

HOPE

life without lupus



LET'S TALK LUPUS

August 2023 E-Newsletter



For more information visit www.lupuscanada.org

With the blue sky and beautiful sunsets in August, we hope you are able to take time to relax and enjoy the summer season and make lasting memories with your family and friends.

Special thanks to our loyal supporters who through your generous donations help us to continue to make an impact by investing in research, advocating for lupus patients and their families, creating the much-needed awareness for this disease, and supporting students living with lupus to achieve their academic goal.

To learn how your donation benefits those living with lupus please click on the link below.



LEARN HOW YOUR DONATION HELPS

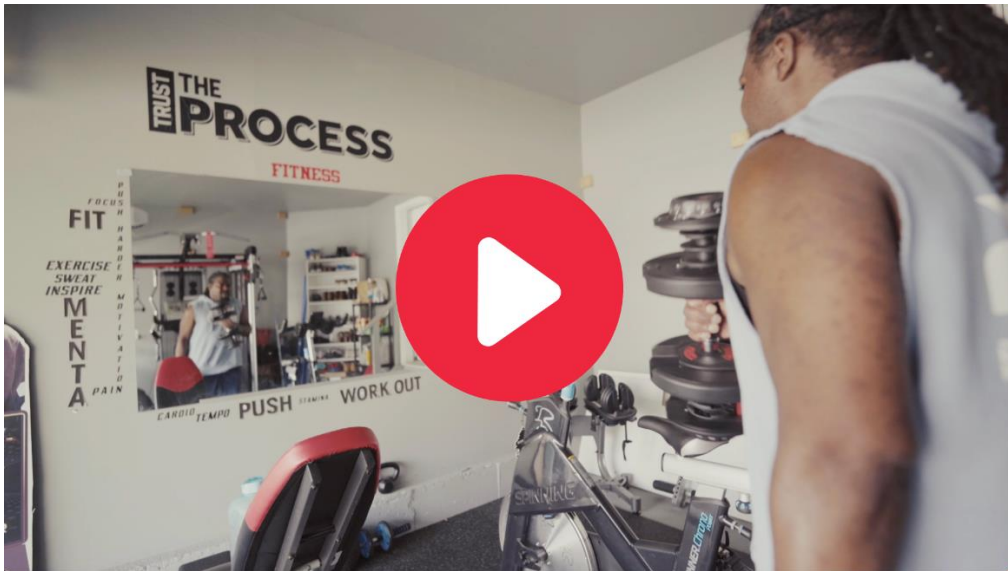


LUPUS CANADA NEWS

Lupus Canada Advocating for Change



We had the opportunity to meet with Mr. Tony Van Bynen, MP for Newmarket-Aurora, Ontario to discuss our initiatives and how together we can make a difference in the lives of those living with lupus. MP Tony Van Bynen understands the need to invest in healthcare and has shown his support for those living with lupus by helping us to create awareness during Lupus Awareness Month. Special thanks to MP Tony Van Bynen for his support.



My Lupus Journey with DJ Prosper: The Strength To Endure

Lupus Canada is honoured to welcome Prosper Laguerre as one of our Ambassadors and to share his journey with our community. Diagnosed in 2013, Prosper has been battling lupus for many years and like many speaking out has not been easy. By sharing his story and helping others it encourages him to keep fighting.

To watch the video visit youtu.be/H1LxqDUzY8o.

Let's Talk Lupus Webinar

Lupus Canada would like to thank Jennifer Tabrizi for joining us on Thursday, July 20th for our Fatigue Management Webinar. The topics discussed included: the importance of sleep and stress management as well as the role they play in managing symptoms, the major signs and symptoms to watch out for that indicate fatigue and exhaustion, and practical habits and lifestyle changes to implement in order to reduce stress, fatigue, and exhaustion.

To watch the recording of the webinar please visit <https://www.lupuscanada.org/webinars/>

LET'S TALK LUPUS
Disease Awareness Webinars

Fatigue Management & Autoimmune Disease

with Jennifer Tabrizi
Thursday, July 20th 2023


Sponsored By AstraZeneca GSK

Lupus Canada's 2023 Virtual Silent Auction

Get ready for exclusive experiences and unique gifts!

Support Lupus Canada by participating in our annual 2023 Virtual Silent Auction.


Looking to support by donating an auction item? Would you like to learn more about sponsorship opportunities? Please email heather.coates@lupuscanada.org.



