

## LET'S TALK LUPUS

February Monthly E-Newsletter



Hello February! Well we did it, we made it through the first month of 2021. Lupus Canada wants to remind everyone of everything we have achieved together. We have learned how to work differently, to love unconditionally and to adapt to an everchanging environment. Let's continue to spread positivity and hope this month. Even though across Canada the rules and regulations around COVID for each province may vary we all must stand together and do our part in helping reduce the spread of COVID-19!

As we look forward to celebrating Valentine's Day and Family Day this month we need to look to alternate ways to express our love to those who mean the most to us. There are so many at home activities that your family or household can do together that are safe. In this e-newsletter we have provided some unique ways to celebrate Valentine's Day and Family Day with your loved ones while staying safe.

This February remember the importance of love and extending that love to others!

Together we stand while staying apart! #LupusCanadaCares!

**GIVE HOPE TODAY**  
your gift makes a difference



## **ADVOCACY WORKSHOPS**

Do you want to learn how to better advocate for you and your needs? Join Lupus Canada's new advocacy workshops. Throughout 2021, we will be holding a series of workshops to strengthen your advocacy skills so that you are able to communicate to others what you need to manage your lupus.

Topics to include:

**Advocacy 101:** What is advocacy and how to become a successful self-advocate

**Advocacy At Work:** How to successfully advocate at work for your lupus needs

**Advocacy and Your Healthcare:** How to advocate to get the best support from your healthcare team

Each workshop will provide skills, tips and tricks on how to become a successful self-advocate, taught by experts.

Do you have an advocacy topic you want to learn more about? Email us your ideas at [info@lupuscanada.org](mailto:info@lupuscanada.org).

Follow us on Twitter, Instagram, Facebook and LinkedIn for more information on our first webinar!

---

## **LUPUS CANADA 2021 CATALYST GRANT PROGRAM**

# LUPUS RESEARCH

## LUPUS CANADA LAUNCHES NEXT COMPETITION FOR CATALYST GRANTS



***One Catalyst Award for a total of \$35,000 CDN\* to fund one project for a term of one year.***

Lupus Canada has partnered with The Lupus Foundation of America for the second 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 systemic 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).

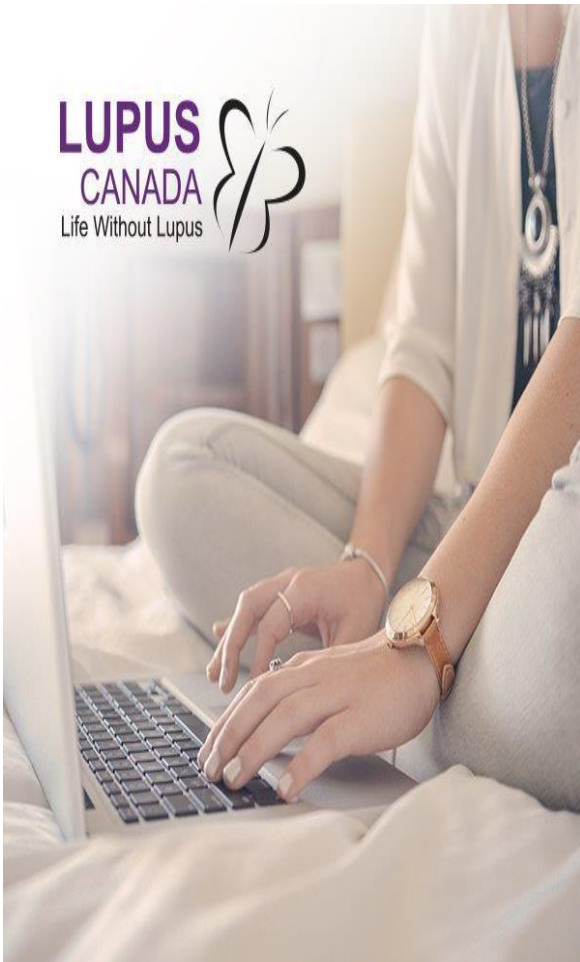
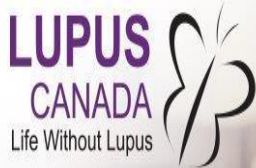
*\*subject to USA/CDN exchange rate at the time of the award*

**Applications are due April 16th, 2021 at 5PM EST**

*To learn more about the Catalyst Grant and how to apply, please visit*

[lupus.org/research/apply-for-funding](https://lupus.org/research/apply-for-funding)

---



## 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 will announce our 2021 Scholarship program in within the next few weeks. Be sure to follow us on Instagram, Twitter and Facebook, with the handle @LupusCanada, for the latest information regarding the Lupus Canada Scholarship's application, regulations, and winners!



