



Let's Talk Lupus

April Monthly E-Newsletter

Living life with lupus and controlling the disease is not always easy especially as we navigate through the coronavirus pandemic (COVID-19). Lupus Canada is working to ensure all Canadians living with lupus have access to their medications. We have created an online, anonymous survey to help us advocate on your behalf during the COVID-19 pandemic. Help us help you by filling out the survey.

<https://docs.google.com/forms/d/1WbjdeUuhQNZ32JwaAR7wEJn9jPMLlo8-t-Ed2FpeBZw/edit?usp=sharing>

On Tuesday March 31st Lupus Canada hosted a Facebook Live Q&A with Dr. Matsos of McMaster University to address lupus patients questions specific to COVID-19 and its impact on lupus. If you missed the Facebook Live Q&A with Dr. Matsos it can be viewed on our website www.lupuscanada.org/COVID19/

A friendly reminder that next month is **Lupus Awareness Month** and during the month we will recognize **World Lupus Day on May 10th** and **Put on Purple on May 15**. These are key dates to help create awareness for this under-funded and under-recognized disease. If you would like to support individuals living with lupus, please consider donating to Lupus Canada with a one-time, in-honour, in-memory or monthly donation. No matter how big or small the donation, it may make a huge difference in the lives of many Canadians. Visit <https://www.lupuscanada.org/ways-to-donate/> for more information on how you can help!

In addition we will also recognize World Health Day on April 7th. This day focuses on global health and aims to create awareness on important health issues including mental health, maternal and childcare, and health services. This day seeks to ensure all people and communities have access to quality health services whenever they need them without discrimination and financial hardship.

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Lupus Canada has been working tirelessly to ensure all Canadians living with lupus have the most up to date information about COVID-19 and its impact on lupus. We are actively advocating on behalf of Canadian lupus patients in light of the recent news of the insufficient supply of critical lupus medication, believed to be a treatment for COVID-19. As information becomes available we will be sure to post it on our website www.lupuscanada.org/COVID19/

Press Release - Potential treatment for COVID-19 should not harm Canadians living with lupus

March 23, 2020 – Lupus Canada and the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS) are calling on the Government of Canada to ensure critical supply of hydroxychloroquine for Canadians living with lupus.

“Like all Canadians, we are eagerly awaiting a treatment for COVID-19, to help end this extraordinary pandemic,” said Tanya Carlton, Volunteer President of Lupus Canada. “We at Lupus Canada, as well as researchers and medical professionals at CaNIOS, are aware of increased efforts of using hydroxychloroquine as a treatment for COVID-19. Let us be clear. While we share in the optimism that hydroxychloroquine may be a viable treatment for COVID-19, this must not impact the supply for Canadians living with lupus.”

Anti-malarial medication like hydroxychloroquine plays a critical role for people living with systemic lupus erythematosus – the most common form of lupus. For those living with lupus, hydroxychloroquine is proven to reduce mortality by 50%, prevent disease flares, reduce the need for hospitalization and potentially harmful immunosuppressive drugs, as well as prevent cardiovascular complications and infections.

“While we welcome clinical trials, and applaud pharmaceutical companies who have donated the drug for these trials, in an attempt to find a treatment for and slow the spread of COVID-19, we are greatly concerned about irresponsible messaging, suggesting that ‘everyone’ should take this drug in the face of very little evidence,” said Dr. Christine Peschkin, Chair of CaNIOS and Head, Section of Rheumatology at the University of Manitoba. “As a result, we are concerned at the difficulty Canadians living with lupus are having filling their prescriptions of hydroxychloroquine.”

Without access to medication such as hydroxychloroquine, this will lead to a further burden on Canada’s healthcare system, at such a precarious time. Lupus Canada and CaNIOS have been working with Canadians living with lupus and physicians to raise awareness in this anxious time.

“Because those living with lupus are already immune-compromised, they are at a high risk for COVID-19. We cannot compromise on the safety of those living with lupus,” said Carlton.

Lupus Canada and CaNIOS are urgently calling on the Government of Canada to ensure that vulnerable patients, like those living with lupus, have access to this critical medication throughout the COVID-19 pandemic.

COVID-19 AND YOUR EMPLOYMENT RIGHTS

While the global coronavirus pandemic escalates, it's understandable that many employees are nervous about heading into work every day – particularly those with lupus or other autoimmune conditions.

Employers have a positive obligation to take reasonable care to protect the health and safety of employees under occupational health and safety legislation. If an employee has reason to believe that there is a dangerous condition in the workplace, the employee may be able to refuse to attend work or perform certain duties. Occupational health and safety legislation states that employers cannot dismiss, discipline, or intimidate employees for properly exercising a health and safety right.

In the context of COVID-19 pandemic, work refusals could be based on

- a confirmed or presumptive case of COVID-19 in the workplace
- a confirmed case of COVID-19 in an employee's immediate family
- the risk of potential exposure to COVID-19 from people at work – other employees, clients, customers
- concerns from employees who are particularly vulnerable (over age 65, compromised immune system, other medical condition) not wishing to report to work

In the event of a work refusal, the employer must respond in accordance with occupational health and safety legislation. An investigation will be made into the concerns and, if appropriate, measures to eliminate or reduce the workplace danger will be adopted. If the employee disagrees with the employer's decision or measures to eliminate the danger, they can contact a health and safety officer who will then investigate the concern. The employer may also contact the HSO if the employee maintains their refusal to perform the work.

