

# May 2021 LUPUS LINK

*Lupus Ontario's Monthly Newsletter*

21-25 Valleywood Drive, Markham, ON L3R 5L9 |  
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Linda Keill

## President's Message

Happy Lupus Awareness Month!

This year, all North American lupus organizations are making lupus awareness a focal point in their messaging. With everything going on in the world, it is important to still bring lupus into the conversation and make the disease known. In a recent conversation with Dr. Murray Urowitz, head of the Toronto Western Hospital Lupus Clinic and a renowned lupus researcher, he stated that the most important thing that Lupus Ontario and all of us can do is to 'raise consciousness' about lupus. Dr. Urowitz feels that if we, as the lupus community, can succeed in making awareness our priority, the money for research and the required supports for lupus patients will follow. The target audience for increasing awareness includes the general public, the provincial and federal governments, employers, educators and your friends and family. Lupus Ontario is working on many of these fronts to increase awareness of lupus and its impacts.

- We continue to work with the Ontario Government to officially recognize World Lupus Day on May 10th. The Bill has passed second reading and we are hopeful that in the near future it will pass third and final reading in the House.
- Through Social Media we post lupus facts and lupus stories that create awareness with a larger audience.
- We engage with corporations to educate them on lupus and its impacts and to solicit their financial support.
- Events, such as the Walk for Lupus Ontario and the Italian Dinner Dance reach out to many people who are not aware of the impacts of lupus and the need for their support.

Speaking of awareness events, the website for the Annual Walk for Lupus Ontario is now live and can be accessed at [www.walkforlupusontario.org](http://www.walkforlupusontario.org). Once again, this year the event will be virtual in order to keep everyone safe. We are off to a great start and have several communities signed up and already raising money.

We know that during the pandemic asking people for money is not easy but remember that for each and every person we contact about donating or participating in the Walk, we build awareness of the disease. Please encourage everyone you contact to share your email messages or social media posts even if they are unable to donate this year. If you are interested in being the Coordinator for your community, please contact [info@lupusontario.org](mailto:info@lupusontario.org) and we can give you more information, get you signed up and started.

In closing, during the month of May and especially on May 10th (World Lupus Day) and May 21st (Put on Purple Day) I encourage everyone to proudly wear purple and be sure to explain to everyone why you are doing so. Together we can increase awareness and continue to improve the treatments and services that lupus patients and their families deserve.

### SLE AND COVID WEBINAR FOLLOW-UP Q & A (MAY 3 @ 7 P.M.)

**REGISTER  
HERE!!!**

Dr. Tselios will be holding a question-and-answer session as a follow to his presentation on May 3 at 7 p.m. This event is free and we ask that you register in advance. We have fixed the Zoom meeting cap on participants, so hopefully no other issues will arise!

## CLASSES

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

May 8 @ 4 p.m.

May 22 @ 4 p.m.

## APRIL WEBINAR

May 18 @ 7 p.m.

Join Lorene Sauro, RHN, for a  
discussion about gut health and  
how it may not be the food  
you're eating's fault.

## SUPPORT MEETINGS

Young Adult Monthly Social  
- May 4 @ 7 p.m.

Ottawa Online Support Group -  
May 10 @ 7 p.m.

Provincial Lupus Online  
Support Group - May 11 @ 7  
p.m.

Durham Online Support Group  
- May 31 @ 7 p.m.

## GUT HEALTH: IT'S NOT THE FOOD'S FAULT WEBINAR

*Presented by Lorene Sauro, RHN*

Lorene Sauro has been a holistic nutrition professional for 20-years and a food professional for 30-years. As co-founder of Canadian Holistic Nutrition Conference and the Canadian Association of Holistic Nutrition Professionals (CAHN-Pro) she has taught hundreds of holistic nutrition students and graduates, helping them with their educational and professional needs. She is a teacher at the Canadian School of Natural Nutrition (CSNN), food developer, acclaimed speaker and published author.

It was her struggles with endometriosis that led her to study holistic nutrition at CSNN. She has spent years reading the research on gut health which has helped her solve her problems and helped many others as it is now understood to be the underlying imbalance with all health conditions.

She founded the Healthy Gut, Healthy Hormones, Mastering Online Workshops and Simply Fermentation programs for practitioners to help provide accurate information and the latest research about food and the wellness industry today to her fellow professionals. She received the Lifetime Achievement award from CSNNAA in 2017.

In this talk, Lorene Sauro, RHN will discuss how gut health issues are connected to the development of many health issues including autoimmune issues. And how foods do not cause gut problems. Gut problems cause food issues. Discover the information that can help restore your ability to choose the foods you enjoy.

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

## VOLUNTEER OF THE MONTH

Sandra Williams- Reid first became involved with Lupus Ontario after she was diagnosed with lupus. Not knowing anything about lupus at the time, she was directed to the Lupus Support Group at Wellesley Hospital. It was there she learned about the disease and got the support she needed. When she moved to Ajax, she and her family got involved with the Durham Walk for Lupus which raises funds for lupus research, support and education. As one of the top fundraisers, she later became a Coordinator for the Durham Walk for Lupus and a Facilitator for the Durham Lupus Support Group. Throughout her time as a volunteer with Lupus Ontario, Sandra has received several awards from the organization including the Making a Difference Award in 2019. Her dedication has motivated her to make a greater impact by joining the Lupus Board of Directors in May 2020 as the Support and Education Chairperson. Since joining the Board there

has been an increase in attendance to the monthly webinars as well as the Support Group meetings. She has helped to relaunch the Ottawa Support Group, the Young Adults Monthly Social and was a speaker for the February webinar: Your Treatment and Support Teams.

