

## LET'S TALK LUPUS

September Monthly E-Newsletter



## A New Month Is Here!

Lupus Canada would like to thank everyone who participated in our *'Loonies For Lupus'* Campaign. We raised \$1 030! We are grateful to have a community of people such as yourselves who support us and are committed to bringing awareness and increasing research opportunities to lupus.

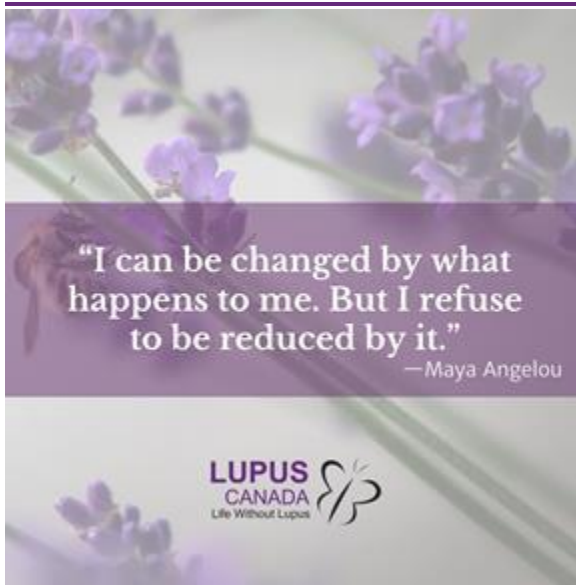
On *Monday September 7th* we celebrate Labour Day so take time to unwind and relax. While September usually involves students going back to school and people returning to work, this 'new normal' may mean beginning school online and working remotely. With all these changes potentially occurring, please remember to be kind to yourself. It may be difficult deciding how to proceed with your work or your children this fall. For these reasons, The Children's Hospital of Eastern Ontario (CHEO) and Sick Kids, are both excellent resources to consider when deciding on whether to take your child back to school or not and other tips. The newsletter will provide highlights from these two articles, however, if you would like more information the links will be included as well.

With this past summer being particularly warm and with the rising temperatures, you may have found it difficult to enjoy outside activities. Thankfully, our first day of fall is on *Tuesday September 22nd* so take advantage of the cooler weather, enjoy the leaves changing colour, and get inspired by all the potential fall activities you can do with friends and loved ones.

Lupus Canada will be including a 'quotation of the month' within each E-Newsletter. It is our hope that these quotations will illuminate the meaning of what it means to be an individual living with lupus, as well as, inspire individuals to challenge themselves on a daily basis.

## DONATE NOW

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Things happen in life. Some of those things change our path in life. Some of them even change our lives. These changes could be for the better, or they could be for the worse. But that's life. That is what I believe the first part of the quote is about. The second part of the quote talks about how we react to that event.

We can choose how we react. We can choose to respond or to ignore what just happened. The quote urges us to not allow what happened to us to make us any less than we were before it happened.

Source:

<https://philosiblog.com/2013/09/26/i-can-be-changed-by-what-happens-to-me-but-i-refuse-to-be-reduced-by-it/>



Lupus Canada is proud to announce the 2020 Lupus Canada Scholarship recipients. This year we offered eight (8) one-time scholarships of \$2,500 CAN to students diagnosed with lupus, who are entering into, or currently enrolled in, a post-secondary educational institution. Thank you to everyone who applied and congratulations to those selected.

Each and every Scholarship applicant has a very important story to be told of their journey with lupus. Every month we will feature one of our Scholarship recipients stories.

## **2020 Lupus Canada Scholarship Recipients**

*Amelia Shivdarsan*

*Gurleen Dhaliwal*

*Amanda Wright*

*Laurianne Belanger*

*Nicole Yawney*

*Rebeca Acosta*

*Julie Bassendowski*

*Daphney Pierre-Louis*

Congratulations to all our recipients of the 2020 Lupus Canada Scholarships!

