

### President's Message

Written by Cathy Ferren



I hope your summer finished on a high note. In preparing for fall, there are a number of things you can do be ready for the cooler weather such as getting out warmer clothing, blankets, hats and gloves. It is also the time to pace yourself with fall chores. The abundance of fall fruits and veggies will help you maintain a nutrient dense diet.

There are exciting things going on in our lupus community. The Hamilton Lupus Clinic welcomed Dr. Kostas Tselios in September. We have completed our first virtual, provincial walk for lupus. Lupus Ontario continues to provide online support groups and education webinars using Zoom. Please go to the Support page [lupusontario.org/support/](https://www.lupusontario.org/support/) and the Education page

[lupusontario.org/education/](https://www.lupusontario.org/education/) for details. Our annual research campaign is coming up in November. Your electronic newsletters will start being posted on our website at <https://www.lupusontario.org/newsletter/>. Watch for our member survey open November 1 to 15.

If you have never volunteered, or have not for some time, there are many different tasks that need your help. The volunteer application form is available on [lupusontario.org/volunteer/](https://www.lupusontario.org/volunteer/). We are a volunteer organization and we need all of us to make life with lupus better.

If you see, talk to or email our volunteer of the month, say THANK YOU! If you would like to nominate someone for the Lupus Ontario volunteer of the month, you can contact me at [CathyFerren@lupusontario.org](mailto:CathyFerren@lupusontario.org).

### Special General Meeting of Membership for Bylaw Changes Summary

The Lupus Ontario membership passed bylaw changes on September 30<sup>th</sup>. Effective for January 1st for the 2021 membership year, there will be no cost to become a member in Lupus Ontario. You still need to join as a member to receive the electronic newsletter as well as the support and education notices. You will still be able to vote at General Meetings. These changes will allow us to reach many more people with lupus and remove the cost barrier. The changes to bylaw 6 allow clean up the language around our investments.

### Annual Research Campaign

Lupus Ontario's Annual Research Campaign will be starting in late October. Lupus Ontario has a long history of supporting lupus research. In 1987, our organization provided funding to establish the Lupus DataBank Research Program at Toronto Western Hospital. According to Dr. Murray Urowitz, "As the database has grown, what we can learn from it has grown immensely," says Dr. Urowitz. "We're discovering things that change the way we treat lupus."

In 1990, the Geoff Carr Fellowship was established with the objective of training a rheumatologist to become an expert in diagnosing and treating lupus and to complete a research project during the Fellowship year. The past Geoff Carr Fellows continue to improve the lives of lupus patients through the skills they learned in their fellowship year and the global research networks they now contribute to.

Lupus Ontario needs to ensure that we can continue to support lupus research. Look for additional information and activities related to 2020 Research Campaign in the coming weeks. By working together, we can achieve Life Without Lupus.

### October Webinar: Skin Infections and Rashes by Nathalie Rozenbojm RN MN

**Join Us on Tuesday, October 20, 2020 @ 7 p.m. EST by Zoom. Free. Preregistration required.**

Registration URL [https://us02web.zoom.us/join/register/tZAtd-yvrzoiHN34rNcl6kfe49545INj\\_7GG](https://us02web.zoom.us/join/register/tZAtd-yvrzoiHN34rNcl6kfe49545INj_7GG)

Nathalie is the Clinical Nurse Specialist for the Lupus Program at Toronto Western Hospital. She works alongside four rheumatologists, Dr. Zahi Touma, Dr. Dafna Gladman, Dr. Murray Urowitz and Dr. Sanchez-Guerrero. Nathalie received her Bachelor of Science in Nursing from the University of Western Ontario, and has been a Registered Nurse for eight years. She has had experience in Medical/Surgical Care, Emergency, Palliative Care, Multi-Organ Transplant and Interstitial Lung Disease.

Most recently, Nathalie completed her Masters of Nursing at Ryerson University and joined the Rheumatology team about a year and a half ago! Please join Nathalie on October 20 for a discussion around common skin infections and rashes seen in Lupus and how to manage them! Topics will be around shingles (herpes zoster), cellulitis and discoid

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lupus rashes. In this presentation, we will discuss prevention, common signs and symptoms, how to manage these concerns and when to consult your rheumatology team.

You can also join the webinar by telephone. Email [support@lupusontario.org](mailto: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.

