



CFA

CANADIAN
FABRY
ASSOCIATION

volume 10 issue 3
summer 2019

NEWSLETTER

in this issue: | NF Patient Empowerment Seminar | Introducing Emma | Webinar | Dr. Kanwal's Corner | Thank You Evelyn | NB Patient Empowerment Seminar

NEWFOUNDLAND PATIENT EMPOWERMENT MEETING

Julia Alton
Executive Director

As we travel throughout Canada spreading empowerment and education we are meeting Fabry patients that haven't had the opportunity to attend our National Conferences. The CFA's goal is to reach ALL Fabry patients. Our

Newfoundland meeting was touching, powerful, and it was a pleasure to come to you and learn your needs.

Thank you to all those who attended in Parson's Pond.



INTRODUCING EMMA

Julia Alton
Executive Director



Emma Thornhill is a 17 year old from Parson's Pond, NL. She learned she had Fabry Disease in 2009 at the age of 7. Her Dad had Fabry and passed away in 2015 when she was 13. Emma is looking forward to meeting other people who also have Fabry Disease and wants to help younger patients who may need help understanding their symptoms.

Emma is our first Youth Ambassador for the CFA and will help our team better meet the needs of our younger patient community. We look forward to all she will bring.

We understand that the Summer months can be a hectic time for everyone.

In order to allow patients and families to enjoy the Summer as much as possible, we will be suspending Webinar Wednesdays until the Fall.

We are always looking for information to present to patients that is informative and helpful in dealing with this disease. We look forward to resuming on October 2.

PATIENT EMPOWERMENT QUESTION:

Q. What is the name of the drug Amicus Therapeutics makes for Fabry Disease?

DR. KANWAL'S CORNER

TIPS FOR STAYING SKIN SAFE THIS SUMMER

Dr. Seema Kanwal, ND
Balance Medical Center
Board Member



Summer has arrived. That means hotter and sunnier days are upon us. Stepping outside and enjoying the great outdoors can be a wonderful way to increase activity and gain mood-stabilizing benefits. However, it also brings the dangers of sun damage. Luckily, there are plenty of natural preventions and remedies to deal with the effects of the sun.

I frequently get asked by patients which sunscreen is best to use for themselves and loved ones. There can be a lot of confusion on the labeling of sunscreen. Manufacturers are required to label an SPF number, which indicates how much protection it provides against UVB radiation, the cause of sunburn. However, it is UVA light that is the cause of skin cancer. To ensure adequate protection from UVA as well as from UVB, look for sunscreens labeled "broad spectrum," which will protect against both.

Natural remedies work great for the whole family and of all ages. Remember prevention is key. Keep your immune system strong and working daily. Here are nutrients that you can add to your daily regimen to help prevent sunburns:

- A. Grapeseed extract:** which is derived from grape seeds, is the best antioxidant in my opinion.
- B. Resveratrol:** which is found in skin of red grapes and red wine.
- C. Vitamin E:** Found in avocado, almonds and sunflower seeds. If you prefer a supplement, ensure that it contains mixed tocopherols.
- D. Vitamin C:** found in tomatoes, red/green peppers and melons. If you prefer a supplement, ensure it is buffered vitamin C without sugar.
- E. Green Tea:** drink at least 1-2 cups per day. Studies indicate green tea helps to reduce skin damage and prevent skin tumours.

Adding the right foods to your diet can also go a long way to prevent sun damage. These five foods are excellent sources of protection against the harmful effects of the sun:

- A. Broccoli sprouts.** A recent study out of John Hopkins University, studied the effects of broccoli sprouts on mice. They fed them the sprouts two times per week for 17 weeks and saw a 70% reduction in the formation of skin tumours.
- B. Turmeric** has excellent anti-oxidant properties, use it in your cooking!
- C. Dark chocolate,** with its rich anti-oxidants is great, but you must choose the ones that are >70% in cocoa
- D. Watermelon,** with its high source of vitamin C and lycopene, is an excellent skin protector
- E. Fish oil.** The omega 3's in fish oil have strong anti-oxidant properties, and are great for the appearance of skin. Have 2 servings of fish per week including wild salmon, snapper, cod, mackerel and sardines. Avoid larger fish such as tuna and halibut due to the greater levels of mercury.

Remedies: It is crucial to protect your skin with a clean, broad-spectrum sunscreen, because if we are not as vigilant, the skin can become sunburned. Manuka is an excellent remedy for sunburned skin. Many great skin creams are available that contain organic manuka honey. Stay safe and enjoy the sunshine!

*The information provided is not intended to diagnose or treat any health condition. Please consult with your doctor or Naturopathic doctor before starting any new supplement program as they may have interactions with certain medications.

The CFA is always open for ideas and wants to serve the Fabry community as best as we can.

If you have ideas, please don't hesitate to reach out to Donna Strauss at Donna.strauss@fabrycanada.com.

Thank You Evelyn

CFA Board



On behalf of the Canadian Fabry Association we want to thank **Evelyn Williamson** for her years of dedication to our organization. Evelyn was instrumental participating in our push for the government to fund enzyme replacement therapy for patients in the province of Nova Scotia. She was always a ray of sunshine to the patients she met and communicated well with families.

We wish Evelyn well, and from everyone in the Fabry community we are grateful for all her efforts and heart she put in over the years.

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



DONATIONS AS MEMORIAM

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



Patient Empowerment WORKSHOP

SAVE *the* DATE

Saturday
September 14th 2019



"Patient empowerment is a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important."

MONCTON, NEW BRUNSWICK

Delta Hotel Beausejour, 750 Main Street, Moncton, New Brunswick E1C 1E6



LEARNING OBJECTIVES

- Patients will be able to comprehend what is meant by an LSD.
- Patients leave with a strong understanding of Fabry Foundations – this includes genetics, classic Fabry/variant Fabry, mutations, etc.
- Patients takeaway key learnings of how to interpret their own labs, and diagnostic tests.
- Looking at health holistically, exploring mindfulness and the benefits it has both short, and long term.

Register now! <https://forms.gle/UfmQMM3KGaAqzUHp7>

or Contact: Sherry Sim, Event Manager sherry@innovative4you.com

Open to New Brunswick patients and families

PATIENT EMPOWERMENT ANSWER:

A): Amicus makes an oral chaperone therapy called Migalstat (Galafold).

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 Canada Fabry patients, their families and caregivers.