

August 2021

# LUPUS LINK



*Lupus Ontario's Monthly Newsletter*

21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099

## President's Message



Linda Keill

I hope everyone is enjoying a wonderful summer and that you have been able to start reconnecting with friends and family.

Here at Lupus Ontario, we are currently focusing a lot of our energy on the Walk for Lupus Ontario which is taking place on August 21st. The Walk is one of our biggest opportunities to create awareness of lupus and its impacts on our community and to raise the funds we need to support the Geoff Carr Research Fellowship, the lupus clinics and to keep our webinars and Support Groups active. So far, we have raised about \$35,000 but we are still a long way from our goal of \$75,000 - we know that we can reach our goal with your support! Every dollar counts! If you have some contacts who might donate, please encourage them to do so. We understand that the pandemic has impacted a lot of people financially, so we understand not everyone can donate. However, if your contacts are unable to donate, we suggest they share our posts to get the word out about our organization and fundraising endeavours. This is what creates awareness!

As well as working on the Walk for Lupus, the Board is busy planning for our new fiscal year which starts on October 1st. It is important to us to understand your needs so that we can work with other organizations to provide improved supports and services. In the fall, we will be sending out a survey which will ask for your input on the issues most important to you. We hope that you will take the time to complete the survey.

In closing, I would like to thank our staff and volunteers who have been working hard over the summer to make the Walk for Lupus a success, keeping our webinars and Support Group Meetings going and working on our plan for the coming year. Without your time and energy, Lupus Ontario could not exist, and we are very thankful for all that you are doing.

## Upcoming Events/Meetings

### CLASSES

Dance and Medicine –  
Intersection Between  
Movement, Art and Chronic  
Illness

Aug 18 @ 7 p.m.

### AUGUST WEBINAR

Aug 17 @ 7 p.m.

Join Brynn Clark as she  
recounts the tips she has  
learned, and the lifestyle skills  
acquired, over the past decade  
since her SLE diagnosis in 2010.

### SUPPORT MEETINGS

Young Adult Monthly Social  
- Aug 3 @ 7 p.m.

Ottawa Online Support Group -  
Aug 9 @ 7 p.m.

Provincial Online Support  
Group - Aug 10 @ 7 p.m.

Durham Online Support Group  
- Aug 30 @ 7 p.m.

**VIRTUAL WALK FOR  
LUPUS ONTARIO -  
AUGUST 21**

## WALK FOR LUPUS ONTARIO 2021

Please join us for the Annual Walk for Lupus Ontario 2021. We have chosen August 21st as the 'official' date for the Walk this year but because it is a virtual event you can participate at whatever time and place you prefer. Although this event is historically known as the 'Walk' for Lupus Ontario, you can choose to do any activity you would like in support of lupus awareness and research. For example, you could complete a craft, do yoga, create a video of something new you have learned to do, etc. We want to ensure that everyone can participate to the best of their abilities. Registration is free and you can [sign up here!](#)

For the day you pick to participate, make sure to tag us on social media! We are fortunate enough to introduce "Double Donation Week" brought to you by Prime Time Messenger. This fundraising campaign is happening from August 2-8, where Prime Time Messenger will match all donations up to \$1,000. Double your efforts by pushing extra hard this week to increase your overall fundraising campaign.



This year, we are putting some incentive to fuel your fundraising efforts! The overall top fundraiser will receive a delicious gift basket from Nutcracker Sweet, valued at over \$150. Donations are being accepted up to and including August 31, 2021. There is also a prize for top fundraiser each week leading up until the walk. For the week of August 2-8, the top fundraiser will be awarded a Weber Smokey Joe Premium Charcoal Grill; for the week of August 9-15, the top fundraiser will receive a \$25 gift card to Ultimate Dining, which includes a wide range of restaurants; finally, for the week leading up to the walk (August 16-22), the top fundraiser will receive a \$25 Canadian Tire gift card. So, what are you waiting for? Try and claim all the prizes by raising the most money each week and overall.

## MANAGING YOUR LIFE WITH LUPUS WEBINAR (AUG 17 @ 7 P.M.)

*Presented by Brynn Clarke*

Discovering the ways and the willpower to overcome the challenges of living an enriched life while managing lupus can be daunting. Brynn is a mother of five, 3rd year university student, COVID-19 survivor, Ottawa Lupus Support Group Co-Facilitator, and a Board Member of Lupus Ontario. Join her as she recounts the tips she has learned, and the lifestyle skills acquired, over the past decade since her SLE diagnosis in 2010. Together, we can redefine our perceptions of what it means to live well with lupus.

This event is free and we ask that you [register in advance](#) - hope to see you there!

## RECAP OF PRACTICAL STRATEGIES FOR MANAGING STRESS AND ANXIETY WEBINAR

This webinar was hosted by Michelle Bruxer, who is a social worker, and volunteers with Lupus Ontario as a Support Group Facilitator and as an Education and Support Committee Member.

The webinar focused on managing symptoms of stress and anxiety. It thought us the following:

- Some stress and anxiety are normal and adaptive - it's part of what makes us human
- Stress and anxiety can be problematic when the levels of stress and anxiety don't match the level of danger at hand
- The fight or flight response: in our "caveman days" we used the fight/flight system to escape danger
- Today we don't experience the same types of threats, but our bodies respond the same way to perceived threats

Michelle covered information about practical strategies to cope, as well as resources and services available. For more information or to listen to the webinar recording, please visit our [Education page](#).