## LAUNCH OF ENGAGEMENT - NATIONAL STRATEGY FOR HIGH-COST DRUGS FOR RARE DISEASES

Source: <https://www.canada.ca/en/health-canada/news/2021/01/canadians-invited-to-share-their-views-on-a-national-strategy-for-high-cost-drugs-for-rare-diseases.html>

Canadians are invited to share their views on a National Strategy for High-Cost Drugs for Rare Diseases. The federal, provincial and territorial officials are working closely to build a strategy that works for all Canadians in the context of Canada's health system and respect the role of provinces and territories in health care delivery. To learn how you can participate please [visit the engagement webpage](#) and read the [discussion paper](#).

**Engagement Webpage-** <https://www.canada.ca/en/health-canada/programs/consultation-national-strategy-high-cost-drugs-rare-diseases-online-engagement.html>

**Discussion paper-** <https://www.canada.ca/en/health-canada/programs/consultation-national-strategy-high-cost-drugs-rare-diseases-online-engagement/discussion-paper.html>

---

## CANADIAN BENLYSTA PATIENT SUPPORT PROGRAM

BENLYSTA is a prescription medicine used to treat adults with for patients with active systemic lupus erythematosus (SLE or lupus) who are also receiving other medicines for lupus. It is not approved for use in children less than 18 years of age.

For appropriate patients, a Patient Support Program is available and provides specialized services including navigation of insurance coverage, financial assistance (co-pays), coordination of infusions or injection training, adverse event reporting, and support with adherence.

For treatment options specific to your well-being please contact your physician.



### **The Importance Of Love And Affection In Your Life And Relationships**

Human beings are social creatures by nature. Some of us may be more needy or outgoing compared to others, but at the end of the day, we're all wired for engaging in social interactions with those around us. Sometimes a person needs to be surrounded by numerous friends and constant communication with others, and sometimes an individual is content with just their family members or a few select close friends. These needs vary depending upon the individual and their lifestyles, experiences, and preferences, but to go without some form of love and affection in our lives can cause problems along the way, especially if this lack of support and interaction begins at a younger age.

#### ***What Does Love Look Like?***

Love can take many different forms, and these variations can intermingle or exist separately on their own depending upon the individual. In the context of coinciding with affection, though, the relevant types of love would mainly be romantic, platonic, friendly, or familiar. These are the types of love that involve the interaction of a positive manner with another

individual. For some, romance is the epitome of love and fills their needs for a passionate form of intimacy with another person. For others, their friends may be the best form of love for their lifestyle, providing them with plenty of close relationships that are like a family they've chosen for themselves. Families are a fantastic example of familial love, which may not always be appealing in that it's the kind of love where you feel strongly for a person but don't always like them (think siblings or parents-they can sometimes drive you crazy!). But familial love can provide the strongest feelings of support when healthily maintained because the relationships are often lifelong and provide ample opportunity for deep bonds, trust, and understanding. Some people may even find the deepest feelings of love to be for their pets, and animals have long been proven to be beneficial to people's mental and physical health regardless of age.

### ***Why We Need Love***

Human beings thrive off of social interaction and forming relationships, regardless of whether it's with a friend, a relative, or a pet. People have an inherent need for experiencing strong bonds and needing love to avoid the detrimental effects of real or perceived isolation and abandonment. The type of love an individual craves determines the course of their entire lives and futures, and without it, it's very likely that a person will completely lack any drive to bother doing anything with their lives and may experience depression and other health concerns.

Those who desire families will be provided with a lifetime of experiencing the joys of parenthood and often marriage as well. Individuals who enjoy meeting others will pursue a lifestyle that allows them to come across many different people from many different backgrounds and have a variety of relationships and experiences expanding their understanding of other human beings and other cultures. Those who aim for finding romance are satisfying their physical needs regarding the inherent impulses to procreate, as well as enjoy the thrills of passion and intimacy with another individual. People who love animals may not only be able to provide a loving home for a pet in need, but they can also reap the benefits of that often unconditional and loving bond. Pets have even been proven to lower stress levels, improve blood pressure levels, and help boost emotional and social development in children. Oddly enough, even a love of something material such as money has its benefits when it comes to inspiring people to work hard to achieve their goals and succeed in the financial world.

