

## President's Message



Linda Keill

Summer has faded away and we are now into the glorious days of fall. Let's hope the fall weather extends well into November so we can continue to enjoy outdoor activities as long as possible.

The Walk for Lupus Ontario has wrapped up for another year. This year's Walk was a tremendous success. With your support, we raised over \$85,800! I want to thank all our Walk Coordinators, our sponsors, our donors and the Lupus Ontario staff who worked so hard to achieve this success. This was a tremendous team effort that shows that great things can be achieved by working together.

October marks the beginning of the Annual Lupus Ontario Research Campaign. Lupus Ontario has a long history of supporting lupus research. Our major contributions include:

- Led by our founder Honey Agar, we raised over a million dollars for the start up of the Lupus Databank at Toronto Western Hospital. This databank has been the source of valuable patient information for countless lupus research projects. These projects have resulted in a better understanding of lupus and, have formed the basis of improved techniques for management of the disease.
- Funded the annual Geoff Carr Lupus Research Fellowship since 1990. This Fellowship has trained over 30 rheumatologists at an Ontario Lupus Clinic to become experts in diagnosing and treating lupus. Each Fellow is also required to complete a research project during their Fellowship year. One of the biggest challenges lupus patients have is getting a timely diagnosis. The doctors trained during the Geoff Carr Fellowship develop the skills needed to do this. Early diagnosis leads to better outcomes.
- Supported lupus clinics across the province by providing funding for their research and patient education activities

In addition to the Geoff Carr Fellowship and lupus clinic funding, this year Lupus Ontario will be providing funding to support a new research initiative at the Hamilton / McMaster Lupus Clinic. Dr. Konstantinos Tselios, a former Geoff Carr Fellow, is starting a Lupus Biobank. This is a very exciting project and we are very honoured to be funding the start up. The samples collected in the Biobank, will support lupus research projects in the years to come.

Lupus Ontario is proud of our accomplishments in supporting lupus research over the past 43 years. With your support, we have accomplished a lot and we have helped to improve the lives of lupus patients in Ontario and around the world. We hope that you will support us in continuing this critical work.

Together, we will get to a *life without lupus*.

# GOVERNMENT SUPPORTS: MOBILITY

*Written by Carolyn Pancham*

## Accessible Parking Permit

People with certain health conditions may apply for an accessible parking permit. There are permanent, temporary, and subject to change disability permits. Permits must be displayed on dashboard or visor. Remember that only the person named on the permit could use an accessible parking space. Contact Service Ontario at 1-800-387-3445 if you require more information.

## Assistive Devices Program

Persons with a long-term physical disability, may get help paying for equipment and supplies under the assistive devices program. To qualify, you must be an Ontario resident, have a valid Ontario health and have a disability requiring the equipment or supplies for six months or longer. Wheelchairs, hearing aids, insulin pumps, CPAP machines and oxygen are a few of the eligible items. The amounts covered are based on the equipment needed. The Assistive Devices Program could be reached at 1-800-268-6021.



## Excise Gasoline Tax Refund

For those that have a permanent mobility impairment and cannot safely use public transportation, there is an excise gasoline tax refund for the gasoline you purchase. The refund equates to \$0.015 per litre. For example, a tank of 100L is eligible for \$1.50 refund. To request a refund, fill out an application for refund of federal excise tax on gasoline. Remember, a qualified medical practitioner must certify the impairment.

Look out for next month's article on Students and Modest-Income Individuals!

**\*This article is intended to provide general information only. Please seek advice from a qualified professional for your situation.**

## Upcoming Events/Meetings

### CLASSES

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

Oct 16 @ 4 p.m.

Oct 30 @ 4 p.m.

### OCT WEBINAR

Oct 18 @ 7 p.m.

Join Abrial Cooke MSc.OT, OT  
Reg. (Ont.) as she discusses  
Fighting Fatigue: Using Energy  
Management Strategies to Live  
Well with Lupus. Abrial is a  
Occupational Therapist with  
lived experienced of chronic  
illness.

### SUPPORT MEETINGS

Young Adult Monthly Social  
- Oct 5 @ 7 p.m.

Ottawa Online Support Group -  
Oct 11 @ 7 p.m.

Provincial Online Support  
Group - Oct 12 @ 7 p.m.

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

## IGIVE TO LUPUS ONTARIO

Help your favorite cause or charity every time you shop online, it's all free and so easy to be socially-conscious. Join us and start Giving #AllYearRound. The stores make this possible because they want you to like them and shop at them over and over again. There's 2295 socially-responsible stores helping to make donations happen. We hope you'll give it a try and donate towards Lupus Ontario.

