

## LET'S TALK LUPUS

February Monthly E-Newsletter



**HOPE**  
life without lupus



Lupus Canada welcomes February and hopes that you take this month to invest in yourself. Make sure to be yourself unapologetically and take every opportunity that comes your way. Do not forget to give yourself a break and do what you love, whether that is spending time with loved ones, getting outside, or just taking some alone time.

**Family Day is February 21st!** Take advantage of this long weekend and, pending COVID-19 protocols, try to enjoy the company of others and create memories with your family or friends. A great activity to consider is doing a family game night. Be sure to read the article, 'The Benefits of Family Game Night' that we have provided below.

**Rare Disease Day is February 28th,** "a globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse- but united in purpose. Rare Disease Day provides an energy and focal point that enables rare diseases advocacy work to progress on the local, national and international levels." To learn more about how you can help make a difference please visit <https://www.rarediseaseday.org/>.

**DONATE NOW**  
your gift makes a difference



**LEANNE MIELCZAREK**  
Executive director, Lupus Canada

**Understanding the burden of Lupus  
in the workplace**

*This session has been made possible by AstraZeneca.*



**2022  
CHRONIC DISEASE  
AT WORK**

**Benefits**

## Understanding the Burden of Lupus in the Workplace

Lupus Canada is excited to participate in Benefits Canada's virtual Chronic Disease at Work conference, on February 8th. Lupus Canada will discuss lupus and its impact on the workplace population from a physical and mental health perspective, as well as some of the barriers in access to treatment today.

## COVID-19 News

In July 2021 GSK received authorization under Health Canada's Interim Order for Sotrovimab for Injection to treat COVID-19 in high-risk adults and adolescents. To read more please visit <https://ca.gsk.com/en-ca/media/press-releases/gsk-receives-authorization-under-health-canada-s-interim-order-for-sotrovimab-for-injection-to-treat-covid-19-in-high-risk-adults-and-adolescents/>

GSK also announced on January 6th that the Government of Canada has purchased additional doses: <https://ca.gsk.com/en-ca/media/press-releases/gsk-announces-additional-purchase-agreements-with-the-government-of-canada-for-covid-19-monoclonal-antibody-therapy-sotrovimab/>

## COVID-19 Vaccine Information

For up to date information on COVID-19 vaccines in your province please visit the links below.

**Alberta** <https://www.alberta.ca/assets/documents/health-covid-19-immunization-update-booster-doses.pdf>

**British Columbia** <https://www2.gov.bc.ca/gov/content/covid-19/vaccine/register#immunocompromised>

**Manitoba** <https://www.manitobavaccine.ca/third-dose-eligibility/>

**New Brunswick** <https://www2.qnb.ca/content/qnb/en/corporate/promo/covid-19/nb-vaccine.html>

**Newfoundland and Labrador** <https://www.gov.nl.ca/covid-19/vaccine/>

**Northwest Territories** <https://www.gov.nt.ca/covid-19/>

**Nova Scotia** <https://novascotia.ca/coronavirus/vaccine/>

**Nunavut** <https://www.gov.nu.ca/health/information/covid-19-novel-coronavirus>

**Ontario** <https://covid-19.ontario.ca/getting-covid-19-vaccine>

**Prince Edward Island** <https://www.princeedwardisland.ca/en/topic/covid-19-vaccines>

**Quebec** <https://www.quebec.ca/en/health/health-issues/a-z/2019-coronavirus/progress-of-the-covid-19-vaccination>

**Saskatchewan** <https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/treatment-procedures-and-guidelines/emerging-public-health-issues/2019-novel-coronavirus/covid-19-vaccine/vaccine-delivery-phases#booster-doses>

**Yukon** <https://yukon.ca/en/covid-19-vaccine>

---



## Lupus Canada Scholarship Program

Living with a chronic illness such as lupus can certainly be stressful on its own, but with the added stress of school, people with lupus often experience flares – unpredictable bouts of increased disease activity resulting in symptoms such as debilitating fatigue, pain in muscles and joints, difficulty breathing or persistent headaches.

