



CFA

CANADIAN
FABRY
ASSOCIATION

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Fall 2021

NEWSLETTER

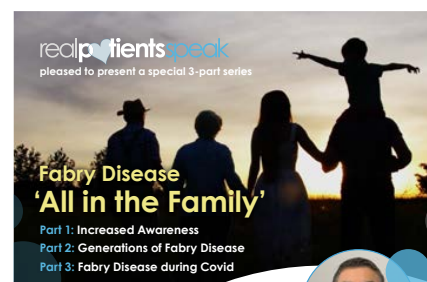
in this issue: | CFA Clothing Line Coming Soon | "All In the Family" | CFA Survey | Cardiac Month Entries | Women's Retreat Flyer | Fall is Here and Winter is Coming

New CFA clothing coming soon!



Keep an eye out on fabrycanada.com

PATIENT EMPOWERMENT QUESTION:
Q. What chromosome is the Fabry gene on?



"Fabry Disease affects more than 400 Canadians. It's a disease that runs in families. It's a disease that's on DNA, so we call it a genetic disease. It's important to understand that about Fabry Disease because most patients with Fabry Disease may take up to 10 years to get a diagnosis, and there are treatments available that can change the course of the disease and reduce the chance of complications. Males with Fabry disease will typically live into their 50s, and women into their 60s."



Dr. Aneal Khan
Medical Director,
M.A.G.I.C. Clinic, Ltd.

Mandie
Married with 3 daughters. All have Fabry Disease.

"I was tested shortly after birth with a skin biopsy. My grandfather was one of the first people tested in and confirmed in Saskatchewan. So it was a known thing in my family. My health today, I think is a mixed bag. Some days I feel really great and that leads me to think that I'm doing really well. The reality is I face kidney issues constantly and I face cardiac issues."

Matt
Living with Fabry Disease

"The thing I want other Fabrys people to know is that you're not alone. Don't isolate yourself. There's more of us out here. We're pretty awesome. I think we have a really great community, and if you're feeling alone, then please just reach out to the Canadian Fabry Association and they'll put you in touch with somebody, maybe me, and we can just walk this journey together. We're just better together."

"My brother, my sister and I, the three of us were diagnosed with Fabry Disease. So yeah, it was a complete shock. For the last few years, my main symptom besides kidney failure, I have 8% kidney function, is nerve pain. I have chronic nerve pain and it's throughout all my limbs."

"As long as I stay positive, I'm just going to keep doing what I do, such as golf, in between infusions and work. I go snowboarding. I walk the dogs, with my wife. And, you know, I do whatever I can do, when I can do it. And just stay as positive as I possibly can."

To learn more about Fabry Disease, please speak with your healthcare provider or visit the Canadian Fabry Association at fabrycanada.com

View this insightful program at realpatientsbook.com/fabrydisease

View Now

realpatientsbook

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Membership Announcement

The CFA is reconfiguring our membership platform and so we will be granting everyone a FREE year! Please take a moment and go to www.fabrycanada.com and sign up if you are not yet a member. We want to make sure we are staying connected and you're tuned in to our events, campaigns, and programs.

CARDIAC MONTH ENTRIES

Thank you to all who participated in Cardiac Month. This September we learned how patients keep their heart healthy, their story of diagnosis, and cardiac questions answered by Dr. Khan.

To see all content, follow the CFA on Instagram & Facebook.

Julia Alton
Executive Director

How is the Fabry heart affected in males vs. females?



#CardiacMonth

SEPTEMBER IS CARDIAC MONTH

#CardiacMonth

"The differences between male and female Fabry hearts aren't that significant. Females can sometimes develop more silent disease, where the heart gets scarring before it gets enlarged. Scarring can only be detected on an MRI, which is why MRIs are increasingly being used to monitor heart disease in Fabry patients. Also, females can have heart disease without any other significant symptoms, like pain or kidney disease. One has to remember that other types of heart disease, such as coronary heart disease, may also co-exist and need to be looked after."

DR. ANEAL KHAN

#CardiacMonth



Congratulations to our Contest Winner:
Karalee Desilets

CFA SURVEY

study opportunity

HELP US UNDERSTAND FABRY DISEASE

Have you been diagnosed with Fabry disease, or are you the caregiver of someone who has? If so, we'd like to hear from you.

We are conducting a market research study to better understand the experiences of patients diagnosed with Fabry disease. The research will help patient education and ultimately improve the quality of patient care.

If you qualify and complete the online survey, you will receive an honorarium for your time.

All information will remain confidential.