To learn more, please [click here](#).

## FIGHTING FATIGUE: USING ENERGY MANAGEMENT STRATEGIES TO LIVE WELL WITH LUPUS WEBINAR (OCTOBER 19 @ 7 P.M.)

*Presented by Abrial Cooke*

Abrial Cooke MSc.OT, OT Reg. (Ont.) is an occupational therapist who owns and operates **RISE Occupational Therapy**.

This presentation will give an overview of Occupational Therapy and how it can assist individuals living with Lupus. It will explain the 4 main principles of Energy Management and how they can be applied to daily living to aid in managing fatigue.

This webinar is free and we ask that you **register in advance**.



## VOLUNTEER OF THE MONTH

Our Volunteer of the Month for October is Joy Phillips. Joy has been a volunteer with Lupus Ontario for almost two years. Joy has lived experience as a young person with lupus. When she was diagnosed at age 22, she noticed a gap in resources and peer support for young adults - this inspires the work Joy does today. Currently, Joy is a Young Adult Support Group Facilitator and contributes to Lupus Ontario's Support & Education Committee, where she has initiated a strategy to utilize social media to better support youth and young adults with lupus. Joy's passion for health advocacy and promotion goes well beyond her work with Lupus Ontario. In 2019, Joy graduated from the University of Toronto with a B.Sc. in Human Biology. Currently, she works in health research in the department of Translational Medicine at The Hospital for Sick Children in Toronto. To learn more about Joy's story, check out her **recent interview** on the Lupus Ontario Podcast where she talks about her experience with post-secondary education and career navigation.

Thank you, Joy, for all you do to raise lupus awareness and to support the youth and young adults living with lupus.



## SEPTEMBER 2021 WEBINAR RECAP

On September 21, 2021 we had the pleasure of having two of the top doctors in their field join us for "The Story Behind Cognitive Impairment and Lupus Brain Fog".

Dr. Zahi Touma, MD, PhD, is an Associate Professor of Medicine, Clinician-Scientist with the University of Toronto and Scientist with the Krembil Research Institute and Schroeder Arthritis Institute. Dr. Touma was joined by Dr. Michelle Barraclough, PhD Post Doc Research Fellow UHN Krembil Research Institute and Schroeder Arthritis Institute. For almost 10 years she has been working in Manchester, UK on projects investigating cognitive dysfunction in SLE, specifically using functional MRI and computerized cognitive batteries. Dr. Barraclough joined Dr. Zahi Touma's team at the Toronto Lupus Program to continue her work in this field with the hope of furthering our knowledge in this debilitating condition.

In his presentation Dr. Touma gave us an overview of what we know so far:

- High prevalence of CI in SLE
- No one tool being used to look at CI in SLE
- Computerized tasks could be use, easier and quicker
- How people with SLE are affected by CI over time has a specific pattern
- Many factors affect CI in SLE and this can be different depending on the individual
- Not everyone has obvious CI but may experience "brain fog", this could be cognitive fatigue

We record all of our webinars and have the presentation slides as a resource on our [Education page](#). Dr. Touma and Dr. Barraclough also took time to answer the the [audience's question](#) that are compiled in a document available on the Education page, as well.

## VOLUNTEER WITH LUPUS ONTARIO

Please consider giving back to the community and volunteering your talents to Lupus Ontario. 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

Young Adult Monthly Social - [Oct 5](#), [Nov 2](#) and [Dec 7](#) @ 7 p.m.

Ottawa Online Support Group - [Oct 11](#), [Nov 8](#) and [Dec 13](#) @ 7 p.m.

Provincial Lupus Online Adult Support Group - [Oct 12](#), [Nov 9](#) and [Dec 14](#) @ 7 p.m.

Cognitive Impairment Webinar - Oct 19 @ 7 p.m.

Dance and Medicine – Intersection Between Movement, Art and Chronic Illness – [Oct 16](#) and [30 @ 4 p.m.](#)

Durham Online Support Group – [Oct 25](#) and [Nov 29](#) @ 7 p.m.



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Lupus Ontario

### MISSION

Lupus Ontario's mission is to provide vital support, education, awareness, advocacy and research through the fundraising efforts of our staff and volunteer community to help those with lupus live longer, healthier and better lives.

**VISION: LIFE WITHOUT LUPUS**