For students, these flares can result in missed classes, lost study time or the need to reduce course load. A sudden flare can jeopardize academic standing as well as the ability to attain and maintain scholarships and financial aid. Many students are unable to maintain a part-time job because of

lupus and so, financial resources are stretched.

Post-secondary education – a significant milestone for many students, brings with it both excitement and stress. For individuals living with lupus, post-secondary education may present an additional set of unique obstacles.

Lupus Canada created our Scholarship program to help students living with lupus to succeed in attaining a post-secondary education. Through the financial support of the Lupus Canada Scholarship, we intend to recognize and raise awareness of the achievement of students living with lupus who have taken a positive and ambitious outlook in achieving their academic goals.

Lupus Canada is pleased to announce we are now accepting 2022 applications. For more information please visit <https://lupuscanada.org/news/lupus-canada-scholarship/>.

---

## Lupus Canada and BigYellowBag Fundraiser

Lupus Canada is excited to share that we will be participating in the BigYellowBag Give & Grow Fundraising program. Last year, BigYellowBag Give & Grow donated more than \$42,000 to community groups & organizations.

### *How Does It Work?*

Use the code **LC22** to save \$5 off a BigYellowBag of soil or mulch. Every time this code is used, BigYellowBag will donate \$10 to Lupus Canada – it's that simple!

To learn more about the program please visit <https://www.giveandgrow.community/>

If you have a fundraising idea please email us at [info@lupuscanada.org](mailto:info@lupuscanada.org).



## RESEARCH & RESOURCES

**LUPUS**  
FOUNDATION OF AMERICA

**APPLY NOW**

### APPLICATIONS DUE: APRIL 15, 2022 AT 5PM EST

#### GARY S. GILKESON CAREER DEVELOPMENT AWARD

*Four grant awards of up to \$70,000 each for up to 2 years*

#### GINA M. FINZI STUDENT SUMMER FELLOWSHIP PROGRAM

*Six fellowship awards of \$4,000*

#### LUPUS CANADA CATALYST GRANT

*One Catalyst Award for a total of \$40,000 CDN*

### Lupus Canada 2022 Catalyst Grant Program

*One Catalyst Award for a total of \$40,000 CDN to fund one project for a term of one year.*

Lupus Canada has partnered with The Lupus Foundation of America for the third year to offer the Lupus Canada Catalyst Grant. The Catalyst grant is intended to help kick start a new project or research idea focused on discoid or systematic lupus erythematosus (SLE). This grant provides support to Canadian investigators to initiate new research ideas and projects and is intended to complement rather than compete with traditional sources of funding such as the Canadian Institutes for Health Research (CIHR).

### Applications are due April 15th, 2022 at 5PM EST

To learn more about each grant and how to apply, please visit <https://www.lupus.org/research/apply-for-funding>



### From Manchester to Toronto – Improving lupus 'brain fog'

*Lupus Canada proudly supports Dr. Barraclough and Dr. Touma's study, Cognitive Dysfunction and Fatigue in Systemic Lupus Erythematosus, through our 2021 Catalyst Grant. To learn more about the grant recipients and their project please visit <https://www.lupus.org/2021-recipients-of-the-lupus-canada-catalyst-award>.*

In early 2021, Dr. Michelle Barraclough, Research Associate for Manchester BRC's Musculoskeletal theme, began a year-long research placement in Toronto to better understand



'brain fog' in lupus patients.

She shares her progress to date, and how this trans-Atlantic collaboration aims to improve care and treatments for patients. To read the full article please visit

<https://www.manchesterbrc.nihr.ac.uk/news-and-events/manchester-to-toronto-improving-lupus-brain-fog/>

## ARTICLES

### THE BENEFITS OF FAMILY GAME NIGHT

With TV and video games competing for our family's attention, board games have been relegated to the dark recesses of our memories, as something we did with our parents when we didn't have cool high-tech gadgets and satellite television. But dusting off these games can lead to a family bonding experience that is not only fun, but can improve kids' mental and emotional development, helping them perform better in school and social settings.

