

LUPUS
CANADA
Life Without Lupus



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*

Taking a Break to Enjoy Spring

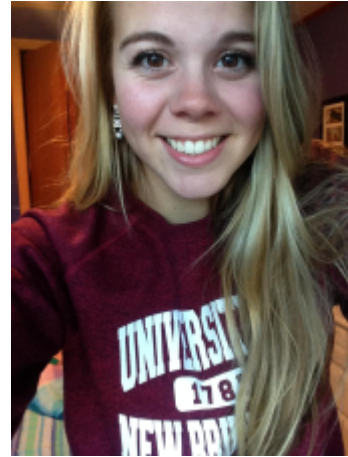
MARCH E-NEWSLETTER

Spring has sprung! On March 20th, spring officially begins and with that, comes hope for warmer days and beautiful sunsets. As the flowers begin to bloom in some areas across Canada, many provinces are still experiencing the occasional snowy day. This is a perfect excuse to pack up your things, book a flight, and vacation somewhere warm. Especially if you have kids in school, March is a great time to take advantage of the 1-week break they have and have and book a family trip. Of course, going to the Caribbean is not always feasible for everyone but, there are so many ways to enjoy this time here at home! Take a road trip, go to your local zoo or explore your own town and community events. Travelling as a lupus patient can be extra difficult, but there are so many ways to remain optimistic and still enjoy your time – take a look in this newsletter for some tips and tricks.

March also marks National Kidney Month in Canada. This is important for many people living with lupus as approximately 40% develop kidney problems at some point in their lives. More information about how these two interact is included in the article, "How lupus affects the renal (kidney) system". Spread awareness and seek help if you are affected by such symptoms.

How the Lupus Canada Scholarship helps students

I am from a small town called Petitcodiac in New Brunswick. I graduated from Petitcodiac Regional School and was named valedictorian of my graduating class in 2016 as well as earning the Governor General's Medal for excellence in academics. Throughout high school I was involved in many sports and was on my grad class executive. In September 2014, I was diagnosed with SLE, which is a form of lupus. This set me back for a few months, as I was trying to adjust to a new way of living, however this did not stop me from working towards my dream of becoming a registered nurse. I pushed myself in school to earn a level of academic excellence, and ended up being one of two top applicants in the Bachelor of Nursing program. At the end of my first year, I made Dean's List with a 3.8 GPA, and this last semester, I also received a 3.8 GPA. I take great pride in my academics and your scholarship has assisted me in pursuing my dreams.



I chose UNB Saint John for my post-secondary education because of their great reputation, particularly in their BN program. With the Saint John Regional Hospital being a 5-minute walk from the campus, I know that I am completing my clinical practicum in the best health care centre in New Brunswick. I am hopeful that at the end of my four years, I pass my NCLEX exam and continue my work as a Registered Nurse in the Emergency Room. As I progress through my next couple of years at UNB, I will have many chances to try different rotations in the hospital and community, so I may change my plans. I am very eager to see where the future takes me!

I wanted to personally thank Lupus Canada for their contribution towards the progression of my academic endeavors in 2017-2018. Lupus Canada gave me the opportunity to continue working towards achieving my goal. It has made a great contribution to my education towards my textbooks (which are very large and also expensive) and my tuition. I cannot begin to thank Lupus Canada enough.

Jillian McMackin

What to Know Before Travelling with Lupus

Source: <https://lupus.newlifeoutlook.com/travelling-with-lupus/>

Traveling with Lupus

For most, travel is an exciting opportunity to experience new sights and sounds, meet new people, and let go of everyday stressors. It's a time for rest, rejuvenation, and turning off your brain.

However, traveling with lupus doesn't change that. Having a chronic illness can add an element of anxiety and fear of, "What if something happens on my trip that will induce a lupus flare?"

It's a scary prospect, especially if you are traveling to another country, but by asking the question, it gives you a chance to prepare and deal with a lupus flare-up. Whether it's travel for pleasure or work, there are several ways you can put yourself in the best position, mentally and physically, before, during, and after you travel.



Scheduling

When scheduling a flight, train or road trip, try to be as cognizant of your sleep or rest needs as possible. For longer trips or international flights, schedule at least a half day or more of transition or rest time when you arrive and when you return home.

Try not to plan too much in one day. It may seem like squeezing in as many activities as possible will make the most of your time abroad, but allowing some flexibility for breaks, if needed, will ensure that you have the energy to last the whole day.

If you are traveling with someone, schedule a time to talk to them about your travel needs, so you can come up with a plan that works for both of you.

If you are away for a conference, be strategic in what you plan to attend and how long. For example, if your energy is low, skip the breakfast keynote and stay in your room for sleep in, but join the after conference mixer for an hour, so you don't miss out on networking opportunities. You can always get updated by a colleague or get a speaker's powerpoint sent to you.

