2015-K175

MEMORIALIZING Governor Andrew M. Cuomo to proclaim March 8, 2015, as Epidermolysis Bullosa Awareness Day in the State of New York, more commonly known as Butterfly Children Awareness Day

WHEREAS, It is the custom of this Legislative Body to recognize official days that are set aside to increase awareness of serious issues that affect the lives of the citizens of New York State; and

WHEREAS, It is the sense of this Legislative Body to memorialize Governor Andrew M. Cuomo to proclaim March 8, 2015, as Epidermolysis Bullosa Awareness Day in the State of New York, more commonly known as Butterfly Children Awareness Day, in an effort to raise public awareness and understanding of Epidermolysis Bullosa; and

WHEREAS, Epidermolysis Bullosa (EB) is a rare, genetic, connective tissue disorder that is characterized by fragile skin and recurrent blister formation, inside and outside the body; today, there is no cure; and

WHEREAS, Severe forms of EB cause patients to live with constant pain and scarring; the worst forms of EB lead to eventual disfigurement, disability and often early death; phenotypes and outcomes run the gamut, from mild to severe; the more severe cases cause fatalities in the first year of life, and in many cases, children who suffer from the more severe forms do not live into their third decade of life; and

WHEREAS, There are five types of EB: EB simplex (EBS), Junctional EB (JEB), Dystrophic EB (DEB), Kindler EB (KEB) and EB Acquisita (EBA); EBS is the most common form of EB, while the other forms are relatively less common and affect the patient more severely; and

WHEREAS, The presence and type of EB is differentiated by the gene that is affected, and the particular protein that is produced by that gene, therefore, EB can be the result of a mutation in genes that produce one of 18 different structural proteins; and

WHEREAS, It has been estimated that one out of every 20,000 live births which is approximately 200 children a year, is affected with some type of EB; the disorder occurs in every racial and ethnic group throughout the world and affects both sexes equally; and

WHEREAS, The only treatment for EB is daily wound care, preventative bandaging and pain management; the simple act of bathing is a tortuous process that may take more than three hours when children are often bathed in a diluted bleach or vinegar solution to fight the ever present threat of infection; and

WHEREAS, EB has a long list of secondary complications including anemia, growth retardation, infection, bacterial sepsis, renal failure, cardiomyopathy, corneal abrasions, malnutrition, premature tooth decay and squamous cell carcinoma; and

WHEREAS, With skin as fragile as a butterfly wing, EB patients are dubbed "Butterfly Children"; on the outside, physical wounds prevent them from normal daily activities enjoyed by other children; the slightest friction produces agonizing wounds that can cover up to 75% of their bodies; and

WHEREAS, There is a frightening lack of institutional knowledge; in other words, most physicians, nationally and internationally, are unaware of the disorder and its complexities, thus resulting in less than optimal treatment options for even the most common secondary complications; and

WHEREAS, Due to public and private insurance coverage limitations, caregivers may lack adequate wound care supplies that are essential in not only preventing infection and supporting wound closure, but also preventing new wounds from everyday activities, such as wearing clothing; many surgical procedures are only performed safely in three or four hospitals in the United States; and

WHEREAS, Researchers from around the globe are investigating new therapies to treat and cure EB, thereby leading to a better quality of life; and

WHEREAS, Seven-year-old Butterfly Child, Rafaella (Rafi) Lily Kopelan, who is a resident of the Upper West Side of Manhattan, was diagnosed with a severe form of Recessive Dystrophic Epidermolysis Bullosa at birth; and

WHEREAS, Rafi Kopelan was the eighth in the world to undergo a stem cell transplant as part of a clinical trial to treat her EB, which has led to her ability to produce the protein (collagen type VII) which she was unable to produce before the procedure; and

WHEREAS, "Rafi's Run" will be held on March 8, 2015, in Riverside Park to provide financial support for the research into a cure for EB, in an effort to aid Rafi Kopelan and other Butterfly Children; and

WHEREAS, Three-year-old Easton Friedel, nicknamed "Baby Easton" of Weedsport, New York, diagnosed with EB at birth, joined by his supportive parents, is educating the public and spreading awareness of this rare disorder; and

WHEREAS, Easton's parents, Danielle and Jared Friedel, and the entire Friedel family were recently honored by the Dystrophic Epidermolysis Bullosa Research Association of America (DEBRA), the only national organization with the stated purpose of funding research and a cure for EB, with the first ever EB Awareness Award for their outreach work; and

WHEREAS, It is imperative that there be greater public awareness of this serious health issue, and more must be done to increase activity at the local, State and national levels to support the patients as well as their families; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim March 8, 2015, as Epidermolysis Bullosa Awareness Day in the State of New York, more commonly known as Butterfly Children Awareness Day; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New

York.