For more information on the Lupus Canada Scholarship program please visit <https://lupuscanada.org/news/lupus-canada-scholarship/>



### **About the Author - Jordan Nguyen is 21 years old and lives in British Columbia.**

In summer 2012, I became very ill for four weeks, I lived with two older brothers and a single mother. In the beginning, mom would take me to a multitude of walk-in clinics, where I was told I had a flu every time. I continued to stay home sick, and by week three, I was bed ridden, couldn't sleep or eat solid food and not even able to even walk to the washroom on my own due to excruciating knee pain, pericarditis and inflammation everywhere else. I feel like I knew something was wrong with me, but deep down denied it, wanting to live a normal life and ignoring my mother's pleas to take me to the hospital. I even remember during the second week, hobbling down the street, to my best friend's

house with a strawberry ensure in my hand, wanting to hang out and play video games like a normal kid, where he sent me home telling me I wasn't okay. It was around the 4th week where I gave in to the symptoms and my mom took me to the Victoria General Hospital, where I went through many tests over a few days with no results. I was transferred to Pediatrics for my extended stay, where I met Dr. Claudia Zuin, who seemed to have a hunch that I had lupus after speaking with me. After some tests, we found that she was correct.

Due to a lack of Rheumatologists in Victoria at the time, I was put on a stretcher and rolled onto a small plane to Vancouver. I remember the flight being very hazy, but my mom stayed by my side the whole time, worried to death. At that point the 12 year old me thought I was dying, and what scares me looking back at my experience, is that I was calm and accepting of it after those four weeks of hell. I was admitted into the BC Children's Hospital, where they started me on high doses of Prednisone, which helped my symptoms very quickly. I was told that I had Systemic Lupus Erythematosus and Rheumatoid Arthritis. At this time I was very grateful to be alive, and starting to feel like myself again. Over the course of my sickness, I lost a lot of colour in my skin and lost about 25 lbs, but with the help of the Prednisone, quickly regained my appetite, ten fold. I can still remember vividly, my mother bringing me some roasted chicken and mashed potatoes from the nearby Safeway, and it tasted so good. To this day that meal is nostalgic to me. On that night, I remember telling myself, "I will never use this condition as an excuse." I still hold onto that, though it's proven difficult, I try my best to be my best. The years forward after recovering were good, I gained a lot of weight in remission due to prednisone, which really cut my confidence going to school everyday. Though I had quite a few flares every once and awhile, usually having symptoms like pericarditis and joint pain, I was able to do most things I wanted to do. I was able to land my first restaurant job at a four star hotel at seventeen, then obtained a culinary scholarship at eighteen.

Fast forward Summer 2018, I was nineteen years old. This sure was a fun year, but there was so much wrong with it. I was careless, not concerned about my health and more concerned about when me and my friends were getting drunk next. I really felt like I forgot that I had lupus. I was binge drinking at least one or two days of the week, hooked on smoking cigarettes and working a stressful kitchen job at a busy restaurant. I started finding myself having pain on a daily basis, slowly getting worse every day I ignored it, powering through my day and dealing with the consequences later. The symptoms would get worse and worse every day. Eventually I met with my Nephrologist Dr. Kevin Horgan, who would then tell me that I'm at risk of kidney failure. I took a medical leave from my job, but eventually told my boss that I wasn't coming back. During my leave, I was to undergo a treatment with an IV drug called Cyclophosphamide. I was terrified. So terrified in fact, I gave myself an intervention about my actions leading to this point. I thought to myself, what can I do to help myself? I was fat, unhealthy and disgusted with myself. I ended up quitting smoking, drinking, and educated myself on holistics and natural healing. I went on a path of being vegan before my treatment started, to me it was just as important. I safely finished my treatment from November to February. Within this time I was doing home workouts and eating very healthy.

The result of my lifestyle changes led to the best year of my life at twenty years old. I was in the gym 5 days a week, not only my physical health, but my mental health was peaking. I felt good, had so much confidence and most importantly was healthy and happy. I suffered no flares this year.

