

February 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



Cathy Ferren

As we move forward in another challenging year, please stay safe. As Health Canada and the province of Ontario publish information on the pandemic, we will continue to post it on social media so that you can make informed decisions about your health and avoid misinformation on the internet.

If you know people with lupus or people with an interest in lupus, please remind them that membership with Lupus Ontario is free and being a member will help them to stay informed about what is going on in our lupus community. They will also receive notices of fundraising events, support groups and educational webinars and articles.

Save the date for the 2021 AGM on Saturday, March 20 at 10 a.m. You can register in zoom on our website or by telephone. Social distancing does not mean you are without support - you can join an online support meeting or receive email support through support@lupusontario.org.

Valentine's day is a great time to be good to yourself by connecting with others, cooking a healthy meal, going out in nature, or relaxing with a good book or video.

Upcoming Events/Meetings

WEBINAR/CLASSES

Your Treatment and Support
Teams - Cathy Ferren

Feb 16 @ 7 p.m.

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

Feb 6 @ 4 p.m.

ANNUAL GENERAL MEETING

Saturday, March 20 @ 10 a.m.

Joining by phone? Call the office to register and you will receive a zoom phone number and meeting ID to use.

SUPPORT MEETINGS

Ottawa Online Support Group -
Feb 8 @ 7 p.m.

Provincial Lupus Online Adult
Support Group - Feb 9 @ 7 p.m.

Young Adults Online Support
Group - Feb 11 @ 6 p.m.

Durham Online Support Group -
Feb 22 @ 7 p.m.

FEBRUARY WEBINAR: YOUR TREATMENT AND SUPPORT TEAMS

Presented by Cathy Ferren

Cathy Ferren has been diagnosed with lupus since 1993 after being sick since 1969. She is a Life Skills Coach, Personality Dimensions Instructor and Registered Holistic Nutritionist with an additional post graduate certificate in Immune Support as well as courses in mental health. She has training in Reiki 2nd Degree and Therapeutic Touch. Cathy has been teaching relaxation techniques for over 35-years. Volunteering with Lupus Ontario since 1993 has been very rewarding and Cathy will share from both her personal experiences and from decades of support work with Lupus Ontario. Come learn about a wide variety of specialties, services and supports that you may want to be part of your treatment team or your support team. There will be a worksheet available on the Lupus Ontario website to help you review your teams. Advocating for yourself and building your treatment and support teams is a vital part of taking care of yourself.

Join Us on Tuesday, February 16, 2021 @ 7 p.m. EST by Zoom for this free webinar. Preregistration is required.



VOLUNTEER OF THE MONTH

Laura Piccione has been organizing the Durham Walk for Lupus Ontario for 8-years. During this time, the walk has continued to grow and has raised over \$140,000 for lupus research and support and education programs. The walk is always a fun family event with Disney characters, a wonderful raffle of donated items and a bake table with items prepared by Laura's family. Laura, with the support of her husband Rob and her entire family, engages several community organizations to donate to the walk. Last year, Laura stepped up to co-lead a Virtual Walk in Durham and succeeded in raising over \$10,000. She also served on the Lupus Ontario Walk Committee and provided excellent input based on her experience. In addition, Laura serves as the Support Group co-leader for Durham Region. In 2019, Laura and her husband Rob received the Donna Chu Award for outstanding service to the lupus community. Thank you, Laura, for all you do to move us closer to a Life Without Lupus.

DANCE AND MEDICINE – INTERSECTION BETWEEN MOVEMENT, ART AND CHRONIC ILLNESS

Join Emma Neary to reflect on her journey living with chronic illness as a dancer and her experiences as a patient, medical student and researcher. These sessions will serve as an introduction to a series of free, online, beginner ballet classes open to the Lupus Ontario community. Emma is a second-year medical student at Queen's University and began dancing at the age of three.

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. Emma recommends having a stable surface to hang on to, like the back of a chair, a countertop, a rail or even a wall. She also advises participants to wear comfortable clothing.

These classes will take place on a bi-weekly basis starting on February 6 at 4 p.m.

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CELEBRATE WITH US IN MIND

If you have an upcoming birthday, anniversary or some other sort of celebration, we ask that you think of Lupus Ontario.

Facebook Fundraising has become quite the way to celebrate, especially in these COVID times. People are asking for donations to a cause close to their heart in place of a gift for their respective celebrations. You can set your own personal fundraising goal and set the time parameters - essentially creating your own personal fundraiser! All donations are processed via PayPal. For your next milestone, please keep Lupus Ontario in mind.

Visit the [Facebook Fundraising](#) page for more information!



JANUARY WEBINAR RECAP

Dr. Landolt led a discussion separating the facts from fiction pertaining to medical cannabis. Main takeaways from this webinar are the differences between THC and CBD and understanding why people use medical cannabis. THC can be useful for nausea, anorexia, pain and sleep – at high doses it is intoxicating or make you feel “high”. CBD can help with pain, muscle spasms and anxiety – it does not cause people to feel high. The strongest evidence says that medical cannabis is used to control symptoms. Pain, nausea, vomiting, sleep, anorexia or loss of appetite, and spasticity or tremors are among the symptoms medical cannabis can assist. For more information, please watch the [recorded version of this webinar](#).

