

## LET'S TALK LUPUS

March Monthly E-Newsletter



**HOPE**  
life without lupus



Spring is the season of new beginnings and symbolizes hope. Longer days of sunlight, the snow melting, the weather starting to get warmer, the ground starting to come to life again with fresh buds blooming and trees blossoming. Take time to enjoy these special moments that come with spring. With the nicer weather on the horizon it is important to remember to properly protect yourself from the sun by applying sunscreen and wear appropriate clothing.

Lupus can affect anyONE, however lupus affects women more often than men, especially between the ages of 15-45. On March 8th we recognize all the women living with lupus on International Women's Day. Together let's celebrate women's achievements. For more information please visit <https://www.internationalwomensday.com/>

Further, the International Day of Happiness, is celebrated on March 20th and is a way to recognize the importance of happiness in the lives of people around the world. For more information please visit <https://www.dayofhappiness.net/>

**DONATE NOW**

your gift makes a difference

A banner with a light purple background and a subtle pattern of overlapping lines. The text "RESEARCH & RESOURCES" is centered in a bold, dark purple font.

## RESEARCH & RESOURCES

### **Lupus Canada is a proud funder of Canadian Network for Improved Outcomes in Systemic Lupus (CaNIOS)**

CaNIOS members are Canadian investigators who come together to do lupus research. The network facilitates easy and rapid collaborative projects.

Reported below are links to just a few of the important projects using registry data.

CaNIOS sites continue to participate in an economic analyses of the costs of SLE. [Economic Evaluation of Damage Accrual in an International Systemic Lupus Erythematosus Inception Cohort Using a Multistate Model Approach.](#)

CaNIOS registry data sets are being used to better understand the risk of toxicity associated with hydroxychloroquine, and understand the risks of lupus flare if hydroxychloroquine is stopped.

[Flares after hydroxychloroquine reduction or discontinuation: results from the Systemic Lupus International Collaborating Clinics \(SLICC\) inception cohort](#)

[CaNIOS data sets will be used to look at the employment experiences of young adults with systemic lupus.](#)

CaNIOS sites are participating in [The Lupus prEGnAnCY \(LEGACY\) Cohort](#). This is an international project to collect more information on lupus pregnancies, to ultimately improve pregnancy outcomes.

CaNIOS sites continue to participate in the [Lupus Clinical Investigators Network \(LuCIN\)](#). LuCIN is an initiative sponsored by the Lupus research alliance in the USA with the goal to conduct clinical trials of diverse and novel interventions, from nutritional supplements and new drugs to psychological interventions.

A banner with a dark purple background and a subtle pattern of overlapping lines. The text "LUPUS NEWS" is centered in a bold, light purple font.

## LUPUS NEWS

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### **May is Lupus Awareness Month**

The countdown officially begins as we are only **2 months away from Lupus Awareness Month!**

Last year, through the determination and passion of those impacted by lupus across Canada, we were able to raise lupus awareness through initiatives such as illuminating significant landmarks throughout Canada and asking Government Officials to proclaim **May 10th as World Lupus Day**. Lupus Canada is excited to make an even bigger impact this year. Follow us on social media as we release information about the initiatives we are launching this year.

In support of **Put on Purple** for lupus, which takes place on the 3rd Friday of May, Lupus Canada's Put on Purple t-shirts are back in stock with a new design! With limited quantities available be sure to order your t-shirt early, in time for Lupus Awareness Month. We look forward to seeing everyone wear lupus awareness merchandise this May. For more information please visit <https://lupuscanada.org/merchandise/>.

Do you know what goes great with the Put On Purple T-Shirt? Matching lupus awareness socks! Each black pair is embroidered with the purple lupus butterfly. For more information on how you can purchase a pair please visit <https://lupuscanada.org/merchandise/socks/>.



