

LET'S TALK LUPUS

January 2023 E-Newsletter

2023 – A year of good health, happiness & hope for a bright future

A Message From The Executive Director

As we look back on 2022 Lupus Canada is so thankful for those who have committed to keep pushing the dial forward to help find new treatments for lupus and to those whose continued advocacy keeps the conversation going until one day we find a cure.

2023 presents the opportunity to reflect and celebrate accomplishments. Lupus Canada would like to thank our community for their support over the past 12 months through initiatives like Giving Tuesday, Lupus Awareness Month, Purple Pumpkin for Lupus, and our Silent Auction. Events like these help to not only raise funds to support our various initiatives in support of those living with lupus in Canada but also create awareness for this debilitating disease. We are dedicated to continuing to make a difference in the lives of those impacted by lupus and with your help we are confident we will make an impact.

In 2022, with your help Lupus Canada was able to accomplish the following:

- Funded a Catalyst Grant titled Megakaryocyte: a new player in systemic lupus erythematosus.
- Continued to provide infrastructure funding to support the CaNIOS national registry. This registry allows for systematic description of the real-world patient journey in terms of clinical features, disease activity and progression, treatment patterns, clinical outcomes, patient reported health outcomes, and healthcare resource utilization in people with lupus from across Canada. Which allows researchers to



collaborate across Canada and across the world sharing and comparing anonymized data.

- Collaborated with researchers to help develop lay language documents reporting the results of international surveys related to the sources of and trust in health information with a particular emphasis on the Canadian data.
- Advocated for people living with lupus and their families to support more government funded lupus medications.
- Provided 6 Post-Secondary scholarships to students living with lupus.
- Offered monthly informative and interactive series of webinars for all Canadians impacted by lupus.
- Through public awareness initiatives we were able to raise lupus awareness and significantly increase our online media presence.
- Worked to help ensure all Canadians living with lupus have equitable access to care.
- Connected with elected officials to help bring a voice to lupus.

We look forward to continuing to bring even more value to our community and subscribers by continuing to build on our initiatives to creating a "Life Without Lupus". On behalf of the Board of Directors and Staff at Lupus Canada, thank you for your continued support. We look forward to 2023 with great hope and immense gratitude. Thank you.



Executive Director, Lupus Canada

On January 1st we rang in the New Year which means some of you have made your annual resolutions. This is a time to examine your life and find opportunities for growth and personal development. It's important to recognize that the pressures of the New Year can also create stress. As we plan ahead remember to take each day as it comes and not to become overwhelmed with our year long goals.

For the next few months, those living with lupus may struggle with mobility, fatigue and the cold weather. If you live with lupus try to have a support system around you to help when needed, or if you know someone living with lupus be sure to check on them to see if they need any additional support. For more information on winter safety please visit <https://www.getprepared.qc.ca/cnt/rsrscs/sfttps/tp201212-en.aspx>.

Thank you to our loyal donors, without your support we wouldn't be able to continue to make an impact within the lupus community.

DONATE NOW
your gift makes a difference

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Lupus Canada's Disease of a Thousand Faces Campaign!

Help us reach our goal of 1,000 pictures of lupus warriors around the world. Lupus is known as the "Disease of a Thousand Faces" due to its wide-ranging symptoms and ability to mimic other diseases. We are grateful to have received over 250 photographs from lupus advocates around the world.

Join Lupus Canada by emailing a photograph of yourself to info@lupuscanada.org or by tagging Lupus Canada on social media.



RESEARCH

Creating A Clearer Picture of Lupus



UM clinician scientist Dr. Lily Lim is using artificial intelligence (AI) to better recognize lupus in patients. Known as “the disease with a thousand faces” symptoms vary from person to person. Lab tests aren’t always conclusive. The autoimmune disorder is infamously difficult to diagnose, leaving patients and medical providers confused. But Dr. Lim is working with AI to make the face of lupus more recognizable.

To continue reading please visit <https://news.umanitoba.ca/creating-a-clearer-picture-of-lupus/>

New Treatments To Better Understand Autoimmune Diseases

Lupus, also known as the disease of a thousand faces, is a complex disease. Due to the wide range symptoms, it can be difficult to manage and can take several years to diagnose. Lupus Canada is pleased to share the work of our 2022 Catalyst Grant recipient, Dr. Boilard, who in collaboration with a team of researchers and a hundred patients, succeeded in developing a test, which is now patented, to facilitate the detection of this disease.