Finally we're in 2020. I'm no longer vegan, but am coming back to it because of a flare I had. Besides that episode, and every other problem 2020 holds, I am looking very forward to the years to come. I want to switch my career from cooking to dedicating something towards people suffering from Lupus and Arthritis. I plan to move to Vancouver to see what I can do to make that happen. Just writing this story was empowering, and therapeutic. It makes me think, this is just my story, I want to hear others, receiving knowledge and sharing mine along the way to help others cope with what is a part of them, just like I feel like I've done. To whomever is reading this, if you have any feedback or advice you wish to share with me so



that I can strive to make this career path happen, I would love to hear it!

Thank you so much for reading such a personal and vulnerable letter.

## BACK TO SCHOOL DURING COVID-19: GUIDANCE AND TIPS

"The primary impetus for reopening schools is to optimize the overall health and welfare of children and youth, rather than solely to facilitate parent/ caregiver return to work or reopening of the economy". Both **Children's Hospital of Eastern Ontario** (CHEO) and **The Hospital for Sick Children** (Sick Kids) have released guidelines and tips that parents and/or caregivers should consider before deciding on whether or not to take their child back to school this fall.

While everyone will have different circumstances, it is important to be aware of your options and to know how to support your child during these difficult times. Further, it is essential to be aware of how to safely transition your child back into a school atmosphere. Thanks to the assistance of Sick Kids, Unity Health Toronto, CHEO, and several other reputable companies, parents are able to clearly and accessibly read through these guidelines and come to their own conclusions.

*"The ability of the public school system to effectively carry out its mission will depend in part on the resources made available to the schools."*

School boards across Canada are now planning to have students back in school this fall and providing parents with these options:

- *returning students physically back to school (ranging from part-time to full-time).*
- *keeping your child at home and continuing with virtual schooling.*
- *a combination of physical return and virtual schooling.*

If as a parents you are uncertain how to proceed with your child, CHEO recommends you visit The Centres for Disease Control and go to their Back to School Decision Making Tool to analyze the risks and benefits of each option.

Below are a list of things to consider when deciding which option to do for your family:

### **Hand Hygiene**

SARS-CoV-2 and other respiratory viruses are primarily spread by respiratory droplet transmission and should be the focus of preventative measures. As a result, and because virus shedding may occur prior to symptom onset or in the absence of symptoms, routine, frequent and proper hand hygiene (soap and water or hand sanitizer) is critical to limit transmission.

Proper hand hygiene is one of the most effective strategies to prevent the spread of most respiratory viruses, including SARS-CoV-2, alongside respiratory etiquette, particularly during the pre-symptomatic phase of illness.

## **Screening to prevent symptomatic individuals from entering the school**

In order to prevent the spread of SARS-CoV-2 infection, students, teachers and other employees who have signs/ symptoms of COVID-19 (according to Ministry of Health and local public health guidance) must stay home and decisions about testing and return to school should be guided by provincial public health guidance. In addition, return to school decisions for those who have had an exposure to SARS-CoV-2 should be in accordance with local public health recommendations.

## **Physical Distancing**

The objective of physical distancing is to reduce the likelihood of contact that may lead to transmission and has been a widely used strategy during the pandemic. In the school setting, several control measures can be put in place to encourage physical distancing, especially when prolonged exposure is expected (e.g. in the classroom). However, while physical distancing and its role in the prevention of infection transmission should be discussed with students of all ages, it is likely not practical to enforce strict physical distancing in elementary school children, especially during periods of play.

## **Non-medical and medical face masks for students**

Some children will be able to wear masks easily but others may have a harder time. Consider the following exposure and desensitization strategies

- Are you buying a mask? Try giving your child some of the newer child-friendly designs to choose from or get them to help decorate a pre-made mask.
- Are you making a mask? Let your child to choose material.
- Create an exposure hierarchy to understand your child's fears. From least scary to most scary it might be: seeing others wear a mask, seeing a mask, touching a mask, putting on a mask for short periods of time and putting on a mask for longer periods of time.
- Teach distraction strategies like distracting with music, videos, video games to help pass the time while wearing a mask.
- Practice calming strategies like deep breathing, going outside, going for a walk, etc.
- Consider motivating kids to get used to wearing a mask by pairing it with something they enjoy, like allowing video game time (within your limits) while wearing their mask.

