

President's Message

By Cathy Ferren



We had a wonderful event full of awareness and raising research dollars at the annual Italian Dinner, February 29th.

Please register for the Lupus Education Day and Annual General Meeting on Saturday May 9 in Markham. This education event gives you access to specialists whom we normally do not get to hear tell us about current issues in lupus.

We need a minimum of 30 volunteers for the HOPE Volleyball event in June. We also need items for the auction. If you can help with anything mentioned in the article below, please contact the office.

For ONLINE Support Group links for both the adult and youth online support groups, see the article under support.

We are currently looking for a support group facilitator for Mississauga for an in person support group. If you are interested in this you can contact me at cathyferren@lupusontario.org.

Thank you to all our volunteers.

AGM 2020 & Lupus Education Day Medical Symposium

Saturday May 9, 2020 9 a.m. to 4:30 p.m.

Courtyard by Marriott Toronto Northeast Markham

Lupus Education Day Medical Symposium

8:30-9:00	Registration
9:00-9:15	Welcome - Sandra Williams-Reid
9:15-10:00	AGM Annual General Meeting
10:00-10:15	BREAK
10:15-11:45	Medical Marijuana - Dr. Carolina Landolt
11:45-12:00	Geoff Carr Research Update
12:00-1:30	LUNCH
1:30-2:30	Dr. Murray Urowitz MD, FACP, FRCPC
2:30-2:40	BREAK
2:40-3:50	Lupus and the Eye - Dr. Easterbrook
3:50-4:30	Youth Component TBA
4:30	Wrap Up

Early Bird Price \$25 until March 31st. Register online at lupusontario.org



Volunteers and Donations Needed for the Toronto HOPE Volleyball Tournament

Lupus Ontario is honoured to have been chosen as one of the charity partners for the Annual Toronto Hope Volleyball Tournament being held June 20th, 2020 at The Docks - Polson Pier.

Lupus Ontario, 21-25 Valleywood Drive, Markham, ON L3R 5L9 | 905-415-1099 or 1-877-240-1099

This is a great opportunity to create lupus awareness and to raise funds for lupus research, support and education. For us to be a successful partner, we need your help! Lupus Ontario has been asked to contribute at least the following:

- 10 volunteers for set-up on Friday June 19th
- 10 volunteers to help run the event from 7:30 am to 3 PM on June 20th
- 10 volunteers for tear down and clean-up from 3 PM to 8 PM on June 20th
- 25 Silent Auction items with a value of at least \$50. We would appreciate you canvassing businesses in your area for donations.

In addition, if you have any contacts who can provide swag such as lip balm, sun screen, etc. it would be much appreciated. **The more support we can give to the event, the more money we will receive.** This is a great opportunity to meet new people, contribute to a great cause and be part of a fun event. Please come out and help us. For more info about the event, go to <https://www.hopevolleyball.com/>

If you are able to volunteer or contribute auction items, please contact the Lupus Ontario office at 1-877-240-1099. Together we can make this event a big success!

Volunteers for the Lupus Office

Can you give a half day or full day once a week or every other week to help in the Markham office? You would be answering the phone and doing administrative tasks. We also need people to help count Walk for Lupus t-shirts. We use MS Word, MS Excel and our email is in Outlook. If you can help out, please contact Karen at the office at 905-415-1099.

My Story

Written by Tanya Mahadeo

You know that feeling when you have the flu? Everything hurts and aches, you feel nauseous, your head pounds and you feel completely unwell. If you're familiar with this feeling, then you know what it's like to have lupus—on a good day, that is.

I've had lupus for 20 years, or to be more accurate, I was diagnosed with lupus 20 years ago, in 2000. Part of me believes that I've had it my entire life. What is lupus? It's an autoimmune disease, a type of self-allergy, where the person's immune system creates antibodies that instead of protecting the body from bacteria and viruses attack the person's tissues. This causes extreme fatigue, joint pain, muscle aches, anemia and general malaise, and it can result in the destruction of vital organs.

