

# Let's Talk Lupus

Monthly E-Newsletter

February is a month of spreading love and celebrating family with Valentine's Day on the 14<sup>th</sup> and Family Day shortly thereafter on the 18<sup>th</sup>. In some provinces, Family Day means a day off work for parents and no school for the kids. More importantly than that however, we can appreciate the people closest to us and thank them for their support. For many people living with lupus, family members make up a huge part of an individual's support system as these people are often the ones we call when we need help. So, with the whole family at home, be sure to do research into some local events that your community is offering for the holiday!

In this month's newsletter, we bring you some information on why exercise is important for lupus patients and how to modify certain fitness routines for you. If you experience arthritis and other physical symptoms of lupus, don't feel like you have to give up working out – this can actually be great for your health, as long as you go at your own pace!

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## ***French experts publish the Top 10 Contemporary Challenges in Lupus***

A prominent group of French specialists led by Laurent Arnaud, MD, PhD, of the University of Strasbourg (France), recently held a roundtable to identify the most important challenges faced today by researchers, patients, and clinicians. These challenges focused on improvement in treatment (limiting steroids, and developing more effective drugs); improving the tools that are used to assess lupus activity; understanding the complexity of both genetics and biomarkers; and holistic management and coordination of pregnancy, fertility and comorbidities (such as cardiovascular disease). It is important to note this list is about challenges with 'management' of lupus, rather than the top issues raised by lupus patients. The full

article is available online in Lupus: Science & Medicine

<https://lupus.bmj.com/content/6/1/e000303>



**LAUGHS FOR LUPUS**  
**MAY 9 • 2019**

**GUESTS OF HONOUR**  
**PATRICK MCKENNA**  
**DEBRA MCGRATH**  
**COLIN MOCHRIE**

**LUPUS CANADA**  
Life Without Lupus

TICKET #

DOORS OPEN AT 7PM SHOWTIME AT 9PM  
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VISIT [LUPUSCANADA.ORG](http://LUPUSCANADA.ORG)  
FOR MORE INFORMATION

TICKET PRICE \$150<sup>00</sup>

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***Laughs for Lupus*** tickets are now available!

Join special guests Patrick McKenna, Colin Mochrie and Debra McGrath in support of those living with lupus. ***Laughs for Lupus*** will be held at Second City in Toronto on May 9, 2019.

To purchase your ticket please visit our website at [www.lupuscanada.org](http://www.lupuscanada.org) or call Lupus Canada at 1 800 661 1468! Get your tickets today before they sell out!

## ***My Lupus Story by Jillian McMackin***

September 25 marked my four year anniversary of being diagnosed with SLE (it's much easier to say systemic lupus erythematosus) or just lupus. It is often called the disease with 1000 faces, because no two cases are the same. The first question I usually get is, what the heck is it? My immune system that is supposed to fight off infection, actually attacks different tissues in my body, causing swelling, fever, INSANE AMOUNTS OF FATIGUE and unbelievable pain in your joints. At 16 years old I couldn't imagine what the hell was going on with my body, why I couldn't get out of bed, why I was no longer able to play an entire soccer game, or why I couldn't sit through a single class without being in excruciating pain. It hurt to walk, sit, breathe. Everything hurt.



After X-rays, bloodwork, and many doctor's appointments, my rheumatologist concluded that it was lupus and officially diagnosed me. The worst part was knowing that there was no known cause of it, and there was also no cure. At 16 years old,

hearing that you're going to be stuck with a chronic condition for the rest of your life sucks. A lot. I can't tell you how many nights I sat with my mom, crying and screaming from the pain mixed with my frustration. The next question I usually get is "is it going to kill you". It won't kill me itself, but complications from the disease like kidney failure, blood clots, etc. might. But hey that's what medication and healthy living is for right? I'm not going to lie, it's absolutely terrifying knowing that my kidneys could start to fail and I'd need a transplant or dialysis (listen to Selena Gomez's story on this) but I try not to think about that too much. I've learned that focusing on the negative only makes things worse, so why dread on what COULD happen when you could focus on what you're doing with your life NOW?

