



APPLICATION FOR PROCLAMATION

(Please complete and submit your completed form to the Town Clerk @ clerks@richmondhill.ca at least three weeks in advance of the occasion)

Please Print

ORGANIZATION NAME: Canadian Fabry Association

CONTACT NAME: Mr. ☐ Mrs. ☒ Ms. ☐ Miss ☐

ADDRESS: 55 Lark Crescent

CITY/TOWN: Richmond Hill

PROVINCE: ON **POSTAL CODE:** L4S 2N2

HOME PHONE: **BUSINESS PHONE:**

FACSIMILE: **EMAIL:**

PROCLAMATION REQUESTED (Name or title of proclamation):

Rare Disease Day

DATES OF PROCLAMATION (Please check and insert dates)

☐ Day(s) ☐ Week

☒ Month February 28/29

PURPOSE OF PROCLAMATION (Please check all that apply):

☐ Civic Promotions ☒ Public Awareness Campaign ☐ Charitable Fundraising Campaign

☐ Arts and Cultural Celebration ☐ Special Honor for individual or Organization

☐ Other (please explain)

DESCRIPTION OF YOUR ORGANIZATION (Please include a brief description and any other relevant information related to your request. Additional information/documentation may be attached to this application):

Please see attached

Has the same or a similar proclamation been requested of the Richmond Hill Council in past years?

☐ Yes (insert date of previous request)

☒ No (new request)

You must provide the draft wording for your proclamation in order to receive an official signed proclamation from the Mayor.

The personal information on this form is collected under the authority of the Municipal Act. The information is used for the purpose of processing the application for proclamation. Questions about this collection of information can be made to the Town Clerk (905) 771-8800.

SIGNATURE: [Signature] **DATE:** January 27, 2019

PLEASE RETURN OUR COMPLETED APPLICATION FORM TO:

Office of the Clerk
225 East Beaver Creek Road
Richmond Hill, ON L4B 3P4
clerks@richmondhill.ca; Fax 905-771-2502

748 Kelly Street
Thunder Bay, ON P7E 2A1

January 27, 2019

Office of the Clerk
225 East Beaver Creek Road
Richmond Hill, ON
L4B 3P4

Dear Mayor Dave Barrow, Office of the Clerk and the Town of Richmond Hill,

Rare Disease Day was established in 2008 by EURORDIS, an organization that represents people living with rare disorders in Europe. This day occurs on the rarest day of the year – February 29 – but when it is not a leap year, Rare Disease Day is recognized on an international level on February 28.

With over 7000 rare diseases in the world*, Rare Disease Day has gained significant attention by more than 80 nations around the globe. There are 1 in 12 Canadians living with a rare disease*; I am one of them. I have a rare lysosomal storage disorder called Fabry Disease that affects approximately 500 Canadians. With Richmond Hill having a population of approximately 200,000, there could be close to 17,000 residents living with a rare disorder. Twenty-five percent of children living with a rare disease will not live to see their 10th birthday*. Many rare diseases are not even supported with treatments or effective treatments, assisted funding programs and the care assistance needed to improve quality of life. Only 60% of treatments for rare disorders make it into Canada and most get approved up to 6 years later than in the USA and Europe*. For many, living with a rare disease has challenges on many different levels.

Although the Canadian Fabry Association is based in Thunder Bay, Ontario, we have Fabry patients living in every province. I am writing to you as a Richmond Hill resident, asking you to consider this request based on those living in Richmond Hill with a rare disorder.

Many rare disease organizations and supporting industries create awareness and recognize Rare Disease Day by initiating events such as fundraisers, empowerment meetings, awards galas, cocktail receptions, tattoo campaigns, special lighting (Niagara Falls, CN Tower and City of Toronto sign have been lit up in the official Rare Disease Day colours – blue, green pink and purple). You can visit rarediseaseday.org to review the different events that are occurring on February 28 around the world.

748 Kelly Street
Thunder Bay, ON P7E 2A1

By the Town of Richmond Hill proclaiming February 28/29 as Rare Disease Day, you are:

- acknowledging and supporting Canadians living with a rare disorder
- inspiring rare disease organizations to request February 28 to be proclaimed by their Town/City as Rare Disease Day
- encouraging more organizations to come together to advocate and to be a proactive voice for the Canadians that are experiencing challenges related to their rare disorder
- inspiring more discussions with policy makers, researchers and health professionals that will hopefully lead to positive outcomes for those living with rare disorders
- providing an opportunity for greater awareness and education of rare diseases that potentially lead to diagnoses – that in itself is a significant benefit for someone who has been living with health challenges from an undiagnosed condition
- providing encouragement to press forward with the hope of one day having improved treatments and care assistance and maybe even a cure for their rare disease
- inspiring rare disease organizations to heighten awareness and challenges through event initiatives on February 28/29

On behalf of the Canadian Fabry Association, and those living in the Town of Richmond Hill with a rare disorder, we thank you for your consideration of proclaiming February 28/29 as Rare Disease Day. I look forward to hearing from you.

Sincerely,



Lori Culum
A Richmond Hill resident living with Fabry Disease

*Information sourced from raredisorders.ca