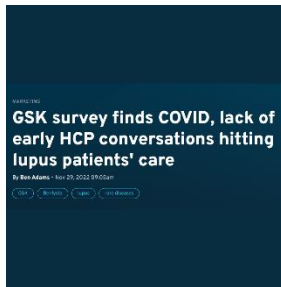
Éric Boilard, professor at the Faculty of Medicine at the Université Laval explains how this teamwork will enable thousands of people to receive better treatments to counter this chronic disease.



To find out more about the work of Éric Boilard please visit <https://www.ulaval.ca/>

LUPUS NEWS

COVID + LUPUS = A real impact in patient care



The impact of the pandemic has been felt worldwide, but the impact to someone living with lupus has been tremendous. A study conducted by GSK indicates that lupus patients have not been receiving 'optimal' care over the past 2 years.

To read more please visit

<https://www.fiercepharma.com/marketing/gsk-survey-finds-covid-lack-early-hcp-conversations-hitting-lupus-patients-treatment>

COVID-19 News

On April 14, Evusheld – the only pre-exposure long-acting monoclonal antibody for COVID-19 prevention – was authorized by Health Canada and recently supported with broad recommendations for use in immune-compromised Canadians by the Canadian Agency for Drugs and Technologies in Health and Institut national d'excellence en santé et en services sociaux. Provinces and territories are currently releasing their own jurisdictional guidance on who is eligible and how to access Evusheld.

The Canadian Public Health Association has developed an [online resource centre](#) with up-to-date information for patients and healthcare providers on preventive long-acting monoclonal antibodies, including:

- Links to the most recent provincial/territorial guidance on who can receive Evusheld and how;
- Resources for immune-compromised Canadians, including information about long-acting monoclonal antibodies;
- Information for health professionals to support decision-making discussions with patients.

For everything you Need To Know About Evusheld in 15 Minutes Or Less – with Dr. Jia <https://19tozero.notion.site/UPDATED-Video-Everything-You-Need-To-Know-About-Evusheld-in-15-Minutes-Or-Less-with-Dr-Jia-Hu-33f3925dd7dc470d806be940a3ce1b95>

To learn more please visit <https://www.cpha.ca/laab>



Did You Know?

If you have Systemic Lupus Erythematosus (SLE or lupus), you are at increased risk for osteoporosis. The good news is that you can learn about your risks, take steps to reduce them, and prevent loss of bone density and fractures.

ARTICLES

Understanding “1,000 Faces Of Lupus” To Improve Care For All Ages

What you need to know

Lupus is a serious inflammatory disease that can involve the joints and many organs. Lupus can act differently in people of different ethnicities, and – as shown in a 2019 study – when it develops in children compared to adults. Understanding these differences could improve lupus care for Canadians of all ages.



What is this research about?

Lupus, or systemic lupus erythematosus (SLE), has been called the “disease of 1,000 faces” because it can strike people in so many ways. The disease can look different in people who developed lupus when they were kids (childhood onset) compared to later in life (adult onset), as well as in people of different ethnicities. The patterns of ethnicities reported by people with childhood- and adult-onset lupus are also different. So, it wasn’t clear whether the differences seen were directly due to the age when the disease developed.

What did the researchers do?

To answer questions like this, a network of lupus researchers has been studying over 1,000 Canadians with lupus at 14 clinics across the country since 2005. This “1,000 Canadian Faces of Lupus” project resulted in a database full of factors that might influence lupus severity and symptoms. In this part of the study, the researchers tried for the first time to unravel whether there were differences in childhood- and adult-onset lupus independent of ethnicity as reported on a patient questionnaire.

What did they find?

The researchers found that lupus looked clinically different when it started in kids compared to adults across many ethnicities. Unexpectedly, the differences seen were not explained by

ethnicity alone. They also weren't fully explained by where the person was treated or how long they had the disease.

How can this research be used?

These findings reinforce that lupus can affect people very differently across our diverse and multi-ethnic country. This gives rheumatologists clues about what to look out for in their lupus patients – young and old – to give them the best care possible. It also raises important questions for researchers to tackle now about what other reasons might help explain the difference between childhood- and adult-onset lupus, like social or economic factors.