Does your child or youth still have struggles with mask wearing, despite your best efforts? Consider seeing your health-care provider to see if there might be other options, including seeing if your child may have a valid medical exemption.

## **Cohorting**

The purpose of cohorting is to limit the mixing of students and staff so that if a child/youth or employee develops infection, the number of exposures would be reduced. It also allows for more timely case and contact follow-up. For example, a single class in Grade 1 could represent a cohort and they should avoid close mixing with individuals from other classes/grades in confined indoor spaces. Cohorting is likely most beneficial in elementary school children where physical distancing is less practical. For high school students, the need to take different classes may make strict cohorting difficult and, as a result, physical distancing should be emphasized. We recognize that this poses a significant infrastructure challenge for many schools. The benefits of cohorting will be attenuated in many, such as those who require bus transport to school and those who require after-school care; such children could potentially be present in several cohorts.

## **Environmental Cleaning**

SARS-CoV-2 has been detected on a variety of surfaces and survival depends on the type of surface. It is possible that infection can be transmitted via fomites by touching contaminated surfaces and then touching mucous membranes (i.e. mouth, nose, eyes). While fomite transmission is not the predominant mode of transmission, environmental cleaning and disinfection are important to reduce the risk of transmission of SARS-CoV-2 and other infections in schools.

## **Special considerations for children and youth with medical, physical, developmental and/or behavioural complexities**

Return to school will present unique challenges to children and youth with medical, developmental and/or behavioural complexities and their families. This includes children requiring intensive supports for activities of daily living and/or medical conditions, such as feeding, toileting or breathing supports. Many of these families have had a prolonged period of time in home isolation compounded by a lack of respite and/or homecare supports. In particular, the challenges for families and children/youth with neurodevelopmental disorders, such as autism spectrum disorder, caused by cessation of school during the pandemic have been identified. Transitioning medically and behaviourally complex children and youth back to school requires specific focus and should be prioritized as many of these children/youth and families have been disproportionately impacted by the pandemic response and are already in crisis mode. Consultation with their parents and families to better understand their individual circumstances and needs is recommended.

## **Mental health awareness and support for all students**

Stay connected to your kids. Kids do best when they feel loved by their caregivers, which happens when you spend quality time with them and listen, validate and empathize with their feelings (as opposed to seeing adults as being angry, upset, and emotionally unavailable to them). Model healthy coping. Kids do best when they learn healthy ways to cope with adversity, such as following public health recommendations with masks and physical distancing (as opposed to unhealthy strategies such as focusing on negatives and blaming).

Attach positive meaning to the pandemic. Kids do best when they can have a positive meaning of a situation. You might say: other hand, we how to cut each other.

## **Routines**

- Gradually get back into school year structure and routines. Bring up the topic that summer is coming to an end and that school will be restarting.
- Talk about routines. You might say: than usual, but now that school is starting up again, we
- Set a bedtime (and/or wake up time) and move it closer to what it should be for the school year.
- Set a screen curfew (a school-aged kids and 8:30-9:30 p.m. for high-school aged kids.
- Consider posting a family calendar with the school start date marked down, to help your family see how many days are left until school starts.
- Ask about routines to continue. during the school year? For example, regular family walks after dinner; family dance night, etc.
- Write down the new COVID-19 school-year schedule.

**Reasons to attend school include:**

- Your child learns best when physically at school.
- Your child benefits from seeing peers and other school activities, such as gym arts and music.
- School allows parents to work and provides access to meal programs and other services.

**Reasons to avoid physical return to school:**

- Your child (or someone living at home such as a parent or sibling) has an underlying condition (or age) that increases the risk for severe illness from COVID-19.
- The level of community spread is high in your area (which increases the risk of COVID-19).

**Reasons to consider virtual schooling from home:**

- Your child has someone that can supervise them at home.
- Your child has access to reliable technology (such as internet) for your child's virtual learning.
- Your child's virtual learning option gives opportunities for real-time interactions with the teachers (e.g., have live instruction).
- Your child's maturity and learning style are sufficient for virtual learning.

