City of Barrie

Legislation Details

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Title: PRESENTATION BY MELISSA VASSALLO IDIENS OF MIATHRIVES - A CHARITABLE ORGANIZATION SUPPORTING FAMILIES AFFECTED BY THE SKIN DISEASE EPIDERMOLYSIS BULLOSA

M. Vassallo Idiens, Executive Director and J. Peters, Managing Director of MiaThrives explained that their charitable organization helps to create awareness and offers support to families affected by the incurable skin disease Epidermolysis Bullosa (EB).   Ms. Peters clarified that EB is a group of genetic conditions causing the skin to be very fragile and blister easily. Ms. Peters and Ms. Vassallo Idiens provided a presentation regarding MiaThrives.

Ms. Peters and Ms. Vassallo Idiens discussed slides concerning the following topics:

·   An overview of Epidermolysis Bullosa noting that children with EB are often referred to as "Butterfly Children";
·   A video entitled "Mia's Story" depicting the challenges faced by those affected by EB;
·   Photographs of events from 2015 to 2018 to promote MiaThrives in the community;
·   Photographs of a local bookstore promotion of the children's book "Mia: A Butterfly Child"; and
·   The launch of the #LoveMiasGloves social media campaign to increase public awareness for those affected by EB.

In closing, Ms. Vassallo Idiens and Ms. Peters requested support from the Accessibility Advisory Committee. Ms. Vassallo Idiens and Ms. Peters noted that they need to recruit board members for MiaThrives and volunteers for their committees and special events. The Accessibility Advisory Committee and C. Dillon, Accessibility Coordinator, offered to assist with the promotion of MiaThrives events in the community.

The Committee asked a number of questions regarding the information provided and received responses from the presenters.

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Date	Ver.	Action By	Action	Result