It's hard to describe to people how I'm feeling when I'm honestly so exhausted that I could sleep 16 hours of the day and the other 8 hours include pain levels ranging from slight to intense. As much as it may seem like an over exaggeration, it is far from it. Over tiredness combined with stress is a common cause of a flare up and ironically, I decided to tackle nursing school where these two things are the base of its existence. Don't get me wrong, there are days when I feel absolutely horrible and can't be bothered to drag myself out of bed, but I do. This disease is not just physical, it's a mental battle. It's discouraging to know that I'm not able to do everything that I want to because of this disease, but through the last four years of weekly/biweekly/monthly blood tests, doctor's appointments, medications, and other obstacles, I have discovered a different part of me. I am so much stronger because of my diagnosis, and honestly, some days I forget I even have it.

Thankfully, through the use of medication (and there's lots of them) and the amazing support from family and friends, I have been able to live a pretty normal life. I'm so thankful that my good days outnumber the bad days. Taking care of myself has been key to remission and I'm hoping that I don't have a flare for a long time. Sure, taking meds everyday sucks big time but I'm healthy and not alone. Around 5 million people live with lupus worldwide (I'm sure everyone knows about Selena Gomez) and each person battles it differently. Even if someone "doesn't look sick", that doesn't mean that they aren't fighting an internal battle day in and day out.

Sorry for the long, sappy post but I am just so proud of the person that I've become! Last year I received one of the Lupus Canada scholarships awarded to students battling this disease throughout their post-secondary education and it felt amazing to be recognized for my hard work. I'm very happy to say that I'm kicking lupus' butt and I'm honoured to be part of the Lupus Warriors who fight every day through this tough battle 🍀 you are not alone!

**What's your lupus story? We'd love to hear it.** Send us your thoughts and experiences to be featured in Lupus Canada's national monthly e-newsletter. Email your stories to [leanne.mielczarek@lupuscanada.org](mailto:leanne.mielczarek@lupuscanada.org)

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**Lupus Canada: Ask the Experts**

***With arthritis, it is really hard to exercise, but I know it is important to keep active. What can I do?***

Source: <https://www.lupuscanada.org/ask-the-experts/>

The first step that must be taken when starting an exercise routine is determining the type of arthritis that is present. People may have both osteoarthritis and rheumatoid arthritis, or they may experience only one at a time. In both cases, exercise is thought to be an excellent way to treat the pain and the loss in range of motion.

Osteoarthritis is usually the result of wear and tear, while rheumatoid arthritis is caused by a malfunction in the body that causes it to attack itself. According to Fischman and Hobson (2005) there are nine ways to help fight both types of arthritis with exercise being number four on the list. The number three on the list also involves strength and balance that can be achieved through training.

High impact exercises like those that involve jumping or hitting the ground at high intensities are not recommended because they may cause more joint damage. Walking, cycling, an elliptical trainer are all cardiovascular exercises that have generally very low impact and are considered to be safe in the presence of arthritis. Exercise in the water such as water aerobics are considered to be good but only in the case of severely advanced arthritis because this type of exercise does not have the impact necessary to help build up the bones and joints in the body.

Weight training is also a very good way to regain some of the range of motion in the joints due to the repetitive movements in the area that is being trained. This will also strengthen the muscles around the joint, help increase balance, and help build up the bones for prevention of osteoporosis. With every weight training program, there should be stretches that follow in order to increase flexibility. It is very important that a qualified individual makes the training program in order for it to be efficient.

Exercise in itself helps balance out the immune system, helps blood circulate better in the body, prevents heart disease and of course, something we all want, it burns calories. To make any training program worthwhile, a balanced diet must be adopted and above all, the doctor's orders must be followed.