### November Webinar: Plaquenil(Hydroxychloroquine) and The Eyes by Dr. Michael Easterbrook

**Join Us on Tuesday, November 17, 2020 @ 7 p.m. EST by Zoom. Free. Preregistration required.**

Registration URL [https://us02web.zoom.us/join/register/tZcudOirgTgpEtSUNB\\_a0b1Wb4SCGsCi0VbJ](https://us02web.zoom.us/join/register/tZcudOirgTgpEtSUNB_a0b1Wb4SCGsCi0VbJ)

Dr Easterbrook would like everyone to submit their questions prior to the webinar. Deadline is November 12. Questions can be forwarded to [support@lupusontario.org](mailto:support@lupusontario.org).

### Public Awareness Campaign for Medical Offices

When social distancing allows access into medical offices, we need your help to spread the word about lupus. Would you be able to take 3 Lupus and Me brochures in to a medical office near you?

If you can help get these into doctors, nurses, physiotherapists, chiropractors, dentists or other medical offices, it will really help increase awareness about lupus and where to get help through Lupus Ontario. You need their permission to place brochures in their offices. If you can visit more than one office, that would be helpful. Alternatively, you could phone them for permission, send the permission email to the office and have the office mail the brochures to them.

Contact us at [admin@lupusontario.org](mailto:admin@lupusontario.org) with public awareness in the subject line and we will mail you the number of brochures you require. Please include your full mailing address and phone number.

### Looking For A Volunteer To Be The Board of Directors Treasurer

The Lupus Ontario Board Treasurer is Chair of the Finance and Audit Committee and has a number of governance and operating responsibilities. The purpose of the Finance and Audit Committee is to provide Lupus Ontario's donors, members and other stakeholders with greater assurance on the integrity of financial information, clarity in reporting and transparency in disclosure.



Lupus Ontario operates in a very lean, cost efficient environment with only two staff members. As a result the organization depends on its Volunteers, Committees and Board members to pick up some of the workload. The Board Treasurer will need to spend approximately 8 hours a week performing the responsibilities noted below.

#### Governance Responsibilities:

- Ensure the annual audit is conducted in an efficient, cost-effective and objective manner.
- Oversee Lupus Ontario's financial control systems and financial policies.
- Recommend to the board for approval of the annual financial statements, including the selection of appropriate financial policies and practices.
- Recommend the appointment of the external auditor and the appropriate fee.

#### Finance Responsibilities:

- Jointly with Management and Board Committees develop an annual operating budget and annual operating plan.
- Recommend to the board the annual operating budget and operating plan.
- Review and recommend to the board the financial assumptions used to develop the operating budget and operating plan.
- Review and report to the board on a quarterly basis the actual performance against the operating budget and operating plan.
- Recommend to the board any required reforecast of the annual operating budget and operating plan.
- Review and report to the board on a quarterly basis the performance of the investment portfolio.
- Oversee, implement and approve along with Management and Board Committees any new technology changes relating to hardware and software platforms.

#### Job Requirements for this position are:

- Qualified accountant with at least 10 years of experience.

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- Advanced skills in Excel; such as budget modelling, complex formulas, data tools and filters.
- Managerial skills required.
- Basic understanding of technology systems.
- Interest in learning new technology platforms (training provided on cloud based donor management system).
- Team player.

Anyone interested in applying should send their resume to [admin@lupusontario.org](mailto:admin@lupusontario.org).

### Walk for Lupus Ontario 2020

The Walk for Lupus Ontario looked a little different this year than it has in the past, but that did not stop us from raising funds in support of lupus education and research programs! The event took place virtually on Saturday, August 15 at any time that was convenient for the participant. The beauty of virtual events is that they can take place wherever, whenever and however you like – you make the rules! We encouraged people to partake in the day's festivities in any way they saw fit to support Lupus Ontario. We saw a range of events taking place from walks around the neighbourhood to hiking to even kayaking – people took to social media across the province to showcase their daily activity.

With everything going on in the world, we noticed that charities and non-profits were seeing donations in the 30-40% range compared to previous years. We were expecting to raise a fraction of what we are used to in previously due to COVID-19, but Lupus Ontario supporters came through and helped us surpass the 30-40% range! We are happy to announce that this year's walk has raised \$58,397. We want to thank all the people who participated and donated and a major shout out to our top fundraiser Yadi Castro for being so dedicated and raising over \$3,000 in support of Lupus Ontario. Yadi is the Team Captain of Yadi's Butterflies, which raised over \$5,000 – congratulations, Yadi!

We are eternally thankful for everyone's participation and generosity in such trying times. This just goes to show that we can come together and create awareness and funds to hopefully live "Life Without Lupus".