Flying

When booking a flight, inform the airline if you have a wheelchair or other boarding needs. Sometimes information can get lost, so call the airline the day before your flight to ensure that your requests have been noted.

Don't be shy about asking for what you need. If you find that you are sitting by someone who is coughing, ask to be moved.

Accommodations

Before booking an accommodation, take some time to do the following:

- If you have mobility issues, call ahead to ensure that you are staying somewhere that is fully accessible (elevator, ramps, etc.).
- Book something close to transit and the attractions/locations you are going to visit.
- Choose an accommodation that is close to a grocery store and or pharmacy.
- Locate the nearest hospital or urgent care facility and keep the addresses on your phone or written down on a note in your wallet.
- Ask if there is a mini fridge – this comes in handy for medications that need to be refrigerated and to store healthy snacks.
- If you are staying at a hotel, ask if they have room service – this is a great option if you are feeling unwell and are unable to leave the hotel to get something to eat.

What to Pack When Traveling With Lupus

Medical Kit

Bring your essential “just in case” medical items, so you have everything you need in the room you are staying in from Day 1. Make sure you pack these in your carry-on suitcase to avoid any stress caused by lost luggage.

- Prescription medications (in the original bottle if flying) plus an extra few days if travel plans are delayed. Don’t forget to refill your prescriptions well in advance before you leave!
- Tylenol / Aspirin for headaches and Gravol for nausea are essentials for a travel medical kit.
- Your favorite essential oil – whether it’s lavender to help you sleep or eucalyptus to chase away the sniffles, these oils are helpful and easy to pack.
- Hand sanitizer.
- Medical emergency information:
 - Emergency phone numbers
 - List of medications and allergies
 - Travel insurance information

Note: It’s important that you notify your rheumatologist that you are planning to travel. If required, ensure that you are given the necessary vaccinations before traveling with lupus.

Flight Essentials

When flying, the beginning of your journey can be quite cramped and uncomfortable.

Pack these flight essentials to make your travels smooth and relaxing from the start:

- Compression socks
- Neck pillow
- Large scarf – can act as a blanket and/or a sleep mask
- Earplugs or earphones
- Dress in layers – the temperature on a plane can fluctuate, so layering prepares you for any scenario!

Pieces of Home

Being away from the comforts of home can be difficult, but even more so when you are feeling under the weather. Be prepared for a little energy day with the following comfort items from home:

- Cozy slippers or socks
- Your favorite pajamas or sweats
- Your favorite tea
- A few tea lights
- Your favorite book
- Download a podcast or relaxing music

Eating Well on the Road

Purchasing food from a grocery store can save you money and keep your energy up while you are traveling with lupus. Knowing you have the option to lounge in your comfy clothes and eat well in your room goes a long way in creating a sense of calm and wellness.

Here are some items that you can pack so that you can eat well on the road:

- Travel cutlery – you never know when you'll need a fork, knife or spoon.
- 1 Tupperware container – the lid and the container can be used as dishes.
- Small amount of dish liquid – you can use a face towel as a dish rag/
- Water bottle with built-in water filter.
- A portable coffee or portable tea mug.
- Protein bars or energy bars.
- Oatmeal packets or make your packets in ziplock bags with a dash of

cinnamon.

- Trail mix with or without dried fruit

Preparation is Key

Don't be afraid to voice your needs, create space for rest, and bring a toolkit of items that will give you options when you aren't feeling well. With thoughtful preparation, you can lessen your lupus-related fears and embark on your next adventure with confidence!

How Lupus Affects the Kidney System

Source: <http://www.resources.lupus.org/entry/how-lupus-affects-the-renal-system>

Lupus is an autoimmune disease that can affect almost any part of your body, most often your [joints](#), [skin](#), kidneys, [heart](#), [lungs](#), [blood](#), or [brain](#). Your two kidneys are part of your renal system, which also includes two ureters, the bladder, and the urethra. As the primary organs of the renal system, your kidneys are responsible for:

- Maintaining the correct amount and type of body fluids
- Removing waste products and toxic substances
- Regulating the hormones (chemical messengers) that help control blood pressure and blood volume

Lupus and Kidney Infections

Lupus itself does not usually cause kidney infection. However, the [medications](#) used to treat lupus and lupus nephritis suppress the immune system, making the person with lupus more likely to get infections of any type, including kidney infections.

Lupus Nephritis

Inflammation of the nephrons, the structures within the kidneys that filter the blood, is called glomerulonephritis, or nephritis. Lupus nephritis is the term used when lupus causes inflammation in your kidneys, making them unable to properly remove waste from your blood or control the amount of fluids in your body.

