

President's Message



Linda Keill

A big congratulations to all the Walk Coordinators and the Lupus Ontario staff for a fantastic result for this year's Walk for Lupus Ontario. To date we have raised over \$82,000 well above our goal of \$75,000. This is all due to the hard work and commitment of our volunteers and staff. August 21st was certainly not a cool day to get out and show our support for the lupus community, but many braved the extreme heat to do so. Thank you to everyone who sent in photos and videos for us to share on social media to create even more awareness. I want to remind everyone that the Walk is not officially over yet, as the walk site will remain up until the end of September.

There has been good news in early August for the lupus community with the FDA approval of Saphnelo (anifrolumab-fnia) for adult patients with moderate to severe systemic lupus erythematosus (SLE) who are receiving standard therapy. Lupus Ontario will be working with other lupus organizations over the coming months to support the Health Canada and Province of Ontario approvals. It is encouraging to know that new treatments are being developed and there is more hope on the horizon for better treatment of SLE. Along the line of research for better treatments, Lupus Ontario has always supported lupus research through our Annual Geoff Carr Lupus Fellowship and funding of Ontario lupus clinics. You will hear more about our commitment to research and new projects next month as we gear up for our annual Research Campaign.

I hope everyone has chance to listen in on our podcasts. They were launched in August and have been very well received. You can access all podcasts recorded to date from our website. Thank you to Brent Leonard and everyone who has offered their time to be interviewed. Although the early recordings focussed on the Walk for Lupus Ontario, through the upcoming of months we plan to have a variety of speakers on topics of interest. Be sure to listen!

In this issue of the newsletter, we have included a tribute to Stewart Stainton, the third President of Lupus Ontario. I never met Stew in person but had several telephone conversations with him over the past few years and his enthusiasm for our organization never waned. Lupus Ontario sends sincere condolences to Stewart's family and his many friends.

As we head into the fall, please continue to follow the public health guidelines including masking, avoiding crowds (especially indoors) and frequent hand washing. COVID is still with us, and I know this poses a significant issue for many of us. At the moment, the approval for the third dose of vaccine does not currently include lupus patients or other patients with rheumatic diseases who are on immunosuppressants. Lupus Ontario is looking into working with other organizations to pressure the province to include lupus patients in the recommendation. In the meantime, stay safe everyone.

We will get through this!

RED BLOOD CELL ALTERATIONS CONTRIBUTE TO LUPUS

The autoimmune disease lupus may be triggered by a defective process in the development of red blood cells (RBCs), according to a study led by researchers at Weill Cornell Medicine. The discovery could lead to new methods for classifying and treating patients with this disease.

Read the full article [here](#).

GOVERNMENT SUPPORTS: HOME SAFETY

Written by Carolyn Pancham

Do you hold a valid disability tax credit certificate or are over the age of 65 and need equipment or renovations to improve safety or mobility access in your residence? You may be able to claim those home accessibility expenses on your federal income tax return. In addition, the senior's home safety tax credit is available to those aged 65+ on their provincial taxes.

Example: Jessica, a lupus warrior, is 65 years of age and has mobility issues. Her home safety and accessibility will improve by installing grab bars, a raised toilet, door levers and a wheelchair ramp in her home. Based on those purchases, she may be eligible to reduce her taxes.

Wheelchair ramp	\$ 3,500
Grab bars (installed)	1,000
Door levers	500
Raised toilet	500
Total accessibility expenses	\$ 5,500
Claimed under Home Accessibility Credit (15% x \$5,500)	\$ 825
Claimed under the Senior's Home Safety Credit (15% x \$5,500)	\$ 1,375
Total Claims	\$ 2,200
Total Out-of-pocket expenses (\$5,500 - \$2,200)	\$ 3,300

March of Dimes Canada administers the Home and Vehicle Modification Program on behalf of the government. A limited number of grants of up to \$15,000 (lifetime maximum) for home modifications and up to \$15,000 (every 10 years) for vehicle modifications are available to eligible individuals in the greatest need of assistance. You must have a disability that restricts your mobility to live safely in your home, be able to be employed or participate in your community. It is expected that you try to fund the projects through other sources before applying to the program. If you have further questions about the program, call MODC at 1-877-369-4867.

Stay tuned for next month's article on Mobility!

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

REALLOCATE UNITED WAY DONATIONS TO LUPUS ONTARIO

Is your company/organization running a United Way employee campaign? You can add Lupus Ontario as your charity of choice and have your donation attributed to your organization's campaign total. Speak to your Payroll or Human Resources department about how you can make this possible.



United Way

Upcoming Events/Meetings

CLASSES

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

TBD - Check for updates on
our website and social

SEPT WEBINAR

Sept 21 @ 7 p.m.

Join Dr. Zahi Touma for a presentation about Cognitive Impairment. His research is focused on patients with SLE and measurement science with a particular interest in the assessment of disease activity, patient reported outcomes and cognitive function.

SUPPORT MEETINGS

Young Adult Monthly Social
- Sept 7 @ 7 p.m.

Ottawa Online Support Group -
Sept 13 @ 7 p.m.

Provincial Online Support
Group - Sept 14 @ 7 p.m.

Durham Online Support Group
- Sept 27 @ 7 p.m.

WALK FOR LUPUS ONTARIO 2021 RECAP

WE DID IT! We were able to exceed our goal of \$75,000 for this year's Walk for Lupus Ontario. We are currently at \$82,000+ raised!!