**MARK YOUR
CALENDARS**

**Lupus Canada's 2023
Virtual Silent Auction
goes live November 13th**

*Looking to support by donating an auction item?
Would you like to learn more about sponsorship opportunities?
Please email heather.coates@lupuscanada.org*

LUPUS
CANADA
Life Without Lupus 

The power to improve lives is in your hands

Give12 - Lupus Canada's Monthly Donor Program

A special and heartfelt thank you to our current monthly donors. Your ongoing support has been instrumental in helping us to continue working on our initiatives. Lupus Canada is making great progress and we thank you for being a part of our monthly donor program. Your monthly contribution through Lupus Canada's Monthly Donor Program (**Give12**) directly supports vital research, advocacy, public awareness and educational initiatives.



Together, we ARE making a difference.

To join **Give12**, our monthly donor program please click [here](#).



University of Manitoba Youth Chronic Pain Study

Research Participants Needed

WE WANT TO UNDERSTAND YOUR CHRONIC PAIN

Research participants needed!!

- Age 12-34 years
- Living with chronic pain since adolescence
- Residing in Canada

What will you do?

- Share your experience as a young person living with chronic pain
- Create art (e.g., videos, music, painting, etc.)
- Meet other young people with chronic pain
- Help teach others (e.g., doctors, teachers, family) about what young people need

"One thing I've gotten told a lot is that it's all in our head and that it's all just mental which it's more like the other way around. The physical affects the mental."
Quote from a participant living with chronic pain

Interested?
Contact: ingauge@umanitoba.ca
204-481-4994
Principal Investigator: Dr. Roberta Woodgate

Logos for University of Manitoba and IN-GAUGE are also present.

The University of Manitoba's research team is looking for young people (age 12-34) living with chronic pain to get involved in a study called 'Advancing patient-centered care for young people living with chronic pain'.

Study Goals:

- (1) Understand the experiences, needs, and preferred outcomes of young people with chronic pain
- (2) Co-design arts-based knowledge translation products to advance key stakeholders understandings

Should you be interested in participating please email ingauge@umanitoba.ca or call 204-481-4994.

Lupus Mental Health Study Patient Survey Opportunity

There is an opportunity to participate in an online survey about the barriers to accessing mental health services in adults with Systemic Lupus Erythematosus (SLE). The purpose of this study is to better understand the challenges that people with SLE face when seeking mental health support. If you choose to participate, you will be asked to complete an online questionnaire that will take approximately 15 minutes to complete. The questions will ask about your experiences with mental health services and any challenges you may have faced when accessing them. Your responses will be confidential and anonymous, and only the research team will have access to them.



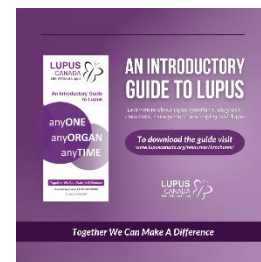
For more information on this survey please visit www.lupuscanada.org/research/whats-happening-in-research/.



Lupus Canada Resources: An Introductory Guide to Lupus

We are pleased to share An Introductory Guide to Lupus to help you learn more about lupus symptoms, diagnosis, treatment, management, and coping with lupus.

Lupus is a lifelong, incurable disease that comes with many challenges. People living with lupus often need to adapt to complicated medical regimens to control symptoms and prevent disease flares. It is crucial for those living with lupus to be educated to help manage their symptoms, to communicate their struggles, and to spread awareness.



To download the Introductory Guide to Lupus please visit www.lupuscanada.org/resources/brochures/.

Canada Dental Benefit Applications Are Now Open

Through the Government of Canada, the Canada Dental Benefit helps lower dental costs for eligible families earning less than \$90,000 per year. Parents and guardians paying for dental care for a child under 12 years old who does not have access to private dental insurance may be eligible for the program. Based on your adjusted family net income, a tax-free payment of \$260, \$390, or \$650 is available for each eligible child.

Applications are open until June 30, 2024 for:

- dental care received between July 1, 2023, and June 30, 2024
- one additional payment if you meet the criteria

For further information or to apply, click [here](#).



ARTICLES

100 Summer Fun Ideas for Kids & Parents



Whether you work from home, are a stay-at-home parent, or work outside the house, you need practical ideas to keep your kids busy, particularly during the summer months. Otherwise, they may end up getting too much screen time, which is not good for their health (mental or physical)

Summer Activities for Kids

Check out this list of 100 things you and your kids can do to fight off summertime boredom. Don't let your kids have all the fun—many of these activities are fun for the whole family to share. So join in!

Whether you turn this list into your summer bucket list, or you just pick a few of your favorites, you will make some great memories. The key is to slow down and enjoy the summer months with your family. If you need a more structured list, check out this series of things for kids to do every week of summer.

Nature Activities for Kids

Take advantage of long sunny days by exploring the natural world (just don't forget the sunscreen).

Go bird watching. Take photos and keep track of your sightings. Use an app or guidebook to identify feathered friends.

Grow fresh herbs in containers. Use old coffee cans, milk jugs, mason jars, plastic cups, or anything else you have around the house. Keep your herb garden on a patio or windowsill.