# GOVERNMENT SUPPORTS: DISABILITY TAX CREDIT

*Written by Carolyn Pancham*

Has Lupus impacted your ability to perform basic activities of daily living? **The Disability Tax Credit (DTC)** is a non-refundable tax credit for persons with disabilities to reduce the amount of taxes they pay. This tax credit may be transferrable to the person that supports you. View this [video on the DTC](#) to learn more about the process. According to the video, a [self-assessment questionnaire](#) could help you determine if you may be eligible for the benefit. Questions include the duration your impairment, the impact of your impairment and the effects of your impairment on the basic activities of daily living. After getting the results, it may be worthwhile having a discussion with your health provider about the scope of your disability and applying for the benefit. A **Disability Tax Credit Certificate** needs to be completed by you and your medical practitioner. Remember to keep a copy for your records before submitting it to the Canada Revenue Agency.

**A guide provides more information on tax measures for persons with disabilities. Here are some tips to navigate the DTC:**

- DTC program has different eligibility requirements than other disability benefits
- Your health care provider may charge a fee to fill out the form
- DTC focuses on your ability to carry out basic activities of daily living (speaking, hearing, walking, feeding, elimination, dressing and mental functions)
- An approved DTC certificate allows you to claim the disability amount on your taxes
- If your application is denied, there is an appeals process
- A Registered Disability Savings Plan (RDSP) access is unlocked when you are eligible for the DTC
- Even though you are denied, you could re-apply if another medical episode worsens your functioning

Next months' article will be on Home Safety!

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



## LUPUS AWARENESS DAY RECOGNIZED

On Saturday, July 24th Markham MPP, Billy Pang, presented Lupus Ontario with the official Royal Assent Document which puts into law Bill 112 recognizing May 10th as Lupus Awareness Day in the Province of Ontario. Our Vice President, June Alikhan, accepted the document on behalf of the organization. She was joined by Diana Bozzo and her daughters, Melissa and Ashley. Lupus Ontario is very grateful to MPP Pang and to Associate Minister of Mental Health and Addiction, Michael Tibollo, for believing in our cause and pushing Bill 112 through the Legislature. We are also very grateful to all the lupus warriors who came to Queens Park to show support for the first reading of the Bill and especially to Tanya Mahadeo Connacher and Yadi Castro who started it all with their moving speeches at the 2019 Italian Dinner. We are hopeful that this official recognition of lupus and Lupus Awareness Day will position us well to advocate for better services and supports for the lupus community.

## ANTIBODY TEST FOR LUPUS PATIENTS

Dr. Tselios has given us an update regarding the antibody test for lupus patients to see if they are making the antibodies after they have taken the vaccine:

It is still not commercially available (even if someone pays out of pocket, it's impossible to have it). The test that is currently being done in Lifelabs (and other labs) detects the antibodies against the virus. This means that it will be positive **ONLY** if you had the virus in the past (not the vaccine).

Regarding the study he was talking about in [May's COVID Q&A](#), the CIHR decided not to fund it. So, we won't be able to offer these tests to lupus patients. For the moment, we only recommend double vaccination for our lupus patients (at least 28 days apart) for either the Pfizer or the Moderna vaccine.

# VOLUNTEER OF THE MONTH

The Volunteer of the Month for August is Brent Leonard. Earlier this year Brent, who hails from Ottawa, began volunteering with Lupus Ontario. He is currently an active member of the Support and Education Committee. Although not a lupus patient himself, Brent was motivated to join Lupus Ontario after directly witnessing the seriousness of lupus on family members. He believes that advocacy, support and knowledge sharing are crucially important to those currently suffering with lupus and will benefit those afflicted and impacted in the future.

One of the challenges that our Support and Education Committee has is to provide relevant and easily accessible information to younger lupus patients. Brent suggested that we create podcasts which can be listened to at any time and in short sections to accommodate busy young lives. He researched the available platforms and developed a solution and a preliminary schedule of podcasts that will begin airing in August.



Brent has a busy life with his career as Assistant Controller at a health-tech firm with the mission to support a holistic and evolving approach to healthcare aimed at supporting individuals through their entire wellness journey. He is also working on completing a Master of Health Administration program at the University of Ottawa. Thank you, Brent, for choosing to work with Lupus Ontario to share your innovative thinking in ways to improve the lives of lupus patients!

## YOUNG ADULTS LUPUS PODCAST

Please join the Young Adults members of Lupus Ontario Brent Leonard, Sara Ramnarine, Joy Phillips, Meghan Wynne and the Support and Education Chairperson, Sandra Williams-Reid as they launch the Lupus Ontario Podcast this coming August. [Listen to the trailer](#) on Spotify - stay tuned for more details to come!

## MEETINGS/EVENTS TO COME

Young Adult Monthly Social - [Aug 3](#) and [Sept 7](#) @ 7 p.m.

Ottawa Online Support Group - [Aug 9](#), [Sept 13](#), [Oct 4](#) and @ 7 p.m.

Provincial Lupus Online Adult Support Group - [Aug 10](#), [Sept 14](#) and [Oct 12](#) @ 7 p.m.

Managing Your Lifestyle with Lupus Webinar - [Aug 17 @ 7 p.m.](#)

Dance and Medicine – Intersection Between Movement, Art and Chronic Illness – [Aug 18 @ 7 p.m.](#)

Durham Online Support Group – [Aug 30](#), [Sept 27](#) and [Oct 25](#) @ 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

Keep up with Lupus Ontario on social media!