Source 1: <https://www.sickkids.ca/PDFs/About-SickKids/81407-COVID19-Recommendations-for-School-Reopening-SickKids.pdf>

Source 2: <https://www.cheo.on.ca/en/resources-and-support/resources/P6225E.pdf>



## ADJUSTING TO ONLINE LEARNING

Making the transition to online learning is stressful for everyone. This resource contains strategies you can use to adjust to this new mode of learning as quickly and smoothly as possible. As a result of moving to a fully online environment, you may be experiencing a number of changes and challenges, including:

- *Studying at home with family and roommates around, or living alone and feeling socially isolated without your usual social interactions.*
- *Trying to focus and stay motivated despite increased distractions and stress (academic, personal, health, financial).*
- *Changes to course evaluation methods and having to rapidly adjust to a different mode of learning.*
- *Staying on top of changes to course delivery as well as university policy updates.*

### **Differences Between Online and In-Person Courses:**

If you have not taken a fully online course before, you may notice some key differences from traditional in-person courses. Online courses offer flexibility and convenience, but you may find online learning to be more difficult compared to in-person learning as it may require extra time for studying, completing assignments, and monitoring your own learning. In addition, students can easily fall into the procrastination trap. Unlike what many believe, procrastination is not the result of a lack of willpower; relying on willpower alone could lead to poor results. To achieve your academic goals consider these tips:

- Maximize your study time.*
- Establish your daily routine.*
- Master the art of single tasking.*
- Design your environment for success.*
- Create a plan and set specific intentions.*
- Put yourself to the test.*
- Distribute practice.*
- Switch up the topics.*
- Prepare for open book exams.*
- Prepare for online exams.*

Source: <https://www.uts.utoronto.ca/aacc/adjusting-online-learning-and-taking-online-exams>

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## EXERCISING WITH LUPUS

We all know how important regular physical activity is at the best of times. In the era of the novel coronavirus, it's even more crucial. If you've found yourself sucked into the vortex of so many heartbreaking and just plain terrifying stories from every corner of the map, unable to sleep, pouring too many Quarantinis and/or contemplating day drinking, and generally feeling paralyzed by the end of the world as we know it, it's time to start (or resume) working out. Keep in mind some of the benefits of fitness on your physical health in general: better cardiovascular function and reduced risk of heart disease, diabetes, blood pressure, stroke, and cancer. The positive effects are way more extensive than that, and we're talking about the ones that can help offset the anxiety people are experiencing these days.

Source: <https://www.straight.com/life/1375581/covid-19-why-we-need-exercise-now-more-ever>

*Exercise is vital for people with lupus – but many workouts that you can find online can be too intense. Start with the basics and do what you can – but definitely do some exercises! It will be worth it.*

The core, the muscles of the torso, abdomen, help keep our posture straight and all of our limbs in the most efficient and least stressful positions for movement. When they are strengthened, basic movements become less tiring and keeping those muscles in shape can open a lot of doors for people with lupus. Please visit the website below by clicking the link for suitable exercising for people living with lupus.

Source: <https://lupuscorner.com/good-exercises-for-lupus-warriors/>



**Aurinia's Voclosporin** receives a priority new drug application review from the US Food and Drug Administration (FDA) for the treatment of Lupus Nephritis (LN).

Voclosporin is an immunosuppressant that blocks the IL-2 expression and T- cell-mediated immune responses in Lupus Nephritis. Voclosporin results in stabilizing the podocytes and reducing proteinuria. Clinical data from Phase II AURA-LV and Phase III AURORA have demonstrated significant improvements in renal function in LN patients, especially in Hispanic/Latino ethnicity patients.

Source: <https://ir.auriniapharma.com/press-releases/detail/187>

Source: <https://www.medpagetoday.com/meetingcoverage/eular/86928>

**AstraZeneca's Anifrolumab** demonstrated early and sustained reduction of disease activity in SLE patients in the Phase III Tulip clinical trial.