Lupus is a disease with many manifestations, and each sufferer's list of symptoms is different. For that reason, it's often referred to as "The Disease of 1,000 Faces."* Although few people have heard of lupus, worldwide it's more common than leukemia, multiple sclerosis and muscular dystrophy combined.*

Part of the reason I'm writing about my journey with lupus is to share how this chronic debilitating disease has negatively impacted my life, but also to share how having this illness has inspired me and given me the strength to fight for myself and create awareness about how underfunded lupus is, and to reveal how many people suffer from it.

Lupus is so underfunded in Canada that no firm numbers are available. In the United States, 1.5 million Americans suffer from lupus. Of that number, 90% are women, and two out of three of those women are minorities. There are reportedly 16,000 new cases of lupus diagnosed every year. Lupus is difficult to diagnose because it mimics many other diseases, so it's impossible to say with certainty how many people have it but haven't been clinically diagnosed.

My story begins before my diagnosis. I was a sickly child; I always had a cold or an infection. I was diagnosed with lupus at 19 after experiencing severe joint pain, fatigue, fevers, night sweats and hair loss. I found out that I had lupus and arthritis. Arthritis at 19? Yup—the two go hand in hand. Once you have one autoimmune disease, you're susceptible to developing others.

I was put on a drug called Plaquenil, an anti-malarial medication that wasn't developed to treat lupus but does mask its symptoms. Shortly after my diagnosis I became more ill, which is known as a "flare" of the disease, when the lupus becomes "active."



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I was in incredible pain and often unable to dress myself, walk or get out of bed. I constantly had fevers. I had lost most of my hair and about 30 pounds in three weeks, making me dangerously thin. My personal life began to suffer. People I thought were my friends began to disappear, and I became insecure about sharing my diagnosis with anyone. If I was around anyone who had the slightest sniffle, I would immediately become sick because of my compromised immune system. So, I began to isolate myself.

As time went on, I began to learn how to live with my lupus. It wasn't easy. Now, years later, I realize that I was in a circle of grief, going through the stages over and over but not being able to master acceptance. How can you with a chronic, always changing illness?

A few years later, I had another flare. This time I was hospitalized. I had protein in my blood, and it appeared that my muscles were breaking down. The doctors couldn't explain why. I was put on a drug called Imuran, which weakens your immune system but may lessen the aggressiveness of the lupus. I took this drug for 10 years. Recently, I stopped taking it when I finally took my health into my own hands and looked up its side effects. I couldn't believe what I read: I was being treated for lupus with a drug that increases the risk of lymphoma and brain infection! This hit home the reason we need a cure for lupus—or until that day comes, a drug formulated specifically to treat this disease.

At the time, I thought Imuran was the answer and that I could live a healthier life with it. I was wrong. Even on Imuran, I continued to flare and get sick, be admitted to hospital and develop new health complications.

In 2013, I had a massive and frightening flare. At that time, my lungs and heart had been compromised by the lupus. I developed pleurisy (inflammation of the pleurae, which impairs the lungs' lubricating function and causes pain when breathing) and pericarditis (inflammation of the lining around the heart, which causes chest pain and fluid build-up around the heart). These were treated with intermittent doses of prednisone, a powerful steroid. I was told that I would continue to develop pericarditis and pleurisy periodically throughout my life, until my heart became too weak to continue beating.

I became so sick in 2013 with pericarditis and pleurisy that I was put on 120 mg of prednisone orally. When I didn't respond after three days, I was prescribed 60 mg orally and 60 mg of solumedrol (prednisone by IV). I could no longer work, because my immune system had completely shut down. I was confined to my apartment, where a nurse came to give me my IV so I wouldn't catch an infection at the hospital.

This was one of the lowest points in my life. The prednisone turned me into an insomniac, and I gained 60 pounds in a short period of time. One of the most hurtful things I recall was running into someone I knew on the train, who said, "Wow, you used to be so beautiful, and now look at you—you're so big." It was one of many painful comments I endured during this at you—you're so big." It was one of many painful comments I endured during this period. It wasn't enough that I had a disease that no one had heard of, or that I had been sick my entire adult life, but now I knew what people thought—or what I believed people thought, based on one ignorant and insensitive person's comment.

That difficult moment taught me one of the greatest lessons of my life: to have compassion and empathy for others. You can never know what's really going on in someone's life, so don't judge them and try to be kind.