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**TILTIFY** Lupus Canada has joined the fundraising platform **Tiltify**. Tiltify is the fundraising platform for the digital generation, providing live, interactive telethon-style technology. Tiltify harnesses the power of both traditional fundraising and modern digital engagement with platforms like Twitch, YouTube, TikTok, and Facebook. To access our Tiltify account please visit <https://tiltify.com/lupus-canada>.

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### Lupus Canada Scholarship

Lupus Canada is proud to announce the 2022 Lupus Canada Scholarship program. This year we will be offering six (6) one-time scholarships of \$2,000 CAD to students diagnosed with lupus, who are entering into, or currently enrolled in, a post-secondary educational institution.

For more information please visit <https://lupuscanada.org/news/lupus-canada-scholarship/>



## ARTICLES

### WHAT EVERY LUPUS PATIENT NEEDS TO KNOW ABOUT VITAMIN D

We mostly get our Vitamin D from the sun, but the vast majority of people with lupus have a tendency to avoid the sun for obvious reasons (cue horrid photosensitivity symptoms...). As a result, some people living with lupus have a Vitamin D deficiency.

Lupus affects the way the body absorb nutrients. Firstly, our immune system murders anything foreign, like vitamins. Secondly, lupus has a real fondness for kidneys. Lupus loves to mess with the kidneys, and the kidneys are the magic tools for absorbing most of our nutrients.

In this article, you will learn about vitamin D, its benefits, how it's significant for lupus patients, and how to get more of it.

*What is Vitamin D?*

*Vitamin D is known as the "sunshine" vitamin because we cannot get ample amounts of it from food. We make this vitamin by absorbing sunlight using cholesterol in our bodies.*

*Why is Vitamin D So Important?*

Vitamin D plays a crucial role in the body's muscles and immune system. Many genes encode proteins that regulate cell proliferation (cell growth), and apoptosis (cell death). These are all controlled in part by vitamin D.

*Vitamin D can:*

- Be used as an antidepressant
- Reduce asthma symptoms
- Help balance the immune system
- Strengthen bones
- Fight brain fog
- Help fight cancer
- Boost fertility
- Protect the heart
- Calm inflammation
- Improve sleep

*Lupus and Vitamin D*

The significance of vitamin D deficiency in lupus is not entirely known. However, it has been

linked to the possible prevention of autoimmune diseases and their symptoms.

Kamen et al., found that Vitamin D deficiency is more prevalent in patients with darker skin pigmentation. Out of 1 to 3 recently diagnosed patients with lupus, levels were significantly lower among African-Americans than among Caucasians. Overall, 67% of patients with lupus were Vitamin D deficient. Severe deficiency was noted in about 18% of patients and was associated with renal disease and photosensitivity.

Another study performed by Costenbader et al., suggests that repletion of Vitamin D may have benefits beyond bone health for patients diagnosed with lupus.

Ultimately, there is optimism that correcting Vitamin D deficiency will lead to better outcomes for patients with lupus.

#### *How To Get More Vitamin D*

The body primarily absorbs Vitamin D through the sun's rays, so many people with lupus often find themselves at a disadvantage in maintaining healthy levels. However, there are some foods that can help.

*Here are 10 foods you can eat that contain high Vitamin D levels:*

- Cod liver oil
- Sardines
- Salmon
- Mackerel
- Tuna
- Raw grass-fed milk
- Caviar
- Organic eggs
- Mushrooms

You can also try to take supplements for Vitamin D. However, if you only take them until your levels normalize and then stop, you will just watch them drop again and find yourself in a vicious cycle. The solution is to wean your body off the supplements after you have gotten your levels normalized.

To sum up, the remedy for a Vitamin D deficiency is not just about replacing what your body is missing, but about training your body to do what it should be doing. Check your Vitamin D levels, eat foods high in Vitamin D, and take supplements, if needed.

