#### November 2021

## **LUPUS LINK**



Lupus Ontario's Monthly Newsletter
21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099



Linda Keill

## President's Message

I hope that everyone has had a wonderful fall and enjoyed more get togethers with family and friends. I always enjoy the beautiful fall colours, the cooler weather and especially the farmers markets with so much wonderful local food. It seems that life is becoming more normal but for those of us with supressed immune systems caution is still required. The good news is that booster shots are now available in Ontario for those who are taking specific immunosuppressive medications. The Province now requires that you only need to take your prescription bottle to a pharmacy or vaccine centre to receive your booster shot. The qualifying medications list can be found at

https://health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/vaccine/COVID-19 vaccine third dose recommendations.pdf

October 1st marked the beginning of a new fiscal year at Lupus Ontario. Despite the continued presence of COVID 19, the last fiscal year was very successful. Lupus Ontario received a lot of media coverage in May for Lupus Awareness Month, the Ontario Government officially recognized May 10th as Lupus Awareness Day in Ontario, the Walk for Lupus exceeded expectations, our monthly webinars and online support groups continue to draw a large audience and we introduced a podcast in August. I want to sincerely thank our staff and all our volunteers who worked so hard to build this success.

The new fiscal year always kicks off with our Research Campaign. At Lupus Ontario one of our most important goals is funding research. Lupus Research is critical to finding better ways to predict flares and complications, to better manage the disease with our existing medications, to find new medications and hopefully one day to find a cure. Our Lupus Ontario Geoff Carr Fellows have all completed research projects with at least one of the objectives listed above. Your donations to research are making a difference and we need your support to continue funding research.

In the coming year, we are planning to have a combination of in person and virtual events. We are hoping that we will be able to have some of our Walks for Lupus in person. It would be so great to meet new friends and to see old friends again. Some very exciting news is our Golf Tournament which is now booked for June 25th 2022. More details will be forthcoming.

In closing, I want to remind everyone that we are here for you, and we always appreciate your feedback. If you are a patient requiring information, please email support@lupusontario.org and I can be contacted at president@lupusontario.org. Thank you for all your past support and we look forward to serving you in our new fiscal year.

## STUDENTS AND MODEST-INCOME INDIVIDUALS

Written by Carolyn Pancham

#### Grants for Students with Permanent Disabilities

If you are a student with a permanent disability and need help paying for school, there are grants for students in the amount of \$4,000 per year for eligible students. Apply through the Ontario Student Assistance Program. portal to see how much you qualify for or call them at 1-877-672-7411 for more information

#### **Disability Supports Deduction**

The disability supports deduction is an income tax credit for selected expenses to assist a disabled person to attend work, school or to participate in a research grant. Certification from a medical practitioner may be required. For inquiries, call CRA at 1-800-959-8281.



(Pixabay.com/Disabilities/2021)

Community Volunteer Income Tax Program (CVITP)

The Canada Revenue Agency and local community organizations collaborate to provide free income tax preparation clinics to help eligible persons with modest income and a simple tax situation. Volunteers operate the tax clinics and you could walk-in, schedule an appointment (either virtually or in-person) or drop-off and pick-up. They could help you with your current year return or help you to catch up on previous years'. Call CRA at 1-800-959-8281 if you require more information.

I hope you have found my series of articles informative. Stay healthy and safe!

\*This article is intended to provide general information only. Please seek advice from a qualified professional for your situation.

## **BOARD OF DIRECTORS CHANGES**

On July 31st, Kuljit Bhogal stepped down from the Lupus Ontario Board. Kuljit joined the Board in May of 2019. During her time on the Board, Kuljit served on the Governance Committee. Under Kuljit's leadership, the committee undertook a major review and revision of Lupus Ontario policies and bylaws. Kuljit's legal background was invaluable to ensuring that the revised bylaws and policies were aligned with current legal requirements. On an as needed, she also reviewed vendor and employee contracts.

We will miss Kuljit's guidance on the Board as a regular member, but she has offered to continue as a volunteer when we require her assistance. Thank you Kuljit for your significant contribution during your time as a Lupus Ontario Director and all best wishes in your future endeavours.



We would like to extend a warm welcome to our newest member of our Board of Directors, Brent Leonard. Brent is a member of the senior finance team at a health-tech firm based in Ottawa, Ontario whose mission is to foster a holistic approach to healthcare aimed at supporting individuals through their entire wellness journey – before and after illness, not just during it. This is a cause he is truly passionate about and has continued to pursue through the Master of Health Administration (MHA) program at the University of Ottawa.