18 virtual walk locations across the province, 150 participants and 38 teams! We could not have done it without all of your ongoing support and generosity – we are so thankful for each and everyone of you that took the time to register, donate and post on social media for this year's Walk. We would also like to acknowledge our great sponsors Alps Welding Inc., BMO Financial Markets, Lexus on the Park, Prime Time Messenger, MHI RJ Aviation ULC, Mills Motors Buick GMC Limited, Hop In and Nutcracker Sweet Gift Basket.

Just because we reached our goal does not mean we are finished yet. If you haven't had a chance to walk or enjoy your planned activity, you still have time. We loved seeing and sharing the pictures and videos submitted, please continue to share and tag us on social media.



We are continuing our campaign and accepting donations up until September 30th to fund the Lupus Ontario Geoff Carr Research Fellowship, support and education programs for lupus patients and their families and advocacy projects aimed at improving programs and services for lupus patients.

It truly takes a village and we are so privileged to have such a strong community at Lupus Ontario.

For more information or to make a donation please [visit our website](#).

COGNITIVE IMPAIRMENT WEBINAR (SEPT 21 @ 7 P.M.)

Presented by Dr. Zahi Touma

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. He is Staff Rheumatologist with the University Health Network/Mount Sinai Hospital, and adjunct scientist with the Institute for Work and Health.

His research is focused on patients with systemic lupus erythematosus (SLE) and measurement science with a particular interest in the assessment of disease activity, patient reported outcomes and cognitive function. One of his most significant contributions has been the development of the SLE disease activity indices – the SLEDAI Responder Index-50 (S2K RI-50) and SLEDAI-2K Glucocorticoids Index (SGI).

This event is free and we ask that you [register in advance](#).

VOLUNTEER OF THE MONTH

Our Volunteer of the Month for September is Beth Beaven. In 2007 Beth was diagnosed with lupus after being misdiagnosed for at least 4-years. She kept getting diagnosed with inflamed eczema for several years and did not know what was happening with her. About a year after being diagnosed, Beth found a Lupus Support Group in Ottawa. Beth became a member of Lupus Ontario and would attend the evening meetings each month, where she learned so much about lupus and how to cope with her diagnosis. She has also been a fundraiser for the Annual Walk for Lupus Ontario and for 2021 has help Lupus Ontario surpassed their target of \$75,000.

Beth agreed to take on the challenge and start a new chapter of the Ottawa Support Group as their Facilitator along with her Co-Facilitators Julie St. George and Brynn Clark. After a great social media campaign, the Ottawa

Support Group was re-launch in December 2020. Together they meet each month and go through the topic of the day as well as talk about various topics that impact each of them and the lupus community. Beth is proud of her team and of each person that shows up each month for the meetings. She is still learning and thanks Lupus Ontario for asking her to step out of her comfort zone to help lead this group that is making a difference in the lives of those living with lupus.

Thank you, Beth, for all you do to help the Ottawa community and to raise funds for lupus research.



REMEMBERING STEWART STANTON

On July 22, 2021 the lupus community lost a true champion of our cause. Stewart Stainton (fondly known as Stew) passed away peacefully at the age of 94. Stewart became involved with the Ontario Lupus Association (now known as Lupus Ontario) in 1978 when his wife Marion was being treated for lupus at the Wellesley Hospital in Toronto with Honey Agar and Linda Ethier, the founders of our organization. He served as the third President of the Ontario Lupus Association (OLA) between 1988 to 1993. Honey Agar states: "It was Stew who had the passion and drive to fulfill our aspirations to create an organization to represent lupus patients. Some of the special insights he brought to the organization were assisting the family members of lupus patients and working with teens with lupus."

Andrea Ou-Hingwan writes, "Stew was the perfect connection for my idea of a Support Group for teens with lupus. He was a genuine teacher to the core and was keen to support, empower and encourage young people to achieve their goals inside and



outside of the classroom. He was ready to help mentor and lead this special group of teens with lupus even more. From that point on, I felt a closer link with the broader lupus community thanks to Stew's various connections and broad network. He quickly became extended family. He was undeniably one of my model teachers. I took notes of traits and characteristics that I appreciated in his style to apply to my own future teaching practice: fun, funny and friendly to name a few! Most importantly, he was simple, unique Stew, a loving angel to Marion and the countless others who were fortunate enough to cross his path."

Frances Gotkin (2nd President of the OLA) remembers: "It was a fun and great working relationship that my husband Gerry and myself had with both Marion and Stew. He was instrumental with the input on our first lupus conference in 1983. From there on, he was my go-to person for help with surveys and anything I could not think of when I was President of the OLA. Stew could also relate to men with lupus. The men are often left behind with all the women! Stew always had a twinkle in his eyes, good humour and was smart except for his lack of expertise with a computer. It was a joke between us because I could not get the hang of a computer either and usually, we wrote or spoke on the phone."

During Stew's tenure as President of the OLA, he also became a member of the Board of Directors at Lupus Canada. Honey Agar summarizes her tribute to Stew Stainton: "I will miss my friend Stew not only for his passion for advocacy, but his happy demeanor and his ability to listen to my thoughts and dreams no matter if they were scrambled or not and responded with great ideas and solutions. Stew Stainton left a legacy to build on for our future generation. I will miss you, my friend."

Lupus Ontario would like to send our thoughts and love to Stew's family during this tough time. Stew will forever be remembered as a champion for the organization and a fierce advocate for the cause.

MEETINGS/EVENTS TO COME

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

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

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

Cognitive Impairment Webinar - [Sept 21 @ 7 p.m.](#)

Dance and Medicine – Intersection Between Movement, Art and Chronic Illness – [Aug 18 @ 7 p.m.](#)

Durham Online Support Group – [Sept 27](#), [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.