Source: <https://lupuschick.com/what-every-lupus-patient-needs-to-know-about-vitamin-d/>

## DEPRESSION IN OLDER ADULTS

*If you have a sad, despairing mood that lasts for more than two weeks, it may be depression.*

Depression is not the same as sadness, though it can be triggered by the sadness caused by loss (e.g., loss of a loved one, loss of hearing), stress or major life change (e.g., retirement, moving). Depression can also be caused by some medical conditions, such as chronic pain, thyroid problems, stroke or Alzheimer's disease. Certain medications and alcohol use can cause depression as well. Depression may also develop for no apparent reason.

People who are depressed cannot just "get over it." Depression is a biological illness caused by a chemical imbalance in the brain. It affects thoughts, feelings, behaviour and physical health.

Older adults who are depressed may have had episodes of depression throughout their lives, or they may have their first episode late in life.

Depression can affect anyone at any age, but is often not recognized in older adults. This is because some signs of depression can be mistaken for signs of aging, and also because older adults who are depressed may not complain about feeling low. When left untreated, depression may continue for weeks, months or even years. Untreated depression is the main cause of suicide in older adults.

*What are the signs of depression?*

People often think that depression in older adults is a normal response to the losses of aging. When they say, for example, "It's no wonder he's depressed, he's 82," or "If I had arthritis, I'd probably be depressed too," they may mean well, but depression is not normal.

*An older adult may be severely depressed if he or she:*

- does not get dressed
- does not answer the phone or the door
- loses interest in activities he or she used to enjoy
- expresses feelings of worthlessness and sadness
- has unusual outbursts of crying, agitation or anger, or shows little emotion
- sleeps poorly or too much
- eats more or less than usual
- complains about physical symptoms that do not have a cause
- lacks energy, is often tired
- seems confused
- has difficulty concentrating
- has trouble remembering things

- has trouble making decisions or following through with plans
- spends more time alone
- talks about suicide

*What can I do about depression?*

Get help: Depression deserves the same care and attention as any other medical condition. There is no shame in seeking help. Treatment options for depression include antidepressant medications, available from a family doctor, and counselling. Both can be very effective. Older adults who are contemplating suicide should speak to their doctor or go to the nearest hospital emergency department.

There are also many things older adults can do on their own or with family and friends to prevent or lessen the effects of depression.

*Be active:* Exercising the body helps to lift the mood. Even taking a short stroll or joining a local aquafit class can help to make the world seem a brighter place.

*Think positively:* Instead of thinking about what you could have done differently in life, think about what you've done right. Remember your strengths and how you overcame challenges in the past.

*Eat well:* Food is your fuel. When you eat nutritious healthy foods in the right amounts, it can boost your strength and help you feel well.

*Get involved:* When you enjoy what you're doing, you enjoy life. Rekindle your interest in activities you used to enjoy or find new ones.

*Manage stress:* Think back on stressful times in the past and how you got through them. Can you use the same techniques again, or is it time to try something new?

*Avoid alcohol:* Having a drink may seem to make you feel better for a short while, but alcohol can actually worsen depression. Being active, enjoying others and eating well can give you a natural high that won't have negative effects.

*Spirituality:* Seeking answers about life and coming to peace with the past and the present can improve your perspective on life. Examining your faith can involve returning to your roots, finding fellowship in an organized religion or seeking understanding outside a traditional religion.

Source: <https://www.camh.ca/en/health-info/guides-and-publications/depression-in-older-adults>

## MY LUPUS STORY



### *My Lupus Journey with Agata*

My name is Agata, and here is my lupus story. At the age of two I suddenly became super sick and was diagnosed with Asthma. But even with this diagnosis I was not getting better. My Paediatrician realized that there was something wrong with my liver and I was sent to the Hospital of Sick Children in Toronto. It was here that I received my second diagnosis of autoimmune hepatitis. I was prescribed immunosuppressants, first prednisone and then prednisone and imuran. I spent years and years on both of these medications and I was having frequent specialist appointments. School was super challenging due to the appointments and the constant wonder of how to stay stable. At the age of about nine I was then diagnosed with growth hormone deficiency and around that time I was also

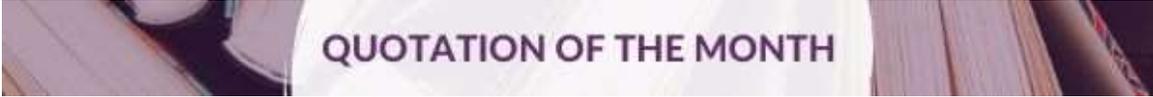
diagnosed with nephro acidosis.

