



CFA

CANADIAN  
FABRY  
ASSOCIATION

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# NEWSLETTER

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## STAYING CONNECTED TO THE GLOBAL FABRY COMMUNITY !!

*Gina Costantino  
President, CFA*

The Canadian Fabry Association stays connected with Rare Disease Communities by regularly attending meetings and conferences. These gatherings are designed to allow for important networking, where people work together for a common goal and patient communities can share strategies to benefit all.

It is important to keep Fabry Disease and the Canadian Fabry Community "on the map" in order for our voice to be heard among the voices of other rare disease organisations.

Here are some upcoming events where you can expect to have CFA Board representation:

**- Lysosomal Disease Network  
(LDN) WORLD Symposium**

Date: February 13 – 17, 2017

Where: San Diego, California USA

**- Canadian Organisation for Rare Diseases (CORD)  
Rare Disease Day**

Date: March 30 – 31, 2017

Where: Vancouver, BC

**- Fabry International Network (FIN) Conference**

Date: May 19 – 20, 2017

Where: Athens, Greece

We are pleased to provide feedback and share information we gather at these meetings. To that end, you may look forward to hearing about these meetings in detail from those who attend via our upcoming newsletters.

## CANADIAN FABRY DISEASE TREATMENT GUIDELINES 2016

*Julia Alton  
Board Member*

The CFDI has updated the Treatment Guidelines, you can log into the Garrod Association Website to see the current criteria.

<http://www.garrod.ca/wp-content/uploads/Canadian-FD-Treatment-Guidelines-2016.pdf>

## REMEMBERING KEVIN JOHN VERGE

Date of Birth - June 13, 1963

Passed Away - Oct. 31, 2016

53 years of age

Lived in Liverpool, NS

Loving Son, Brother and Uncle

Local Historian, working for over 30 years

at Queens County Museum

## ON THE HORIZON



*Julia Alton  
Board Member*

Early plans for a Family Fabry Camp are in the making. Stay tuned for dates and exciting details regarding this incredible weekend.

## GENZYME PLANT TOUR - BOSTON



*Lee Strauss  
Board Member*

Matthew Sterling (Genzyme) was an excellent host and treated us to a great Italian restaurant on our first night there. We then all met in the hotel lobby in the morning for a quick breakfast before leaving for the Genzyme plant. The plant is a state-of-the-art building and I feel fortunate to have been able to have seen it. We were given a tour and were able to see where the magic happens, again, quite the place!

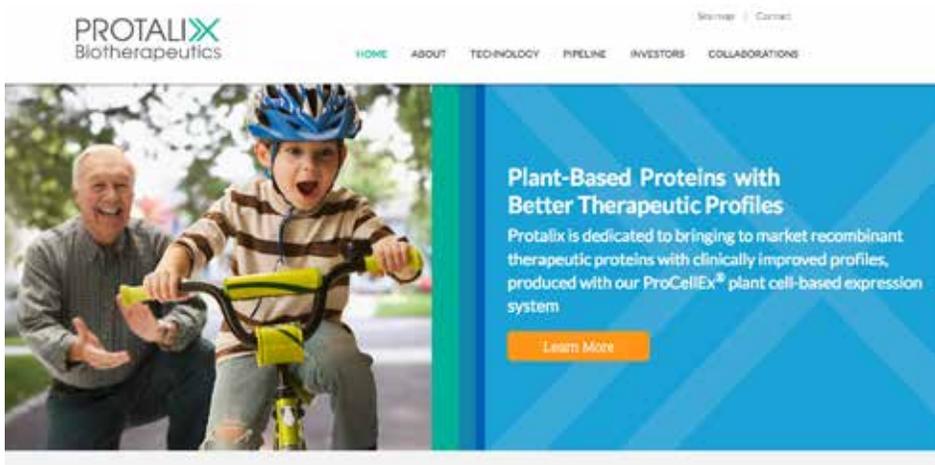
We were put in the front of a conference room and introduced ourselves to a number of the staff at the Genzyme plant. The employees had the opportunity to ask us a number of questions and it turned out to be a great experience for all involved. We all took the opportunity to Thank them on behalf of all Fabry's patients.

We were transported back into Boston to the Genzyme center building to meet some members of the US Genzyme teams as well as the US patient advocacy team. All of the US members seemed very interested and excited with what we have been doing as a group as well as the progress and plans we have!

