

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

### **President's Message**

Written by Cathy Ferren



I hope everyone enjoyed some fall colour this year. As we prepare for winter, stocking up on food, consumable products and extra medications for snow or ice storms is helpful. It is also time to bring out and w ash or repair the winter blankets, boots, mittens, batteries, other household items and winter tires.

To all our members and supporters who have been diagnosed with COVID-19, we wish you a speedy and complete recovery. The rest of us need to continue taking the maximum precautions recommended by our public health officials.

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.

### Membership in Lupus Ontario is Now Free

At a recent Special General Meeting of the members of Lupus Ontario, a bylaw was changed to make membership in our organization free. Your current Lupus Ontario membership will expire on December 31<sup>st</sup>. As in the past, the membership renew al coincides with our Annual Research Campaign. It you would like to renew your membership which expires on December 31, 2020 and/or to make a research donation, you can do so online by clicking on https://app.etapestry.com/onlineforms/LupusOntario/membership.html

If you prefer to just renew your membership at this time, please call the office at 1-877-240-1099. We look forw ard to welcoming you as a member and for your support.

### Annual Research Campaign

Lupus Ontario's Annual Research Campaign is now underway. We need your support to raise money to support the Annual Geoff Carr Lupus Fellow ship. This year's Fellow is Dr. Ambika Gupta. She will be studying at the Toronto Western Hospital Lupus Clinic and doing research related to Cognitive Impairment in Lupus. Lupus Ontario has been funding the Geoff Carr Lupus Fellow ship since 1990. As a result, 31 research projects have been done on a variety of topics such as lupus nephritis, impact of antimalarials on the heart, depression in pediatric lupus patients, transition of pediatric patients to adult care and more. All these projects have added to the global body of know ledge of better predictors of the progression of lupus and therefore, better treatments for lupus patients of all ages.

We know that these are very challenging times, but even a small donation can help to keep the Geoff Carr Lupus Fellow ship going. You can be assured that all research donations will go directly to the Geoff Carr Fellow ship and that Lupus Ontario will continue to help in improving the lives of lupus patients in Ontario and around the world. To make your donation, click on the link below and select Research Contribution.

https://app.etapestry.com/onlineforms/LupusOntario/donation.html

We thank you for your support.

# Webinar: Plaquenil (Hydroxychloroquine): Eye Safety, Testing and Dosage by Dr. Michael Easterbrook MD, FRCS(C), FACS

I am a Professor of Ophthalmology at the University of Toronto. I am on staff at Saint Michael's Hospital, Toronto Western Hospital and have an office on Bay Street at College.

Over many years, I've had the opportunity to see many patients on Plaquenil, referred by rheumatologists and dermatologists. With improved testing methods, we are able to pick up, early, the very rare situation where the drug may affect the eye. This short talk will illustrate these tests but allow lots of time for questions.

*Dr* Easterbrook would like everyone to submit their questions prior to the webinar. Deadline is November 12. Questions can be forw arded to sw illiams-reid@lupusontario.org.

Join Us on Tuesday, November 17, 2020 @ 4 p.m. EST by Zoom. Free. Preregistration required. Registration URL <u>https://us02w.eb.zoom.us/meeting/register/tZcudOirqTgpEtSUNB\_a0b1Wb4SCGsCi0VbJ</u>

### September Webinar Summary: Skin Infections and Rashes

Nathalie Rozenbojm, Clinical Nurse Specialist for the Lupus Program at Toronto Western Hospital, shared information and photos that explained the malar or butterfly rash, raynaud's phenomenon, shingles rashes and a lot

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IMonday #WarriorWednesdayLO #TastyThursday



# Lupus Ontario's ONLINE Newsletter "Lupus Link" November 2020

Lupus Ontario, 21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099 of information about the different shingles and flu vaccines. She indicated that lupus patients should receive the Shingrix brand vaccine not the live vaccine. Seniors can now get this covered under ODB – Ontario Drug Benefit. Others should check with their extended health insurance if they have coverage. She talked about treatments your medical team may prescribe for each condition. Nathalie also emphasized that lupus patients need to get the influenza vaccine and that we should book early as many doctors and pharmacies do not have enough flu vaccine this year. Thank you Nathalie for a very informative presentation.

