

"Lupus Link" August 2020

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

President's Message

By Cathy Ferren



Thank you to everyone who participated in spreading positivity and hope to others in July. I am grateful to everyone who has and some who still are working on the Virtual Walk for Lupus. Funds from this event are needed to help with the Geoff Carr Research Fellowship.

Save the date for the September 22nd Mental Health Webinar.

By now we have all had challenges with ill-fitting masks. Please watch the short video linked below on how to easily adjust your mask to fit you properly so that you and others are actually protected.

If you see, talk to or email our volunteer of the month, say THANK YOU! If you would like to nominate someone for volunteer of the month, you can contact me at CathyFerren@lupusontario.org.

SAVE THE DATE September 22nd

Webinar: Self Care During Social Distancing

2020 has been quite the year, which has quickly made many big changes in our lives. COVID-19 has changed the way we live, the way we interact with others, and our daily routines. As we adjust to our new way of life, it's important to recognize the importance of taking care of ourselves and building self-care back into our lives. Presented by: Michelle Bruxer is the Support Group Facilitator for the Windsor area. Michelle is a social worker who has experience working with children, adults, families, and communities in various settings.

Join Us on Tuesday, September 22, 2020 @ 7 p.m. EST by Zoom. Free. Preregistration required. Registration URL https://us02web.zoom.us/i/88263236917

Event: Virtual Walk for Lupus 2020

The 2020 Walk for Lupus Ontario has Gone Virtual! You can still participate.

The Virtual Walk for Lupus Ontario is an opportunity to come together, anytime and anywhere to raise funds and provide hope to the millions of people living with Lupus. COVID-19 may be keeping people apart, but the Lupus Ontario Virtual Walk will prove that we are a strong and supportive community—even when we are not physically together. We have chosen **August 15, 2020** as the day for you to walk, run, cycle, dance, do yoga, ...whatever you choose to do to raise lupus awareness and funds for lupus research, support and education programs. We are delighted to announce that we have coordinators for the virtual walks in the following communities: Durham, North Simcoe County, Toronto, Mississauga, Vaughn, Markham, St. Catharines, Hamilton, Ottawa, Muskoka, Woodstock, Keswick, Windsor, Kitchener, Grey Bruce and the Lupus Ontario Virtual Walk for communities not listed.

Find your local Walk for Lupus location:

Register for the Virtual Walk in your community or join the Lupus Ontario Virtual Walk and fundraise to help find a cure and live a Life without Lupus.

Special General Meeting of Membership for Bylaw Changes Wednesday, September 30, 2020 at 7:30 pm EST

Lupus Ontario can only amend bylaws of our organization through a majority vote of the membership at an annual general meeting or a special general meeting.

The Board of Directors has researched changes necessary to convert our membership from the current paid membership at \$25 per year to no charge membership. This will allow us to reach many more people with lupus and remove the cost barrier. Our fundraising and research drive will be increased to make up the difference in income to the association.

Below are the changes that will be voted on at a special general meeting to be held on September 30, 2020 at 7:30 pm EST by Zoom. The registration URL for the meeting is

https://us02web.zoom.us/meeting/register/tZ0ude6qqjosGNcs92ar2R6QaRu62x7BBDBv

www.lupusontario.org

#MotivationalMonday #WarriorWednesdayLO #TastyThursday



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BYLAW 2 - ARTICLE 1. Members - Members in good standing shall be the directors and those persons who from time to time may be enrolled as members of the organization at the head office, or as members of any Branch of the organization established in Ontario.

BYLAW 3 - I THE MEMBERSHIP. The Membership of Lupus Ontario is made up of those with lupus, their families, friends and caregivers from across Ontario who enrol in order to belong to the Ontario organization.

BYLAW 9 - ENACTMENTS, REPEAL AND A MENDMENT OF BY-LAWS. The Board of Directors may enact or pass by-laws, not contrary to law or to the charter of the Corporation, by a vote of a majority of the directors at a meeting of the Board of Directors. Such by-law shall not have any force until sanctioned by a majority vote at a special general meeting of the members of the Corporation duly called for that purpose.

How to Adjust Your Face Mask

By Jeremy Houston

If you have had the opportunity to sign up for the Virtual Walk for Lupus Ontario, you've hopefully received your Lupus Ontario mask - please contact info@lupusontario.org if you have not.