All in all it was a great experience and I believe it was very beneficial!

# PROTALIX UPDATE

Kevin Fowler  
Protalix Biotherapeutics



Dear Fabry Community,

The purpose of this article is to inform you about a new clinical trial. Protalix Biotherapeutics ([www.protalix.com](http://www.protalix.com)) is looking for Fabry patients to participate in their Phase III investigational trial for Fabry disease. To learn about this trial, visit [www.fabrynext.com](http://www.fabrynext.com). If you have any questions about this trial, you can contact Protalix directly at [patient-info@protalix.com](mailto:patient-info@protalix.com).

## WELCOMING LEE STRAUSS

Gina Costantino  
President, CFA

The CFA Board of Directors is very pleased to announce the interim appointment of our newest Board Member, Mr. Lee Strauss, who resides in Kitchener Ontario. Lee has much to offer the Canadian Fabry Community. He is a full time firefighter, a smart businessman and real estate investor and enthusiast. Lee doesn't back down from hardship or work and is looking forward to applying his skills to the betterment of the CFA. Lee will be seeking election during the AGM, which should be held shortly.

Following is the bio Lee submitted with his nomination:

My name is Lee Strauss and I live in Kitchener, Ontario. Although I am not biologically affected by Fabry disease, it has affected me my entire life through seeing the daily struggles that my Dad was faced with in his life. Fabry also affects my sister and it is very difficult to see her face many of the same hardships that my Dad also faced. I became a board member to continue as an active part of the Canadian Fabry Association. I will assist in continuing to create more awareness about Fabry as a rare disease, support the Fabry community nationally and continue to learn about Fabry with my family and other affected people. I look forward to learning new knowledge in the medical field of Fabry and continuing this journey with you.

Please feel free to reach out to me if you have any questions, thoughts or need any assistance in regards to Fabry.

On behalf of the CFA, thank you Lee for your willingness to donate your time to serve with us. Your desire to join the Board, together with your many diverse skills, have us all looking forward to great things to come!

## THE WEBSITE

The Website Committee - Gina, Ryan, Lee

Hello everyone, we are continuing our work on the redesign of our website. The site will feature dynamic content that can easily be updated to keep everyone as up-to-date as possible. Our new website will conform to the wide variety of devices used to connect to the internet, be it a phone, tablet, desktop or laptop. This will mean less scrolling and faster access to the information you want to see.

While some information will still be under construction, we will be launching the new website very soon!

This website will conform to the wide variety of devices used to connect to the internet, be it a phone, tablet, desktop or laptop. This means less scrolling and faster access to the information you want to see. We are looking forward to the launch and hope you are too.

## THANKS TO SUPPORTERS

We would like to thank all of our supporters that helped make this newsletter possible.

We receive financial support from the Pharmaceutical companies who are currently providing hope for Fabry patients through their research and the products they provide.



We would also like to thank all of the physicians, specialists and medical professionals that have helped in so many ways. From providing guidance on medical terms and details to caring for members of our community every day.

And of course we would like to thank all of the patients and family members that have volunteered their time and energy to assist in all the many ways that are necessary in the creation of such a large effort. It is through their efforts that we hope to inform and build a community of Fabry patients for the benefit of patients, their families and caregivers.

## REMEMBERING FRIENDS

Would you like to have a note of remembrance included in our newsletter? These notices would be for Fabry Patients and Association Members whom we have lost over the years.

Please contact us at: [secretary@fabrycanada.com](mailto:secretary@fabrycanada.com)

## MAKE A DONATION

Would you or a family member like to make a donation so that we can continue to educate and advocate for the best treatment as well as communicating with and for Fabry patients in Canada?

The Canadian Fabry Association (CFA) is a registered not-for-profit organization. If you are interested in making a charitable donation and would like a tax receipt, please make your cheque payable to The Fabry's Charity Association.

100% of donations to the CFA are used to promote education, patient support and access to treatment for Canadian Fabry patients. You can make donation cheques payable to The Fabry's Charity Association and mail the cheque to us.

Send the cheque to:  
**The Fabry's Charity Association**

52 Glen Forest Drive  
Hamilton ON  
L8K 5V8

or register online by visiting our website:  
[www.fabrycanada.ca](http://www.fabrycanada.ca)

Thanks for your donation to the CFA! It goes to help Canada Fabry patients, their families and caregivers.