### The 2020-2021 Influenza Vaccine

Written by: Nathalie Rozenbojm, RN MN - Clinical Nurse Specialist for Lupus - University Health Network

It has been a tough year! Although our focus has been on COVID-19 we can't forget that Flu Season is also upon us. This year, more than ever, protecting yourself from the flu is extremely important. Influenza can be a scary illness to catch, especially when you have Lupus and are taking many immune suppressing medications. In general, the flu vaccine is safe for patients with SLE. It is a well-tolerated vaccine that is inactive meaning individuals *cannot* become sick from receiving this immunization. You should not be receiving the flu vaccine if you are allergic to eggs, have had a previous serious reaction to the vaccine, are under 6 months of age or are recovering from an acute infection/viral illness. Patients who are immunocompromised (Lupus patients), pregnant or planning to become pregnant, elderly or children over the age of 6 months should be receiving this vaccine. The 2020-2021 Flu Vaccine will cover four different strains of the virus including two strains of Influenza A and two strains of Influenza B

There are common side effects of receiving the vaccine, which include pain at the administration site, nasal congestion or runny nose. If you do experience pain in your arm, you may take acetaminophen to help as long as your medical team feels this is safe. Due to COVID-19 flu shot administration looks a little bit different this year. Shoppers Drug Mart Pharmacies are asking that you make an appointment first before getting your vaccine. There are some other "drive-through" type programs that family doctor's offices are offering – make sure to check with your General Practitioner.

Lupus patients have a lot to keep track of including doctor's visits and lists of medications; to keep track of all your vaccinations try dow nloading the application CANImmunize on your phone or tablet (available for lphone and Android). This application provides a fantastic interface and will remind you of when you are due for your next vaccine.

### Protect yourself and others, please get your flu shot this season!!

For weekly reports on the upcoming flu season in your area follow this website: <u>https://www.canada.ca/en/public-health/services/diseases/flu-influenza/influenza-surveillance/weekly-influenza-reports.html</u>

### **Public Awareness Campaign for Schools**

Do you attend or know anyone who attends a junior high school or regular high school? You can spread the facts about lupus by giving a short 10 minute online presentation about Lupus Ontario (Pow erPoint presentation supplied by the Lupus Ontario office) follow ed by a 5 to 10 minute talk about your lupus journey, or if you do not have lupus, the story of someone you know with lupus. We have templates for both a 5 minute and a 10 minute talk to email you.

Contact us at <u>admin@lupusontario.org</u> with public aw areness for schools in the subject line and we will mail you the My Lupus Story templates, and the number of brochures and bookmarks that you require. Please include your full mailing address and phone number. One of our volunteers will contact you and help you prepare.

### 2020 Lupus Support and Education Survey

Please take 2 minutes to complete the online 2020 survey. The Support and Education Committee wants to know what your needs are to plan activities. Take the survey <u>https://www.surveymonkey.com/r/JJ2CNDR</u>

### Lupus Canada 2020 Scholarship Recipients in Ontario

Congratulations to Amelia Shivdarsan, Gurleen Dhaliwal, Nicole Yawney and Rebeca Acosta.

### 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

If you will be joining this meeting by telephone only, call the office to registerand you will receive a zoom phone number and meeting ID to use on the day of the meeting.www.lupusontario.org#MotivationalMonday#MotivationalMonday#WarriorWednesdayLO#TastyThursday



Lupus Ontario's ONLINE Newsletter

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Ashley has been a loyal and dedicated volunteer for Lupus Ontario since 2012. Ashley started as a volunteer photographer for the Durham Walk for Lupus and expanded her photography role to include the Italian Dinner, the Annual General Meeting & Health Symposium, and Education days. She is a very active member with the Durham Lupus Support Group, as well as her community and is alw ays helping others by sharing her know ledge and compassion, as well as being an advocate for many causes. Ashley was the inspirational speaker at the 2019 Durham Walk for Lupus and shared her lupus journey - no matter w hat happens to her, she never gives up! Ashley received the Making A Difference Aw ard from Lupus Ontario in 2019.

