

NEWSLETTER

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DR. KANWAL'S CORNER

Dr. Seema Kanwal
Board Member

Fall is by far my most favorite time of year. The sun rises later, the dew in the morning on the car, and the nights coming a bit quicker. For anyone who has children, it's much easier to have bedtime when it's dark outside! There's lots of maintenance that must be done to prepare our homes for this time such as trimming back trees, snipping perennials, covering delicate plants, and even removing debris from the gutters. (Can you guess what my weekends have been like?)

What we forget about is our bodies. 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 5 important tips to ensure you have a successful Fall and Winter.

1. Buy in season veggies.



Veggies such as beets, cauliflower, brussels sprouts contain high amounts of Vitamin A, which is a great anti-infection. My family likes these all roasted with a bit of salt and pepper, making this easy to incorporate in weeknight meals. Remember to rotate each week so we do not get sick of these too quickly.

2. Ditch the salads.



In Chinese medicine and Ayurvedic Medicine (an old holistic ["whole-body"] healing system), this is the time to stop eating raw and move towards warming, easily digestible foods. Warm herbal teas as well such as ginger will also boost the immune system. My personal favorite is to use more garlic in cooking but remember, the best way is to add garlic at the end of cooking to benefit from the power of an anti-microbial.

3. Hydration!



I myself am guilty of this as when it's colder out, I tend to drink less water. If water is difficult to drink as well for you, have lots of herbal, non-caffeinated teas; 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.

Continued on next page

WELCOMING DR. KANWAL

Julia Alton
Executive Director


The CFA is proud to announce that Dr. Seema Kanwal is our newest Board Member. Dr. Kanwal brings a wealth of knowledge to our team and is both motivated and passionate to help all Fabry patients manage their disease better through naturopathic medicine.

Welcome to the team Dr. Kanwal!

WEBINAR WEDNESDAY

DATE: September 26/2018

TOPIC: Chaperone Therapy Overview

PRESENTER: Dr. Bichet

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

Find instructions to join this Webinar at:
<https://www.fabrycanada.com/>

DR. KANWAL'S CORNER Continued

4. Get enough Vitamin D



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 years old, a straight D is great, anywhere from 2000 – 5000iu per day. If you are above 40, then ensure that the Vitamin D also has K2.

This will prevent calcium from depositing on the arterial wall, and ensure the D supports the bones as well as 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.

5. Sugar sadly



This is a culprit like no other. In research, sugar has been shown to have negative effects time and time again. When someone is down in the immune department, 1 serving of sugar will decrease their immune function up to 6 hours. Especially for Fabry patients, pain can actually increase with the inflammatory aspect that sugar has on the cellular level.

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

COCONUT CURRY with protein of choice.

(I prefer Cod or salmon, but chicken works well too)



Ingredients:

- ¼ c coconut oil
- ½ c chopped onion
- 2-4 cloves garlic minced
- 2 tsp cumin
- ½ tsp turmeric
- ½ tsp chili flakes
- 1 tsp salt, or more to taste
- 2-3 carrots, cut into matchsticks
- 1 red pepper cut into bite size pieces
- Juice of 1 lime
- 1 can or 2 cups of organic coconut milk
- 1 pound of protein
- 2 cups of greens (I use spinach)
- Cilantro or parsley to garnish

Method:

- In a heavy pot, melt coconut oil, sauté onion and ½ garlic about 5 min or until onion is soft
- Add all the spices
- Stir in carrots, pepper, lime juice, and coconut milk
- Add in protein, stir and let it simmer for about 20 min (depending on protein)
- Once protein is cooked, gently stir in greens and remainder of garlic, and remove from heat
- Serve with rice or rice noodles (or on its own), with garnish

BE RARE BE YOU CAMPAIGN

Lori Cullum
CFA Member



Be Rare Be You holds different meaning for each and every one of us. It may mean embracing uniqueness, aspiring to inspire, or conquering life on your terms. We all have our own intentions, our own way of living and our own way of managing our disease.

On February 28, 2019, we invite you to proudly wear our **Be Rare Be You** temporary tattoo to support over 7000 rare diseases affecting Canadians and people around the globe. Many are living without treatment or effective treatments. Bringing rare diseases to the forefront could mean greater focus on access to more effective treatments that could improve quality of life.

As Julia Alton embarks on her exciting journey of motherhood, I have accepted the voluntary position of Campaign Coordinator of the **Be Rare Be You** campaign. I look forward to meeting patients in Winnipeg and Halifax next month where I will be speaking further about this campaign.

You are all encouraged to participate in the **Be Rare Be You** campaign. To purchase tattoos, please visit our website: <https://www.fabrycanada.com/shop/>.

If you know of a company, school or another type of organization in your community that would like to support the **Be Rare Be You** campaign by purchasing our temporary tattoos, please email me at l-culum@rogers.com.



PATIENT EMPOWERMENT MEETINGS

- OAK ISLAND, NS

- WINNIPEG, MB



Register NOW
October 14th 2018
NOVA SCOTIA

Patient Empowerment Workshop

empowerment

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.

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 take away 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.

Link for registration: [Click here](#)

CONTACT:
Sherry Sim, Event Manager,
Innovative Business Solutions
sherry@innovative4you.com
1-866-655-8545 / 416-595-5975

OAK ISLAND RESORT, NOVA SCOTIA
Oak Island Resort, 36 Treasure Drive,
Western Shore, Nova Scotia



Register NOW
October 27th 2018
WINNIPEG, MANITOBA

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WINNIPEG, MANITOBA
Inn at the Forks
75 Forks Market Road, Winnipeg

Please register by October 1st [Click Here](#)

Please register by October 10th [Click Here](#)

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

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

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.