

## House Resolution 282

By: Representatives Cooper of the 41<sup>st</sup>, Wilkinson of the 52<sup>nd</sup>, and Henson of the 87<sup>th</sup>

## A RESOLUTION

1 Supporting the goals and ideals of a National Epidermolysis Bullosa Awareness Week to  
2 raise public awareness and understanding of epidermolysis bullosa, recognizing the need for  
3 a cure for the disease, and encouraging the people of this state and interested groups to  
4 support the week; and for other purposes.

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

9 WHEREAS, approximately 12,500 individuals in the United States are affected by the  
10 disease; and

11 WHEREAS, data from the National Epidermolysis Bullosa Registry indicate that of every  
12 one million live births, 20 infants are born with the disease; and

13 WHEREAS, there currently is no cure for the disease; and

14 WHEREAS, children with the disease require almost around-the-clock care; and

15 WHEREAS, approximately 90 percent of individuals with epidermolysis bullosa report  
16 experiencing pain on an average day; and

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

20 WHEREAS, most individuals with the disease have inherited the disease through genes they  
21 receive from one or both parents; and

22 WHEREAS, epidermolysis bullosa is so rare that many health care practitioners have never  
23 heard of it or seen a patient with it; and

24 WHEREAS, individuals with epidermolysis bullosa often feel isolated because of the lack  
25 of knowledge about the disease and the impact that it has on the body; and

26 WHEREAS, more funds should be dedicated toward research to develop treatments and  
27 eventually a cure for the disease; and

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

32 NOW, THEREFORE, BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES that  
33 the members of this body:

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

36 (2) Recognize the need for a cure for the disease; and

37 (3) Encourage the people of this state and interested groups to support the week through  
38 appropriate ceremonies and activities to promote public awareness of epidermolysis bullosa  
39 and to foster understanding of the impact of the disease on patients and their families.