Lupus nephritis most often develops within the first five years after the [symptoms of lupus](#) start. It usually affects people between 20 and 40. In the early stages of lupus nephritis, there are very few signs that anything is wrong. Often the first symptoms of lupus nephritis are weight gain and puffiness in your feet, ankles, legs, hands, and/or eyelids. This swelling often becomes worse throughout the day. Also, your urine may be foamy or frothy, or have a red color. The first signs of lupus nephritis often show up in clinical laboratory tests on the urine.

It's estimated that as many as 40 percent of all people with lupus, and as many as two-thirds of all children with lupus, will develop kidney complications that require medical evaluation and treatment. Testing your urine is very important because there are so few symptoms of kidney disease. Significant damage to your kidneys can happen before you are diagnosed with lupus. Nephrologists are the physicians who treat the renal system. The tests they use to diagnose lupus nephritis are: Collection of urine, usually over a 24-hour period; blood tests; and often, a kidney biopsy.

Symptoms of Lupus Nephritis

- Sudden and unexplained swelling, especially in the extremities (feet, ankles, legs, fingers, arms) or the eyes
- Blood in the urine
- Elevated blood pressure
- Foamy appearance in urine
- Increased urination, especially at night

Urinalysis

Kidneys process your body's waste matter. Therefore, testing a sample of your urine can show any problems with the way your kidneys are functioning. The most common tests look for cell casts (fragments of cells normally found in the blood, or fragments of the tubules of the kidneys) and proteinuria (protein being spilled into your body because your kidneys are not filtering the waste properly).

Blood Tests

Certain blood tests can provide information about kidney damage and how well your body is filtering waste. The creatinine blood test is usually ordered along with a blood urea nitrogen (BUN) test to assess kidney function. A combination of blood and urine creatinine levels may be used to calculate a creatinine clearance. This measures how effectively your kidneys are filtering small molecules like creatinine out of your blood. Serum creatinine measurements (along with your age, weight, and gender) are used to calculate the estimated glomerular filtration rate (EGFR), which is used as a screening test for evidence of kidney damage.

Kidney Biopsy

A kidney biopsy is done in a hospital. While you lie on your stomach your nephrologist will insert a very thin, long needle through the skin of your back and remove a tiny piece of tissue from one of your kidneys. The tissue will be examined under a microscope to determine how much inflammation or scarring is present.

Treatments

Even though lupus nephritis is among the more serious complications of lupus, there are effective treatments. Prednisone and other corticosteroids are generally prescribed to stop inflammation.

Immunosuppressive drugs may also be used (with or in place of steroid treatments), such as cyclophosphamide (Cytoxan®), azathioprine (Imuran®), cyclosporin A, and mycophenolate mofetil (CellCept®). Medications developed for other illnesses are also being studied as treatments for lupus nephritis, including rituximab (Rituxan®), and eculizumab (Soliris™).

Other Lupus-Related Kidney Disorders

Not all kidney problems in people with lupus are due to lupus nephritis.

- Infections of the urinary tract, causing frequent urination or burning when urinating, are quite common.
- Fluid retention or even loss of kidney function can be a side effect of non-steroidal anti-inflammatory drugs (NSAIDs) and medications such as aspirin.
- Interstitial nephritis, which is inflammation of the connective tissue inside the glomerulus, can be a side effect of anti-inflammatory medications or antibiotics.
- Thrombosis and vasculitis, two blood-related lupus symptoms, can damage the kidneys and may even cause kidney failure.
- Lupus cystitis, which is inflammation of the lining of the bladder, may cause frequent urination and is associated with abdominal discomfort, including vomiting and weight loss.
- Medications used to treat lupus may cause signs or symptoms of kidney disease that can be confused with lupus nephritis.

All of these complications can be treated, so if you develop any new symptoms, contact your doctor promptly.

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Recipe: Quinoa Pizza Bites

Yields 40 pizza bites

Ingredients:

- 2 cups [cooked quinoa](#) (cook in low sodium chicken broth for extra flavor)
- 2 large eggs
- 1 cup chopped onion
- 1 cup shredded low-fat mozzarella cheese
- 2 tsp minced garlic
- 1/2 cup fresh basil, chopped
- 1 cup chopped pepperoni slices (~1/2 of a 7 oz bag)
- 1/2 tsp seasoning salt
- 1 tsp paprika
- 1 tsp dried crushed oregano
- pizza sauce for dipping



Directions:

1. Preheat oven to 350 degrees.
2. Mix together all ingredients, except pizza sauce, in a medium mixing bowl.
3. Distribute mixture into a greased mini muffin tin, filling each cup to the top (1 heaping Tbs each), and press down gently to compact.
4. Bake for 15-20 minutes.

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

Source: <https://soveryblessed.com/2012/02/quinoa-pizza-bites-recipe/>

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