Toronto mom of three, Robin Hicks, has enjoyed playing board games since she was a child, and loves sharing her favourite pastime with her kids, Joseph, 7, Helen, 4 and Georgia, 2. With more than 40 board games in their game closet, family game night is a regular occurrence in the Hicks' household. "We usually play board games together once a week," says Robin. As a paramedic, Robin's shift work hours don't allow her to spend as much time as she would like with her kids, making face-to-face playtime even more meaningful. In addition to facilitating family bonding, Robin says board games are a useful learning tool for her young brood. Good sportsmanship, following rules and taking turns are important social skills Robin hopes to reinforce in her children through playing board games.

Jennifer Kolari, child psychologist and author of *Connected Parenting*, says playing as a family is a great way for parents to assess how well children have developed certain social skills. "We let our true emotions out more with family than with others," says Jennifer. The ability of board games to reinforce important social skills makes them a unique developmental tool. "Kids learn so much about sharing and being a good sport and getting along with each other through board game playing."

#### **Practise good sportsmanship**

Nothing sours family game night faster than a sore loser. Temper tantrums can quickly cause games to be locked in the closet for the rest of eternity. That's a shame, says Jennifer, who argues board games can be an excellent forum for teaching good sportsmanship. "Part of a game is winning and losing, and being happy for other people when things go well for them in the game, and learning to be a good winner if it's you that wins," says Jennifer. Robin says talking to her kids about winning and losing before playing can help set the stage for a tantrum-free game night.

#### **Follow the rules**

While no parent likes to transform into the role of traffic cop during family fun time, Jennifer says controlling cheating is a good way to teach kids the importance of following rules, a skill

that will last them well into adulthood. "The tendency as a parent is either to come down on them and say 'no one's going to play with you if you do that' or just let them do it because you want family game night to go well," she says. Talk about the rules of the game before playing and stress the importance of being honest.

### **Learn to win and lose gracefully**

Losing a game can bring on the waterworks in many kids, but Jennifer says learning to lose gracefully is an important skill all kids need to hone to succeed in life. Jennifer herself has faced the dreaded game night tears. "My son was the biggest sore loser and every time we played a game, he would end up in tears," she says. In response, the family decided there would be two winners. "The winner who won the game and the winner who handled losing the best," she says. Don't forget to control your own emotions, too, demonstrating to kids how to handle themselves when things don't go their way in the game.

### **Encourage behavioural changes**

"Everything that happens in board games can be applicable to life," says Jennifer. Robin agrees, saying she has witnessed behavioural changes in her children that she attributes to the board games they've played as a family. "Since we've been playing board games together, they've been getting along better and can work through their differences," she says. One notable difference is improved sharing and negotiation skills. "They all really like books and if one of them is looking at a book that the other one wants, they'll go get a different book and say, 'here, I'll trade you'," says Robin.

### **Choosing a board game**

With thousands of board games to choose from, selecting the right one for your family can be a challenge. Follow these pointers to ensure your family game night starts with the right move.

### **Focus on skills**

Select a game that will reinforce the specific skills that you want to focus on. Sean Jacquemain, Events Coordinator at Toronto's Snakes and Lattes, a board game café with more than 3,500 games for adults and kids, says having a clear idea of what you want to accomplish by playing the game will help narrow the selection. Some games are educational and aim to reinforce cognitive skills such as reading, logical reasoning or spelling; others are effective at teaching the value of co-operation, sharing or trading. Jennifer recommends finding a toy store where staff can walk you through the advantages of different games.