In addition to his 15+ years of experience in finance and operations at several start-up companies and software firms, Brent is actively involved in the community. Among other areas, he serves on the Board of Directors for the Canadian Immunodeficiency Patient Organization (CIPO, www.cipo.ca) where he is Board Treasurer. Brent also participates annually in fundraisers for The Ottawa Hospital and SickKids Hospital in Toronto.

Brent is passionate about health advocacy, awareness and education and strongly believes that knowledge is power in dealing with illness and that engagement in care is key for patients. It is with this mindset that Brent spearheaded the development and launch of the Lupus Ontario Podcast geared toward helping those with Lupus better understand the disease and empower them to become more involved in their health journey.

## RESEARCH CAMPAIGN

Lupus Ontario has launched our Research Campaign 2021/22. This year we have set a campaign goal of raising \$75,000.

Lupus Ontario is proud of our accomplishments in supporting lupus research over the past 43 years.

In addition to the Geoff Carr Fellowship and Lupus Clinic funding, this year Lupus Ontario will be providing funding to support a new research initiative at the Hamilton/McMaster Lupus Clinic. Dr. Konstantinos Tselios, a former Geoff Carr Fellow, is establishing the Lupus Ontario Anne Matheson Biobank. The samples collected in the Biobank will support lupus research projects in the years to come.



With your support, we have accomplished a great deal and have helped to improve the lives of lupus patients in Ontario and around the world. We hope that you will support us in continuing this critical work. To make a research donation please visit www.lupusontario.org or call our office at 1-877-240-1099. Sponsorship opportunities are also available, please email mwhittick@lupusontario.org for more details.

With your help, Lupus Ontario hopes to someday find a way to live Life Without Lupus.

## **GIVING TUESDAY**

We at Lupus Ontario are happy to announce that we are once again participating in #GivingTuesday.

#GivingTuesday is a global movement for giving and volunteering, taking place each year after Black Friday. The "Opening day of the giving season," it's a time when charities, companies and individuals join together and rally for favourite causes. In the same way that retailers take part in Black Friday, the giving community comes together for #GivingTuesday.

We are so thankful for all donations we receive, especially during these challenging times. It is with the support from all of you that allows us to maintain the likes of the Geoff Carr Fellowship. If you are interested in participating in #GivingTuesday, please consider donating to Lupus Ontario on November 30th!

We thank you in advance for your contribution towards our Annual Research Campaign.

# VOLUNTEER OF THE MONTH JUNE ALIKHAN

Our volunteer for the month of October is June Alikhan. June has been a member of the Lupus Ontario board for almost 6 years. She is currently Vice President and is involved in the Advocacy Committee, Public Awareness Committee, Finance Committee, Fund Development and Governance Committee. She has lived with lupus for 33 years and was originally diagnosed in 1989 after the birth of her son. When she was first diagnosed she found helpful educational and support resources at Lupus Ontario. She found very few people were aware of this chronic, invisible, autoimmune disease and had to educate her friends, family, employer and work colleagues.



On retirement she found herself drawn to the idea of continuing to bring awareness, support and education of this complex, life-threatening disease and Lupus Ontario was the perfect vehicle to help accomplish this goal. June went through several severe flares in the early years of her journey, but once her disease went into a drug-induced remission found that she could still meet personal and career expectations as long as she had a strong support network in place. June is passionate about travelling and hopes to get back to this soon.

## CHECK OUT THE LUPUS ONTARIO PODCAST!

Lupus Ontario launched a podcast aimed at providing our community with additional information, resources, tools and knowledge to better understand the disease and improve the quality of life for those with lupus, as well as their support network.

Some of our most recent episodes:

Lupus From The Physician Perspective (the new Lupus Biobank!), With Dr. Konstantinos Tselios
Student Life with Lupus – A three-episode series with College and University Students
An Introduction to Lupus Ontario, With Linda Keill, President of Lupus Ontario



Upcoming episodes will include conversations about: Lupus from the Naturopathic Medicine perspective, behind the scenes at the lab to talk about blood tests, nutrition and chronic disease, as well as financial planning with a chronic illness.

Listen wherever finer podcasts are available including: Spotify and Apple Podcasts!

#### FIGHTING FATIGUE: USING ENERGY MANAGEMENT STRATEGIES TO LIVE WELL WITH LUPUS WEBINAR

Presented by Abrial Cooke MSc.OT, OT Reg. (Ont.) an occupational therapist who owns and operates RISE Occupational Therapy

In her presentation she gave an overview of Occupational Therapy and how it can assist individuals living with Lupus. She explained the 4 main principles of Energy Management and how they can be applied to daily living to aid in managing fatigue. She also referred to the Spoon Therapy, which was a highlight of her discussion later with the group.

