

August 2017 Newsletter

Enjoying the Final Days of Summer

In a few weeks, we will be saying goodbye to summer break. For now, we still have some warm days and beautiful weather to look forward to! For lupus patients however, it is important to remain sun smart whenever you may be coming into contact with sunlight. UV light is a very common trigger for a flare and so, wearing sunscreen and covering up is always a precaution you should take. This shouldn't feel like a burden - instead, try to enjoy the summer weather while remaining healthy and safe!

This time of year may also serve as a fresh start. For many people, the coming of August means preparing for the start of a new school year. Communicating with teachers and school staff is very important, whether you or a loved one will be returning to school. This newsletter provides some great information on what teachers should know about lupus, accommodations they may provide and what they can do to support their student.

Also look in this newsletter for information about lupus in the workplace. Adjusting to a new job or a new employer can be a challenge, but it is important to know that lupus does not need to be a barrier on your road to success!

Lupus Canada Updates

New Brochures!

Take a look at our new and improved informational brochures! **'Lupus & Me'** is full of suggestions to help you lead a healthier lupus lifestyle. **'Living Well With Lupus: An Introductory Guide'** is a great introduction to lupus symptoms, treatments and ways that you can support someone affected by lupus. Call us at 1-800-661-1714 or email info@lupuscanada.org to request one in the mail!

share stories from past recipients how our Scholarship has helped them.

Blood Type Distribution in Autoimmune Diseases

Along with other colleagues, Ed Harris, a Fellow from the Department of Medical Microbiology and Immunology at the University of Wisconsin, has initiated a pilot study to analyze possible associations between blood type and various autoimmune diseases. After receiving some unexpected results from an SSc survey conducted in spring of 2017, Mr. Harris has decided to expand the scope of the study to determine if this unusual blood type distribution pattern occurred in similar diseases. The study is an anonymous, two question survey (blood type and country of birth.)

They are looking at blood type distributions in five diseases:

- Systemic Sclerosis (SSc)
- Systemic Lupus Erythematosus (SLE)
- Rheumatoid Arthritis (RA)
- Psoriasis
- Ankylosing Spondylitis

SSc, SLE and RA share some similarities in their patterns including: being antinuclear antibody (ANA) positive, share some overlapping symptoms and tend to be diagnosed in middle aged women. Psoriasis and Ankylosing Spondylitis are being used as control groups and differ from the others in several factors. After getting approval for the study from the Institutional Review Board at the University, recruiting for the study has now begun. However, due to possible research design issues that come along with self-reports, a minimum of 1000 patients are needed to complete the survey.

Who Should Take This Survey

You should complete this survey only if you have been formally diagnosed with Systemic Lupus Erythematosus (SLE).

Who Should Not Take This Survey

Patients with a tentative diagnosis, such as UCTD (Undifferentiated Connective Tissue Disease)

or those with a lupus/scleroderma overlap syndrome such as Mixed Connective Tissue Disorder (MCTD).

Depending on the initial results from the pilot study, follow-up research will be conducted using actual patient records to eliminate these self-report biases. If similar blood type distribution patterns are seen in related autoimmune diseases, this could reveal important information about the genetic basis for a broader class of autoimmune diseases. Ultimately, results from this study may help to increase understanding of autoimmune diseases and help in the quest to develop better treatments for major autoimmune diseases like SLE.

If you are living with SLE and are interested in participating in this large-scale anonymous survey of your blood type, please follow the link Survey Link to complete the questionnaire: <https://www.surveymonkey.com/r/8F57BC6n>

For more information about the study <http://sclerodermainfo.org/pdf/Blood-Type-Survey-Info.pdf>.

Note: if you wish to participate in this survey but don't know your blood type, please call your doctor's office to see if they have this information on file.

My Lupus Story



My name is Katherine Jarzecki. I am a 27 year old B.Sc graduate from McMaster University currently pursuing my second undergraduate degree in materials engineering at the same institution – I will be in my final year of studies starting in September 2017. I am also a Miss Universe Canada 2017 national finalist, a triathlete and passionate health/fitness enthusiast, and baker. I would like to share with you all my lupus story.

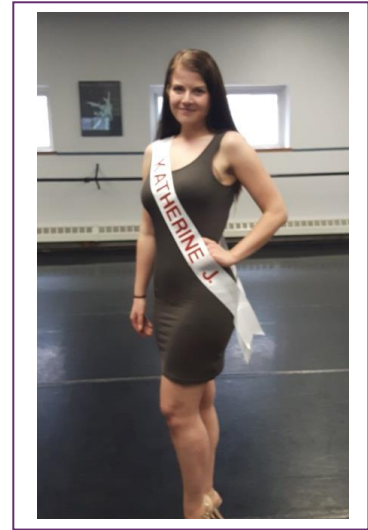
Like many people diagnosed with lupus I experienced a variety of debilitating symptoms for a number of years, completely unaware that I had this disease. My lupus causes very painful and swollen joints, making it difficult some days to do basic tasks such as walking, carrying things, opening containers or doors, writing, typing, and performing standard house chores. I also experience severe chest pains and shortness of breath. This makes walking or going up a flight of stairs difficult and leaves me gasping for air and

winded. The fatigue I experience causes me to feel exhausted after a day of work or going to classes, making it extremely challenging to find the energy to continue studying for the remainder of the evening, as is necessary for an intense program like engineering. I have lost hair, and regularly get mouth ulcers. In addition to the physical difficulties, I also struggled immensely with anxiety and depression until I eventually received treatment for the lupus.