### ***What Does Affection Look Like?***

Affection can be defined as "any touch intended to arouse feelings of love in the giver and recipient." This can be anything from a kiss with your significant other or spouse to holding hands with someone close to you. A hug, holding a puppy or a baby, or even just stroking someone's arm or back qualifies as physical affection, and all of these are done with the intent to express our love for another person (or animal, for the pet owners). Even among friends, a hug or a pat on the back signifies positive emotions for the other individual, and all of these gestures are necessary for building strong bonds in our relationships.

### ***Why We Need Affection***

To love and to feel loved is important, but to express those sentiments and be the recipient of such actions confirming love are essential in cementing the beliefs of such emotions and the bonds with those close to us. Gestures of affection help an individual more easily feel the

love that someone has for them, and as stated in the studies referenced above, physical touch is practically a necessity for human wellbeing and meaningful relationships.

In romantic relationships, a lack of affection or intimacy can cause doubts and feelings of neglect in a partner and lead to conflicts and concerns. It's okay to tell your partner, "I need love and affection in this relationship," because those two factors are the backbone of a healthy bond to last you a lifetime and it is expected when dating or exclusively being involved with another person, especially in more serious and long-term commitments. Family members have close bonds with one another when they're comfortable with showing their emotions via hugs and other forms of physical contact, and this especially applies to children, who learn to express themselves better as well as feel validated when receiving affection from their parents, siblings, and other relatives. Friendships may not always require as much affection to be still strong, but small gestures of an appropriate nature expressing your love and appreciation of someone close to you can go a long way in deepening the level of trust, comfort, and closeness you share with that other person.

Source: <https://www.betterhelp.com/advice/love/the-importance-of-love-and-affection-in-your-life-and-relationships/>

## ARTICLES

### FAMILY TOGETHERNESS DURING THE PANDEMIC

Some of the best parenting advice I ever received was: "When it rains, play in the rain." There are ways of making the best out of any situation, this one included. We have a unique opportunity here: We can make the COVID-19 crisis into a moment that will live vividly in our kids' memories, so that in other times of uncertainty they'll recall fondly how their family pulled together and made the best of things, and they'll be able to do the same.

Click the link below to find 250+ creative ways to keep your family sane during the COVID-19 crisis including some of these topics:

- *Games and Activities*
- *Clean / Fix*
- *Plan*
- *Cook*
- *Science Experiments*
- *Arts & Crafts*
- *Perform*
- *Outside your Perimeter: Driveway, Yard, Garden, and Beyond*
- *Links to Online Fun and Learning*
- *Surprise! You're Homeschooling! Here are tips for success.*
- *Operation Storytime*
- *Virtual / Online Event Calendar*

Source: <https://toronto.kidsoutandabout.com/content/250-creative-ways-keep-your-family-sane-during-covid-19-crisis#games>

## 6 WAYS TO CELEBRATE VALENTINE'S DAY DURING COVID-19

Celebrating Valentine's Day during the COVID-19 pandemic doesn't mean you can't have fun. Here are some ways to enjoy yourself on February 14.

Valentine's Day isn't only about dating, chocolate and roses. February 14 is also a day to celebrate all of the loving relationships in your life, from yourself to friends to family. Here are some ways to enjoy yourself on February 14 this year:

### 1. Send virtual valentines

Whether you're single or in a dating relationship, you can take part in Valentine's Day celebrations. Sending virtual valentines (or fun memes or photos) to your friends, classmates, community members, siblings or co-workers can be a lot of fun and a great way to make someone feel good. You can also try making your own with craft supplies and send them through the mail.

### 2. Hang out with loved ones

Spend some time (following local health and safety guidelines) with your family, friends and anyone else you love to let them know how much you care about them. There are lots of ways to stay connected and spend time together during the COVID-19 pandemic.

February 14 can also be a great day to try reconnecting with an old friend. Consider reaching out to someone you'd like to get in touch with again by phone, email or social media.

### 3. Focus on yourself

Like any other day, February 14 can be a good time to practise self-acceptance, work on your self-esteem and think about being more hopeful. You can make a list of the things you're good at, what you're most proud of so far and what your goals are. Doing these activities can help you improve your relationship with yourself and create intentional space to be kind to yourself!

