

March 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 I come to the end of my term as your president, I want to thank every Lupus Ontario member and others in the lupus community. It has been a great honour to serve the membership and the lupus community during these unusual times. Your Board of Directors are a hands-on working Board and you have many excellent volunteers as the organization moves forward. We will be welcoming some new Board Members at our AGM on March 20, 2021 and I am looking forward to working with them as your Past President. Please stay connected to the lupus community and stay safe as the pandemic continues.

Upcoming Events/Meetings

CLASSES

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

March 13 @ 4 p.m.

March 27 @ 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 -
March 8 @ 7 p.m.

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

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

Durham Online Support Group
- March 29 @ 7 p.m.

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 info!

DONATE WITH YOUR OPTIMUM POINTS

Many are taking to Shoppers Drug Mart and Loblaws to conduct your day-to-day shopping, so why not put those PC Optimum Points to use? You can donate some or all of your PC Optimum Points to Lupus Ontario. Above all this will help us purchase merchandise at Shoppers Drug Mart and Loblaws such as office supplies and fundraising items. To find out how you can convert your points in to a donation, please [click here](#).

Go ahead and splurge a little with your next shopping trip and earn more points... it's for charity after all!



VOLUNTEER OF THE MONTH

Yadi Castro was diagnosed with Systemic Lupus in December 2013 after being sick for nine months and receiving several misdiagnoses. Lupus has had a severe impact on Yadi's life. Throughout the years she has dealt with many episodes of renal failure, heart issues and sepsis. She has been hospitalized several times with very severe illness that required life saving interventions. Yadi learned about Lupus Ontario through the North York Lupus Support Group where she met Dr. Tselios from the Toronto Western Hospital Lupus Clinic. She feels that there is a reason that she is still with us and is determined to make a significant contribution to raising lupus awareness and funds for research. Yadi and her family have been great supporters of the Annual Italian Dinner Dance and have organized the Vaughn Walk for Lupus Ontario for the past three years. In 2019, Yadi was the keynote speaker at the Italian Dinner Dance. Thank you, Yadi, for all you do to increase lupus awareness and to raise funds for lupus research.

GOVERNMENT SUPPORTS

Written by Carolyn Pancham

Are you in need of additional supports for managing life with lupus? Both the Federal and Provincial government offer resources to help those living with chronic illness. The following links are for a tool that summarizes programs and services based on your criteria: [Government of Canada - Benefits Finder](#) + [Government of Ontario - Benefits Finder](#).

Alternatively, a list of some of the benefits (subject to program eligibility requirements) are outlined below. This summary is for information purposes only. Please speak with a customer service agent to see if the program is a good fit for you.

Federal Government of Canada – Contact 1-800-O-CANADA (1-800-622-6281)

1. **Canada Pension Plan Benefits (CPPD)** – income benefits for qualified disabled persons
2. **Community Volunteer Income Tax Program (CVITP)** – eligible persons get their tax returns completed at no charge
3. **Compassionate Care Benefits** – employment insurance benefits for caregivers providing end-of-life support
4. **Disability Supports Deduction** - income tax credit for selected equipment to assist a disabled person to attend work, school or to participate in a research grant
5. **Disability Tax Credit (DTC)** – income tax credit for eligible disabled persons
6. **Employment Insurance – Sickness Benefits** – employment insurance for medical reasons
7. **Enabling Accessibility Fund** – funding to make Canadian communities and workplaces more accessible for persons with disabilities in order for them to take part in activities, programs, services and employment
8. **Excise Gasoline Tax Refund** – a refund for part of the gas tax you buy if you have a permanent mobility impairment and cannot safely use public transportation
9. **Family Caregiver Benefits** – employment insurance benefits for a caregiver taking care of a critically ill or injured persons
10. **Grants for Students with Permanent Disabilities** – education grant for a qualified student
11. **Home Accessibility Expenses** – income tax credit for eligible expenses for a qualifying home renovation that improves safety or mobility access for a qualifying individual
12. **Medical Expenses Credit** – income tax credit for eligible medical expenses
13. **Registered Disability Savings Plan (RDSP)** – a savings plan to help a disabled person that qualifies for the Disability Tax Credit (DTC)