By the time I was twelve I was seeing a liver specialist, endrochronologist, and a nephrologist. I went through many tests and appointments. At the age of fourteen I became super sick and I became very stressed. I wanted to finish elementary school and I wanted to be able to start high school, let alone I worried I wouldn't make it to my elementary graduation trip.

I went through extensive blood tests, a liver biopsy and other tests. It was when I was preparing for my liver biopsy a resident was wondering if I was ever diagnosed or tested for lupus. When I was little I was tested but the results were negative. The doctors and nurses told me to do research for lupus and understand it. I did my research though when reviewing the symptoms, I tried to tell myself that I did not have any of those symptoms and there is no way I have it. I was wrong, in 2009 I was diagnosed with lupus, oh and was given one more doctor, a rheumatologist. It wasn't an easy diagnosis to accept but I did. After 16 years I was finally able to stop taking prednisone and was prescribed hydroxychloroquine and imuran. At the age of 18 patients are no longer able to attend a children's hospital and have to move forward to a general hospital.

At the age of 18 I was transferred to Toronto General hospital and Toronto Western. I had enrolled in post-secondary education despite everyone questioning the ability that I had. I was always told good luck, don't forget about your sickness. I used this as an inspiration to complete my education. I enrolled in college and completed an Advanced diploma in Child and Youth Work and I then furthered my education and did an undergrad in Child and Youth Care. During my undergrad I also began working. After completing my undergraduate I enrolled in my masters of Education and Leadership and began working full-time to pay for my studies. I have recently

finished my masters. I hope my story inspires others who may lose hope. It is okay to ask for help. I had to do it while completing my undergrad. I am currently 26 and continuing my battle with lupus and with all my specialists but I am stronger than ever.



## QUOTATION OF THE MONTH

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*“The very least you can do in your life is figure out what you hope for. And the most you can do is live inside that hope. Not admire it from a distance but live right in it, under its roof.”*

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BARBARA KINGSOLVER



## RECIPES



### Asparagus Salmon Foil Packet

#### INGREDIENTS

- 4 SALMON FILLETS
- 1 LEMON SLICED
- 1 TSP PAPRIKA
- 1 TSP GARLIC POWDER
- 1 TSP SALT
- 1 TSP BLACK PEPPER
- 1 POUND ASPARAGUS SPEARS, ENDS TRIMMED
- 1/2 CUP BUTTER, MELTED
- 1 TBSP GARLIC, MINCED
- 2 TEASPOONS FRESH BASIL

#### GARNISH

- FRESH BASIL
- LEMON WEDGES

#### DIRECTIONS

Preheat oven to 400°F. Cut 4 sheets of foil, 12 X 18 inches, heavy duty foil. Place 2 lemon slices on each sheet of foil.

Mix paprika, garlic powder, salt and pepper together, and rub it over the salmon.

Place each salmon fillet in the centre of the lemon slices.

Divide the asparagus into 4 equal portions and arrange next to the salmon on each foil piece.

In a small bowl, mix together the melted butter, lemon juice, garlic and basil.

Pour the butter mixture evenly over each piece of salmon and asparagus.

Wrap the salmon and asparagus in foil, and secure and seal the edges to create a packet.

Bake in preheated oven for 15-20 minutes.

Open foil packets and enjoy, or broil for 1-2 minutes to crisp up exterior.

Garnish with additional lemon juice and fresh basil.

The recipes used by Lupus Canada have been reviewed and approved by Heather Penney, Registered Dietitian.

Source: <https://www.spendwithpennies.com/asparagus-salmon-foil-packets/>

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