



CANADIAN
FABRY
ASSOCIATION

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NEWSLETTER

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VANCOUVER PATIENT EMPOWERMENT MEETING

Donna Strauss
Vice President

The Vancouver patient empowerment meeting that was held on October 19th was a huge success. We had many new patients and families attend and the feedback was incredibly positive.

The meeting consisted of updates from Dr. Sirrs and Wendy Paquin, followed by recognition for caregivers. Caregivers are often forgotten and we took some time to recognize them as heroes. It was extremely emotional.

Kaye LeMoine and Dr Kanwal's presentations were well received by everyone as always. We did an overview of

the **Be Rare Be You** campaign and launched our new clothing line. Order yours today by visiting:
www.fabrycanada.com/

We ended our day off with a walking library, so anyone could ask our professional speakers any questions they had.

It was a great empowering experience.
Thank you to all who joined us.



PATIENT EMPOWERMENT QUESTION:

Q. What are the red spots that can be found on some Fabry patients?

THE CFA IS PROUD TO ANNOUNCE OUR NEWEST MEDICAL ADVISOR: DR. ANEAL KHAN

Julia Alton
Executive Director



As a pediatrician, medical geneticist and metabolic diseases specialist, Dr. Khan's research is to investigate novel methods of treatment of childhood onset genetic diseases.

In February 2017, as a principal investigator, for a pan-Canadian group, they were the first in the world to treat Fabry disease with ex - vivo gene therapy and the first group in Canada to treat a human with an inborn error of metabolism with gene therapy at Foothills Medical Centre.

He has been nominated for the Alberta Health Services Life Time Achievement Award and we are fortunate to have him on our Medical Advisory Board.

MISS THE NOVEMBER 18TH WEBINAR?

Don't worry, you can play this and all our other past Webinars (on a variety of Fabry related topics) on our website at:

<https://www.fabrycanada.com/previous-webinar-and-newsletters/>

Oh! You can see past issues of the Newsletters there too!

DR. KANWAL'S CORNER PLANNING FOR THE HOLIDAYS

Dr. Seema Kanwal, ND
Balance Medical Center
Board Member

December can be incredibly daunting. It tends to throw us for a loop when it comes to healthy eating that will nourish our body and sticking to a normal exercise and stress management plan. There are parties to maneuver, tempting baked goods in the office staff room, and of course family gatherings that must be attended. Home baked goodies, office parties, family holiday feasts, food given as gifts... an invitation for indulgence is everywhere (even for naturopathic doctors and medical physicians!).

Holidays are challenging for many of us, but know this, it's temporary. Before you know it, you will be back to your normal routine. It can be difficult to keep perspective during this frantic and hectic time of year. But remember to remind yourself every night of what is important to you, and what is not. Then make the time to plan for what is important, and forget about what is not. Sounds so simple in theory.

Schedule the most important events first, including down time and buffer time. Down time is critical as this is your recovery period - resting, taking a nap, reading a book, or simply doing nothing and just being. Buffer time gives you that extra space in case an event runs longer than expected.

I like to practice the health to stress theory. Meaning, how many times am I willing to say yes to enduring chaos, shopping and spending tendencies. Make sure you have the opportunity to say yes if you really want to do that particular event, and no if you are simply done. Honor this.

We've all heard "eat before you head to the party"; it's probably one of the best tips out there. The missing piece for me is HYDRATION. Often we forget to hydrate and drink water, as we are busy consuming glasses of wine, and holiday egg nog.

The holidays often mean getting together with relatives. I have been through enough family gatherings to know that not everyone gets along - remember Kevin's mean uncle in Home Alone? If you are having to go home and are not looking forward to that one particular relative, remind yourself that it is a temporary moment in time.

Don't deny yourself 100% of holiday foods. Relax and keep your stress levels down. The holidays can be very stressful and it's common to self-medicate with sweet holiday foods to feel better. Instead, breathe deeply, drink water, go for a walk, and keep your stress levels in check. Your state-of-mind always affects your body.

Over the years, I have slowly learned to say yes to things I truly want to be present for. There have been so many competing priorities in December that I have found myself miserable in January. The holidays are supposed to be a magical time, so do not sabotage yourself for the sake of saving face. You will be surprised how much stronger you will feel.

Enjoy the holidays.

NEW BRUNSWICK PATIENT EMPOWERMENT MEETING

Ryan Deveau
Secretary, CFA -
Nova Scotia

As someone from the Maritimes I was very excited to have our first meeting in New Brunswick this September. It was a small meeting but meeting and talking with everyone went so well. We had the pleasure of hearing **Dr. Alier Marrero** speak about a new angle on brain involvement. I look forward to networking and meeting new patients in the future.

We as patients need to stick together and learn from each other, every single meeting I attend I learn something new. Thank you to the patients and their families for taking the time to join us!



EMORY
UNIVERSITY

LIVING WITH FABRY DISEASE? INTERESTED IN JOINING AN EXCITING NEW STUDY?

Lacie Mehr
Emory University

We are seeking people of ALL AGES with a genetic diagnosis of Fabry disease to join a different kind of study that includes completing a very short survey and uploading one or more photos of yourself to help us learn about facial features in Fabry.

For this study, we are using a cutting-edge facial recognition software to analyze the many faces of those with Fabry to see if we can see any similarities or differences based on gene changes and other factors (for example: between men and women).