You may notice that the mask tends to fit a little big, but no need to worry, we have you covered! It is essential to have a mask that adheres to WHO standards, so please watch the tutorial <u>here.</u> All you need are two elastics of any size to tighten your mask to your desired liking.



Make sure to sign up for the Virtual Walk for Lupus Ontario to get your hands on this season's hottest accessory.

Corn Chowder

Submitted by Gloria Checkley

Traditional corn chowder is usually prepared with excess cream and butter. This version uses evaporated milk. You'll be surprised at how creamy and rich the soup tastes at just 211 calories and 3.7 grams of fat per serving.

2 cups corn niblets

½ tsp. vegetable oil

1 cup chopped onion

11/2 tsp. finely chopped garlic

1/2 cup chopped red bell pepper

1 cup peeled and diced potato

21/2 cups chicken stock

1/2 tsp. hot chili sauce (optional)

2 tsp. all-purpose flour

1 cup canned evaporated milk (2%)

Pinch of salt and pepper

3 tbs. chopped parsley

- 1. Lightly coat non-stick skillet with cooking spray and set over medium heat. Sauté corn 8 minutes, stirring often until lightly browned. Puree half of corn in food processor. Combine pureed corn with the whole corn in small bowl and set aside.
- 2. Add oil to large, non-stick pot and set over medium heat. Add onion and garlic and sauté 4 minutes. Add red pepper and sauté another 2 minutes. Add potato, stock, chili sauce and corn mixture. Bring to a boil, then reduce the heat to low and simmer, covered, for about 15 minutes, or until the potato is tender.



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Lupus Ontario, 21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099 3. Whisk flour and milk in a small bowl and gradually add to the soup. Add salt and pepper. Simmer, stirring occasionally for 3 minutes or until slightly thickened and heated through. Serve in bowls and garnish with parsley.

Volunteer of the Month: Kuljit Bhogal



Kuljit joined the Board of Lupus Ontario as a Director at Large in May, 2017. Kuljit graduated from the University of Windsor Faculty of Law in 2016 and was called to the Bar in 2017. Her undergrad degree also included a minor in Human Resources. Since joining the Board, Kuljit has been a great asset to our Board of Directors. She has been working on the Governance Committee updating Lupus Ontario policies to comply with the latest legal requirements and advising on many other matters and assisting with recruiting.

Prior to joining Lupus Ontario, Kuljit has participated in International Volunteer projects such as an environmental project in Peru and teaching in Bali. During her university years she volunteered with several organizations including Holland Bloorview and Community Legal Aid. Kuljit is an avid traveller and we all enjoy following her adventures on Social Media. She also enjoys cycling, running, yoga and cooking.

Outside of her role as Board Member, she works full-time as a corporate lawyer for LoyaltyOne (the company that operates the Air Miles Reward Program). In her spare time, Kuljit enjoys spending as much time as she can outdoors in nature and travelling (pre-Covid, of course!) - she has spent most of this summer hiking and camping in various parks throughout Ontario.

Thank you Kuljit for all that you are doing for Lupus Ontario!

Social Media at Lupus Ontario

We are making strides to become more engaged in the digital atmosphere! Currently, we are focusing on <u>Facebook</u>, <u>Twitter</u> and <u>Instagram</u> to disseminate information about lupus in hopes of generating awareness and funds to help support research and education initiatives.

#MotivationalMonday is a positive start to the week! We share a simple, yet uplifting, quote, phrase, etc. that we hope to get the week off to a stellar start.

#WarriorWednesdayLO is a campaign in which we feature a Lupus Warrior and their journey with lupus. We invite anyone to send a photo and their story to info@lupusontario.org if they wish to be featured. This type of content helps us humanize the disease and allows for people to understand that lupus varies from person to person. Featuring stories about perseverance, defying the odds and just simply not letting lupus get in the way of everyday life.

#TastyThursday features yummy and nutritious snacks from the recipe book of our very own Cathy Ferren. It's important to live a healthy life and to eat accordingly, but that doesn't mean the snacks can't be delicious!

Make sure to check out our social media channels and to keep up to date with everything going on at Lupus Ontario.

Support and Education Committee: Summary of the July 21st Webinar on Dealing with Summer UV, Heat and Humidity.

