109TH CONGRESS
2D SESSION

S. RES. 180

Supporting the goals and ideals of a National Epidermolysis Bullosa Awareness Week to raise public awareness and understanding of the disease and to foster understanding of the impact of the disease on patients and their families.

IN THE SENATE OF THE UNITED STATES

JUNE 23, 2005

Mr. SCHUMER (for himself, Mrs. CLINTON, Mr. KERRY, Mrs. FEINSTEIN, Mr. JOHNSON, Mr. CORZINE, Mr. COCHRAN, Mr. DORGAN, Mr. REID, Mr. COLEMAN, Mr. WARNER, Mr. KOHL, Mr. HATCH, Mr. BENNETT, and Mr. FEINGOLD) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

SEPTEMBER 21, 2006

Committee discharged; considered and agreed to

RESOLUTION

Supporting the goals and ideals of a National Epidermolysis Bullosa Awareness Week to raise public awareness and understanding of the disease and to foster understanding of the impact of the disease on patients and their families.

Whereas epidermolysis bullosa is a rare disease characterized by the presence of extremely fragile skin that results in the development of recurrent, painful blisters, open sores, and in some forms of the disease, in disfiguring scars, disabling musculoskeletal deformities, and internal blistering;

Whereas approximately 12,500 individuals in the United States are affected by the disease;

Whereas data from the National Epidermolysis Bullosa Registry indicates that of every 1,000,000 live births, 20 infants are born with the disease;

Whereas there currently is no cure for the disease;

Whereas children with the disease require almost around-the-clock care;

Whereas approximately 90 percent of individuals with epidermolysis bullosa report experiencing pain on an average day;

Whereas the skin is so fragile for individuals with the disease that even minor rubbing and day-to-day activity may cause blistering, including from activities such as writing, eating, walking, and from the seams on their clothes;

Whereas most individuals with the disease have inherited the disease through genes they receive from one or both parents;

Whereas epidermolysis bullosa is so rare that many health care practitioners have never heard of it or seen a patient with it;

Whereas individuals with epidermolysis bullosa often feel isolated because of the lack of knowledge in the Nation about the disease and the impact that it has on the body;

Whereas more funds should be dedicated toward research to develop treatments and eventually a cure for the disease; and

Whereas the last week of October would be an appropriate time to recognize National Epidermolysis Bullosa Week in order to raise public awareness about the prevalence of epidermolysis bullosa, the impact it has on families, and the need for additional research into a cure for the disease: Now, therefore, be it

Resolved, That the Senate—

(1) supports the goals and ideals of a National Epidermolysis Bullosa Awareness Week to raise public awareness and understanding of epidermolysis bullosa;

(2) recognizes the need for a cure for the disease; and

(3) encourages the people of the United States and interested groups to support the week through appropriate ceremonies and activities to promote public awareness of epidermolysis bullosa and to foster understanding of the impact of the disease on patients and their families.

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