



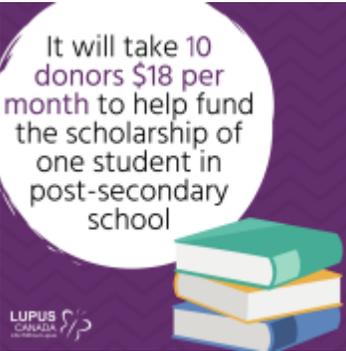
Welcome September! This month marks a period of change for many people nationwide. At the beginning of the month, we will see thousands of students going back to school to continue their studies. Whether going to kindergarten for the first time, finishing a degree or starting a new job, this is an exciting time for so many people nationwide. Take a look in this month's newsletter to get more information on how to apply for an Individualized Education Plan in school or how to talk to your employer about lupus.

Just this past weekend on September 3rd, Canadians celebrated Labour Day – we hope that you enjoyed your long weekend by taking some time to relax! We will also see a turn in the season on September 22nd with the first day of autumn which means the cold weather is not too far off.

Lupus Canada Scholarship Program

With Back to School season in full swing, we would like to reach out and remind our incredible supporters of Lupus Canada's Scholarship program for students living with lupus. This provides five students with a \$2000 scholarship to put towards their university or college fees.

It will take 10 monthly donors \$18 per month to help fund the scholarship of one student in post-secondary education. We kindly ask that you consider helping us continue to make these life-changing impacts on students all across Canada with a donation today by becoming a monthly donor.



Take a look at this month's My Lupus Story to hear how the Lupus Canada Scholarship helped Tara Howse achieve her postgraduate goals.

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My Lupus Story by Tara Howse

Although I can't say definitively that my trigger can be traced to an episode of giardia, there's no doubt that the parasite was, at minimum, a significant contributor to my flare. A common backcountry parasite that is transmitted through untreated water, it causes severe gastrointestinal issues (a.k.a. diarrhea – and lots of it). I picked it up somewhere in Northern California during my 2015 attempted thru-hike of the Pacific Crest Trail. After about a month of hiking over 20 miles a day without any desire to eat and unable to keep what food I did try inside



of me, I was forced to quit the trail upon entering Oregon in late August. To say I was devastated would be an understatement. I spun into depression and here is where the official lupus-story enters my life. Although I began to improve physically, my gastro issues were never quite restored and my emotional and mental states hadn't recovered by the winter of 2016.

Falling ill in late February, I assumed the flu had finally caught up with me. I remember coming back from a meeting with my forearm screaming at me. I was wracking my brain seeking for the incident when I had broken or fractured it. Within 48 hours, I was sobbing on the couch from any effort I made to walk, sit, laydown, or pick up anything. My husband was travelling for work but I eventually told him what was happening to me. Urging me to see our family doctor, I made an appointment and hobbled my way to the office the following week wherein her concern was palpable as she took in my swollen. Her very touch on any part of my body made me involuntarily cry out and my wedding rings would not budge off my fingers.

I knew when I received the call from the doctor's office to come in that it wasn't good news. Although she couldn't provide the formal diagnosis, she indicated her suspicions to be lupus, based on my ridiculously high ANA results, and referred me to a rheumatologist. Blood and urine work revealed I would also need a nephrologist (plus kidney biopsy) and, later on that summer, a respirologist as a result of a pulmonary embolism (and pleurisy).

I was now experiencing depression as I came to terms with what this illness' encroachment in my life would mean plus still trying to recover from knowing I was a failed thru-hiker. Although Lyme disease was regularly discussed, I can now say, without hesitation, that I do have lupus. Learning the symptoms made me realize

that I used to experience some flares as a youth (albeit, on a considerably less intense scale).

During that terrible summer of 2016, I could not engage in the outdoor activity I love nor had any work to occupy me. My husband and I decided it was time for me to complete my Undergraduate degree, something I had been working on for 6 years. Self-paced, I could register with the disability services offered and be given some leniency with due dates and exam scheduling. I created an aggressive school plan for myself to complete my degree by the fall of 2017 and this goal provided me some direction and purpose, ultimately helping improve my mental state. When I received the call in August 2016 that I had been selected as a recipient for the Lupus Canada Scholarship Program, I cried. Although the money was obviously appreciated, it was the effect of knowing that a national organization believed in my scholastic ability to achieve that overwhelmed me. Having recently undergone my kidney biopsy, it was a small piece of good news that I badly needed at that point. Whenever I was feeling upset or frustrated at my slow progress or my reduced capacity to sit and concentrate (how that brain fog was intruding in my studies!), I thought of the gift I received and harnessed that energy to pursue my goal.