## **IGIVE TO LUPUS ONTARIO**

Help your favorite cause or charity every time you shop online, it's all free and so easy to be socially-conscious. Join us and start Giving #AllYearRound. The stores make this possible because they want you to like them and shop at them over and over again. There's 2295 socially-responsible stores helping to make donations happen.

We hope you'll give it a try and donate towards Lupus Ontario.

To learn more, please click here.

#### **SAVE THE DATE:**

#### **OFFICE UPDATE**

Lupus Ontario Golf Tournament Saturday June 25th, 2021 Tee Off 12:30pm We have moved our office to a new online virtual platform thereby making funds available to redirect to important support and research initiatives

Even though we are now virtual, our telephone number, email and mailing address remain the same.

More information to follow!

Our new virtual office is still lead by Office Manager, Karen Furlotte, along with Martina Whittick, Fundraising & Marketing Manager and Hajra Batool, Digital Marketing & Social Media Coordinator.

You can get in touch with us by phone at 1 877 240-1099 or 905 415-1099 or email info@lupusontario.org. We will be happy to hear from you.

## I AM A LUPUS WARRIOR

#### **FEATURING BRYNN CLARK**

"I remember it like it was yesterday, not back in 2010. A beautiful September day. 'I don't know how to say this, exactly, but you have lupus,' my doctor informed me. It had taken years...YEARS...to be able to finally have a diagnosis of symptoms that could have been explained away by any part of my made-for-tv-movie kind'o'life: extreme fatigue (the 'bone-crushing' type kind), deep pain in my muscles and joints...I was 36, working full time, and a mother of five. Of course, I was fatigued. Of course, I was exhausted.

For me, lupus means the full 'systemic lupus erythematosus'. I have had three cardiac infarctions. I have kidney damage. I have had pleurisy. What I needed in the start of my lupus journey was to find somewhere to read about other patients' experience with lupus. What I DID, was start a blog, 'Lupus Interrupted'. It was meant as a place to share my journey for family and friends. My family didn't read it. Who read it? People from all over the world who wanted a real conversation about what it is like living with this disease. I wrote to become a patient advocate. I wrote to highlight a lupus journey filled with hardships, but rife with positive actions. I wrote for Stanford University's medical blog, 'Scope', to illustrate to new doctors what living with lupus really feels like.

That wasn't entirely enough. I studied hard and received my certification as a Chartered Herbalist in 2015, in the hopes that I could find complimentary means of health care while managing my lupus. I have participated in numerous Ottawa Walks for Lupus Ontario in order to raise funds for patient support and for research programs.

I didn't like the hand I'd been dealt in life, so I changed the game. My epiphany came when I realized that at the end of the day, it's only my choices that will determine whether this life will be remembered and measured in pain, or in memories. I am an on-my-own mother of five, managing the best that I can with what I've been given. My wish for my children is that they be educated on patient rights, and compassionate to the journey of others, no matter their circumstance or afflictions."



If you would like to be featured as a warrior, please send a story and photo to <a href="mailto:info@lupusontario.org">info@lupusontario.org</a>

### MEETINGS/EVENTS TO COME

## **CLASSES**

Dance and Medicine Intersection Between Movement, Art and Chronic Illness

> Nov 27th @4pm Dec 11th @ 4pm

Check for updates on our website and socials!

## **NOVEMBER WEBINAR**

Nov. 27 @ 11am - 12:30pm Many of our members are living with Multiple Autoimmune Conditions or a Secondary Diagnosis along with their Lupus. Lupus Ontario in collaboration with Sjogren's Society of Canada, Arthritis Society, Raynaud's Association of America, and the Fibromyalgia London Group will be hosting an information session to introduce these other support networks to our members. Each panelist will introduce their organization and discuss what support/resources/activities they offer and how our members can get involve.

## SUPPORT MEETINGS

Young Adult Monthly Social Dec 7th @ 7 p.m.

Ottawa Online Support Group Dec 13th @ 7 p.m.

Provincial Online Support Group Dec 14th @ 7 p.m.

Durham Online Support Group Nov 29th @ 7 p.m.

### MISSION

Lupus Ontario's mission is to provide vital support, education, awareness, advocacy and research through the fundraising efforts of our staff and volunteer community to help those with lupus live longer, healthier and better lives.

VISION: LIFE WITHOUT LUPUS



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**Lupus Ontario** 



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