112TH CONGRESS
1ST SESSION

S. RES. 286

Recognizing May 16, 2012, as Hereditary Angioedema Awareness Day and expressing the sense of the Senate that more research and treatments are needed for Hereditary Angioedema.

IN THE SENATE OF THE UNITED STATES

OCTOBER 5, 2011

Mr. INOUYE (for himself and Mr. CHAMBLISS) submitted the following resolution; which was referred to the Committee on the Judiciary

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RESOLUTION

Recognizing May 16, 2012, as Hereditary Angioedema Awareness Day and expressing the sense of the Senate that more research and treatments are needed for Hereditary Angioedema.

Whereas Hereditary Angioedema (HAE) is a rare and potentially life-threatening genetic disease, affecting between 1 in 10,000 and 1 in 50,000 people, leading to patients being undiagnosed or misdiagnosed for many years;

Whereas HAE is characterized by symptoms including episodes of edema or swelling in various body parts including the hands, feet, gastrointestinal tract, face, and airway;

Whereas patients often experience swelling in the intestinal wall, causing bouts of excruciating abdominal pain, nausea, and vomiting, and swelling of the airway, which can lead to death by asphyxiation;

Whereas a defect in the gene that controls the C1-inhibitor blood protein causes production of either inadequate or non-functioning C1-inhibitor protein, leading to an inability to regulate complex biochemical interactions of blood-based systems involved in disease fighting, inflammatory response, and coagulation;

Whereas HAE is an autosomal dominant disease, and 50 percent of patients with the disease inherited the defective gene from a parent, while the other 50 percent developed a spontaneous mutation of the C1-inhibitor gene at conception;

Whereas HAE patients often experience their first HAE attack during childhood or adolescence, and continue to suffer from subsequent attacks for the duration of their lives;

Whereas HAE attacks can be triggered by infections, minor injuries or dental procedures, emotional or mental stress, and certain hormonal or blood medications;

Whereas the onset or duration of an HAE attack can negatively affect a person's physical, emotional, economic, educational, and social well-being due to activity limitations;

Whereas the annual cost for treatment per patient can exceed $500,000, causing a substantial economic burden;

Whereas there is a significant need for increased and normalized medical professional education regarding HAE; and

Whereas there is also a significant need for further research on HAE to improve diagnosis and treatment options for patients; Now, therefore, be it

Resolved, That—

(1) the Senate—

(A) recognizes and celebrates May 16, 2012, as Hereditary Angioedema Awareness Day; and

(B) supports increased awareness of Hereditary Angioedema (HAE) by physicians and the public; and

(2) it is the sense of the Senate that increased Federal research on HAE is needed, including that—

(A) the Director of the National Institutes of Health (NIH) should take a leadership role in the search for new treatment options and a cure for HAE by—

(i) encouraging the National Institute of Allergy and Infectious Diseases (NIAID) to implement the research recommendations of the international HAE research community;

(ii) exploring collaborative research opportunities between the NIAID, the Office of Rare Diseases Research, and other NIH Institutes and Centers; and

(iii) encouraging NIAID to provide the necessary funding for continued expansion and advancement of the HAE research portfolio through intramural and extramural research; and

(B) the Commissioner of Food and Drugs should take a leadership role in ensuring new HAE treatments are developed and appropriately monitored by—

(i) issuing further guidance to industry on the development criteria and adverse event standards for HAE treatments; and

(ii) encouraging the participation of patient groups and considering the views of patients when discussing standards and protocols for the development and monitoring of HAE treatments.

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