



President's Message

Written by Cathy Ferren



I hope everyone has a safe holiday with social distancing, pacing and self-care as priorities. Enjoying life and sharing with family and friends is good for both our physical and mental health. If you are not able to be with others in person, there are many options to connect with family and friends through facetime, Facebook, zoom, WebEx, email, telephone and other platforms. Perhaps this is a year to do hand written letters or custom emails. I wish each of you joy during whichever holidays you celebrate.

Not everyone can donate during this COVID year, however, if you are able to, please donate to the annual research campaign. With so much government funding diverted to covid expenses, Lupus Ontario needs your help more than ever to continue to fund important initiatives like the Geoff Carr Fellowship and other research projects.

The 2021 AGM – Annual General Meeting will be virtual on Zoom on Saturday March 20, 2021 at 10 am. Register now and reserve your spot. See the save the date notice below.

Shop at Lupus Ontario This Holiday Season

Lupus Ontario is happy to offer some exclusive merchandise this Holiday season! We have WHO regulated non-surgical masks with Lupus Ontario branding available for \$10; Lupus Ontario branded tote bags for \$25; and Lupus Ontario pens available for \$2. Prices may vary with shipping depending on your area.

If interested in making a Holiday purchase, please email info@lupusontario.org for further instruction on how to place your order and process your payment.



Annual Research Campaign

The Annual Research Campaign is on until the end of December 2020. This year more than ever funds are needed to support lupus research. Many funding agencies have diverted assets to COVID research so there is very little left to conduct urgently needed lupus research into adult and pediatric lupus. The 31 Fellows that Lupus Ontario has supported over the years have all contributed to the global body of knowledge of best ways to treat and diagnose lupus.

Dr. Deborah Levy head of the Lupus Clinic at SickKids Hospital has said:

"The Geoff Carr Lupus Fellowship fills a crucial need in training the next generation of pediatric rheumatologists who recognize and expertly care for infants with NLE, and children and adolescents with SLE. The fellowship provides the opportunity to spend a year in the largest pediatric SLE and NLE clinics in Canada. Research projects supported by the fellowship have significantly increased our knowledge of the etiology and long-term effects of both NLE and SLE. By continuing to fund important research we will further advance clinical care and improve outcomes for all patients."

We know that these are challenging times but if you can [please donate](#) - every dollar donated gets us closer to Life Without Lupus.

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

Ottawa Online Support Group Launch

Lupus Ontario is inviting you to the launch of the Ottawa Support Group on December 14, 2020 at 7 p.m. It will be Facilitated by Elizabeth Beaven, Julie St. George and Brynn Clark.

You can register [here](#), or email lupusottawaenglish@gmail.com if you have any questions.



January Webinar: Medical Cannabis – Separating Facts from Fiction by 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. Free. Preregistration required.

Registration URL https://us02web.zoom.us/meeting/register/tZakdeyqgTosHdXRHOvP9000b1F2K-chWf_p

Education Materials

You can download a free copy from the Lupus Ontario website of the:

[Lupus and the Body Poster](#)

[Lupus Facts Booklet revised 2020](#)

Holidays! No Problem!

By Cathy Ferren RHN



For those who have read my articles on kitchen coping, you may remember me writing, living with a chronic illness means adapting to various types of limitations, basically doing things differently than we did before the current flare up of symptoms. Holidays do not have to set you back for weeks or months. There are simple steps you can take to conserve your energy and actually enjoy yourself this holiday season.

The most obvious yet least often performed task is to make your health the number one priority. Only plan to attend or accept invitations to the number of parties, shopping trips, visits to friends or family and other events that you can do without pushing past your activity threshold. This threshold is the amount of things you can do without getting over tired, without causing dramatically increased muscle or joint pain, sleep deprivation, headaches or other symptoms.

The natural human tendency is to want to do more than we should, to perhaps do as much as we used to be able to do before we got sick. Before going out or hosting a party, plan for it. Organize the shopping, cleaning, cooking and other preparations over a period of days or weeks limiting the amount of energy that you spend to the same amount of time you would spend on a typical day if it was not the holidays. Don't try to do everything on the day of an event. If you do, you will be setting yourself up for a flare, exhaustion or both.

Try something new, host a pre-planned pot luck instead of you making everything for a dinner. You can get a friend, child or family member to help. You can make and freeze food in advance. Give yourself time to prepare well in advance so that an event is not a stressor but a stress reliever. The time it takes to prepare for events or shopping well in advance, pays big dividends while hosting or attending the events because you are more rested and having less symptoms.

You have lupus, a chronic illness. You do not have to explain yourself to anyone, or justify why you cannot participate in things. Family and friends need to learn to respect your limitations, not criticize you for them. If they refuse to accept your reality, sometimes it may be necessary to stay away or take a vacation from negative people for awhile until they learn to respect you.