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**What are safe exercises for lupus?**

Source: [https://www.medicinenet.com/what\\_are\\_safe\\_exercises\\_with\\_lupus/ask.htm](https://www.medicinenet.com/what_are_safe_exercises_with_lupus/ask.htm)

Exercise will help you manage lupus and arthritis, but you need to be prudent and follow certain precautions.

1. Avoid outdoor exercise in the sun because sunlight can trigger flares. Cover up by wearing a hat, long-sleeved shirts, and long pants, and use sunscreens with a sun protection factor of at least 15 if you walk or bike outdoors.
2. Listen to your body and exercise when your symptoms are minimal. There are no specifics as to how much you should do or when you should do it and so you need to know your own body and what you can tolerate. Some people with lupus or arthritis can walk for 30 minutes first thing in the morning without a problem while others may not be able to. Everyone is different, and so you need to become an expert about your own body.
3. Start gradually and build up slowly. Starting with too much or increasing too quickly can bring on symptoms. Use the 10% rule to gauge how much to increase; that is, increase the duration and intensity of your workout by 10% per week. For example, increase by one minute if you walk for 10 minutes. Your endurance will improve as you do more. A general rule for assessing your plan is that if you experience pain after your workout that lasts for more than two hours, then you know you did too much. You can expect to have some pain but it should not persist.
4. Don't exercise if your joints feel hot, swollen, or tender. Exercise will make these symptoms worse. Again, you can expect some pain, but you also need to be safe.
5. Some days will be better than others. Again, pay attention to your body and modify appropriately.
6. Always check with your doctor before you begin an exercise program or make modifications to the exercise prescription he or she already gave you.

Many people with arthritis, lupus, and other chronic diseases who manage to exercise regularly despite the pain or inconvenience that their condition presents because they say the benefits are definitely worth it. Exercise can reduce the symptoms of these conditions, increase endurance and strength, improve mood, and mobility, and for my money, the most important benefit of all is the increase in control and quality of life that virtually everyone reports when they exercise regularly.

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## **Recipe: Hearty Vegetable Stew**

## Ingredients

- 1 small Onion (minced)
- 1 clove Garlic (minced)
- 1 rib Celery (minced)
- 1 Carrot (minced)
- 1/4 cup Low Sodium Vegetable Broth
- 1 large Onion (chopped)
- 8 oz Button Mushrooms (sliced)
- 8 oz Portobello Mushrooms (sliced)
- 1 tsp Dried Rosemary
- 1 tsp Italian Seasoning
- 1/2 cup Red Wine (or broth)
- 3 cups Low Sodium Vegetable Broth
- 1/2 tsp Salt
- 1/4 tsp Ground Pepper
- 1 can Diced Tomatoes - no salt added (15oz)
- 2 medium Carrots (chopped)
- 2 ribs Celery (chopped)
- 2 Yukon Gold Potatoes (chopped)
- 1 can Tomato Sauce (8oz)
- 1/2 tsp Kitchen Bouquet (optional for color)
- 1 Tbs Balsamic Vinegar
- 1 Tbs Cornstarch
- 1 cup Frozen Peas



## Directions:

- Mince the carrot, celery stalk, and small onion very fine.
- Saute this mixture in 1/4 cup of veggie broth until the veggies are nice and soft.
- Add the large chopped onion and continue cooking until softened.
- It's ok if the liquid gets a little low – the brown bits add to the flavor.
- Add the mushrooms and cook on medium high until they lose their liquid.
- Season with the rosemary and italian seasoning.
- Add the wine and deglaze any brown spots in your pan. (This is the good stuff!)
- After a few minutes add the rest of the broth, the tomatoes and tomato sauce.
- Add all your chopped veggies and turn the heat up to boil.
- Add the rest of the seasonings – but not the cornstarch.
- Once it's boiling, turn down the heat to low and add the peas.
- Mix the cornstarch with a tablespoon of cold water and stir this in to thicken.
- Simmer to desired consistency

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

Source: <https://www.brandnewvegan.com/recipes/soups/vegetable-stew>

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**Working together to conquer lupus**

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