### 4. Treat yourself

Is there a better way to celebrate Valentine's Day than practising self-care? Here's some inspiration to get you thinking about how you'd like to treat yourself during the coronavirus disease outbreak:

- *watch your favourite movie or TV show*
- *read a good book*
- *take a bubble bath*
- *shop (following local health and safety guidelines) for something you've been saving for indulge in your favourite food*



- *try journaling*
- *paint or draw*
- *dance to your favourite music*
- *spend time in nature*

### **5. Remember, it's just another day**

Everyone has different opinions on (and preferred ways to spend) Valentine's Day. Some people are more into celebrating it than others. It may help you to remember that February 14 is just another 24 hours that will come and go. You don't have to participate in the festivities if you don't want to — it's OK to maintain your regular routine as if it's any other day.

### **6. Get support**

If you're feeling down on Valentine's Day (or any other day of the year), it's important to get support. Talking about things can help — you can reach out to a friend, relative, Elder, counsellor, teacher or anyone else you trust. You can also contact Kids Help Phone to talk about what's going on for you.

Valentine's Day doesn't have to be about dating relationships. Celebrating the other loving relationships in your life, especially the one with yourself, is a great way to spend February 14.

Source: <https://kidshelpphone.ca/get-info/6-ways-to-celebrate-valentines-day-during-covid-19>

## **10 WAYS TO CELEBRATE FAMILY DAY WITH YOUR LOVED ONES**

Family Day is fast approaching! Below are a list of activities for you to enjoy with your loved ones. You don't need to do anything elaborate to enjoy their company. A simple activity is the perfect way to spend the day.

If you're looking for some inspiration, here are 10 easy activities you can do on Family Day:

### **1. Make breakfast together.**

A celebration calls for a good start to the day. There are lots of kid-friendly recipes you can choose from or you can use mixes to make things easier. No matter what you end up making, note that it will taste extra good because you made it as a group.

### **2. Make your own cards.**

A store-bought card can never express how you truly feel about your relatives. Instead of having everyone run around in secret buying cards, encourage everyone to come together and make a group craft project out of it. Don't forget the glitter and markers.

### **3. Go out and enjoy the weather.**

It's probably a bit chilly where you are, but that doesn't mean you have to stay inside. Think of Family Day as a guaranteed snow day. Grab the toboggan and items to build a snowman and get playing.

### **4. Take cheesy family portraits.**

Did your family get professional photos done? Or have you been trying to do it forever? Instead of serious portraits, grab some various props and have your own photo shoot at home. It will feel way less awkward than a formal session. Plus, you'll have some amazing photos for Instagram.

### **5. Have a family movie marathon**

Grab some popcorn and sit back and enjoy reminiscing about some of your old holidays. Alternatively, you could have each person in the family select their favorite movie and you can take turns watching those.

### **6. Don't forget about your pets.**

You probably consider your pets to be part of the family so include them in your celebrations. You can gather up the whole brood and take your dog for a walk or you can all snuggle up with your cat by the fire.

### **7. Make your own scrapbooks.**

Instagram and Facebook are great for scrolling through photos, but they're not quite the same as flipping through the pages of an actual scrapbook. Print out some photos and have your relatives create their own one-of-a-kind scrapbooks.

### **8. Create a tradition.**

Chances are your family probably already has some great traditions. However, there is always room for another one. Think about something fun you can do each Family Day and try and commit to doing it every year. Write it down on a calendar so you'll remember it next year.

### **9. Bust out the games.**

There's nothing like an afternoon of fun. It doesn't matter whether your family is into board games, puzzles, or karaoke. Grab all of the fun activities you can find and have everyone pick and choose what they want to do.

### **10. Create a time capsule.**

Even if you have relatives who write diaries, they're not the same as creating a group time capsule. Ask everyone to bring something special that will fit in an empty shoe box or pop bottle. Then hide the time capsule away for a few years. When you're celebrating Family

Day five years from now, you will be able to look back at all of the things you were into in 2017.

Source: <https://www.influenster.com/article/family-day-ideas>

## THE DYNAMICS OF RELATIONSHIPS

Whether you consider your family as the family you were born or married into, the one you've created with your partner or spouse, or one you've hand-picked from close friends over the years, the strong support system these people provide in your life is as vital to your health and well-being as any medication that may be prescribed to treat your lupus. Keeping these relationships rewarding, however, takes time and tender loving care.