Things to Prepare

- Get out your sunscreen, as natural as possible, high UVA and UVB rated, example 110, 60, etc. include UV rated lip balm. Consider any contact allergies you have when deciding on which product to buy. Ask your naturopath or pharmacist for suggestions.
- Your UV protective clothing, shirts, shorts, long pants, hats, gloves, swimwear, etc. with a UVA/UVB rating of 30 or more.
- Sunglasses, wrap around, polarized.
- Fans: check electrical cords, clean blades.
- Air Conditioner or Dehumidifier: check electrical cords and controls/thermostats, clean filters and reservoirs or drain lines, use only heavy duty appliance extension cords.





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- Evaporative Cooling: Water spray bottle. Ice packs. Hot water bottle for cold water. Wet cloth or towel.
- Automobile Sun Protection: 100% UVA/UVB sun protection window film. Available Clear and tinted.
 Darker tints require a doctor's prescription to be kept in the vehicle at all times. The glove box is a
 good spot. It will be required if stopped by police due to the dark tint or at a border crossing. At least
 one bottle of water. Inside windshield screen to keep out heat when parked, usually cardboard, bubble
 foil or fabric.
- Auto Air Conditioner: Change cabin air filter, clean the accessible part of vents. Remove leaves and debris from outside air intake vents.

Hydration or Water Intake

- Clean, safe water. Room temperature is the most hydrating.
- Aim for 2 litres or 2 quarts of water daily. More if you exercise.
- Add fresh lemon or lime juice.
- For every cup of coffee or black tea which are dehydrating, you need to drink an equal amount of plain water
- High water content fruits and vegetables:
- Apricots, blueberries oranges, peaches, pineapple, plums and raspberries have over 80% water.
- Cantaloupe and watermelon have over 90% water. Pears 92%, cucumber 96%, tomato 94%, romaine lettuce and celery 95%, broccoli 89%, carrots 87%, spinach 92%, sweet peppers 92%, green cabbage 93%, watercress 90%, zucchini, strawberries, grapefruit and radishes are also good.

Avoiding Heat Stroke and Heat Exhaustion

- Stay out of direct sun during the hottest hours of the day, especially from 9 am to 5 pm, longer if you are very sensitive.
- Keep cool by misting yourself or wrapping part of you in damp towels, or damp towels wrapped around ice packs.
- Wear sunscreen, hats, and wear eye protection during daylight hours, even when it is cloudy. UV can still be very high.
- Stay hydrated.
- Keep cool by staying in deep shade, stay indoors, or by going to air conditioned spaces.
- Keep your eyes hydrated with natural artificial tears.
- Keep your skin hydrated with natural lotions.
- Ask for help if you need it. Call 911 if needed.
- Get medical attention if you are feeling ill. Pay attention to nausea, headaches, dry mouth, inability to sweat, etc

Summary

- Be prepared!
- Summer can be fun and not just a trial. Pace yourself to avoid or reduce flare ups of symptoms.
- Try summer sports if you are able, canoe, kayak, badminton, tennis, indoor golf, tubing, walking, swimming, yoga, tai chi, etc.
- You have choices.
- Have a safe and enjoyable rest of the summer.

Additional Information from Participants

This is the site that I referenced last night https://www.outdoorgearlab.com/topics/clothing-womens/best-sun-shirt-womens. It is an American site and provides unbiased reviews.
 I purchased their top listed long sleeve shirt and have been very happy with it. I purchased one directly from Mountain Hardware and the other from The Last Hunt. I made both purchases online as I am not





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Lupus Ontario, 21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099 going out and shopping during covid-19. I also use and recommend the Columbia brand Omni Freeze products. They cool you down as you sweat. I hope that helps Sarah-Jane

• 2 brands of SPF 30 lip balm I bought at Shoppers Drug Mart are Sunthera3 and Sunbum. The ones from Walmart were only SPF 15. I was able to get Columbia Sportswear and Bass Pro brand SPF 50 clothing at Bass Pro(GTA) and Columbia Sportswear outlet in London. I bought Sunveil clothing directly from them. I got SPF 30 and 45 hats from Mountain Equipment Coop. Cathy

Mental Health Tools

By Cathy Ferren RHN

There are so many digital tools available for managing stress I can't begin to list all of them. My favourite go-to APPS are: StopBreatheThink; CALM; Insight Timer; and MindShift CBT.

