



CANADIAN  
FABRY  
ASSOCIATION

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# NEWSLETTER

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Patient Empowerment Workshop

Be Rare Be You Campaign

Webinar Wednesday

## PATIENT EMPOWERMENT MEETING – NOV 2018

*What treatment options are Health Canada approved?  
How much Vitamin D should I be taking?  
What treatment options are coming down the pipeline?  
What is my mutation?*

The vision for having an Empowerment Meeting was to give patients educated answers for some of the most asked questions. It was to give patients knowledge and power over their health, to share some mindfulness and nutrition strategies, and most importantly, to turn patients into champions of their own quality of life. The Ontario pilot project showed our vision and goals were achieved, and we look forward to sharing that the CFA will be holding 3-4 Empowerment Meetings throughout Canada in 2018 - Stay tuned for locations and dates coming to you soon.

*Julia Alton  
Executive Director*

As Vice President of the Canadian Fabry Association, I was extremely happy with our very first empowerment meeting. I have been involved for 14 years, and the progress that I have seen is mind blowing.

Today patients have more choices than ever. Two different Enzyme Replacement Therapies are available. Oral Therapy has now been approved, which is so exciting. Also, Gene Therapy & other therapies are coming in the future.

Being at these meetings and seeing the choices that patients have today is very exciting. I feel these meetings are so important for patients and their families, because it keeps them up-to-date, so they can make educated medical decisions for their own health. That to me is empowering.

*Donna Strauss  
Board Member*

I was a great pleasure to attend and be part of the first Canadian Fabry Empowerment meeting.

It is a great honor being part of such a progressive organization. As the treasurer, seeing everyone come together from various backgrounds and with various hopes, goals and agendas is astounding

*Lee Strauss  
Treasurer*

The first Patient Empowerment Meeting, held in Ontario, was very different than any Fabry meeting I have ever attended. I have been to many meetings that focus mainly on the medical aspects of the disease but while there was information about this and the newest therapies and those on the horizon, they were delivered by speaker Dawn Laney with wit and in such a way that terms weren't flying over my head. Kaye Lemoine gave a great talk about what to expect in Clinic and Dawn returned on a similar theme of how to talk to your Doctor so that they know how to help you best.

Included as well, were several talks that discussed me as a person not just a patient. Things like a Meditation Session by Melinda Hill and Warrior Teas by Keisha Luke were both things new to me. Moving your focus from medications and symptoms that can be so tiring and stressful, can really improve your outlook and state of mind.

Meetings are always times to connect or reconnect to other people that can relate to what you are experiencing. We are so few and spread across such distances that it is really important to be able to tell a story and have several heads nod in understanding.

The meeting was well attended in a very nice environment and I think it was a great success. The CFA intends to hold more, and I encourage you all to try and attend one when held near you.

*Graham Crouse  
Board Member*

I attended my first Patient Empowerment meeting in November.

There were many wonderful speakers and very interesting topics and I enjoyed them all. My favourite experience was the relaxing exercises that we took part in, they were very refreshing and calming.

Our tattoos were a big hit and had so much meaning. I enjoyed meeting many patients and interacting with them. I feel our meeting was a huge success and believe everyone left feeling energized by the whole experience

*Evelyn Williamson  
Board Member*

As always, I love meeting everyone from around Canada and catching up with everyone I've got to know over the years. For me a large part of these meetings is seeing other people and knowing you're not alone (or your family is not alone).

The mediation and mindfulness session reminded me that taking time for yourself is very important. Focusing on the positives of what you have is key to maintaining a positive mind-set.

The "What's up Doc" talk I also found to be important. There were key points I found very important. Your doctor is there for you, help them help you. 1) Tell them EVERYTHING, no matter how small if something changes. I thought a few things my body was doing was normal, I was certainly wrong. Had I not mentioned it, I would still be suffering from some symptoms I didn't need to. 2) Do your tests, go to your appointments. Always. It's so easy to let some of these things slide, but they are the data that the doctors use to help us. They are so important. Also, if you have questions, your clinic appointment is YOUR time to get the answers or at least bring your questions to light. If you decide "maybe not today" you have to wait 6 months or more until you're back in clinic.

I very much enjoyed seeing everyone and look forward to the next time we meet.

*Ryan Deveau  
Secretary*

## WEBINAR WEDNESDAY

DATE: February 21/2018

TOPIC: Your most asked naturopathic questions answered.

PRESENTER: Dr. Seema Kanwal

TIME: 4pm PST / 5pm MST / 6pm CST /  
7pm EST / 8pm AST / 8:30pm NST

# BE RARE. BE YOU.

## RARE DISEASE DAY CAMPAIGN

Julia Alton  
Executive Director



We are all rare in our own way... we all have a story and individually, we are unique. You can find beauty in uniqueness if you own your story – if you simply be YOU. Temporary on the skin, deep-rooted on the Soul.

Manifestation tattoos can have a profound effect on us by acting as a reminder of our intentions. As you put on this tattoo, let it act as a reminder to own your life. Be rare, and be the very best version of yourself.

Our tattoos are safe, non-toxic, and last between 3-7 days. They make a great gift, can be used to empower any campaign or conference, and bring inspiration to a classroom. Whether you or someone you love is suffering from a rare disease, or just trying to refocus on being true to who you are, these tattoos can be used boundlessly.

All proceeds go to the Canadian Fabry Association. Share the ink and spread the message... [Be Rare. Be YOU.](#)

### Share Your Tattoo

Share your tattoo widely, as well as tag and post on any of our social media platforms and use the hashtag #BeRareBeYou. Website: [www.fabrycanada.com](http://www.fabrycanada.com)  
Facebook: Canadian Fabry Association  
Instagram: Canadian Fabry Association  
Twitter: @CdnFabry

### EVENT:

Rare Disease Day – February 28, 2018  
Rare Diseases affect 1/12 individuals. Help the CFA launch our Be Rare. Be You campaign by sharing the tattoos with your employer, friends, family, and community to show your support, and empower your soul.  
Order Online @ [www.fabrycanada.com](http://www.fabrycanada.com)

Patient/Family/Student Discount: \$5.00 Pack of 2  
Regular: \$10.00 Pack of 2 (Markdown offered on bulk orders)



## THANKS TO OUR 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.

 **Amicus**  
Therapeutics

 **genzyme**

 **Shire**

 **PROTALIX**  
Biotherapeutics

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.

## 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**

748 Kelly Street  
Thunder Bay, ON  
P7E 2A1

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

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