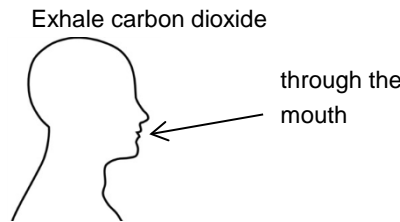
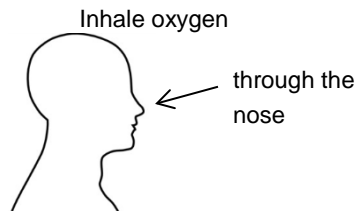
Reclaim the holidays on your terms. Be good to yourself by planning ahead and only doing as much as your body is capable of. Rest when you need to. When you absolutely cannot do the cooking, driving or shopping yourself, allow

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yourself the grace to accept it and then have the wisdom and courage to ask for help from family or a friend. Joy, fun and friendship are good for the body, the mind and the spirit. Enjoy this holiday season!

Breathing Techniques for Stress and Pain Management

Breathing Basics

Breathing exercises cover a range of techniques such as deep breathing, rhythmic breathing, diaphragmatic breathing and many more. The ability to focus in on specific body sensations like breathing can help the body work efficiently and heal more quickly.



Diaphragmatic Breathing

This exercise helps you become aware of your breath, feeling both the inhalation and the exhalation. It can be done with your eyes either open or closed. Allow your breath to flow, be natural and unforced.

Notice your breathing right now. Observe the movements and sensations that occur in your body as you breathe in and out. Place a hand on your abdomen, and feel the abdomen rise as you inhale and fall as you exhale.

Visualize in your mind's eye, gently drawing the breath into your abdomen and then letting it go easily, not forcing it out, letting go of tension. Take in only as much air as you need in each breath and then let it out.

Feel your inhalation expand your abdomen and lower back, then your chest. Make the breaths very slow and deep, but not to the point of strain. Allow the muscles in your body to soften, to go limp and relax as you feel the rising and falling of the breath and abdomen. Practice during random moments in your day, at home, work or on public transit.

Try diaphragmatic breathing for five or ten minutes. Write down how it felt or any sensations in your body.

Breathing to a Count

Breathing to a count increases our ability to breathe slower and deeper.

Sit or lie down comfortably. Inhale for a count of two seconds, then exhale for a count of two seconds, saying to yourself inhale one, two, exhale one, two.

Once you get the idea and feel of breathing in rhythm, start an increasing progression; inhale for a count of three seconds and then exhale for three seconds. Next, inhale for a count of four seconds and then exhale for four seconds.

Continue, increasing the number of seconds, until you reach a comfortable limit, then work your way back down. If you got as high as inhaling and exhaling to a count of twelve seconds, go back to eleven, then back to ten, and so on, until you reach a very comfortable pace, maybe five seconds and maintain that pace.

In one or two weeks you will notice measurable increase in the number of seconds you inhale and exhale, and a deeper sense of relaxation each time you practice this.

Try breathing to a count for 5 minutes. Write down how it felt in your body and any thoughts or feelings you had. Repeat when you want to feel deeper relaxation.

Save the date: Saturday March 20, 2021 @ 10 am

Lupus Ontario Annual General Meeting by Zoom

https://us02web.zoom.us/meeting/register/tZYud-6prjlrE9C3fnyMdqUOtFgSFZUP_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

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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.

January is the month to complete and email back your annual signed confidentiality agreement. You can download it from the support page [lupusontario.org/support](https://www.lupusontario.org/support)

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/> 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. **If you are not comfortable using zoom you can also join the meetings by telephone.** Call the office for the dial in phone number and meeting id.

Dec 8 click https://us02web.zoom.us/meeting/register/vpAvf--rrj8jakTaXGOXL5LSG_5vf5LsNQ

Jan 12 click https://us02web.zoom.us/meeting/register/tZUrdOmtrDMoGdBultMtk32J9P_JJgAqijy

Feb 9 click https://us02web.zoom.us/meeting/register/tZYufuygqD4iG9XpcnrBUilvOp_A_LA-aZP

Upcoming Support and Education Events

Young Adult Online Support Group Sun Dec 13 3:00 pm EST
age 18-35 years

Ottawa Online Support Group Mon Dec 14 7:00 pm EST

Provincial Online Support Group Tues Jan 12 7:00 pm EST

Webinar: Medical Cannabis - Separating Facts from Fiction by Dr. Carolina Landolt Tues Jan 19 7:00 pm EST

Durham Online Support Group Mon Jan 25 7:00 pm EST

Provincial Online Support Group Tues Feb 9 7:00 pm EST

Webinar: Your Treatment and Support Teams by Cathy Ferren RHN Tues Feb 16 7:00 pm EST

Durham Online Support Group Mon Feb 22 7:00 pm EST

Provincial Online Support Group Tues Mar 9 7:00 pm EST

November Webinar Summary on Plaquenil (Hydroxychloroquine): Eye Safety, Testing and Dosage

Dr. Easterbrook is a Professor of Ophthalmology at the University of Toronto. He is on staff at Saint Michael's Hospital, Toronto Western Hospital and has an office on Bay Street at College.

Over many years, he has had the opportunity to see many patients on Plaquenil, referred by rheumatologists and dermatologists. With improved testing methods, Dr. Easterbrook and team are able to pick up, early, the very rare situation where the drug may affect the eye. His short talk illustrated these tests but lots of time was allowed for questions. Many questions were asked concerning the effects of Plaquenil on the eyes, and how do you know when to stop taking this medication. This was another topic of interest to our members and 44 attended it.

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!