What impact could this have?

Understanding fundamental differences between the impact of lupus that started in childhood or adulthood could reveal ways to improve the diagnosis of this complex disease, which can be tricky. It may also eventually shed light on new treatment strategies for each of these two groups. This could change the lives of the 1 in every 1,000 to 2,000 Canadians with lupus, 90% of whom are women or girls.

About the researchers

The 1,000 Canadian Faces of Lupus project was supported by an Arthritis Society Canada research grant awarded to Dr. Christine Peschken in 2005. Dr. Peschken, a rheumatologist and associate professor at the University of Manitoba, led researchers from the Canadian Network for Improving Outcomes in Systemic Lupus Erythematosus (CaNIOS) to produce several discoveries on what lupus looks like and how it acts.

Dr. Janet Pope, a rheumatologist and professor at Western University, was the lead CaNIOS researcher for the team's study on age of lupus onset and ethnicity. Dr. Pope's early introduction to research was supported by an Arthritis Society Canada Research Fellowship, and she has been actively engaged over many years as the leader of the Arthritis Centre at St. Joseph's Health Care London and Western University

Source: <https://arthritis.ca/about-us/what-we-do/research/research-impact-snapshots-en/understanding-lupus-at-all-ages>

Lupus, Emotional Stress, & Depression: What You Need To Know

People with lupus are at higher risk of depression and anxiety because of all the stressors a chronic condition can bring on. Here's how to cope.

The licensed clinical psychologist Monica Blied, PhD, was a 27-year-old graduate student and single mother when she discovered that the debilitating fatigue and body-wide pain she was experiencing had a name: systemic lupus erythematosus. "My lupus diagnosis was a shock. I lost the hope of a healthy me," she says.



At the time she had a 4-year-old. She worried about losing her ability to walk, she says. "I thought that losing my ability to walk would be the ultimate irony; I had been a runway model for Los Angeles Fashion Week and Ebony Fashion Fair!"

She lived in Southern California and loved trips to the beach. "But you're supposed to avoid sun exposure with lupus. So, no more beach trips," she says.

She worried about finishing the doctoral program she was working on. "For someone with a type A personality like me, who equated my success with my level of productivity, it was devastating. I questioned my self-worth," Dr. Blied says.

Blied felt anxious, depressed, and scared.

These feelings are unfortunately common in people with lupus. Rates of depression and anxiety are twice as high in people with lupus compared with those who don't have the condition, according to a review of 59 studies involving 10,828 people with lupus, published in the journal *BMC Psychiatry* in 2017. The data showed that one in four had signs of major depression and 40 percent had anxiety.

Blied, now 36, worked toward discovering a new normal. It took years. "I had to learn what 'health' really looks like. The gift and opportunity lupus gave me is that I'm now more mindful of what my body needs and of the beauty in every day," she says.

Today, Blied is the director of the Faces of Health Wellness Center in Claremont, California, and an adjunct professor of psychology at Pepperdine University. She's on the boards of several lupus organizations and works with people facing mental health challenges due to lupus and other chronic health conditions.

"I've met amazing people living remarkable lives with lupus," Blied says. "I know firsthand that you can reduce the stress and prevent, treat, and reduce the depression that can come with it. You can live a life filled with purpose, value, and joy."

Here's what else experts say people with lupus should know about how the chronic condition, stress, and depression are linked.

Can Stress or Depression Actually Cause Lupus?

It's not likely that depression or stress could independently cause systemic lupus, says Sarah Patterson, MD, a rheumatologist at the University of California in San Francisco. "We know that lupus is caused by a biological problem — the body's loss of tolerance to cells in the adaptive immune system."

What specifically causes the body's immune system cells to malfunction in this way is less clear. But researchers generally agree it's likely a combination of factors, including the genes you're born with that may predispose you to lupus, hormones, and things in the environment that you're exposed to (like viruses, drugs, chemicals, and stress); ultimately all these factors play a role in determining if you develop lupus or not, according to the Lupus Foundation of America.

And for people with the chronic condition, feeling stressed can trigger flare-ups of symptoms, according to the Centers for Disease Control and Prevention (CDC).

There's even some evidence from a small study (only 45 people were included) that people with lupus who underwent 10 cognitive behavioral therapy sessions reported less stress, depression, anxiety, and pain afterward, as well as fewer skin and musculoskeletal lupus symptoms.