<u>Starling Minds'</u> 5-session course provides tools and techniques to help you regulate emotions and balance thoughts during this stressful time. The 60-minute course can be completed all at once, or in daily 10 minute increments. It will help you: Cope with stress; Regulate emotions; Balance negative thoughts; Set healthy boundaries for COVID-19 news.

<u>Anxiety Canada – Covid-19 specific resources</u> – Learn from the experts at Anxiety Canada on how you can cope. They've compiled a list of most-used resources and provided them on their website, for free. Check out their virtual Town Halls, articles, MindShift CBT mobile APP, and My Anxiety Plan (MAP) on-line courses.

<u>BounceBack®</u> is a free skill-building program managed by the Canadian Mental Health Association (CMHA). It is designed to help adults and youth 15+ manage low mood, mild to moderate depression and anxiety, stress or worry. Delivered over the phone, with or without a coach and through online videos, you will get access to tools that will support you on your path to mental wellness. BounceBack is not a crisis service, psychotherapy or counselling, but a life-skills program that participants work with to develop coping techniques so they can overcome challenges now or in the future.

<u>Tolerance for Uncertainty: A Covid-19 Workbook</u> developed by psychologist <u>Dr. Sachiko Nagasawa</u>. This workbook was created to assist with managing the strong emotions that will arise during this difficult time by using a form of psychological treatment called Dialectical Behaviour Therapy (DBT). DBT is an evidence based intervention that helps individuals identify their feelings and learn skills to better manage their emotions.

Peer Support Groups

Lupus Ontario offers in person and online peer support groups.

Check the support page on the web site for schedules and locations. Peer support groups are a safe place to share your lupus journey and learn from others in the group what has worked for them. They are not therapy sessions. Check the Support page on the web site for locations and schedules. During COVID 19 we have online meetings only using Zoom.



Imagine never having to leave the comfort of your safe place, no need to travel and not having to worry about the ever changing weather; join us for our live online audio/visual lupus peer support group.

You need to **REGISTER IN ADVANCE**. After registering, you will receive a confirmation email containing the link and information about joining the meeting. Provincial Meetings are 7 to 8 pm EST. The time varies for other online support meetings see https://www.lupusontario.org/support/

August 11 click https://us02web.zoom.us/meeting/register/vJIrcO6qqjsvGxoKNen69XfC cJLs-3kGA Sept 15 click https://us02web.zoom.us/meeting/register/vpwvd-2gqjoopdEUTBZDFal1vBDz44Td2A Oct 13 click https://us02web.zoom.us/meeting/register/vpMpd--uqjgibor5y63VwjjtnyJpjRCC6w Nov 10 click https://us02web.zoom.us/meeting/register/vpMkduqurzopHTqtcmLR isI7JfkQaBfoQ



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Upcoming Events

Provincial Online Support Group Tues Aug 11 7:00 pm EST

Virtual Walk for Lupus 2020 Sat Aug 15 all day

Durham Online Support Group Mon Aug 31 7:00 pm EST

Mon Sept 7 Office Closed for Labour Day

Youth Online Support Group Sun Sept 12 3:00 pm EST

Provincial Online Support Group Tues Sept 15 7:00 pm EST

Webinar: Taking Care of Our Mental

Health During Social Distancing

Tues Sept 22 7:00 pm EST

Durham Online Support Group Mon Sept 28 7:00 pm EST

Special General Meeting Wed Sept 30 7:30 pm EST

Office Closed for Thanksgiving Mon Oct 12

Provincial Online Support Group Tues Oct 13 7:00 pm EST

Youth Online Support Group Sun Oct 18 3:00 pm EST

Webinar: Tues Oct 20 7:00 pm EST

Topic TBD

Durham Online Support Group Mon Oct 26 7:00 pm EST

Lupus Education Days and Online Workshops

The Lupus Ontario Support and Education Committee organizes information and education events about lupus, treatment, coping and support.

Lupus Education Days or LEDs include a variety of speakers and presentations on lupus related topics. Whenever possible, an education day includes a rheumatologist, pharmacist, and other treatment professionals.

Online workshops are generally one (1) hour long online meetings with Q&A time at the end. Watch for a special workshop emails and social media posts. Details at www.lupusontaio.org/education/

Let us know if there is a particular topic you are interested in. We will do our best to find a suitable presenter on the

Mission Statement

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!