Look for shapes in the clouds. Put a blanket in the grass and stare up at the sky. Take turns talking about what you see in the clouds.

Make a bird feeder. Watch birds visit your yard and add to your list of bird sightings

Make fairy houses. Use moss, bark, and leaves to create a dwelling fit for Thumbelina.

Pick your own plants. Find a farm with blueberries, strawberries, raspberries, veggies, or flowers and get picking.

Plant a butterfly or hummingbird garden. Create a backyard wildlife habitat.

To read more please visit <https://www.verywellfamily.com/summer-fun-ideas-kids-and-parents-3542627>



MY LUPUS JOURNEY

with Victoria T.

My name is Victoria. I am a 21 year old learning to live with lupus and this is my story.

I started university in 2020 excited. I was on top of the world. I had great grades, was recruited to play varsity basketball and I felt healthy and strong.

By the end of first year I started experiencing symptoms. My knees, wrists, fingers and elbows would swell and be very sore. I was tired a lot too. At first I thought maybe it was related to being an athlete, maybe the stress of school and of the pandemic.



But some mornings it became difficult to do even simple things like walking up the stairs, opening up a water bottle, or doing up buttons. Sometimes in the mornings my eyes would be swollen or I would have hives. I knew something more was wrong.

Luckily I was referred to a rheumatologist fairly quickly where I was at first diagnosed with Rheumatoid. A few months later I developed the butterfly rash and my diagnosis changed to "lupus".

This is when my journey with medications began. I won't lie. It has been a struggle as a young person to manage all the pills and to fully understand the science behind it all. It a lot of pills. There have been many changes to my medications and dosages depending on what is happening to my body. This is still a work in progress for me.

As with any medications there can be side effects. Some of them are harder to deal with than others. Hair loss, fluctuations in weight, brain fog, changes in mood, hand tremors and nausea are all the not so great things that I battle. But the flare ups are painful and if not managed can wipe you out for days! I also would like to keep my organs and be able to function as a normal student as much as possible.

At first I tried to carry on as usual, and just push through the pain hoping the medications would just work alone. Living a fast paced life of a student can be stressful. Managing a full load of classes, studying for exams, wanting to socialize, living on my own for the first time is huge. I also had daily practices and was on the road with ball. But now.. on top of this, I had to remember pills, doctors appointments, bloodwork, getting prescriptions filled and dealing with feeling sick.

It was quite the juggling act and pretty stressful! It came to head just before Christmas this year, and my body just could not handle me doing all of that. I was a mess emotionally and physically. I ended up in hospital very sick and missed one of my exams. I lost a ton of weight. I had been flared for weeks and I had no energy. I was severely dehydrated, my insides were swollen so badly they put me on prednisone. I felt like a pin cushion and a bit of a science experiment undergoing so many tests from head to toe. I ended up needing a kidney biopsy. Now I was more specifically diagnosed with Lupus Nephritis. That was a pretty scary and eye opening experience for me.

I think the hardest has been learning to accept and embrace that I have this chronic illness and it doesn't just go away. I am forced to rethink my lifestyle which isn't easy. Many days I feel good, so I want to just jump right back into things and forget about the medications and lupus. But then when a flare comes I am reminded quickly.

It's been challenging on my mental health too. It's hard for others, especially peers to empathize and understand. It's not a common talked about disease, so I have to regularly remind myself that when they say things, it's because they just don't know. Many don't realize how intense the prescribed medications can be, and no, a Tylenol can't just fix it! It also doesn't help that the symptoms can come and go or they manifest in different parts of your body. It can be unpredictable and because a lot of what is happening is internal, it is invisible. I put in hair extensions, use makeup to cover the rash and just push through the pain. So as a result, many people are questioning, make assumptions, doubt me or cast judgement. It's a challenge some days to stay positive, often feeling insecure, lonely and trying to just focus on my long term goals.

I knew I needed to change some things, slow down and cut out some of the stressors that were a huge contributor to my flares. Although I still keep active, it was a tough decision to take a pause playing varsity ball. I have also learned the value in surrounding myself with supportive people and in choosing the right friends. When you are not well, you need friends who are patient, kind and understanding. It can be tough on some of your closest people. Sometimes you just need to lean on them a bit more, which may come across as one sided.

I feel lucky to have a specialized clinical team all in my corner monitoring my condition. My family has also been involved, helping me process and learning along side of me too. They are helping to spread awareness. My mom, dad and her friend made bracelets and donated the funds to Lupus Canada for research and it is heartwarming to see people wearing them around in support.