Last year I was finally diagnosed as I was preparing to compete nationally for the title of Miss Universe Canada 2016. I woke up one morning paralyzed and swollen with pain from head to toe, struggling to breathe. After healthily losing 40lbs, I initially thought I had pushed myself too hard during my training for the competition, but a later blood test would reveal that I had tested positive for RA and lupus. The timing of this flare was particularly bad as I had just gotten hired for a 16-month internship at Stackpole International, and was one month away from the Miss Universe Canada competition. My career and dreams were supposed to be taking off, not abruptly halted because of uncontrollable flares.

The treatments I received were mild compared to many that suffer with lupus. I was put on anti-malarial drugs, steroids, anti-inflammatories that hurt my stomach, and was downing bottles of "Tylenol for Arthritis" (which sadly did not help) every morning when I woke up. It was extremely difficult seeing my body change from the steroids after working very hard for 8 months to reach my physical peak, but I never lost hope or gave up. I knew that this was just another stepping stone in my journey to recovery and that I would come out stronger and better after this, ready to compete again the following year. The difficult part was waiting. I did my best to continue eating a very healthy diet and tried to keep as active as possible. I used this time in my life to train for a triathlon, another dream of mine. On September 10, 2016 I competed in my first sprint triathlon. My joints were mildly flaring throughout the race but I was determined. My goal was not to place, but simply to compete in the race without pausing or stopping, and I did just that. Now that my symptoms have improved, I am looking forward to competing in an Olympic Triathlon sometime in the future.

My road to remission is still in progress, but I have now made it my goal to show as many people as I can that it is possible to live a functional life while battling lupus. I have made it to nationals again for this year's Miss Universe Canada 2017, and not only do I want to use this platform as an opportunity to encourage young women to pursue STEM-related and engineering career paths, but to promote a healthy and active lifestyle, despite living with chronic illness. I want to show women across the country that every obstacle is an opportunity for us to grow as individuals, and that we are more than capable of accomplishing any goals we set for ourselves despite having what appear to be 'disadvantages'. Our disadvantages should fuel us even more to be successful.



To anyone else struggling with lupus, please know that you are not alone. Take care of yourselves as best as you can through diet, sleep and exercise. They will not cure the problem but they will create a healthy environment in your body for the best potential to heal it. Take things one day at a time.

Thanks for taking the time to read, and I wish everyone all the best in their recoveries.

Best regards,

Katherine Jarzecki

What Teachers Should Know

Source: <http://kidshealth.org/en/parents/lupus-factsheet.html>

Lupus is a disease that causes the immune system to mistakenly work against the body's own tissues and attack healthy cells. Lupus can affect almost any organ.

Symptoms of lupus — such as joint or muscle pain, extreme fatigue, rashes, mouth ulcers, and hair loss — can vary widely from person to person. Other common symptoms are sensitivity to sunlight and some kinds of fluorescent lights, arthritis, seizures, kidney problems, and inflammation around the heart, lungs, and abdomen. The cause of lupus is unknown.

There are three kinds of lupus:

1. **Systemic lupus erythematosus (SLE)**, the most common kind, can affect multiple organs.
2. **Cutaneous (skin) lupus** usually affects only the skin, with rashes on the scalp, legs, or arms.
3. **Drug-induced lupus** happens as a reaction to certain medications. In kids, anti-seizure, thyroid, and acne medications can cause lupus. Symptoms usually go away when patients stop taking the medication.

Almost all people with lupus take medication to control inflammation and reduce the risk of flare-ups, (times when symptoms get worse).

Students with lupus may:

- need to sit in a warm area of a classroom and be able to move away from sick classmates
- need to visit the school nurse for medications or to rest during flare-ups
- need accommodations for missing class time or assignments due to absences because of flare-ups or medical appointments
- need to wear sunscreen or protective clothing, or limit time outdoors
- have difficulty concentrating and staying on task
- need extra time to move between classes
- need adaptive equipment to complete assignments
- benefit from having an [individualized education plan \(IEP\)](#)

What Teachers Can Do

During flare-ups, students with lupus may feel much more tired, sick, feverish, and achy than usual. Make sure you know your student's symptoms, and work with parents and other educators to make a plan that promotes your student's academic success.

Encourage your student to participate in all classroom and physical education activities, because regular exercise can help prevent fatigue and joint stiffness. During flare-ups, however, your student with lupus may need to rest or be excused from activities.

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: Fruit Salsa and Cinnamon Chips



10 servings
Prep: 15 mins
Cook: 10 mins

Ingredients:

- 2 kiwis, peeled and diced
- 2 Golden Delicious apples - peeled, cored and diced
- 8 ounces raspberries
- 1 pound strawberries
- 2 tablespoons white sugar
- 1 tablespoon brown sugar
- 3 tablespoons fruit preserves, any flavor
- 10 (10 inch) flour tortillas
- butter flavored cooking spray
- 2 tablespoons cinnamon sugar

Directions:

1. In a large bowl, thoroughly mix kiwis, Golden Delicious apples, raspberries, strawberries, white sugar, brown sugar and fruit preserves. Cover and chill in the refrigerator at least 15 minutes.
2. Preheat oven to 350 degrees F (175 degrees C).
3. Coat one side of each flour tortilla with butter flavored cooking spray. Cut into wedges and arrange in a single layer on a large baking sheet. Sprinkle wedges with desired amount of cinnamon sugar. Spray again with cooking spray.
4. Bake in the preheated oven 8 to 10 minutes. Repeat with any remaining tortilla wedges. Allow to cool approximately 15 minutes. Serve with chilled fruit mixture.

*The recipes used by Lupus Canada have been reviewed and approved by Heather Penney, Registered Dietitian. Please note that sugar content is higher than recommended if more than one serving is consumed***

Source: <http://allrecipes.com/recipe/26692/annies-fruit-salsa-and-cinnamon-chips/>