

June 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

Lupus Awareness Month has now drawn to a close and what a month it has been for Lupus Ontario! Our social media team has done a fantastic job with their daily lupus facts posts. The reaction from our followers has been extremely positive. In addition to this, we have been covered in four digital publications and have had two live radio interviews. Links to these are included below in the newsletter. A big thank you to all who made this happen.

Another highlight of the month was the official recognition by the Province of Ontario of Lupus Awareness Day on May 10th! This has been a three-year project for us and it was wonderful to have the final reading of bill 112 pass in the House on May 10th. Thank you to Markham MPP Billy Pang, Associate Minister of Health and Addiction Michael Tibollo, Diana Bozzo, Yadi Castro, Tanya Mahadeo Connacher and all the others who came to Queens Park for the first reading to represent the lupus community. You made it happen! Going forward this recognition of lupus as a serious disease, should help us in our future work with the government to improve the services and programs for lupus patients.

During May, we have been trying to get the government to update the vaccination priority list to allow lupus patients on immunosuppressant medications to have their second dose of COVID vaccine within three to four weeks of the first. We have sent a letter to Health Minister Christine Elliott and members of the Ontario Vaccine Advisory Committee. So far, there has been no progress on this, but we do know that other organizations such as the Canadian Rheumatology Association are also working on this issue.

Looking forward, we are well on our way to having another successful Virtual Walk for Lupus Ontario this summer. Mark August 21st as the day to walk, do a craft, yoga, whatever you would like to raise awareness for lupus. So far, we have 14 locations signed up and we hope to add a few more. A big thank you to all the Walk Coordinators who already have the event off to a great start. If you would like to organize a walk in your community, please contact the Lupus Ontario office at 1-877-240-1099 or 905-415-1099 (extension 3 to speak to our Fundraising Team) and we will help you get started.

If you want to register to participate in the walk or to donate go to www.walkforlupusontario.org. Please share our social media posts about the Walk to let your contacts know about it.

In closing, I would like to note that May has been a month of great collaboration of many people to raise awareness for lupus. It is important that we continue these efforts to ensure that more people recognize lupus as a disease impacting many people in our communities. Through this increased awareness, we will be able to raise the money required for research and improved supports for the lupus community. Thank you to everyone for all your hard work and together we will get to *Life Without Lupus*.

VOLUNTEER OF THE MONTH

Rupinder was diagnosed with Lupus in 1996 and has been learning about Lupus ever since! Throughout her journey she has focused on building her own understanding and sharing with friends and family what it's like to live with lupus. After many years of knowing about Lupus Ontario through the lupus clinic and website, Rupinder decided to put her skills to use and began volunteering last year when she noticed a vacancy for an organizer for the Mississauga Walk for Lupus Ontario. She promoted the cause, motivated a great deal of supporters to do the Virtual Walk and successfully raised critical funds! Rupinder looks forward to growing the walk in Mississauga this year and is encouraging last year's walkers to get more involved. Rupinder has also joined the Support and Education committee at Lupus Ontario and has been helping to plan and facilitate support meetings and webinars. Throughout May, Rupinder has been actively advocating for lupus awareness, including participating in an interview on Sauga960AM in hopes to



help build recognition of the disease and to improve early diagnosis. Rupinder enjoys being part of the team, is excited to continue to support Lupus Ontario and to advocate for further research in order to move us all another step closer to *Life Without Lupus*.

Thanks, Rupinder for all that you do!

MAKE UP, SKIN CARE GETTING READY FOR SUMMER WEBINAR (JUNE 15 @ 7 P.M.)

Presented by Colleen Mack

Colleen Mack is a 27-year-old self-taught makeup artist and mother from Belleville, Ontario. Shortly after giving birth to her son, Colleen was diagnosed in 2013 with lupus and struggled to accept the prognosis and began battling anxiety along with painful symptoms of her disease. In 2018, deciding to attend college, Colleen graduated with a degree in Business, Public Relations and Event Management, but her passion and love for makeup never waned. She began experimenting and practicing makeup techniques to express her creativity in the hopes of inspiring and educating others. Colleen has discovered a sense of peace within herself, and in the future, hopes to become a professional makeup artist to help spread awareness and educate people about lupus.

In this talk, Colleen will discuss how she uses her skills to spread awareness and educate others about lupus. Makeup has become a form of expression and creative outlet that has helped her to cope with her illness.

This webinar is free and we ask that you [register in advance](#).

The Support and Education Committee would like to thank the members of Lupus Ontario for coming out each month to learn and show support to our guest speakers who have taken time out of their busy schedule to volunteer their time to Lupus Ontario.

Upcoming Events/Meetings



CLASSES

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

June 9 @ 7 p.m.

June 23 @ 7 p.m.

JUNE WEBINAR

June 15 @ 7 p.m.

Join Colleen Mack for a
discussion makeup, skincare
and preparing for the hot
summer months.

SUPPORT MEETINGS

Young Adult Monthly Social
- June 1 @ 7 p.m.

Provincial Lupus Online
Support Group - June 8 @ 7
p.m.

Ottawa Online Support Group -
June 14 @ 7 p.m.

Durham Online Support Group
- June 28 @ 7 p.m.

GOVERNMENT SUPPORTS: INCOME BENEFITS

Written by Carolyn Pancham

Are you experiencing a period of illness and cannot work for medical reasons? It could be stressful worrying about finances, navigating benefits and filling out forms when you are unwell. Thankfully, there are a few financial options to help you through these trying times.