Dr. Patterson and others at UCSF are currently looking closely at whether chronic stress, as well as big stressful events, are really exacerbating lupus flares (times of intense pain and fatigue). "We want to find out whether it's really the stress, or if something else that is happening during a difficult time could be responsible — such as trouble getting regular physical activity, having sleep problems, or not being able to take medications or get needed treatments," she says.

The results could help people with lupus better manage their health.

Does Lupus Cause Depression?

People with lupus face a higher depression risk for many reasons, Patterson says. Severe pain, chronic fatigue and ongoing sleep problems can all contribute to this mood disorder, she says. So can ongoing stress.

Lupus pain and fatigue can also lead to social isolation, another depression risk factor.

You may face new challenges at work, discover that you don't have the energy for socializing, or find it difficult to continue a relationship with a romantic partner or start a new one after being diagnosed with lupus, Blied says. You may find that while your friends are building careers, romantic partnerships, and families, you're busy managing a chronic illness instead.

"Physical limitations and a decreased quality of life can play roles in depression," Patterson says.

Lupus is most common in women, and it's often diagnosed when people are in their twenties and thirties — during their reproductive years. "You may face new questions about your reproductive health due to lupus, and feel isolated from friends who don't relate to the experience of living with a chronic condition," Patterson says.

Meanwhile, people whose severe lupus began in childhood may also be dealing with emotional trauma, especially if they were hospitalized with life-threatening lupus or took medications with severe side effects as children.

Blied adds that Black, Latinx, and Native American people with lupus — groups at highest risk for the condition — may face extra anxiety, particularly at work. "If you feel like you have to work twice as hard in order to be respected and acknowledged, then the prospect of asking for time off or accommodations due to lupus is very difficult," she says. "Even just telling people you have a chronic condition that causes pain and fatigue and organ damage is very stressful."

In a study published in 2018 in the journal *Arthritis Care & Research* of 682 women with lupus, financial worry increased the risk of depression by 85 percent over two years, in contrast with the women who had fewer money concerns. Work disability is common among people with lupus, the study authors note. "Worrying about income and paying bills all the time can definitely increase your stress level," says Patricia Katz, PhD, an author of the study and a professor of medicine and health policy at UCSF.

If you've received a lupus diagnosis, there is also the chance that some of the medications you take, especially corticosteroids like prednisone at higher doses, could contribute to depression, according to the Lupus Foundation of America. Lupus can also affect your nervous system and cause symptoms such as memory problems, difficulty concentrating, mood swings, and confusion. These symptoms are sometimes referred to as "lupus fog," according to the Lupus Foundation.

Dr. Katz notes that pain, fatigue, and poor sleep — everyday hallmarks of lupus that can rev up stress and depression — aren't well-controlled by the immune-suppressing medications that battle the underlying cause of the disease. These treatments are crucial for slowing disease progression and organ damage, but people with lupus may have to work with their doctor and look to self-care strategies to ease these daily symptoms, Katz says.

"Worrying about income and paying bills all the time can really increase your stress level," she says.

What Should You Do if You Have Lupus and Think You're Depressed?

Call your doctor right away if you've been experiencing any of these warning signs of depression over the past two weeks.

- Persistent sad, anxious, or "empty" mood
- Feelings of hopelessness or pessimism
- Irritability
- Feelings of guilt, worthlessness, or helplessness
- Loss of interest or pleasure in hobbies and activities
- Decreased energy or fatigue
- Moving or talking more slowly
- Feeling restless or having trouble sitting still
- Difficulty concentrating, remembering, or making decisions
- Difficulty sleeping, early-morning awakening, or oversleeping
- Appetite or weight changes
- Aches or pains, headaches, cramps, or digestive problems without a clear physical cause or that do not ease even with treatment

"Having the courage to reach out and ask for help is critical," Patterson says. "Talk to your doctor and ask for a referral to a mental health provider. Don't be afraid to use all the tools available to you." This could mean taking an antidepressant, working with a psychologist or a psychiatrist, getting support from friends and family, and making lifestyle changes that can help, such as making more time to be physically active and working on getting high-quality sleep.

Patterson notes that if you do have depression, lifestyle changes are still important, but those alone may not have the power to lift your mood. "If you're already taking a lot of

medications you may be reticent about adding one more. But taking an antidepressant to get you through a rough patch can be very helpful," she says. "Depression doesn't typically improve without assertive treatment."

