



WHERE AS, Epidermolysis Bullosa (EB) is a rare connective tissue disorder with many genetic and symptomatic variations, all sharing 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; and

WHERE AS, approximately 1 out of every 20,000 individuals in the United States are affected by the disease and data from the National EB Registry indicates that it occurs in every racial and ethnic group throughout the world and affects both sexes equally; and

WHERE AS, there is currently no cure for the disease and approximately 90 percent of individuals with EB report experiencing pain on an average day; and

WHERE AS, EB is so rare that many health care practitioners have never heard of it or seen a patient with it; and

WHERE AS, individuals with EB often feel isolated because of the lack of knowledge in the Nation about the disease and the impact that it has on the body; and

WHERE AS, as first legislated by Ronald Reagan and the U.S. Congress in 1984 the last week of October would be an appropriate time to recognize National EB Week in order to raise public awareness about EB, its impact, and the need for additional research for a cure,

NOW, THEREFORE I, _____, do hereby proclaim October 25 through 31, 2019 as National Epidermolysis Bullosa Awareness Week in the _____ and join DEBRA (Dystrophic Epidermolysis Bullosa Research Association) of America to raise public awareness, recognize the need for a cure, and to foster understanding of the impact of the disease on patients and their families.

IN WITNESS WHEREOF, I have hereunto set my hand and seal this _____.

Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

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