The Phase III Tulip trial on Anifrolumab (a monoclonal antibody that blocks type 1 interferons) evaluated the efficacy and safety of anifrolumab in autoantibody-positive SLE who are receiving standard of care. Besides meeting the primary endpoint, the Tulip 2 trial provides encouraging results for the efficacy of Anifrolumab in moderately to severe SLE.

Source: <https://www.astrazeneca.com/media-centre/medical-releases/anifrolumab-showed-early-and-sustained-treatment-benefit-for-patients-with-systemic-lupus-erythematosus-in-the-tulip-clinical-trial-programme.html>

**GSK's Belinumab** shows significant improvement in renal function in the largest Lupus Nephritis (LN) clinical study.

In the most extensive study to date, GSK's Belinumab (alongside Standard therapy) vs. placebo showed a significant improvement in LN renal response, such as renal filtration and urine protein creatinine. Moreover, Belinumab also demonstrated a favorable safety profile. The results were presented at the 2020 EULAR e-congress.

Source: [https://ard.bmj.com/content/79/Suppl\\_1/103](https://ard.bmj.com/content/79/Suppl_1/103)

Source: <https://clinicaltrials.gov/ct2/show/NCT01639339>

Promising clinical data from the clinical investigations of **Eli Lilly's Olumiant** were highlighted at the 2020 EULAR e-congress.

Olumiant (Baricitinib) is a JAK kinase inhibitor that is being investigated in SLE patients. It results from a Phase II clinical trial JAHH study, was presented at the 2020 EULAR e-congress. In the Phase II clinical trial, a 4mg dose of Baricitinib showed an improvement in SLE patients who weren't responding to the standard care.

Source: <https://www.lilly.ca/en/newsreleases/articles/20.06.10-eular-2020-olumiant-news-release-en.aspx>

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## RECIPES



### Arugula Pesto Pasta Bowl with Broccoli

**PREPARATION: 10MIN**  
**COOKING: 20MIN**  
**READY IN: 30MIN**

#### Ingredients

##### *For the Pesto:*

- ½ cup of raw pecans
- 2 cups fresh basil leaves stems removed
- 1 cup of fresh arugula
- 2 small garlic cloves
- Zest and juice from 1-2 lemons (depending on size)
- 2 tablespoons nutritional yeast
- Salt and pepper to taste
- ¼ cup extra virgin olive oil

##### *For Roasted Broccoli:*

- 2 heads of broccoli cut off the stem and cut into small pieces
- 2 tablespoons avocado oil
- Salt, pepper and garlic powder to taste

##### *For the Pasta:*

- 1 box gluten free pasta
- 1 big handful of arugula about 1 to 1 ½ cups
- Garnish: hemp seeds, vegan parmesan, and sprouts

#### Directions

- 1** Preheat oven to 400°F. Line a large baking sheet with parchment paper. Place the chopped broccoli on the baking sheet and drizzle with avocado oil. Sprinkle on your spices and use your hands to toss to combine, making sure all of the broccoli is lightly coated in spices and oil. Roast for about 20 minutes, or until lightly browned.
- 2** Bring 6 cups of salted water to a boil in a large pot. Add the pasta and cook according to package directions.
- 3** For the pesto. Combine all of the ingredients in a food processor or high-powered blender. Pulse on low speed until the ingredients come together. Make sure to scrape down the sides if you're using a food processor. If you're using a blender, keep the motor on low and use a tamper/scrape down the sides to make sure your pesto doesn't become too smooth and pureed. You want the ingredients broken up into little bits, but not completely smooth. Taste, and adjust salt, pepper, and lemon to taste.
- 4** Once everything is finished, add the broccoli and pesto to the pasta, along with a big handful of fresh arugula. Stir together over very low heat to warm everything up and help wilt the arugula. Once the arugula is wilted, you're ready to serve. Add to bowls and garnish with hemp seeds, sprouts, and vegan parmesan cheese.

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

Source: <https://www.bakerita.com/arugula-pesto-pasta-bowl-with-broccoli-gluten-free-vegan/>

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