Knowing that change is inevitable and knowing how to communicate effectively about your feelings can maintain the harmony and balance of these relationships while making sure your needs are met when you have lupus.

In "Managing Other People's Feelings When You Are Ill", we talk about acknowledging your own feelings as well as the feelings of those around you and how difficult that may be. A little effort up front, however, can make a huge difference later when you may not be feeling up to par. Setting the framework for effective communications and realistic expectations will help to ensure that your relationships stay strong and loving.

### **Changing Dynamics: How Expectations and the Role You Play in Your Relationships May Change with a Lupus Diagnosis**

Your kids may run to you as the one who helps them with their homework. Your partner or spouse may rely on you to do the grocery shopping, fix the car or clean the house. Your friends may expect you to plan road trips or nights on the town. With a lupus diagnosis, however, those roles and expectations may have to change to some degree. The question is, how to take this opportunity – create healthy, new expectations for whatever changes need to occur in your relationships and even make them stronger?

First and foremost, it's important to try to not feel guilty about changes in your role as a member of the family. You have to take care of yourself and make yourself a priority – maybe for the first time in your life – in order to, in turn, be there for others. Second, you may have to change how you communicate with your loved ones in order to be heard and ensure needs are met – developing assertiveness skills is a boon. Third, you need to get comfortable telling others exactly how you are feeling and asking for help – you may have to ask your spouse or partner to pick up dinner, your kids to do their own laundry, or your friends to drive you to an event. This will undoubtedly be awkward at first, but in time you'll develop a routine and it should become second nature and the "new norm" for all involved.

### **Starting the Discussion – How to Talk about Lupus With Your Family and Other Support Systems**

Chances are that your support system doesn't have the knowledge about lupus that you do, and you may not even always fully understand what you're experiencing. The people who love you may honestly be afraid for you of what your lupus diagnosis means – any change especially where health is concerned can cause anxiety. In "How Lupus May Affect My Life",

the Lupus Foundation of America suggests starting with the basics of lupus to open the conversation of what you are experiencing:

- *Lupus is not contagious.*
- *Lupus is not necessarily hereditary.*
- *Lupus is not like or related to AIDS or cancer – it is an autoimmune disease where the body attacks itself as a foreign body..*
- *Lupus is a chronic, life-long disease for which there is no cure, but there are viable treatments. Many people who have lupus are able to live full, happy, productive lives.*  
*Individuals with lupus all experience the disease differently and how you experience it may change – it's unpredictable.*
- *Lupus may present itself in skin rashes, or it can present internally and affect the kidneys, heart, or other internal organs. In other words, you may look perfectly healthy, but feel sick.*
- *Because of lupus, you may have to make some changes in your life and family and support roles may change. It's important to come to terms and accept that change is inevitable.*

The biggest takeaway here is to eliminate fear of the unknown. Once everyone becomes less afraid of lupus, energy can be spent on how to make the changes that need to be made in order for everyone to live more comfortably with this disease.

### **Communicating with Your Spouse or Partner**

As your spouse or partner may share in the raising of your family and the day-to-day operations of the household, it's important to keep the lines of communication open. R. Morgan Griffin of WebMD recommends talking openly and honestly about how your diagnosis makes each of you feel and how it impacts day-to-day life. Avoiding the topic altogether can be incredibly detrimental to your relationships. Griffin also recommends, however, that if you are having a hard time speaking about your feelings and lupus, seek therapy in order to gain effective coping and communication skills as a couple or family. It's important for everyone to know how to ask for what they need, know when to give encouragement, and even know when to give each other space. How you, as partners, communicate will impact how your family communicates as a whole. For more information on the unique communication skills around intimacy with your spouse or partner, read "Lupus and Intimacy."

### **Communicating with Your Friends and Extended Support System**

The same communication guidelines above go for communicating with your broader support system – they are still people who love you and care about you. It is equally important to make sure that your friends understand lupus and what changes to expect. It's important for them to know that late night parties may be out of the question for you, but brunch on Sunday is a great substitute. When you were once able to drive yourself around town to meet up with them for dinner, you may now need to coordinate rides with someone. You may occasionally even have to ask friends for help – you may need help with childcare, picking up the dry cleaning, or need a ride to a doctor's appointment. Chances are your friends will be more than willing to help when they can as long as they know what the expectations are and understand why. Be clear and – much like with your children – don't over-burden them. Rather, make them feel comfortable to express their ideas and feelings.