1. **Accessible Parking Permit** – people with certain health conditions may be granted an accessible parking permit
2. **Assistive Devices Program** – financial assistance for listed equipment or supplies for eligible persons with disabilities
3. **Home and Vehicle Modification Program** – persons that meet program criteria may get grant funding for home or vehicle modifications
4. **Ontario Disability Support Program (ODSP)** – supports for persons living with a disability
5. **Ontario Local Health Integration Networks (LHINs)** – community health-care services and support
6. **Special Drugs Program (SDP)** – coverage for some drug treatments not covered by other drug program for eligible applicants
7. **Trillium Drug Program (ODB)** – financial help for high prescription drug costs

PREPARE YOUR MIND

Written by Michelle Bruxer

The winter blues are a wave of low emotions that come with these cold, dark days. If you're experiencing the winter blues, you might feel the need to sleep a bit longer, indulge more often in comfort food, and spend more time with Netflix than with your friends and family.

You may have heard people referring to this as seasonal affective disorder (SAD), but the winter blues and SAD are two different things. The difference between the winter blues and seasonal affective disorder: About 15 per cent of people in Canada experience the winter blues, while only about 2-3 per cent of people in Canada experience SAD.

SAD is a widely researched condition of regularly occurring depression in the winter season that can impair one's daily life. Treatment can include light therapy, counselling, medication, or a combination of the three. A professional can help determine if you are experiencing SAD.

Here are some ways you can improve or maintain your mood this winter:



1. **Let the light in** - Get outside during the day if you can, keep your curtains open, and when indoors, spend as much time as you can near the windows. Even if it's cloudy, getting some daylight can help boost your mood.
2. **Get physical** - Even though hitting the gym might be the last thing you feel like doing, physical activity is always a great tool to help you manage your mental health. Start small and try a lunchtime walk around the block.
3. **Try to keep a normal sleep schedule** - It might feel like your bed is the only one who understands this funk you're in but over-sleeping can actually worsen the symptoms of the winter blues.
4. **Give yourself a pat on the back** – You're doing great. Battling low moods is no easy feat, and it's important to be kind to yourself. You're stronger than you think!

Remember to have regular check-ins with yourself, and to spend that extra time on self-care if you need to.

Source: Canadian Mental Health Association: <https://cmha.ca/blogs/winter-blues-101>

THE HIDDEN COSTS OF LUPUS

Written by Cathy Ferren

There are a surprising number of hidden costs on the road to a lupus diagnosis and your treatment. The examples I give come from my own experience, my clients and others I have met in the lupus community. I was reminded recently with price shock when I got to the blood laboratory of this issue. The purpose is not to scare you or give you anxiety but to make you aware of things that you will need to budget for, even if you live paycheck to paycheck.

Some laboratory tests are not covered by OHIP. Lupus anticoagulant or antiphospholipid antibodies blood test \$70, food sensitivity/allergy immunoglobulin IgE and IgG (such as those done by LifeLabs using Rocky Mountain Analytical) blood test not skin pricks varies from \$100 to \$400, T3 and T4 if your TSH is in the normal range, free T4, PSA for men, etc. The point is to ask your health care practitioner when they give you a laboratory requisition if any of the tests are not covered by OHIP.

Co-payments on prescription medications and medication delivery devices. I have found this to range from a few hundred dollars a month to a couple thousand dollars a month. I also found that banks, trust companies and cooperatives will not lend money for medical expenses.

Co-payments on medical devices. The example that I have run into several times is there is the co-payment on the actual main part of the device but no coverage for the related components under ADP the Assistive Devices Program.

It is important to have a discussion with your family about finances and how lupus affects your overall budget. It breaks my heart when I talk to people with lupus who cannot get most of the medication and treatments they need. I ask you, even if you are a household of one person, to sit down and take a serious look at your finances and plan for extra costs. Put your plan down on paper and review it once per year or when your health changes.

The bottom line: **be prepared!** The full article is available on [our website](#).

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!

MEETINGS/EVENTS TO COME

Ottawa Online Support Group - March 8, April 12, May 10 and June 14 @ 7 p.m.

Provincial Lupus Online Adult Support Group - March 9, April 13, May 11, June 8 @ 7 p.m.

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

Dance and Medicine – Intersection Between Movement, Art and Chronic Illness – March 13 and March 27 @ 4 p.m.

Lupus Ontario General Meetings - March 20 @ 10 a.m.

Durham Online Support Group – March 29, April 26, May 31, June 28 @ 7 p.m.

SLE and COVID-19: What is the Evidence? Webinar – April 20 @ 7 p.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