THE NEW EULAR/ACR 2019 SLE CLASSIFICATION CRITERIA: DEFINING OMINOSITY IN SLE

Written by Dr. Whittal Garcia (2019/2020 Geoff Carr Fellow)

Systemic Lupus Erythematosus is a heterogeneous disease, characterized by an unpredictable activity course. Persistent disease activity is known to increase mortality and morbidity. Recently, a new set of classification criteria for lupus has been introduced, the 2019 European League Against Rheumatism/American College of Rheumatology classification criteria (EULAR/ACR criteria). The EULAR/ACR criteria have proven to be sensitive and specific. Furthermore, this set of criteria have been shown to parallel with SLE disease activity and organ damage.

The aim of this study was to determine the ominosity of the EULAR/ACR criteria, by establishing the ability of this new set of criteria to predict disease severity in the first 5-years following diagnosis.

We included eight hundred and sixty-seven systemic lupus erythematosus patients from the Toronto Lupus Clinic (all entered the clinic in the first 12 months after lupus diagnosis). For each patient, the EULAR/ACR criteria score was calculated. To determine disease severity we used disease activity, number of flares, remission and use of immunosuppressive treatment as outcomes in the first 5-years of disease. The Systemic Lupus International Collaborating Clinics (SLICC) registry was used as a validation cohort.

The median EULAR/ACR score was 20, which was used as a threshold to compare outcomes between groups.

In the first 5 years of disease course patients with a score ≥ 20 had higher disease activity, more frequently experienced ≥ 2 flares, were less likely to accomplish remission and had higher requirements for immunosuppressive therapy. The results were similar for the SLICC cohort.

Based on these results we concluded that, a EULAR/ACR score ≥ 20 is an indicator of ominosity in SLE, as patients with a score ≥ 20 were characterized by a more active disease course throughout the first 5 years.

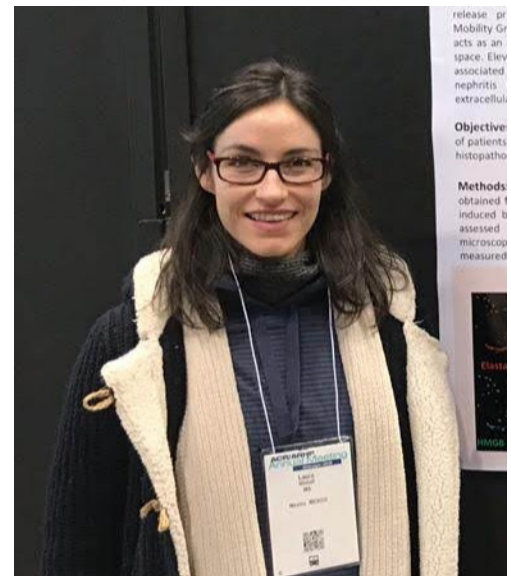
PEER SUPPORT GROUPS

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. Check the Support page on the web site for locations and schedules. During COVID-19 we are only hosting online meetings via Zoom.

We ask that you please register in advance for these meetings. After registering, you will receive a confirmation email containing the link and information about joining the meeting. Provincial Meetings are 7 to 8 p.m. EST. The time varies for other Online Support Meetings and they are outlined on our Support Page. You can also join by telephone. Email support@lupusontario.org or call the office at 1-877-240-1099 to register and receive the call in telephone number and meeting ID.

February is the month to complete and return via email your annual signed Confidentiality Agreement. Please send the signed copy to support@lupusontario.org at your earliest convenience.

To maintain privacy we cannot publish the numbers in the newsletter.



CANADA'S COVID IMMUNIZATION PLAN

We know there are many questions regarding the upcoming COVID vaccine, so we have updated our website with [Canada's COVID-19 Immunization Plan](#) to help answer some of those questions. Canada is preparing to roll out an immunization response, which will provide Canadians with access to safe and effective vaccines to protect against COVID-19. This ambitious plan will be delivered through a principled and evidence-informed approach that puts protecting the health and safety of Canadians first.

We also invite you to stay up-to-date with [COVID restrictions](#) in your respective area!

ANNUAL GENERAL MEETING

This year's Annual General Meeting will be taking place [Saturday, March 20 at 10 a.m.](#) We will go over what the association has been doing this past year, present the audited financial statements and introduce the new Board Members and Executive Team. This will be taking place over Zoom and we invite you to participate by phone if you do not have access to a computer. Call the office to register and you will receive a zoom phone number and meeting ID to use. We hope to see you there!



VOLUNTEER WITH LUPUS ONTARIO

Please consider giving back to the community and volunteering your talents to Lupus Ontario. The volunteer [application form](#) is on our website.

People always ask for more personal stories of member's lupus journey in the newsletter - please consider submitting yours for the newsletter. There is always room on the committees for new members. Examples of committees are Fund Development, Public Awareness, Newsletter, and Support and Education.

MEETINGS/EVENTS TO COME

Dance and Medicine – Intersection Between Movement, Art and Chronic Illness - [Feb 6](#) @ 4 p.m.

Ottawa Online Support Group - [Feb 8](#) and [March 8](#) @ 7 p.m.

Provincial Lupus Online Adult Support Group - [Feb 9](#) and [March 9](#) @ 7 p.m.

Young Adults Online Support Group - [Feb 11](#) and [March 11](#) @ 6 p.m.

Your Treatment and Support Teams Webinar - [Feb 16](#) @ 7 p.m.

Durham Online Support Group - [Feb 22](#) @ 7 p.m.

Lupus Ontario General Meetings - [March 20](#) @ 10 a.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