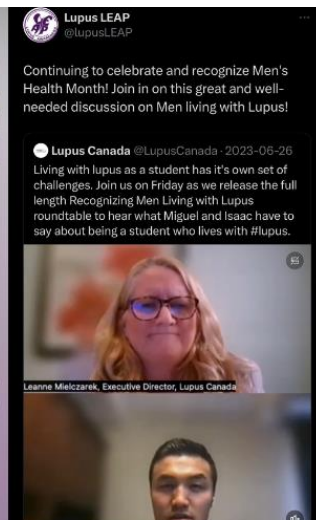
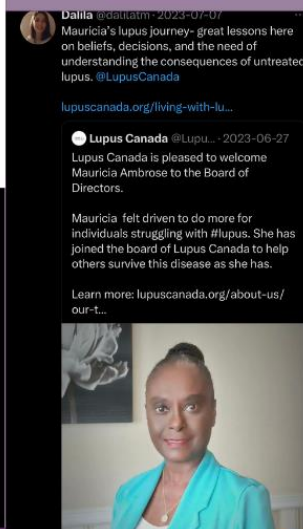
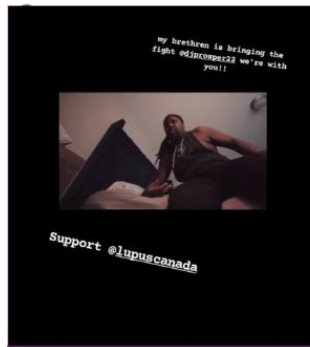
I am studying to become a teacher and am determined to finish strong! I know I am a warrior and can get through this. Things in life happen, and they are meant to teach us valuable lessons. I am certainly learning them along the way, but it has also given me a chance to share those lessons with others. I worked as an emergency supply and some of the students noticed my rash and asked. It was a natural and great opportunity to spread awareness teaching kids to show empathy, acceptance and kindness. Another student who had an autoimmune disease told me she was inspired and felt normalized. She was able to see herself reflected in me. Even the staff, became more aware and all bought and wore bracelets in support. Having a chronic illness like lupus is not fun, but it's all about perspective. I have this tattooed on my arm along with the butterflies, which are the symbol for lupus. It reminds me that, when things get tough, you can push on, focus on what you can control and don't let it define you because you are strong!



COMMUNITY ENGAGEMENT

Social Media Highlights

Thank you to our supporters who continue to spread lupus awareness. Here is a little recap of our favourite community posts in July. Keep tagging us in your posts for a chance to be featured in our Social Media Highlights.





RECIPES

Approved by registered dietitian Heather Penny



A Delicious And Healthy Meal

On The Menu: Smoked Trout and Summer Bean Salad

INGREDIENTS

- 12 oz. (2-3/4 cups) green beans (or an assortment of string beans), string removed if tough, cut into 1/2-inch pieces
- 1/2 cup sunflower seed or grapeseed oil, preferably unfiltered
- 4 cups cooked cranberry or cannellini beans (fresh, dried, or canned)
- 2 small or 1 large cucumber, peeled if skin is tough, cut into 1/2-inch dice (about 3 cups)
- 1 cup oil-cured black olives, pitted and halved
- 1/2 cup finely chopped red onion
- 1/2 cup toasted sunflower seeds
- 1/4 cup chopped fresh dill, 1 tsp. reserved for garnish
- 3 Tbs. fresh lemon juice
- 3 Tbs. red wine vinegar
- 2 Tbs. fresh marjoram leaves, coarsely chopped, 1 tsp. reserved for garnish
- 1 Tbs. finely grated lemon zest
- 2 medium cloves garlic, finely chopped
- Kosher or sea salt and freshly ground black pepper
- 1 cup plain Greek yogurt
- 8 to 10 oz. skinless smoked trout fillet

INSTRUCTIONS

- 1** In a 12-inch skillet, cook the green beans in the oil over medium heat until they begin to sizzle, 1 minute. Add 1 Tbs. water, cover, and steam until crisp-tender, about 4 minutes. Transfer to a large bowl and let cool to room temperature, about 15 minutes.
- 2** Add the cranberry beans, cucumber, olives, onion, sunflower seeds, parsley, dill, lemon juice, vinegar, marjoram, lemon zest, and garlic. Season to taste with salt and pepper and mix gently.
- 3** Arrange the salad on a large serving platter and top with dollops of yogurt. Crumble the trout into chunks and scatter over the top. Garnish with the reserved herbs and more black pepper and serve.

Source: <https://www.foodandwine.com/>



QUICK LINKS



Merchandise

Help support Lupus Canada by shopping our merchandise catalogue [here](#).



Q&A's

All your lupus related questions answered by trusted professionals [here](#).



Let's Talk Lupus Disease Awareness Webinars

Sponsored By
AstraZeneca GSK

Webinars

An informative and interactive series of webinars for all Canadians impacted by lupus. To watch the recordings visit [here](#).

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