To this day, even though I'm stronger, smarter and calmer, remembering the pain of that moment can reduce me to tears. Since then, I've had a hard time looking at myself in the mirror with kindness, but I'm working on it.

In 2014, I took matters into my own hands. At that point, lupus hadn't killed me—even though I sometimes wished it had—so I had to find a way to live with and manage it better. I became obsessed with reading research reports, analyzing drug interactions and symptoms and learning more about alternative remedies. I stopped taking all of my medications except prednisone, because withdrawal from it is brutal and not something I'd recommend. My reasoning was that if I still had flares while taking the medications, why put up with their side effects?

To say that lupus frustrates me is an understatement. In addition to living with chronic pain, I constantly feel like I'm failing in some area of my life and letting people down. My symptoms sometimes cause me to miss work and cancel plans with family and friends. So I've decided to turn my frustration into anger, and this anger won't allow me to keep quiet. Now I talk about lupus all the time, to help educate people and bring awareness to this debilitating disease that flies under the radar.

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I have lost so many things to lupus: my hair; my memory; half the capacity of my left lung; the full function of my heart; my left ovary and fallopian tube; a piece of my bowel; my adrenal function due to prolonged steroid use; bits of skin to biopsies. I have collapsed veins from multiple IVs. I have early onset osteoporosis, also due to prolonged steroid use. My self-esteem has suffered, and I've lost a great deal of compassion for myself.

I shouldn't have to lose anything else, should I? There's one thing I haven't mentioned yet: my age. I'm only 34.

I have had some luck though – I have a family that is loving and supportive no matter what, friends who are always there for me and willing to change their schedules to accommodate my illness and a wonderful partner who loves me unconditionally and fights for me, sometimes harder than I do. I am grateful.

Please share my story to help raise awareness about what it's like to live with lupus, and how it affects me, my family, my friends, my coworkers and all other "Lupies" (that's what we call ourselves) out there.

*Source: Lupus Ontario

Peer Support Groups

Lupus Ontario offers in person and online peer support groups.

Check the support page on the web site for schedules and locations. Peer support groups are a safe place to share your lupus journey and learn from others in the group what has worked for them. They are not therapy sessions. Check the Support page on the web site for locations and schedules. During COVID 19 we have online meetings only using Zoom. Imagine never having to leave the comfort of your safe place, no need to travel and not having to worry about the ever changing weather; join us for our live online audio/visual lupus peer support group.



You need to **REGISTER IN ADVANCE**. After registering, you will receive a confirmation email containing the link and information about joining the meeting. Provincial Meetings are 7 to 8 pm EST. The time varies for other online support meetings see <https://www.lupusontario.org/support/>

Adult

March 10 click <https://zoom.us/meeting/register/u5UpdOCrrTgq4hnuNMEvDRSpCmq3PEjtgQ>

April 14 click <https://zoom.us/meeting/register/vJAKd-qpgDguFL7NRKWC4oc8HEI-F0tXSA>

May 10 click <https://zoom.us/meeting/register/tZUkcOiqrlszJ7xHTqf-RSgrjrFgsjDRA>

Youth

April 19 click <https://zoom.us/meeting/register/tJUude-qpiwjHLdjkLICTCqzhACU0JYdA>

Lupus Education Days and Online Workshops

The Lupus Ontario Support and Education Committee organizes information and education events about lupus, treatment, coping and support.

Lupus Education Days or **LEDs** include a variety of speakers and presentations on lupus related topics. Whenever possible, an education day includes a rheumatologist, pharmacist, and other treatment professionals.

Online workshops are generally one (1) hour long online meetings with Q&A time at the end. Watch for a special workshop emails and social media posts. Details at www.lupusontario.org/education/ Let us know if there is a particular topic you are interested in. We will do our best to find a suitable presenter on the topic.

WebMd Slideshow: A Visual Guide to Understanding Lupus

<https://www.webmd.com/lupus/ss/slideshow-lupus-overview>

You can read more of Rosanna Lee's articles at healthydirections.ca

Mission Statement

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!

www.lupusontario.org

#MotivationalMonday #WarriorWednesdayLO #TastyThursday