

January 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

I hope each of you had a holiday season of good health and quality time with family and friends.

As we start a new year, please consider how you can use your time and talents to further the goals of the association. There are opportunities to volunteer on committees, write articles, or join the Board.

Hopefully we will all get some relief from the dangers of the pandemic and regain better access to our health care professionals. Thank you to everyone who took the time to do the online survey last November. It will help the Support and Education Committee plan the programs for 2021. It is exciting to see our membership increasing with the elimination of the membership fee.

Welcome to all our new members.

Upcoming Events/Meetings

JANUARY WEBINAR

Medical Cannabis – Separating
Facts from Fiction by Dr. Carolina
Landolt

Jan 19 @ 7 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 -
Jan 11 @ 7 p.m.

Provincial Lupus Online Adult
Support Group - Jan 12 @ 7 p.m.

Young Adults Online Support
Group - Jan 14 @ 6 p.m.

Durham Online Support Group -
Jan 25 @ 7 p.m.

JANUARY WEBINAR: MEDICAL CANNABIS – SEPARATING FACTS FROM FICTION

Presented Dr. Carolina Landolt

Dr. Carolina Landolt has been practicing in the emerging field of cannabinoid medicine for over 5-years and established the first specialty run clinic in Canada. Her practice focuses on the use of cannabinoids in the management of conditions including degenerative and inflammatory arthritis, musculoskeletal and neuropathic pain and fibromyalgia. She has developed unique expertise in this emerging area of medicine and is a sought-after speaker academic, educational and public media.

Questions can be submitted prior to the webinar to support@lupusontario.org.

Join Us on Tuesday, January 19, 2021 @ 7 p.m. EST by Zoom for this free webinar. Preregistration required.



ANNUAL RESEARCH CAMPAIGN

The Annual Membership Research Campaign will wrap up at the end of this month. To date, we have raised over \$8,000 and have welcomed 40 new members. Thank you to everyone who has generously donated. We know that 2020 has not been an easy year and we are very grateful for your support.

As mentioned in previous newsletters, every dollar donated to the Research Campaign goes directly towards the Geoff Carr Fellowship. The 2020 Fellow, Dr. Laura Whittall Garcia (pictured above), has now completed her year at Toronto Western and we look forward to publishing a summary of her research findings on lupus nephritis in the near future – please keep your eye out for this!

Through your continued support, Lupus Ontario can fund the critical research performed by the Geoff Carr Fellows. If you have not already donated and would like to do so, you can donate online through our [website](#), by phone or mail your cheque to the Lupus Ontario office. Together, we will some day get to have a Life Without Lupus.



2021 GEOFF CARR FELLOW

The 2021 Fellow, Dr. Ambika Gupta, is now at the Toronto Western Lupus Clinic starting her research on cognitive impairment in lupus patients. She will be working under the supervision of Dr. Zahi Touma, a former Geoff Carr Fellow. It has been shown that more than 30% of lupus patients are affected by cognitive impairment - this can include memory loss, difficulty concentrating and other related symptoms. The goal of Dr. Gupta's research is to identify which patients are at risk of developing cognitive impairment and to identify which ones could have persistent issues over time.

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Rheumatologists with expertise in lupus clinical research are essential to delivering high quality patient care, developing innovative research studies and inspiring future research. The importance of these opportunities to lupus research fellows is countless as it offers a chance for them to further develop their research skills which can be taken into a future career in academia and/or clinical care to improve the life of patients with lupus.

- Dr. Zahi Touma

SUPPORT AND EDUCATION

With everything that happened in 2020, we took to the digital realm for both Support and Education initiatives. All of our Support Meetings are taking place on Zoom until otherwise indicated and the attendance has surpassed our expectations. In December, we launched an Ottawa Support Group with the first meeting taking place on December 14, 2020. We are excited to add another Support Group to the Lupus Ontario network.

A major takeaway from 2020 is the need for webinars and we are happy to keep this going in 2021. Dr. Landolt will be discussing medical cannabis with us on January 19 to sort through common misconceptions and identifying facts about the substance. Coming up on February 16, we have Lupus Ontario's own Cathy Ferren guiding us through "Your Treatment and Support Teams" taking place at 7 p.m. on Zoom.

Back in November we asked members for insight/feedback as to what you would like Lupus Ontario to offer and you delivered some great results! Latest Lupus Research, Everyday Management Strategies, Mental Health + Wellness, Alternative Medicine + Therapies, Lupus Medications and Lifestyle with Lupus were among the most requested webinar topics. When asked what people are hoping to gain from Support Groups, the top three answers were: improving understanding of lupus and your own experience with it, management with improving skills to cope with challenges of lupus and social benefits of feeling less lonely, isolated or judged. We are so thankful for all of those that took the time to complete the Lupus Ontario General Survey and look forward to implementing these insightful requests in the coming months.

There has been a change to one of our existing Support Groups: the Toronto Youth Support Group will now be known as the "Young Adults Support Group". Joy Phillips will begin hosting Support Meetings for young adults, 18-35 years old. This is a great way for young adults with lupus to connect with peers and find age-appropriate resources and support. Meetings will be held on the second Thursday of the month, with the first meeting taking place on January 14 at 6 p.m.

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.

January 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.

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.

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

If your New Year's Resolutions include giving back to the community, consider volunteering your talents. 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

Ottawa Online Support Group - [Jan 11](#), [Feb 8](#) and [March 8](#) @ 7 p.m.

Provincial Lupus Online Adult Support Group - [Jan 12](#), [Feb 9](#) and [March 9](#) @ 7 p.m.

Young Adults Online Support Group - [Jan 14](#), [Feb 11](#) and [March 11](#) @ 6 p.m.

Medical Cannabis – Separating Facts from Fiction Webinar - [Jan 19](#) @ 7 p.m.

Durham Online Support Group - [Jan 25](#) and [Feb 22](#) @ 7 p.m.

Your Treatment and Support Teams Webinar - [Feb 16](#) @ 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