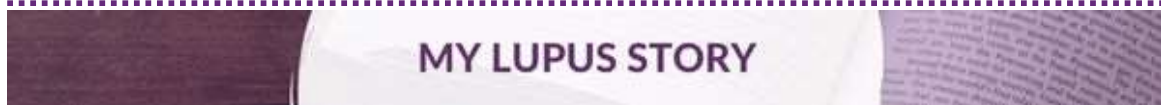
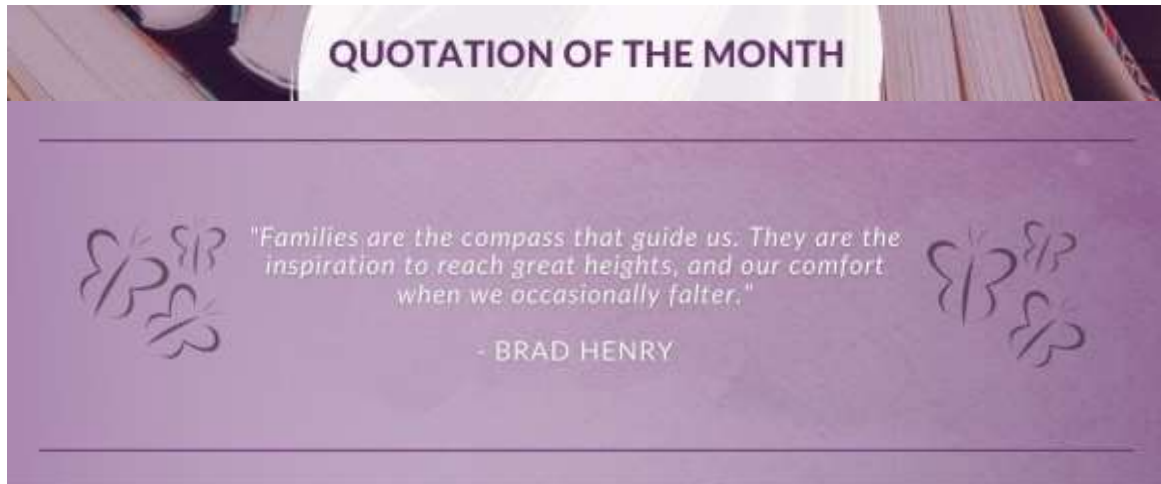
### **Know your kid**

Choose a game that's not only age-appropriate, but that also suits the temperament of your child. Chance games such as Snakes and Ladders, where winning or losing is purely based on the roll of the dice, can be hard on kids who don't handle losing well. "Although they're simple games, when you're sent all the way back to the start of the game when you were at the end can be really devastating," says Jennifer. While she doesn't advocate eliminating chance games all together since adversity is also an important skill to learn, switching it up with memory games or cooperative games that encourage team work and sharing can help make family game night not only about winning and losing, but simply about having fun.

### **Look for what new games have to offer**

While many of the parents Sean meets in Snakes and Lattes arrive for the nostalgic factor of sharing their favourite childhood board games with their own kids, he says new designer board games have a lot to offer and are more adept at encouraging skills of co-operation. "In older board games like Monopoly or Risk, you get eliminated and then you sit around and watch others play," says Sean. Newer board games, especially storytelling games, have been designed in a more sophisticated way that promotes interaction and bonding, rather than eliminating players.

Source: [https://www.cbc.ca/parents/learning/view/family\\_game\\_night\\_is\\_more\\_than\\_just\\_fun](https://www.cbc.ca/parents/learning/view/family_game_night_is_more_than_just_fun)



### **My Lupus Journey by Thaina Plancher**

Hi, my name is Thaina, and I was diagnosed with Systemic Lupus Erythemous, also known as lupus, in April 2021.

Before being diagnosed with lupus, I started experiencing joint pain, extreme fatigue, swollen knees, feet, and hands, and rashes, all symptoms of lupus. All of this began in November 2020, but it got worse in January 2021. I was working at the time and constantly kept on calling in sick. My job was upset with me missing multiple days. I had to decide to either put my health first or my job. So I had to quit in February 2021.

I had a feeling that I had lupus but I did not say anything. I had also heard that many people experiencing lupus would get diagnosed years later because it is hard to diagnose. But I was determined to figure out what was going on with me and gave all the doctors I saw a hard time to hurry up because I could not deal with the amount of pain I was going through. I felt horrible and like I was giving them a hard time.



I was always in bed and always sleeping. Even though I had 12+ hours of sleep, I was always tired; I needed rest. Also, I was often called lazy because I did not do my work around the house as much as I used to. I even had a lot of difficulties unlocking the door to my own home, got frustrated, and started crying in front of my house. It is pretty funny as I think about crying in front of my house, but the experience was painful.