Not only did I finish my degree in September 2017, I completed it with distinction. But, wait! There's more. The boost I received from completing my degree encouraged me towards further education: I have been accepted into the Master's program of my choice for a January 2018 start date.

Of course, it's not all smiles and positive thoughts. I am still adapting to the new restraints on my life and I imagine it will be a continual internal dialogue I conduct as I balance my needs versus my wants.

An avid outdoors lover, being told to stay out of both the sun and the cold has been the most difficult aspect for me to handle. (I love the outdoors so much I created a website in 2014 to encourage more women to get outside: www.activewomen.ca). The outdoors is a great healer – it reduces blood pressure, alleviates stress through cortisol reduction, improves mood and mental health, helps you sleep better, and makes us both happier and more creative. These are all measured outcomes of the positive impacts of outdoor activity and being told to avoid this was unacceptable. I knew that by measuring the distance and duration of my walks each day would empower and encourage me. I have had to make adjustments to my "post-lupus" life expectations. I've learned how to alter my clothing, equipment, and actions to facilitate my love of mountain biking, hiking, backpacking, and skiing. Although always cautious while in the backcountry, those concerns are heightened now that I'm on a blood thinner. To my fellow outdoorsfolk who are being told to give up these activities, don't despair! It is possible to continue on with what you love. I discuss these issues of exercise and lupus on Active Women and encourage you to follow my blog there for more details, insights, and inspiration.

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

Talking About Your Lupus in School and in the Workplace

Lupus patients are always encouraged to advocate for their own health, whether that be in the classroom or at your workplace. In particular, it is important to recognize your right to inform teachers and employers about your lupus so that they can advocate for you as well. However, this is an extremely personal choice - if you feel that this is not the right step for you, remember you know your health best and go with what will be best.

For students with lupus, they may benefit from an Individualized Education Plan that clearly outlines their specific accommodations and what exactly would benefit them in a classroom setting.

Individualized Education Plan

Source: <http://www.edu.gov.on.ca/eng/general/elemsec/speced/individu.html>

When an Identification, Placement, and Review Committee (IPRC) identifies a student as an exceptional pupil, the principal must ensure that an Individual Education Plan (IEP) for that student is developed and maintained. An IEP must be developed with input from the parent(s)/guardian(s) and from the student if he or she is sixteen years of age or older. An IEP must be developed within thirty days of the placement of an exceptional pupil in a particular program. The parents/guardian(s) must be provided with a copy; the student must also be given a copy if he or she is sixteen years of age or older. An IEP may also be prepared for students who require accommodations, program modifications and/or alternative programs, but who have not been identified as exceptional by an IPRC.

An IEP identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate accommodations, program modifications and/or alternative programs as well as specific instructional and assessment strategies. The learning program provided for the student is modified on the basis of the results obtained through continuous assessment and evaluation.

The IEP for an exceptional pupil who is fourteen years of age or older and who is not identified solely as gifted must also contain a plan for the transition to postsecondary education, or the workplace, or to help the student live as independently as possible in the community. In developing or reviewing the student's IEP, consideration must be given to any recommendations made by the IPRC concerning special education programs and services that may be particularly appropriate for meeting the student's needs.

To assist teachers and other support professionals in developing Individual Education Plans for exceptional pupils, the ministry has published [The Individual Education Plan \(IEP\), A Resource Guide, 2004](#).

In the workplace, it is important to think about how your lupus diagnosis may affect your day to day life. Whether this is informing your employer, or choosing not to, there are several factors to consider. Take a look at this article that explains this process

Lupus in the Workplace

Source: <https://www.lupuscanada.org/advokit-lupus-in-the-workplace/>

If you have been diagnosed with lupus at a time in your life when work is important to you, adjusting to a new lifestyle can be an additional challenge. Almost everyone wants to work and to be productive. Working, whether it is in a paid job or volunteering, is very important to our well-being and self-esteem. However, for a person who has lupus, that can be a difficult task.

On the job

The first question becomes 'Should I tell my employer I have lupus?'. This is a personal decision that only you can make. Here are some situations and examples that may help you decide. All considerations need to be weighed carefully.

Some enlightened employers are willing to make changes to the work environment and schedule to accommodate an employee's changing needs. Where it would be helpful, for example, they might:

- make working hours more flexible,
- change the lighting (for some, sunlight and fluorescent lighting can cause lupus flares),
- provide rest periods,
- change work duties,
- provide a temporary leave of absence,
- or, if the job can be done away from the workplace, making it possible to work from home.