MITTS

Thank you Ashley, we are very grateful for your time and talents!

### PREPARING FOR WINTER

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Crossw ord puzzles, sudoku and w ord searches are all excellent w ays to exercise your brain.

Try it and see if you can find all the words. Perhaps this puzzle will remind you of how much you already know about preparing for winter.

Have fun! BLANKETS PACING BOOTS PARTY (supplies) DE-ICER PROPRANE EYE (drops) SHOP FOOD (extra) SHOVELS GAS SUNSCREEN HOT (packs) TIRES (snow) LOTION TOYS MEDICATION VITAMINS

### Recipe of the Month: Barb's Mac & Cheese Soufflé

Submitted by Barbara Hutchison, Serves 8 to 10

#### Ingredients:

- 2 cups uncooked elbow macaroni (can be gluten free)
  1/4 cup melted butter, olive oil or coconut oil
  1 medium to large diced onion
  2 cups cubed bread, can be gluten free
  4 to 6 cups shredded sharp cheddar cheese
  1 tsp sea salt
  1 tablespoon Herbs de Provence
- 1/4 cup minced parsley
- 2 cups milk
- 6 eggs



Cook the macaroni and drain. Melt butter, add salt, onions and herbs. Sauté until translucent. Combine the onions and herbs with the macaroni and store in the refrigerator until you are ready to serve.

One hour before you wish to serve it, stir 6 beaten eggs into 2 cups milk. Stir in macaroni mixture, bread cubes and 4 cups of the cheese.

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Put into a 9"x13" pan and spread the last two cups of cheese on top. Set that pan into a pan of water. Bake at 350 deg. F for 40 minutes.or until it is firmly set. It will puff up. The baked mac & cheese can be portioned and frozen.

### Welcome to the Board of Directors

The board is pleased to welcome a new volunteer Chaudry Semalulu. He will be helping with the Secretary position and he is also interested in social media. Thank you Chaudry for volunteering.

### **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.

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 <u>https://www.lupusontario.org/support/</u> You can also join by telephone. Email <u>support@lupusontario.org</u> 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 new sletter.

Nov 10 click https://us02web.zoom.us/meeting/register/vpMkdugurzopHTgtcmLR\_isI7JfkQaBfoQ Dec 8 click https://us02web.zoom.us/meeting/register/vpAvf--rri8jakTaXGOXL5LSG\_5vf5LsNQ Jan 12 click https://us02web.zoom.us/meeting/register/tZUrdOmtrDMoGdBultMtk32J9P\_JJgAqjjy

### **Upcoming Support and Education Events**

Youth Online Support Group	Sun Nov 8	3:00 pm EST
Provincial Online Support Group	Tues Nov 10	7:00 pm EST

Webinar: Plaquenil(Hydroxychloroquine) Tues Nov 17 7:00 pm EST Eye Safety, Testing and Dosage by Dr. Michael Easterbrook

Durham Online Support Group	Mon Nov 30	7:00 pm EST
Provincial Online Support Group	Tues Dec 8	7:00 pm EST
Youth Online Support Group	Sun Dec 13	3:00 pm EST
Ottaw a Online Support Group	Mon Dec 14	7:00 pm EST
Durham Online Support Group	Tues Dec 28	7:00 pm EST
Provincial Online Support Group	Tues Jan 12	7:00 pm EST
Webinar: Cannabis by Dr. Landolt	Tues Jan 19	7:00 pm EST
Durham Online Support Group	Tues Jan 25	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.

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 <u>swilliams-reid@lupusontario.org</u> or <u>support@lupusontario.org</u>

### **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, aw areness and research.

### **Goal: Life Without Lupus!**

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