

COMMITTEE OF THE WHOLE SEPTEMBER 29, 2009

PROCLAMATION REQUEST EPIDERMOLYSIS BULLOSA AWARENESS WEEK OCTOBER 25 – 31, 2009

Recommendation

The City Clerk recommends:

- 1) That October 25 – 31, 2009 be proclaimed as “Epidermolysis Bullosa Awareness Week”; and
- 2) That the proclamation be posted on the City's website and published on the City Page Online.

Economic Impact

N/A

Communications Plan

The Corporate Communications Department posts proclamations issued by the City on the City's website under “Events – Proclamations” and on the City Page Online.

Purpose

To respond to the request received on behalf of the Dystrophic Epidermolysis Bullosa Research Association of Canada (DEBRA).

Background - Analysis and Options

The correspondence received on behalf of the Dystrophic Epidermolysis Bullosa Research Association of Canada is attached. (Attachment 1)

The proclamation request meets the City's Proclamation Policy, as follows:

“That upon request, the City of Vaughan issue Proclamations for events, campaigns or other similar matters:

- (i) which are promoted by any organization that is a registered charity pursuant to Section 248 of the Income Tax Act”

Epidermolysis Bullosa is a group of debilitating genetic skin diseases that results in the development of recurrent, painful blisters, open sores and in more severe cases major complications including disabling musculoskeletal deformities and early mortality risk. The goals of the Dystrophic Epidermolysis Bullosa Research Association of Canada (DEBRA) are to increase public awareness, recognize the need for a cure and encourage citizens and interested groups to foster understanding of the impact of the disease on patients and their families.

Relationship to Vaughan Vision 2020/Strategic Plan

This report supports the strategic priorities established by Vaughan Vision 2020, in particular “Enhance and Ensure Community Safety, Health and Wellness”.

Regional Implications

N/A

Conclusion

Staff is recommending that October 25 – 31, 2009 be proclaimed as “Epidermolysis Bullosa Awareness Week”; and that the proclamation be posted on the City’s website and published on the City Page Online.

Attachments

Attachment: Correspondence from Dystrophic Epidermolysis Bullosa Research Association of Canada, dated September 17, 2009

Report prepared by:

Connie Bonsignore, Administrative Assistant to the City Clerk

Respectfully submitted,

Jeffrey A Abrams
City Clerk

September 17, 2009

Attachment 1

Mayor Linda Jackson

Office of the Mayor, Town of Vaughan
2141 Major Mackenzie Drive
Vaughan, Ontario
L6A 1T1

Dear Mayor Jackson,

As a concerned citizen of this country and in alliance with worldwide charities (DEBRA organizations and EB Medical Research Foundation), in support of people with the genetic disease Epidermolysis Bullosa, I would like to request that you issue a proclamation declaring **October 25-31, 2009** as "**International Epidermolysis Bullosa Awareness Week**" in Vaughan, Ontario. Your proclamation will be declared in conjunction with similar announcements by officials around the globe.

Picture for a moment... a young child wrapped in gauze to protect agonizing sores that cover the majority of a small, frail body. Imagine that child smiling bravely through tears because it's hard to understand why every day hurts so much. If you can envision an image of this child, you've pictured someone who needs your help – but more importantly, someone you can help.

Epidermolysis Bullosa (EB) is a group of genetic disorders characterized by exceptionally fragile skin and chronic, painful wounds and blisters caused by the slightest trauma, even normal day-to-day activities. The disease affects people of both genders and every ethnicity. As many as 500,000 people (constituents) worldwide suffer from some form of EB. It is often disabling and life-threatening, requiring daily wound care similar to that of severe burn patients. There is no cure, but there is something about the word "incurable" that is contrary to the indomitable nature of people living with EB.

In terms of awareness and knowledge, there is an unfortunate gap between what is and what should be. Changing this is vital to the future of EB research and universal patient support. The EB community is determined to lead a movement to fundamentally change its experiences and expectations – to speak with one voice in our relentless quest for effective treatments and a cure for all types of EB. Your proclamation will serve to support the continuing work of EB charities as a critical link in the effective delivery of healthcare to EB patients around the globe.

I am one of many global volunteers working in accord to promote October 25-31, 2009 as the first official "International Epidermolysis Bullosa Awareness Week." These efforts will improve the quality of life for people with EB by increasing recognition of this genetic condition among the public, media, government and medical communities.

I enclose a sample proclamation detailing the goals of our week. Feel free to consolidate them or generalize. If you agree to participate, I will be happy to work with your staff to issue a press release to local media, and coordinate coverage of a proclamation presentation.

I will call your office in a few days to further discuss the proclamation and answer any questions you may have. Thank you in advance for your consideration and approval of our request. Your help will be greatly appreciated by the hundreds of thousands of people worldwide who suffer from EB.

Sincerely,

Laura Kwan-Torzsas

Volunteer, Walk a Mile in My Shoes campaign for
International Epidermolysis Bullosa Awareness Week

torzsas@sympatico.ca

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SEP 17 2009
CLERK'S DEPT.