An employee who exercises a right of refusal must still be paid until the situation is resolved with the employer, or until the health and safety officer renders a decision. The worker may be assigned alternative duties by the employer in the interim.

If the employer cannot make work adjustments to eliminate the danger, then the employee could be placed on alternate duties. If that's not possible, then they'd likely explore options like unpaid leave. In this situation, the person would still be employed and not eligible for EI. So this is one of the situations that the new emergency benefit is intended for.

<https://www.canada.ca/en/department-finance/news/2020/03/introduces-canada-emergency-response-benefit-to-help-workers-and-businesses.html>





Stay Connected

#LupusCanadaCares

These are new days. What we once cherished as normalcy has become a possible precursor to illness.

Visiting with loved ones. A hug, a handshake. All forms of communication that we thrive on and need yet we are being asked to disengage for the greater good and the greater health of our population. We understand that social distancing is our safest and smartest approach to flatten the curve during the coronavirus pandemic (COVID-19).

This new normal can feel strange. It can feel sad. It can feel lonely. In this time of self

isolation, it's even more important that we reach out and connect via phone, text, video-chat to check in on our friends and family living with lupus.

In the spirit of togetherness, we ask our supporters to share via Facebook, Twitter and Instagram a hand drawn heart with a "L" for lupus with the hashtag **#LupusCanadaCares**.

Lupus Canada continues to put our lupus community at the forefront of everything we are working on. We are here for you. **#LupusCanadaCares**

Laughs for Lupus

It is Lupus Canada's top priority to ensure the safety and well-being of Canadians impacted by lupus. Given the uncertainty with the coronavirus pandemic (COVID-19) Lupus Canada has decided to postpone our annual fundraising and awareness event Laughs for Lupus until this crisis has passed.

We appreciate all the support from our lupus community during this time. We will be taking this additional time to add some exciting elements to our annual event, stay tuned for updates.

Lupus Canada continues to provide up-to-date relevant information on the coronavirus pandemic as it becomes available. For more information on COVID-19 please visit our website www.lupuscanada.org/COVID19/

Thank you for your continued support

MAINTAINING A HEALTHY LIFESTYLE:

Source: <https://www.foundationforpn.org/living-well/lifestyle/>

Many people equate being healthy to being physically fit, however one does not correlate to another. Being healthy entails being physically, mentally and emotionally fit. You probably have heard this your entire life, but being healthy means living a healthy lifestyle. Many people find it impossible to balance sleeping, eating, socializing, and working. Just remember to be conscious of all these factors and do your best. There are some nights that you will find that you cannot go to sleep, just try to make up this time so that it does not become a habit. You will find that if one facet of your life is being neglected it will ultimately affect everything else.

Living a healthy lifestyle can help prevent chronic diseases and long-term illnesses. Maintaining a healthy lifestyle is doing what is right for your body. Here are a couple of staying healthy tips that may help:

Maintain a regular exercise routine.

- Exercising does not have to be engaging in heavy physical activity. It means being as active as possible and this may mean going swimming, walking or doing household chores. Do what your body allows you to do.

Be conscious of your diet.

- Living a healthy lifestyle means eating healthy. It means ensuring you are eating healthy fats and sugar. Avoid eating junk food but also do not skip meals. Remember it is all about balance.

Engage in the things you are passionate about.

- Every now and then, to keep the stress and the demands of life from taking over, take a break to do something you love doing.

Surround yourself with positive energy.

- In order to have a sound mental and emotional state, you must surround yourself with positive energy. Yes, not all problems can be avoided. But it helps to face such obstacles with an optimist outlook.

LIVING A HEALTHY LIFESTYLE WITH LUPUS:

Source: <https://www.cdc.gov/lupus/basics/managing.htm>

The best way to keep your lupus under control is by following your treatment plan and taking care of yourself. These steps can help.

- Learn how to tell that a flare is coming.
- See your doctors regularly.
- Reduce stress by setting realistic goals for yourself.
- Limit the time you spend in the sun and in fluorescent and halogen light.
- Choose healthy foods most of the time.
- Get enough sleep and rest.
- Exercise moderately with your doctor's OK and when you're feeling up to it.
- Build a support system made up of people you trust and can go to for help.

Despite your best efforts to follow your treatment plan and take good care of yourself, you may have times when your lupus symptoms are worse. Talk to your doctor or nurse about ways to relieve symptoms when this happens.



Salmon Teriyaki

This is a simple, yet healthy way to prepare salmon. Serve salmon with steamed broccoli and brown rice. Recipe serves 2.

Ingredients:

- 8 oz salmon filet
- ¾ cup thawed pineapple juice concentrate
- 1 Tbsp chopped fresh ginger
- 1 Tbsp chopped garlic
- 3 Tbsp low sodium organic soy sauce
- 1 Tbsp rice vinegar



How to Make It:

Step 1: Divide the salmon into two 4 oz portions.

Step 2: Combine the pineapple juice concentration, rice vinegar, soy sauce, garlic and ginger in a small bowl.

Step 3: In a non-stick skillet, over medium-high heat, brown the salmon filets, about 3 minutes each side.

Step 4: Pour half the teriyaki sauce over the salmon in the skillet and cook for an additional 5 minutes or until the salmon is cooked through.

Step 5: Serve with the remaining teriyaki sauce.

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

Source: <https://www.lifescholarship.org/recipes>

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