Sandra's passion is supporting those newly diagnosed and those living with lupus. Her goal is cemented with the goal of Lupus Ontario which is "Life Without Lupus." Thank you, Sandra, for all you do!





## Sahara Mehdi

Sahara is a 19-year-old journalism student in her second year at Ryerson University in Toronto, Ontario. Sahara has been creating videos and other content under the alias “Miss Brainy” on YouTube since she was 15 years old. She also loves to write fiction and poetry and hopes to publish her own novel someday. Last year, Sahara was diagnosed with rheumatoid arthritis, so she is very interested in helping and learning more about others with chronic illnesses, such as lupus. She is very excited to be working with the amazing team at Lupus Ontario! Welcome, Sahara!

## TRILLIUM DRUG PROGRAM

*Written by Carolyn Pancham*

Prescription medications may be a part of your treatment plan. Whether it is maintenance drugs to treat chronic long-term conditions or a pulse therapy for an acute episode, expenses add up. The **Trillium Drug Program (TDP)** is an income-based coverage that helps with the cost of eligible prescription drugs listed under the **Ontario Drug Benefit (ODB) Formulary**.

You could apply to the program, if you meet the following criteria:

- Live in Ontario
- Have a valid Ontario Health card number
- Are between the ages of 25 and 64
- Do not have an insurance plan that covers 100% of your prescription drugs
- Spend approximately 4% or more of your after-tax household income on medications

The **Trillium Drug Program Application** could be found online, at your local pharmacy or by calling 1-866-811-9893.

A **Guide to Understanding the Trillium Drug Program** provides the full details about the program, enrolment, and renewal. Here are some tips to navigate the TDP:

- The program runs from August 1st to July 31st
- Application deadline is September 30th
- All household members that share a residence, have a family relationship and are financially dependent on each other, need to be included on the application
- Proof of household income is required annually to determine how much of your prescription costs will be counted towards the deductible
- Once approved, it is recommended that you inform your doctor that you have ODB coverage and confirm that the drugs prescribed are covered under the program
- If your drugs are not covered under ODB, check if coverage is available under the **Exceptional Access Program** or **Special Drugs Program**
- If you have other insurance, submit to the primary insurance (e.g. through work/school), then secondary insurance (e.g. private insurance/spousal insurance), and lastly to the TDP (deductible requirements need to be met before coverage is provided)
- A co-payment of \$2 may apply to each ODB prescription after the quarterly deductible has been satisfied
- Any unpaid deductible in a quarter will be added to the next quarter's deductible
- Renewal letters will be mailed before the start of the next program year
- Remember to contact TDP for questions or to report changes that may impact your benefits

Example: Priya is single and earns \$35,000 per year. Unfortunately, she does not have drug coverage for six medications, which cost \$600 for a three-month supply. After applying for the TDP, she was approved and her quarterly deductible was \$350. All of her drugs were eligible for coverage. When she went to the pharmacy for a refill and presented her Ontario Health card, the breakdown of the costs was:

Total	\$ 600
Deductible payable by patient	\$ 350
Co-payment payable by patient	<u>6</u>
Total payable by patient	\$ 356
Covered by Trillium Drug Plan	\$ 244

If you still have questions about the program, they could be reached at 1-800-575-5386.

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



## WALK FOR LUPUS ONTARIO 2021

Please join us for the Annual Walk for Lupus Ontario 2021. We have chosen August 21st as the 'official' date for the Walk this year but because it is a virtual event you can participate at whatever time and place you prefer. Although this event is historically known as the 'Walk' for Lupus Ontario, you can choose to do any activity you would like in support of lupus awareness and research. For example, you could complete a craft, do yoga, create a video of something new you have learned to do, etc. We want to ensure that everyone can participate to the best of their abilities. Registration is free and you can sign up at [www.walkforlupusontario.org](http://www.walkforlupusontario.org).

Last year we raised almost \$60,000 and with everyone's support, we hope to reach this year's goal of \$75,000.

Please register, encourage your friends and family to join you and have some fun with the event.



### Thank You!

When you support  
handmade you are not  
only supporting a person,  
family, or small business,  
you are purchasing a small  
part of a persons heart!

Ashley & Melissa



## "TWO CHARMED" BRACELETS WITH PROCEEDS TO SICKKIDS

*Written by Diana Bozzo*

Welcome to *Two Charmed*. This small, local business is run by twin 11-year old CEO's, Child Executive Officers, and me, their mom Diana. *Two Charmed* began for a reason: my girls are trying to find a way to help others and trying to make a difference in their community. With their love of creating, came making beaded bracelets and so much more!

They are also selling with a purpose: they will be donating part of proceeds from the sale of the bracelets to local charities and hospitals bi-monthly. Another reason for doing this, it helps them work through anxieties they are facing for various reasons as what is going on in the world around them while dealing with their own battles. It helps them to be creative and focus while knowing that they are making beautiful bracelets that will make a difference for someone in the community.

The girls decided that their first charity they will be supporting is The Pediatric Lupus Clinic in SickKids. The girls both frequent this clinic regularly and a disease that has deeply and personally affected our family as I too, suffer with lupus. Our hope is that a cure for this debilitating and life-threatening disease will be found in my girls' lifetime. May is also Lupus Awareness Month, so what better way then to launch *Two Charmed* while raising awareness about pediatric lupus and the Lupus Clinic in SickKids.

Please visit us [@two\\_charmed](https://www.instagram.com/two_charmed) on Instagram, their page at [Two Charmed](https://www.facebook.com/TwoCharmed) on Facebook or by email at [twocharmed09@gmail.com](mailto:twocharmed09@gmail.com). We hope you enjoy our creations as much as my girls enjoy making them!

### 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

Keep up with Lupus Ontario on social media!