## **Communicating with Your Children**

As a parent with lupus, it's important to try to not feel guilty about your disease or how it may change your life and your children's lives – you may need their help more than usual around the house on certain days when you're experiencing symptoms or a flare. It is a delicate balance and you want to make sure your children feel heard as well. As you gain communication skills, be sure to teach them how to effectively express themselves and make them feel comfortable about coming to you when they feel troubled. WebMD suggests some of the following for reducing your own stress around lupus as well as the stress your children may experience:

Let your kids ask questions – children are naturally curious – and may be scared when they know you're not feeling well. Let their questions guide the conversation in a reassuring way. This practice should be on-going, and let your kids know that it's okay to ask honest questions as they come up.

Make expressing how you are feeling each day simple – devise a number rating system and write it on a chalkboard or white board in the kitchen or wherever your family centrally gathers. "1" may be a great day with minimal symptoms or "10" may be a bad day when you're going to need a little extra help around the house. A number may be more impactful to a child than a longer explanation that may confuse or scare them.

Create new traditions with your children – create low-stress ways to spend family time together even when you may not feel up to par or feel like leaving the house. Designate Saturday nights as "movie night," or Sunday afternoons as "game day." Even if you're experiencing lupus fog a rousing game of Jenga may seem overwhelming. Just being near your family on the couch or at the table is an expression of engagement and love.

## **In Conclusion**

While your relationships will change to some degree, they may also be greatly enriched. Developing patience, understanding, and effective communication skills will go a long way in sustaining and maintaining the loving relationships that you've all worked hard to create. Being authentic, open, and vulnerable will enable others to do the same. Yes, the dynamics may change, but your relationships, family, and support systems may become more resilient as they are built on a strong foundation of trust, support, respect, and love.

*Source:* <https://kaleidoscopefightinglupus.org/dynamics-relationships-lupus-family-support-systems/>

## My Lupus Story

### LIFE WITHOUT LUPUS

I think for generations, we have been taught that our productivity determines our worth; if you're not doing more, you're not aiming high, you're not refining a skill, then you're not doing enough. So, for years, this is how I came to know myself.

Since kindergarten, I have always loved and done well in school. And I sure got the praise for it too from my family members – "Maahum is going to be the one to do big things" or "make sure you're always being the best." I began to internalize these things a lot, to the point of not allowing myself to rest or to accept failure. And it wasn't until I found out I had lupus that I realized how damaging this way of thinking of myself would be for me.

In November of 2018, when I was 19 years old, I began experiencing my first bit of symptoms. Obviously, nothing showed up on ultrasounds, so I focused on school and other responsibilities. But, by May 2019, my health took a nosedive and I became very ill very quickly. I remember countless visits to the hospital and doctors' offices who would not advocate for me. I remember yelling because I was in pain and there were doctors who made me feel like it was in my head or I was exaggerating the constant pressure I felt all over and inside my body. I have experienced being brushed off by male doctors before, but this time I refused to put up with it. So, I went to a different hospital and demanded to be taken seriously and by July 2019, I found out that I had Systemic Lupus Erythematosus.

I remember feeling relief flush through me because for the first time, a doctor, my current rheumatologist, did not invalidate what I was feeling and could understand the pain I was in. But, while I was caught up in feeling heard, I did not realize that this was only the beginning of what would be an uphill battle for me.

Since my diagnosis, I have watched my body change into one I don't know or recognize on some days. There are days where I love the way I look and days when I hate myself. I lost and gained weight, my skin cracked and peeled, there were hot flashes, muscle pains, and constant fatigue. In the months following my diagnosis, I experienced extreme hair loss, not just on my head, but my eyebrows, lashes, and body hair too. But the hair loss on my head is what hurt me the most. We understand our femininity so much through the way our hair looks – it's a blanket of comfort and what we are told is beautiful. Seeing hair on my pillowcase every morning, on my floors, in my car, it felt like watching my femininity get stripped away. And the thing is, it is not superficial, it is a grievance. I cried a lot going to

school, and if it were not for my family reminding me that I am so much more than my hair, I really don't know where I would be today.