These are just some of the actions that could be taken to enable you to do your job with a minimum of discomfort. Such accommodations will also reduce your stress level in the workplace. Remember, stress, whether good or bad, can make your lupus worse, and in some instances might even bring on a lupus flare.

Consider Jack: he lives on the West Coast and works for a professional firm. He decided to tell his employer that he had lupus. His employer was very concerned about his well-being and looked into what could be done to assist him with his work.

His desk chair was replaced with an ergonomic one. The lighting in his office was adjusted and his work schedule rearranged.

These actions made it easier for Jack to deal with his illness and his lupus remains under control. Needless to say, Jack continues to work happily at his job.

On the other hand, it does not always go that well. Consider Jane, twenty-seven years old, employed by two professionals. She had lupus since childhood, and made no secret of it, both with her employers and co-workers.

Everything was fine for about five years until Jane started to flare and began losing time at work. She explained her condition to her employers and to her co-workers, thinking she could make them understand about her joint pain, fever and flu-like symptoms.

Lupus often does not affect a person's appearance, and Jane didn't realize that, because she looked so well, her colleagues didn't understand what she was going through.

Inevitably, problems arose. Her employers had misgivings about the time she was missing from work but were reluctant to discuss it with her. Her co-workers resented having to pick up the slack and started to make nasty comments.

When Jane walked into a room, they would immediately fall silent. She knew they had been talking about her. The situation grew worse and worse until Jane finally resigned.

It was years before she was able to resolve in her own mind the hurt and anger she felt about how she had been treated because of her lupus.

If you decide to tell your employers about having lupus, make sure you educate them with an up-to-date information package. But that is not enough. You need to tell your employer about your particular symptoms (remember, symptoms vary widely from person to person) and to communicate your specific accommodation needs clearly, rationally and coherently.

Applying for a job

Should you indicate that you have lupus when completing a job application form? Again, this is a personal decision that only you can make.

Some employers follow the trend to be sensitive to equity issues and people with disabilities, and will be quite willing to hire you if you have the skills for the job. Others will not. Existing policies seldom cover every situation.

The Human Rights Code in your province prohibits discrimination on the basis of a disability, and if you feel you have been refused employment for which you are qualified, you can file a complaint with the Human Rights Commission in your province (see the examples in the section 'Case Law'). Bear in mind, though, that such appeals take a long time to go through, and can be quite stressful.

In any case, you do not have to mention any disability in your application, and whether you do or not depends on whether you feel right about it, and whether you think it will be useful or not.

Recipe: Cuban Cauliflower Rice Bowl

Ingredients:

- 1 medium sweet potato, peeled if desired, sliced ¼ inch thick
- 2 teaspoons extra-virgin olive oil plus 2 tablespoons, divided
- 2 pinches salt plus ½ teaspoon, divided
- ½ teaspoon ground pepper, divided
- ¼ cup orange juice
- 2 tablespoons lime juice
- ½ cup chopped fresh cilantro, divided
- 3 cloves garlic, minced, divided
- ½ teaspoon ground cumin
- ½ teaspoon dried oregano
- 5 cups cauliflower florets
- 1 (15 ounce) can black beans, rinsed
- 1 firm ripe avocado, sliced
- ½ cup pico de gallo



Directions:

- Preheat oven to 400°F.
- Toss sweet potato in a medium bowl with 2 teaspoons oil, a pinch of salt and ¼ teaspoon pepper. Transfer to a baking sheet. Roast until tender, 10 to 14 minutes
- Meanwhile, combine orange juice, lime juice, ¼ cup cilantro, 1 minced garlic clove, cumin, oregano and a pinch of salt in a small bowl.
- Pulse cauliflower florets in two batches in a food processor until chopped into rice-size pieces. Heat the remaining 2 tablespoons oil in a large skillet over medium heat. Add the remaining 2 garlic cloves and cook until fragrant, about 30 seconds. Add the cauliflower rice, the remaining ½ teaspoon salt and ¼ teaspoon pepper; cook, stirring, until softened, 3 to 5 minutes. Remove from heat and stir in the remaining ¼ cup cilantro.
- To serve, divide the cauliflower among 4 bowls. Top with the sweet potato, black beans, avocado and pico de gallo. Drizzle each portion with the mojo sauce.

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

Source: <http://www.eatingwell.com/recipe/258449/cuban-cauliflower-rice-bowl>

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