Interested?

To see if you qualify or to get more information, please contact Eva Woo:

Email: eva@cccresearch.com
Phone: 1-866-711-5948

WOMEN'S RETREAT JUNE 3-5TH 2022

We're pleased to announce that after the great success of the first retreat, we are planning another one!

You can download this information PDF at:

https://www.fabrycanada.com/content/uploads/CFA_Flyer-ThunderBay_2ndFemalesRetreat_Jun3-5_2021_final.pdf

We can't wait to see you there!

Julia Alton
Executive Director



Are you a female whose life has been affected by Fabry?

Join us in Thunder Bay for an opportunity to celebrate your uniqueness, address topics of interest with our speakers and take part in activities geared to women.

Leave the Retreat feeling empowered!



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Indicate your interest and provide feedback:
<https://www.fabrycanada.com/CFAFemaleRetreat.htm>
For more info contact: Sherry Sim, Event Manager
1-866-655-8548 | sherry@innovativelyyou.com



Donations to the CFA are greatly appreciated

FALL IS UPON US WHICH MEANS WINTER IS JUST A FEW MONTHS AWAY...

The sun rises later, and the night falls sooner. There's lots of maintenance that must be done to prepare our homes and our bodies for this time. Some external, such as trimming back trees, snipping perennials, and some internal, such as checking our vitamin D levels, our nutrient status. Sometimes we forget about our bodies also go through a shift which we tend to overlook. This is the time now where we need to support our bodies through various nutrients to ensure we remain strong throughout the colder months ahead. Here are a few important tips to ensure you have a successful Fall and Winter.

1. Hydration!

a. If water is difficult for you when the temperature drops, drink lots of herbal, non-caffeinated teas as this will count towards water intake. Fall is a very drying time of year. If you are prone to nose bleeds, or sinus infections, you want to ensure you maintain hydration to moisten the mucus membranes, to prevent dryness in the first place. In order to know how much water to drink, take your weight in pounds and divide by 2. That will give you the ounces required by your body per day!

2. Get enough vitamin D

a. This is an important one for Fabry. If we think of when cold and flu season occur, it is when the sun is not around. Thus Vitamin D is critical in maintaining our immunity at a time when the sun is unable to help us. If you are someone below 40 yoa, a straight D is great, anywhere from 2000 – 5000iu per day. If you are above 40, then ensure that the vitamin D you have also has K2. This will prevent calcium from depositing on the arterial wall, and ensure the D supports the bones as well we the immune function. And remember, D has an inverse relationship with melatonin, thus only take in the morning with breakfast especially if you have any sleep disturbances.

3. Vitamin C intake

a. C is an important nutrient your body needs to form blood vessels, cartilage, muscle and collagen in bones. Vitamin C is also vital to your body's healing process. Especially for Fabry, the pains can actually increase with the inflammatory aspect that a deficiency can have on the cellular level. I like powders that you can mix in water (then you are getting some hydration at the same time!)

To end, here is a simple recipe that is warming and immune boosting!

Dr. Seema Kanwal, ND
BOARD MEMBER

Immune Boosting Chicken Soup

Ingredients:

- 2 tbsp olive oil
- 1 onion chopped
- 3 large celery chopped
- 2-3 large carrots chopped
- 1 cup any mushrooms sliced
- 10 cloves of garlic minced
- 8 cups chicken or vegetable stock
- 2 bay leaves
- ½ tsp or turmeric and crushed red pepper
- 1.5 tsp sea salt, more or less to taste
- 1 (15oz) can chick peas
- 3 cups cooked shredded chicken
- 2 cups of baby kale or spinach or any greens of choice

Instructions:

1. In a large pot, heat oil and sauté onions, celery carrots, and stir occasionally. About 5 min. Add in mushrooms and garlic and cook another 3 min.
2. Stir in stock, bay leaves, spices, and chick peas. Bring to a boil. Mix in shredded chicken, cover and simmer for 15 – 20 min.
3. Add in greens, cover and simmer a few more minutes. Discard Bay leaves, serve and enjoy with cut up avocado on top!



PATIENT EMPOWERMENT ANSWER:

A. The X chromosome.

OUR INTERNET PRESENCE

Our Website: www.fabrycanada.com

Facebook: Canadian Fabry Association

Instagram: Canadian Fabry Association

Twitter: [@CdnFabry](https://twitter.com/CdnFabry)

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
1964 Hawkrig Dr.
Thunder Bay, ON
P7J 1H2

or register online by visiting our website:
www.fabrycanada.com

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