

16105113D

HOUSE RESOLUTION NO. 127

Offered February 9, 2016

*Commending debra of America.*

Patrons—Peace, Albo, Anderson, Bell, Robert B. and Hugo

WHEREAS, debra of America, the only organization in the United States providing all-inclusive support to individuals with epidermolysis bullosa, a rare, genetic connective tissue disorder characterized by extremely fragile skin, has served individuals living with the disease and their families for 35 years; and

WHEREAS, debra (Dystrophic Epidermolysis Bullosa Research Association) of America was founded in 1980 by Arlene Pessar and her son, the late Eric Lopez, who was born with epidermolysis bullosa at a time when medical information on the disease was extremely limited; in its early years, the organization worked to promote awareness of the disease and identified regional representatives to disseminate information; and

WHEREAS, individuals with epidermolysis bullosa can develop recurrent, painful blisters and open sores, as well as disfiguring scars, disabling musculoskeletal deformities, internal blistering, and shortened lifespan due to secondary complications; and

WHEREAS, epidermolysis bullosa affects thousands of individuals in the United States, and research indicates that one in every 20,000 children is born with the disease; there is currently no known cure or treatment, and children with the disease require extensive care, as even minor rubbing from every day activities can cause blistering; and

WHEREAS, debra of America supported Eric Lopez as he passionately advocated for legislation to increase funding for research and create a network of five specialized clinical treatment centers and a national registry for patients; and

WHEREAS, with an electronic newsletter that reaches thousands of patients, families, and health professionals, debra of America works to fill gaps in knowledge about the cause, diagnosis, and treatment of epidermolysis bullosa, which is so rare that many health care practitioners have never heard of it, despite the fact that it affects both genders and all racial and ethnic backgrounds equally; and

WHEREAS, the emotional and financial burdens associated with living with epidermolysis bullosa are very high, and debra of America provides direct assistance to affected individuals and their families, regardless of their ability to pay, as well as funding research to find a cure; now, therefore, be it

RESOLVED by the House of Delegates, That debra of America hereby be commended for its service to individuals living with epidermolysis bullosa on the occasion of its 35th anniversary; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to debra of America as an expression of the House of Delegates' admiration for its benevolent mission.