



2010-499

Date: August 10, 2010

Moved by: *Michael deBoer*

Seconded by: *Dan Belfort*

Whereas International Epidermolysis Bullosa Awareness Week is a global effort dedicated to the promotion of "EB" awareness in countries around the world; and

Whereas International Epidermolysis Bullosa Awareness Week was founded in 2009 by Gena Brumitt, daughter of Lillian "Pat" Barbrey (1934-2000), an exceptionally courageous woman with a severe form of EB who wanted awareness raised so that people with EB would come to realize that they are not alone, and to expand EB research toward the creation of effective treatments and a cure; and

Whereas Epidermolysis Bullosa is a group of debilitating genetic diseases characterized by the presence of extremely fragile skin that results in the development of recurrent, painful blisters and open sores likened to a 3<sup>rd</sup> degree burn and, in more severe forms of the disease, major complications including disabling musculoskeletal deformities, disfiguring scars, internal blistering, malnutrition, dehydration and early mortality risk, and it is known as a rare or "orphan" disease, resulting in a lack of significant research; and

Whereas the skin is so fragile for individuals with the disease that even minor rubbing and day-to-day activity may cause blistering, including activities such as writing, eating, walking, and even minor chafing from rolling over in bed or the seams and tags on clothing; and

Whereas approximately 3,000 people in Canada are impacted by this disease, which takes its toll on hundreds of thousands of patients, families and caregivers internationally at a rate of about 1 in 12,000, affecting both genders and occurring in every racial and ethnic group throughout the world; and

Whereas presently, there is no known cure for Epidermolysis Bullosa, most healthcare practitioners are not familiar enough with Epidermolysis Bullosa to respond with best practices when interdisciplinary care is critical to address the disorder's multiple

RECORDED VOTE	YES	NO	CONFLICT	ABSENT
Councillor Belfort				
Councillor deBoer				
Councillor Groves				
Councillor McClure				
Mayor Morrison				
Councillor Paterak				
Councillor Payne				
Councillor Thompson				
Councillor Whitehead				
<b>TOTAL</b>				

MAYOR: *Marilyn Morrison*


<input checked="" type="checkbox"/> CARRIED	<input type="checkbox"/> LOST
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aspects, and vital wound care supplies are unavailable in some regions, or may be costly and not covered by health insurance; and

Whereas International Epidermolysis Bullosa Awareness Week will be celebrated the last week of October annually, to increase understanding, reduce unnecessary deaths, and improve the quality of life for people with EB in our Canadian communities; and

Therefore be it resolved that the week of October 25-31, 2010 be proclaimed "International Epidermolysis Bullosa Awareness Week" in the Town of Caledon.

<u>RECORDED VOTE</u>	<u>YES</u>	<u>NO</u>	<u>CONFLICT</u>	<u>ABSENT</u>
Councillor Beffort				
Councillor deBoer				
Councillor Groves				
Councillor McClure				
Mayor Morrison				
Councillor Paterak				
Councillor Payne				
Councillor Thompson				
Councillor Whitehead				
<b>TOTAL</b>				

MAYOR:   
 CARRIED       LOST