorrhagic Telangiectasia (HHT) Month" and supporting efforts to educate the public about HHT.

Whereas HHT, also known as Osler-Weber-Rendu Syndrome, is a complex genetic blood vessel disorder characterized by telangiectases and artery-vein malformations that occur in major organs, including the lungs, brain, and liver, as well as the nasal mucosa, mouth, gastrointestinal tract, and skin of the face and hands;

Whereas left untreated, HHT can result in considerable morbidity and mortality, including acute and chronic health problems or sudden death;

Whereas 20 percent of those with HHT, regardless of age, suffer death or disability due to the sudden rupture of blood vessels in the major organs in the body;

Whereas, due to widespread lack of knowledge of the disorder, approximately 90 percent of those suffering from HHT are not yet diagnosed and are at risk for death or disability;

Whereas HHT is often misdiagnosed or mistreated;

Whereas tests exist for the early detection and proper diagnosis of HHT, and certain treatments are available in facilities such as the 9 HHT Treatment Centers of Excellence in the United States;

Whereas an estimated 20 to 40 percent of deaths and disabilities resulting from HHT are preventable;

Whereas HHT is a national health problem that affects approximately 70,000 people in the United States and 1,200,000 worldwide;

Whereas a leading academic institution has estimated that \$6,600,000,000 of one-time health care costs can be saved by the aggressive management of the HHT at-risk population;

Whereas support is needed for research, outreach, and education to prevent death and disability, improve outcomes, reduce costs, and increase the quality of life for people living with HHT;

Whereas “National Hereditary Hemorrhagic Telangiectasia Month” will increase public awareness of HHT; and

Whereas the HHT Foundation International has designated June as “National Hereditary Hemorrhagic Telangiectasia Month”: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports HHT Foundation International’s
3 designation of a “National Hereditary Hemorrhagic
4 Telangiectasia Month” and supports efforts to edu-
5 cate the public about HHT;

6 (2) recognizes the need to pursue research into
7 better treatments and an eventual cure for HHT;

8 (3) supports the work of the HHT Foundation
9 International to find a cure for HHT while saving
10 lives and improving the well-being of individuals and
11 families affected by HHT through research, out-
12 reach, education, and support; and

13 (4) encourages the people of the United States
14 and interested groups to observe and support the
15 month through appropriate programs and activities
16 that promote public awareness of HHT and poten-
17 tial treatments for it.

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