Source: <https://www.everydayhealth.com/lupus/lupus-emotional-stress-and-depression.aspx>

Free and confidential mental health and substance use support is available 24 hours a day, 7 days a week from Wellness Together Canada via <https://www.wellnesstogether.ca/en-CA/crisis> or by calling 1-866-585-0445. Call 911 if you or someone you know is in immediate danger or needs urgent medical care.

MY LUPUS JOURNEY WITH NAINA



Naina has had quite a journey since birth. She is truly a princess warrior and at such a young age has been through a lot already. When she was born, she was admitted at Sick Kids hospital for 4 months and had a breathing and feeding tube. She was discharged when she was 4 months old after having her first surgery for Laryngomalacia-Laryngoplasty Surgery.

Naina had a G tube for the first two years of her life because of her severe GERD. Her Cleft Palate surgery was done when she was one year old. She was born with hip dysplasia (left hip surgery) and that surgery was done at 2 years of age. She was in a full body cast for two months. She was born with PRS and because of that she needs

major dental work done because of her small jaw. She got her braces now.

We were lucky to have had a break of few years with just follow ups for her cleft, ENT for Laryngomalacia, Hip, Dermatologist for her severe Eczema and Orthodontist.

Her lupus journey began this year 2022. In February after her second COVID shot she had one week of fever and we weren't too concerned because doctors said it could be because of the shot. Then she started having yellow hands (which now I know was Reynaud's) and I thought maybe eczema related or something else. I showed her hand pictures to the dermatologist in March and she referred Naina to the rheumatologist at Sick Kids.

In April, the Rheumatologist did blood work and Naina tested positive for ANA but had no symptoms so they just said they will monitor and maybe follow up in 6 months or so. At that time, they said MCTD. Naina's only symptom was Raynaud's.

On June 26 2022 Naina started high fevers of 40s. After two weeks I took her to Sick Kids emergency and they said it might be just a viral and sent us home. Then again after another week I took her to Sick Kids emergency they did more blood work. She didn't test positive

for any infections so they sent me home with follow up with Pediatrician in Scarborough general hospital. Their too there was no answer so I requested to be seen by Rheumatologist on July 18. There they did more blood work and then on July 20th Rheumatology called me and said Naina needs to be admitted and to bring her to the hospital ASAP.

On July 20 they did lots more blood work and ultrasounds. Sick Kids admitted her in a general floor so that all departments could be involved and they could rule out what was causing a month-long fever and she was very lethargic. They had to rule out infectious disease, oncology, neurology and ophthalmology. After all those were ruled out then rheumatology did more blood work and found out it was lupus. Myositis was what we were told.

She had lost so much weight and ran out of energy from the one month of fevers. The scariest time was the not knowing part of all this. No one has answers and they kept doing blood work. On July 23rd she was diagnosed with lupus. She was discharged with high dose of prednisone which helped her fever go away. We were given the next appointment to see the lupus clinic and now that is where she is followed.

Naina's main problems now are Arthritis (painful swollen joints, Myositis (muscle weakness), fatigue and general malaise and Raynaud's. She used to love karate and now that is put on hold. She is mostly tired. Since this autoimmune disease doesn't have a cure yet we got her a dog to help her motivate to walk and dog therapy helps a lot for mental health. Naina used to love to colour but due to her arthritis she couldn't and so I told her to start drawing and she practiced so much that she is now an artist. Just like Terry fox ran in his pain to create awareness and fundraise for cancer, my princess warrior draws to make coloring books to fund raise and create awareness of lupus. She tries her best every day to go to school but some days does half days due to her pains. It is a tough journey ahead but Naina is tougher. Her strong will power and positive attitude has always helped her overcome her medical issues. We pray for a cure and a miracle every day.

The coloring books give Naina a purpose too and keep her motivated to not give up on drawing and holding a pencil. I am happy she is keeping away from electronics as much as she can and keeps drawing and moving her joints. Hoping her books can create awareness and raise funds for finding a cure.

This is the beginning of an interesting journey and I am sure Naina with her high spirits will keep going and spreading joy and love. My warrior princess. She is my diamond who keeps going through pressures of life and just like a diamond she shines brighter than ever.