First, check with your employer to see if they have short-term disability benefits (STD). If they do not, the **Employment Insurance - Sickness Benefit** provides financial assistance of 55% of your earnings (maximum of \$595 a week) up to 15 weeks for qualified individuals. During the COVID-19 pandemic, the program implemented temporary measures that make the qualification criteria more accessible. For further assistance, call 1-800-206-7218 or TTY 1-800-529-3742.

Second, if your illness is prolonged, your workplace may have long-term disability benefits (LTD) that replaces some of your income. Otherwise, the **Canada Pension Plan Disability Benefit** offers a monthly payment to those that are eligible. Apply if you are under 65 years of age, made sufficient contributions into the CPP, have a disability that regularly stops you from any type of substantially gainful work and your disability is long-term in nature or is likely to result in death. Call 1-800-277-9914 or TTY 1-800-255-4786 for more help.

Last, if you are not eligible for the above-mentioned benefits, you could try the **Ontario Disability Support Program (ODSP)**. Qualification criteria includes being at least 18 years old, an Ontario resident, in financial need and a person with disability as defined by the program. Ask to connect with an ODSP caseworker at 1-888-789-4199 or TTY 1-800-387-5559 to find out more.

Keep an eye out for next weeks' article on Caregiver Benefits!

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



LUPUS AWARENESS MONTH RECAP

The month of May is deemed Lupus Awareness Month and did we ever create awareness! We took to our various social media channels and flooded them with lupus facts, initiatives, virtual events, and the importance of talking about lupus loudly and proudly. A major win for the organization and lupus patients in the province is that Ontario now recognizes May 10 as Lupus Awareness Day due to the hard work put forward by Ontario's Lupus Warriors. With this traction, our President, Linda Keill, has made several attempts in contacting the Health Minister to expedite the vaccine process for lupus patients. We hear you and want you to know that we are working ferociously to get you the second dose in a quicker manner.

May also served as a time for some Lupus Warriors to take to various media channels and speak about Lupus Ontario and the importance of lupus awareness. Major kudos to Brynn Clarke, Rupinder Sandhu and Linda Keill for taking their time to bring lupus awareness forward and for truly conveying the values of Lupus Ontario. Hopefully with this attention comes more attention and awareness to the cause. One day we will get to live a "Life Without Lupus".

[Brian Crombie Radio Hour – Epi 392 – Lupus Awareness Month with Rupinder Sandhu](#)

[Charitable Choices: Lupus Ontario, Awareness and Support For Canadians – Toronto Guardian](#)

[The disease with 1,000 faces now has 1,000 masks: Recognizing World Lupus Day during COVID – Bradford Today](#)

DANCE AND MEDICINE BI-WEEKLY CLASSES

What comes to mind when you think of the word “ballet”? For many, ballet is an art form that embodies discipline, structure and stoicism. This year, it has been Emma Neary’s goal to turn this perception of ballet on its head through her series of classes, “Dance and Medicine – Intersection Between Movement, Art and Chronic Illness”.

Emma is a second-year medical student at Queen’s University and alumni of the Queen’s Accelerated Route to Medical School (QuARMS) program. Born and raised in St. John’s, Newfoundland and Labrador, she began dancing at the age of 3. Emma’s journey with chronic illness began in 2014. However, in 2017, a Lupus flare that stopped her from dancing sparked her interest in sharing dance with others as a tool to cope with illness.

The Dance and Medicine series aims to use dance to foster a community unrestricted by age or ability. In class, the group focuses on transforming ballet from a performative to a communicative act. In addition to developing friendships and sharing new experiences as a team, the goal is for dancers to spark a dialogue within themselves to reflect their own physical and mental health through emotion and movement.

Join our wonderful group of dancers this summer in our biweekly Zoom classes, beginning on **Wednesday, June 9 at 7:00 pm**. Dancers should wear comfortable clothing and have access to a stable surface to hold, such as a chair, countertop, rail or even a wall.

MAY WEBINAR RECAP - GUT HEALTH: IT’S NOT THE FOOD’S FAULT

On May 18, 2021 Lorene Sauro, RHN was Lupus Ontario guest speaker. She has been a holistic nutrition professional for 20 years and a food professional for 30-years. She is a teacher at the Canadian School of Natural Nutrition (CSNN), food developer, acclaimed speaker, and published author. She received the Lifetime Achievement award from CSNNAA in 2017.

In her talk, Lorene discussed how gut health issues are connected to the development of many health issues including autoimmune issues. And how foods do not cause gut problems. Gut problems cause food issues. Her goal was for us to discover the information that can help restore our ability to choose the foods we enjoy.

We **record all of our webinars** for your convenience and supply the **presentation** when given authorization!

MEETINGS/EVENTS TO COME

Young Adult Monthly Social - June 1, July 6 and Aug 3 @ 7 p.m.

Provincial Lupus Online Adult Support Group - June 8, July 13 and Aug 10 @ 7 p.m.

Dance and Medicine – Intersection Between Movement, Art and Chronic Illness – June 9 and June 23 @ 7 p.m.

Ottawa Online Support Group - June 14, July 12 and Aug 9 @ 7 p.m.

Make Up, Skin Care Getting Ready for Summer Webinar - June 15 @ 7 p.m.


Durham Online Support Group – June 28, July 26 and Aug 30 @ 7 p.m.

MISSION

Lupus Ontario is a team of caring and enthusiastic volunteers and staff who are passionately committed to helping those with lupus live longer and better by raising funds that deliver vital support, education, awareness and research.

GOAL: LIFE WITHOUT LUPUS

Keep up with Lupus Ontario on social media!

 @LupusOntario

 @LupusON

 Lupus Ontario