I had many tests done, like X-rays, blood, and urine tests. I've lost count of the amount of blood tests and urine tests I got done.

My family doctor referred me to a rheumatologist here in Ottawa and was so blessed to have met her. She has been so patient with me and helped me understand what is happening in my body. After meeting with my rheumatologist in March 2021, a few weeks later, we had an appointment to discuss what my test results say and what my symptoms meant. Unfortunately, she came to the conclusion that I have SLE. Being diagnosed at 18 was hard.

My life has changed completely. One moment I was a healthy teenager taking no medication, working out 5 times a week to taking around 6-8 different types of medications, and not working out at all for months now. Lupus has taken a lot from me, my youth and my confidence. I started losing hair on my scalp and my eyebrows. But now, with the new year, I have promised myself to begin advocating for my lupus warriors. And start raising as much money as possible to find a cure for this disease.

Lupus has taken a lot from me, but it is time for me to stand up and start fighting back and using my voice. That is my story.

## RECIPES



### Artichoke Pesto Pasta

#### INGREDIENTS

- 1 BAG OF FROZEN ARTICHOKE HEARTS - OR 1 CAN OF ARTICHOKE HEARTS IN WATER, CHOPPED
- 2 LEMONS JUICED - DIVIDED
- 1 PACKAGE OF BASIL LEAVES
- 1 TBSP OF OLIVE OIL
- 1 TSP SALT, DIVIDED
- 1 TSP GARLIC POWDER - OR 1 CLOVE GARLIC, GRATED
- 3 TBSP OF HEMP HEARTS - OR CASHEWS, ALMOND, WALNUT, SUNFLOWER OR PUMPKIN SEEDS
- 1/4 CUP OF WATER
- 1 BOX OF GLUTEN FREE PASTA - BROWN RICE OR LENTIL PASTA WORKS BEST
- 1/2 TBSP OF OLIVE OIL
- 10-12 CHERRY TOMATOES
- SALT AND PEPPER TO TASTE

#### DIRECTIONS

Add water to a large pot for the pasta and bring to a boil.

While the water is boiling, heat a large skillet over medium heat. Add the artichoke hearts and cook on medium for 5-7 minutes.

After the artichokes are fully defrosted and starting to brown, turn off the heat and add the juice of 1 lemon and 1/2 tsp of salt. Stir well.

Once the water has come to a boil, add the pasta and cook according to the directions on the package. Check 1 minute before the timer goes off.

While the pasta is cooking make the pesto.

Add 1/3 of the artichoke hearts to the food processors, put the other half to the side to add to the pasta. Add all but a few leaves of basil to food processor with the artichoke hearts. Add the juice of 1 lemon, garlic powder, 1/2 tsp of salt, olive oil and hemp hearts.

Blend on high until combined and pesto starts to form. You may need to scrape down the sides.

Add 1/4 cup of water to the pesto to thin it out. Pulse to incorporate the water.

Drain the water from the pasta and add it back to the pot. Add 1/2 tsp of oil to the pasta to make sure it won't stick together.

Chop the artichokes that were set aside as well as the cherry tomatoes.

In a large bowl or the pot the pasta was cooked in, add the pesto, pasta, chopped artichoke hearts and chopped tomatoes and stir well.

Chop the rest of the basil and sprinkle it over the pasta.

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

Source: <https://bitesofwellness.com/artichoke-pesto-pasta-sunday-supper/>

---

## Visit Our Website

[Home](#) | [Contact](#) | [About Us](#) | [Make a Donation](#)

---

### STAY CONNECTED:



PO Box 8, LCD 1  
Newmarket, ON L3Y 4W3



Toll Free: 1-800-661-1468  
Local: 905-235-1714



[info@lupuscanada.org](mailto:info@lupuscanada.org)



[www.lupuscanada.org](http://www.lupuscanada.org)

***Working together to conquer lupus***

[Privacy Policy](#) | [Unsubscribe](#)

[Lupus Canada](#)

PO Box 8 LCD 1, Newmarket, ON L3Y 4W3