<https://www.nainasjourney.com/>



COMMUNITY ENGAGEMENT

Social Media Highlights

Thank you to everyone for tagging us in their social media posts, here's a little recap of our favourite community posts from December! Keep tagging us in your posts for a chance to be featured in our Social Media Highlights!

Vikas Tiwari
@tweetsbyvik

Had a wonderful time celebrating 50 years of Dr. Murray Urowitz's career and the team at @SchroederInst's Lupus Clinic. What an incredible career of advancing research and helping patients. #lupus @LupusCanada



10:24 AM · 2022-12-02

1 Quote Tweet 4 Likes

Very important to take care during the holidays ❤️

[@LupusCanada](#)

Fatigue & Autoimmune Disease

Strategies To Manage Fatigue:

- 1 Take it easy
- 2 Plan ahead
- 3 Inform family and friends
- 4 Eat a healthy diet
- 5 Get regular exercise
- 6 Get enough sleep
- 7 Find support



LUPUS CANADA

LupusCanada Lupus is a lifelong, incurable autoimmune disease that may require lifestyle changes and adjustments...

Miguel's World
@miguelsworld01

This is part of my lupus story and why I am a lupus advocate ❤️🦋

#lupuswarrior #lupusawareness #chronicillness #invisibleillness @LupusCanada @LupusOrg

What is SLE?

My Lupus Advocacy ❤️🦋

systemic Lupus

32 views

Being diagnosed with a heart condition at 5, showing everyone how cool I was like a robot

maddison_tory_

Thank you for sharing your story with us!

MY LUPUS JOURNEY WITH KAYLA B.

Thank you @LupusCanada for sharing my story... check it out

LUPUSCANADA.ORG

COMMUNITY ENGAGEMENT

Social Media Highlights

DeMar DeRoza
@DeMar_DeRoza

Give the gift of hope this holiday season.

Your donations help fund lupus research grants, advocate for those impacted by lupus, and provide scholarships to students living with lupus.

Please consider donating to @LupusCanada today 🙏

lupuscanada.org/getinvolved/wa...

GIVE BACK THIS HOLIDAY SEASON

Accounts Of Interest

Dealing with chronic illnesses may be hard so it's important to stay connected with pages that can help boost morale and keep a positive mindset. We've decided to group together some great social media pages that we think can help make things easier!



[@acejointhealth](https://www.instagram.com/acejointhealth)

Arthritis Consumer Experts (ACE) provides free, science-based information and education programs to people living with arthritis



[@erinmeghanhitch23](https://www.instagram.com/erinmeghanhitch23)

Lupus warrior since 2011. Realizing my strength every single day. Working to help support others throughout their journeys by sharing my story! I will never stop giving back to the lupus community.



[@faretheewellbychefjill](https://www.instagram.com/faretheewellbychefjill)

Fare Thee Well originally started as an outlet to showcase my love of food after my Lupus diagnosis. My diagnosis forced me to reimagine my relationship with food. Proper nourishment has played a pivotal role in my disease management. This is a place for us to come together, share a meal (or two) at the virtual table and talk about all things food, fashion and wellness - because for me, they're all connected. When you feel good, you look good and show up as the best version of yourself - GLOWING!

RECIPES

Approved by registered dietitian Heather Penny

A Delicious And Healthy Meal

On The Menu:

Baked Blueberry Nectarine Oatmeal

Ingredients

- 2 cups old-fashioned rolled oats
- 2 cups unsweetened almond milk (or another unsweetened plant milk)
- 1 teaspoon vanilla extract
- 1 to 2 tablespoons maple syrup
- 1 cup blueberries (fresh or thawed frozen blueberries)
- 1 nectarine, sliced



Instructions

- 1** Preheat oven to 375 degrees Fahrenheit.
- 2** Mix all ingredients thoroughly in a bowl. Divide evenly into four small (4) ramekins or other small baking dishes and bake for 25 minutes or until the top is slightly browned.

Servings: 4



Source: <https://lupusjourneys.com/baked-blueberry-nectarine-oatmeal/>



QUICK LINKS



Q&A's

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



Personal Stories

What is life like living with lupus? Read the personal stories of some of our friends living with lupus [here](#).

LUPUS
CANADA
Life Without Lupus



Brochures

Read and learn about everything lupus related [here](#).

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