



CFA

CANADIAN
FABRY
ASSOCIATION

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NEWSLETTER

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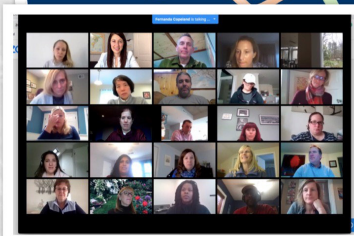
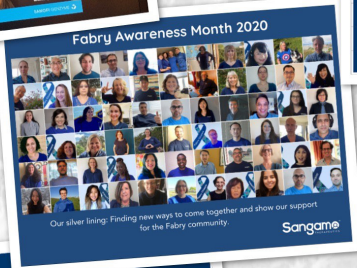
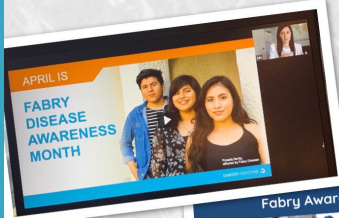
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Fabry Awareness Month



Julia Alton
Executive Director

This year, Fabry Disease Awareness Month was overshadowed by uncertainty related to the COVID-19 crisis.

Awareness months are so important because one of the biggest tools we have to fight health conditions is human connection. We need to come together to get educated, get support, and to become aware.

With so much uncertainty at this time, let this be a reminder of all the people working, researching, and doing their part to bring awareness.

This April was filled with dedication from our industry partners as they stand with the CFA.

PATIENT EMPOWERMENT QUESTION:

Q. How many Canadians are affected by a Rare Disease?

COVID Masks

Donna Strauss
Vice President



The CFA has got you covered! We want to keep you safe and healthy. We have created three masks and would like to send them out to members of the CFA. If you are not a member yet - make sure to join now by visiting our website. Email your address to Donna.strauss@fabrycanada.com.

Get yours while supplies last.

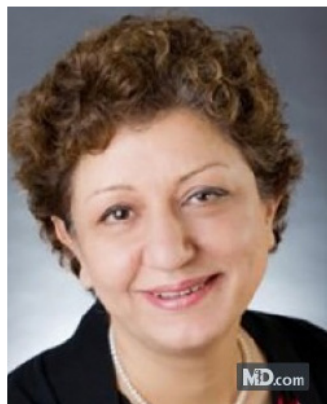
Fabry Camp Box



Julia Alton
Executive Director

For all those campers registered for camp, keep your eyes on your mailbox - a Fabry box is enroute!

UNDERSTANDING THE IMPACT OF COVID-19 IN THE FABRY COMMUNITY



Maryam Banikazemi, MD,
Clinical & Biochemical
Geneticist; Director, Fabry Disease Program;
Co-Director, Lysosomal Storage Disorders Center
Boston Children's Health Physicians
– New York Medical College in Valhalla, NY.

She answered these questions for us from her home, where she is advising many patients with Fabry on their risks and how to help stay safe during this time.

Q: What should patients with Fabry know about COVID-19? Is the Fabry community at an increased risk?

I have gotten this question a lot recently! According to the CDC, older adults and people of any age who have serious underlying medical conditions might be at higher risk for severe illness from COVID-19. This includes people who are 65 years and older, people of all ages with underlying medical conditions, particularly if not well controlled, including chronic lung disease or asthma, people who have heart conditions or who are immunocompromised. The CDC also states that people with chronic kidney disease and those who are on dialysis may be at increased risk as well, and I encourage those patients to connect with their treating physician.

Like all of us, I encourage the Fabry community to adhere to the guidelines set forth from the CDC regarding social distancing and handwashing, and, if you or a loved one believes they are having COVID-19 symptoms, isolate from others and connect with your doctor immediately.

“I encourage the Fabry community to adhere to the guidelines set forth from the CDC regarding social distancing and handwashing.”

Q: What about children diagnosed with Fabry?

While I have not seen data specific to Fabry, remember that even if you are young or otherwise healthy, you are at risk for COVID-19, and you can put others at risk as well if you do test positive. It's important that we all do our part to slow the spread of this virus including following the directions of local and state authorities.

Q: Should I continue receiving treatment for Fabry?

If you are receiving your infusions at home, my advice is to continue as long as you are feeling well and not experiencing symptoms of COVID-19. If you are, please check with your infusion nurse first before a home visit. If you receive treatment in a hospital, that's a different story.

Depending on your other risk factors like age or other co-morbidities, it might be better to skip an infusion or ask if home infusion would be available to you. I recommend you consult with your treating physician, and together you can decide what is best for you.

Q: If I am on dialysis, should I continue to go to infusion centers?

It is important to continue receiving dialysis. Please contact your treating physician and transplant team to determine the best way to continue care.

Q: What about caregivers?

Just like patients with Fabry, caregivers should be following social distancing and other current guidelines. It is also important to take time for self-care, and to take time for things they enjoy – reading a book, cooking a special meal, taking a walk outside for fresh air and a change of scenery!

Q: What else can I be doing?

I know this is a hard time for all of us, and living with a disease like Fabry may cause additional anxiety. But there are things you can do to stay your personal best mentally and physically. I encourage you to make smart choices – do your best to stop smoking if you do, maintain a healthy diet, stay hydrated and remain active to the best of your ability. Take walks in your backyard and get fresh air. You can also consider taking zinc supplements.

“I recommend you consult with your treating physician, and together you can decide what is best for you.”

Zinc has been demonstrated to support the immune system and help control infection. It may also provide “add-on” benefit in rehabilitation of various pulmonary diseases including COPD and asthma.

Stay connected to the Fabry community and to other friends and family for sources of support. You are not alone, and I am hopeful that brighter, healthier days are ahead of us.

Sponsored by Chiesi Global Rare Diseases

Chiesi Global Rare Disease is committed to connecting patients with information from experts and healthcare professionals. This information is intended for patient education and should not replace or modify the information provided by your treating physician.

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 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.



Donations to the CFA are greatly appreciated

VIRTUAL FRIDAY NIGHT FIRESIDE

- MAY 29TH, 2020

Julia Alton
Executive Director



We found ourselves in an extraordinary time, didn't we? As you know, the Fabry Camp has been cancelled, and although you may feel disappointed, know that it will be rescheduled and we will still be able to canoe on the lake, sleep in a cabin with your family, and have meals in the dining hall together. This just gives us all more time to get excited, plan, and get to know each other before camp!

We were supposed to be together on Friday May 29th, and so I invite you to join on Zoom for a Kids/Youth/Teen Talk. It will be an hour and an opportunity to meet everyone, hang out in something comfy, get questions answered about Fabry if you like, and anything you would like the CFA to plan or help with. It will be fun to see each other face to face over video. To join, first ask your parents – I have sent them an email. If they don't have it you can get zoom on your device and join by using this:

<https://zoom.us/j/97690915419>
Meeting ID: 976 9091 5419.

This is open to anyone ages 6-19 years of age.

Stronger Together

Julia Alton
Executive Director

In the midst of this pandemic, there is no better time to show that we are stronger together.

Order your long sleeve shirt today from fabrycanada.com.

A great shirt to show off on your next Zoom video call.



PATIENT EMPOWERMENT ANSWER:

A. 1/12 Canadians are affected by a Rare Disease.

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.

 **Amicus**
Therapeutics

AVROBIO

 **Chiesi**

idorsia

SANOFI GENZYME
Empowering Life

 **Takeda**

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 Canada Fabry patients, their families and caregivers.