But what hurt even more than seeing my body change was how I could no longer understand myself how I once did. As I mentioned, we often perceive ourselves as products of what we accomplish. With my body needing constant breaks when studying or going to work, or even just hanging out with my friends, it was so difficult to reconcile my identity with being a person that has a chronic illness. I find it very difficult now to focus on what people are saying; I often cannot process it unless it is written down and I read it over multiple times. I've also become very forgetful – I remember realizing that I was constantly forgetting things and Googled it – apparently "lupus fog" is a thing??? I was convinced that I would no longer be the Maahum who was going to do big things. I was never a person who liked asking for help or extended deadlines or any sort of accommodations, but this is what I had to learn to become. Because being this person is absolutely okay!

I am 21 years old today, in my fourth year at my university and getting ready to go to Teacher's College in September. I am also working from home (grateful for this during a pandemic) and doing social justice and advocacy work on the side, something I reserve a lot of passion for. In other words, I am doing everything and more because, what I realize now is that, being diagnosed with lupus did not mean I wouldn't be able to do big things. I just means that I take breaks and I sleep on time and I take my medication and I go on walks. It means that I swallow my pride and ask for help when I need it because I suck at this (LOL). And it especially means that I wake up every morning, look in the mirror, and tell myself I am a bad bitch. I have quite literally become my biggest hype-woman since my diagnosis, and I am honestly so grateful for it. I have learned to be kinder to myself and to know my limits.

In no way is this meant to romanticize the experiences of lupus. I have spent days in bed just throwing up or feeling really sad about being so young with a chronic illness. There are some incredibly difficult days that you have to pick yourself up from. There are also days where you just can't be picked up. But you really have to take it one day, one task, at a time.

I am still moving through my diagnosis slowly and it really is an uphill battle. My recommendation is to start off your day with a dance party to "The Tide is High" by Atomic Kitten and remind yourself that you are still the main character, not your lupus!!!





## Thai Pineapple Fried Rice

PREPARATION: 15MIN

COOKING: 10MIN

SERVES: 2-4

### INGREDIENTS

- 2 tablespoons coconut oil or quality vegetable oil, divided
- 2 eggs, beaten with a dash of salt
- 1 ½ cups chopped fresh pineapple
- 1 large red bell pepper, diced
- ¾ cup chopped green onions (about ½ bunch)
- 2 cloves garlic, pressed or minced
- ½ cup chopped raw, unsalted cashews
- 2 cups cooked and chilled brown rice, preferably long-grain
- brown jasmine rice
- 1 tablespoon reduced-sodium tamari or soy sauce
- 1 to 2 teaspoons chili garlic sauce or sriracha
- 1 small lime, halved
- Salt to taste
- Handful of fresh cilantro leaves, torn into little pieces for garnishing

### DIRECTIONS: STOVE INSTRUCTIONS

Heat a large wok or non-stick frying pan over medium-high heat and place an empty serving bowl nearby. Once the pan is hot enough that a drop of water sizzles on contact, add 1 teaspoon oil. Pour in the egg and cook, stirring frequently, until the eggs are scrambled and lightly set, about 30 seconds to 1 minute. Transfer the eggs to the empty bowl. Wipe out the pan if necessary with a paper towel.

Add 1 tablespoon oil to the pan and add the pineapple and red bell pepper. Cook, stirring constantly, until the liquid has evaporated and the pineapple is caramelized on the edges, about 3 to 5 minutes. Add the green onion and garlic. Cook until fragrant while stirring constantly, about 30 seconds. Transfer contents of the pan to your bowl of eggs.

Reduce the heat to medium and add the remaining 2 teaspoons oil to the pan. Pour in the cashews and cook until fragrant, stirring constantly about 30 seconds. Add the rice to the pan and stir to combine. Cook until the rice is hot, stirring occasionally, about 3 minutes.

Pour contents of the bowl back into the pan and stir to combine, breaking up the scrambled eggs with your spoon. Cook until the contents are warmed through, then remove the pan from heat. Add the tamari and chili garlic sauce, to taste. Squeeze the juice of ½ lime over the dish and stir to combine. Season to taste with salt and set aside.

Slice remaining ½ lime into 4 wedges. Transfer the stir-fry to individual serving bowls and garnish each bowl with a lime wedge and a light sprinkle of cilantro. Serve with bottles of tamari and chili garlic sauce or sriracha on the side.



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

Source: <https://cookieandkate.com/thai-pineapple-fried-rice-recipe/>

---


## Visit Our Website


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

---

### STAY CONNECTED:



 615 Davis Drive Suite 306  
Newmarket, ON L3Y 2R2

 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  
306-615 Davis Drive, Newmarket, ON L3Y 2R2