We also want to see if treatment can affect people in a fashion that can be seen among facial features by looking at photos of those diagnosed with Fabry disease. You do need to know your variant in the GLA gene for this study.

You will be compensated for your participation. You will receive a gift card to Amazon for \$5.

INTERESTED?!!

Go to: <https://www.surveymonkey.com/r/SBY7RJT>

Study: Fabry Facial Phenotyping Emory
IRB: IRB0000106386

This study is being performed at Emory University by Lacie Mehr, Dawn Laney, MS, CGC, and Morgan Simmons, MS, CGC.

If you have any questions, please contact **Lacie Mehr** at 385-209-5174 or [email lmehr@emory.edu](mailto:lmehr@emory.edu)

Be Rare Be You Tattoo Campaign

Lori Culum
"Be Rare. Be You." Program Manager



Looking for great stocking stuffers??

We are excited to share with you our new **Be Rare Be You** tattoo package. We would like to express our gratitude and appreciation to Stefan Culum, a 4th year OCAD Illustration student living with Fabry, for creating this package and to Marketing Kitchen who has sponsored the printing of the information cards.

The package containing two tattoos and an information card are available in English and French. We hope you will help to spread the word of empowerment on **Rare Disease Day, February 29, 2020**, by wearing this tattoo and posting a photo of yourself on social media with **#BeRareBeYou**.

With Christmas just around the corner, you can even order them now as they make great stocking stuffers! The tattoo package costs \$5 plus shipping for patients, family and friends (\$10 plus shipping for companies/industry). All proceeds support **FABRY FAMILY CAMP!!** Click here: www.fabrycanada.com to order yours today!!

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

FABRY FAMILY CAMP

Let's get out of the conference room and get outside together!

Julia Alton
Executive Director

The CFA is hosting our first ever Fabry Camp for families in a central location held on the weekend of **May 29-31 2020**. Camp Manitou is nestled in the great northern forests of Muskoka, Ontario. Your family will have the true experience of camp, and the child in you will enjoy family meals in the dining hall, early morning fishing or canoeing, and campfires under the stars at night. This weekend is about acknowledging Fabry for the whole family, cultivating community, and learning, while having fun in a beautiful surrounding.

DATE: May 29-31, 2020

LOCATION: Camp Manitou in Mckellar, Ontario

Eligibility Criteria:

1. If you have one or more child(ren)/teen between the ages of 6-20 years of age.
2. One person in your family has been diagnosed with Fabry Disease (Parent, partner, child, or sibling).

Volunteers:

We are looking for creative, fun, and spirited leaders who are committed to creating the best experience for our campers and families. If you are interested in volunteering, please click on the link at the bottom of this page to complete your application. Once your application has been reviewed, you will be contacted by a CFA coordinator to discuss further details.



Q. Are there any costs associated? A. Flights, transportation to/from camp, and your time at camp will be covered for all families and volunteers. We invite families to have their own fundraising initiatives (this is not mandatory) in your communities.

How can you help? We invite you to help us fundraise. Simply post on social media or send an email to family and friends to let them know that they can support our Fabry Family Camp by purchasing our clothing and tattoo packages. Be sure to include our homepage where they will have access to everything: <https://www.fabrycanada.com/>

Q. What are the sleeping arrangements? A. Each family will enjoy a woodsy cabin for the duration of their stay. Your cabin comes equipped with ample sleeping arrangements with enough comfy bunk beds for everyone.

Q. What activities are available at camp? A. Ropes course, climbing wall, archery, creative arts, field games, culinary arts, slip 'n' slide, mini putt, baseball, tennis, various land sports, canoe & kayak, fire-building/outdoor cooking, fishing, and more!

Q. Is it a peanut free facility? A. Camp Manitou is a peanut and tree nut safe facility.

Request: If you or your child(ren) play an instrument, we would love to hear you play around the campfire!

CAMP REGISTRATION & VOLUNTEER APPLICATION

Join the experience! Register your family and/or as a volunteer. Click on the following link to complete your application: <https://forms.gle/7SnRU6evh9Kmwcas5>

**SAVE THE DATE
MAY 29 - 31**

FABRY FAMILY CAMP

JOIN US AT CAMP MANITOU IN MCKELLAR, ONTARIO.

**THIS EVENT IS OPEN TO FAMILIES WITH AT LEAST
ONE IMMEDIATE MEMBER DIAGNOSED WITH FABRY DISEASE**



DONATIONS AS MEMORIAM

We have been asked if a donation to the Fabry's Charity Association can be made as a Memoriam for a family member. The answer is Yes. Please contact us at: secretary@fabrycanada.com

CREW NECK SWEATERS

CFA merch now available! We are excited to launch our new adult and kids clothing line. Dress to impress and wear clothing with a powerful message.

These sweaters make great gifts for the holiday season. All sales help to support Fabry Family Camp. **Order yours today!**

<https://fabrycanada.entripyshirts.com/>



PATIENT EMPOWERMENT ANSWER:

A): Angiokeratoma is the name of the red, blue, and purple spots that appear on the skin of some, but not all Fabry patients. Angiokeratoma typically appear in childhood or adolescence and appear most commonly in the bathing trunk area (buttocks, groin, belly button, and upper thighs), but can appear anywhere in the body.

THANKS TO OUR SUPPORTERS

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

We receive financial support from these 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.

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

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