**Save the date: Saturday March 27, 2021 @ 10 am**

**Lupus Ontario Annual General Meeting by Zoom**

[https://us02web.zoom.us/meeting/register/tZYud-6prjlrE9C3fnyMdqUOtFqSFZUP\\_UG6](https://us02web.zoom.us/meeting/register/tZYud-6prjlrE9C3fnyMdqUOtFqSFZUP_UG6)

If you will be joining this meeting by telephone only, call the office to register and you will receive a zoom phone number and meeting ID to use on the day of the meeting.

### Mask Update: Getting a Rash?

If you have gotten a rash after wearing a face mask, it may be that you are allergic to something in the materials it is made from or from a dirty mask. Try washing cloth masks before use and every few uses to cleanse them of manufacturing chemicals initially and to cleanse them from germs from your breath and the environment. I keep them in a food grade plastic bag like a ziplock bag so the masks do not get contaminated from a backpack, purse, car seat or shopping bag. I wash a couple masks at a time and hang them to dry so that I always have access to a clean mask.

### Volunteer of the Month: Heather Knoll



Heather began volunteering with Lupus Ontario in Sudbury in 2004 as a support group facilitator. She served on the Board of Directors of Lupus Ontario for 10 years. During her time on the Board, her efforts were mostly focussed on patient support and education and the newsletter committee. Heather's nursing experience combined with her experience as a lupus patient make her an ideal person to provide patient support. Since leaving the Board in 2017, Heather has continued to volunteer with Lupus Ontario providing patient support in the Midland Penetanguishene area. In the past, she has been very active on the Public Awareness and Communications Committee.

In 2018, Heather was presented with the Donna Chu award at the Annual Italian Dinner Dance. This award is given to a person who has provided outstanding service to the lupus community. Heather's volunteer work with Lupus Ontario continues. In 2019, she was the co-coordinator of the very successful Barrie Glow in the Dark Walk for Lupus. This year Heather stepped up to be co-coordinator for the North Simcoe Virtual Walk for Lupus. Thank you Heather for your outstanding service to Lupus Ontario!

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### 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/>

Oct 13 click <https://us02web.zoom.us/meeting/register/v5Mpd--uqjgibor5y63VwjtnyJpRCC6w>

Nov 10 click [https://us02web.zoom.us/meeting/register/vpMkduqurzopHTqtcmlR\\_isl7JfkQaBfoQ](https://us02web.zoom.us/meeting/register/vpMkduqurzopHTqtcmlR_isl7JfkQaBfoQ)

Dec 8 click [https://us02web.zoom.us/meeting/register/vpAvf--rrj8jakTaXGOXL5LSG\\_5vf5LsNQ](https://us02web.zoom.us/meeting/register/vpAvf--rrj8jakTaXGOXL5LSG_5vf5LsNQ)

**Ottawa Online Support Group Launch** Monday December 14<sup>th</sup> 7:00-9:00 pm EST

You can also join support meetings by telephone. Email [support@lupusontario.org](mailto: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.

### Upcoming Events

<b>Office Closed for Thanksgiving</b>	Mon Oct 12
<b>Provincial Online Support Group</b>	Tues Oct 13 7:00 pm EST
<b>Youth Online Support Group</b>	Sun Oct 18 3:00 pm EST
<b>Webinar: Skin Infections and Rashes By Nathalie Rozenbojm RN MN</b>	Tues Oct 20 7:00 pm EST
<b>Durham Online Support Group</b>	Mon Oct 26 7:00 pm EST
<b>Youth Online Support Group</b>	Sun Nov 8 3:00 pm EST
<b>Provincial Online Support Group</b>	Tues Nov 10 7:00 pm EST
<b>Webinar: Plaquenil(Hydroxychloroquine) And The Eyes by Dr. Michael Easterbrook</b>	Tues Nov 17 7:00 pm EST
<b>Durham Online Support Group</b>	Mon Nov 30 7:00 pm EST

### September Webinar Notes

If you missed the September 22<sup>nd</sup> webinar on Taking Care of Our Mental Health During Social Distancing you can download the notes at <https://www.lupusontario.org/education/>

### 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.lupusontario.org/education/](http://www.lupusontario.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 topic. Email Sandra at [support@lupusontario.org](mailto:support@lupusontario.org)

### 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!

[www.lupusontario.org](http://www.lupusontario.org)

#MotivationalMonday

#WarriorWednesdayLO

#TastyThursday