



Let's Talk Lupus

Monthly E-Newsletter

As summer comes to a close, we may see some cooler nights and less humidity however, Canada is famous for ragweed-caused allergies from mid-August all the way until mid-October. This may sound like a nightmare for lupus patients. However, having an existing autoimmune disease interact with seasonal allergies does not need to be as daunting as it sounds! Look in this newsletter for more information on hyper-immune responses.

Also included in this month's newsletter are some great online resources we have collected that may help a lupus patient, whether that's you, a relative or a friend. The end of summer for a lot of people means the start of a new year, whether that is school, work or other commitments you have. These websites are a great resource to have bookmarked in the coming few months and may provide a relatable point of view on a variety of issues.

MyLupusGuide

Soon to become available for all patients with lupus across Canada...

MyLupusGuide is a website tailored to the needs of patients with lupus that was developed to provide relevant information, resources, and support to better understand and manage their illness. Control of disease activity is associated with better outcomes and the ability to self-manage one's health is an important skill towards this goal. Lupus Canada is pleased to partner on this study by taking a lead role on the Patient Advisory Committee for the project.

The *MyLupusGuide* study was completed on July 31 and analysis of the data collected has begun. The purpose of this study was to determine whether *MyLupusGuide* would be a useful tool for patients with lupus to manage their illness.

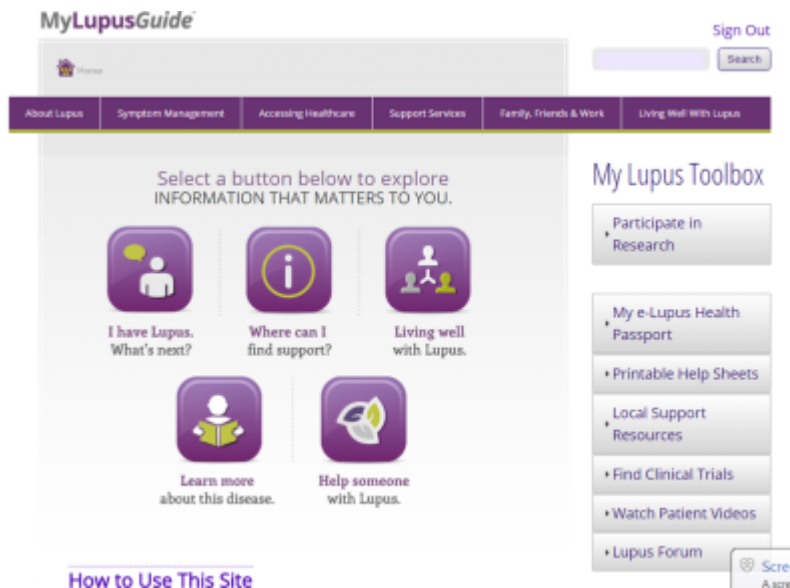
Recruitment began on the week of October 30, 2017 with a massive mail-out to over 1900 persons with lupus who were being treated at 10 Canadian Network for Improved Outcomes in patients with Systemic Lupus Erythematosus (CaNIOS) centres. 541 patients with lupus agreed to participate in this study. They were asked to complete on-line questionnaires on three occasions (baseline, three month and six

months).

The study was designed so that participants would have a 50:50 chance of either accessing *MyLupusGuide* website immediately or in three months. This allowed comparison between those who had used *MyLupusGuide* with those who did not have access until three months later.

Preliminary baseline data showed that more than one third of lupus patients in the study had a low level of self-management activation which is a common barrier to improvement of outcomes and health status for patients with lupus. Baseline data was also used to describe doctor-patient communication in lupus patients. Better communication has been shown to be associated with higher health self-management and improved health outcomes. Further analysis will be done to determine factors that influence patient activation and doctor-patient communication.

Final results of this study are expected by the end of September.



MyLupusGuide website

CrossFit Nanaimo Lupus Fundraiser

Lupus Canada would like to extend a big thank you to CrossFit Nanaimo for coming together and hosting a fundraiser for lupus on behalf of one of their staff members, Dallyn Giroux. Dallyn is a coach and athlete who has been living with lupus for over

12 years and continues to pursue her passion for fitness. This month, Dallyn shared her story with us – read on to hear more about her journey with lupus. Through the incredible efforts of everyone who supported this event, lupus is getting the recognition and awareness it needs and deserves!

A special thank you to CrossFit Nanaimo, SLR, Glenn Houle Custom Masonry Ltd, The Primal Movement and everyone else who contributed for their donations – together, over \$1,800 was raised in support of Lupus Canada! Without the collective support of people all over the country, we would be unable to continue our work in supporting those living with lupus and so, we thank you for your dedication. Together, we are working towards Life Without Lupus!



CrossFit Nanaimo fundraiser honouring Dallyn Giroux

My Lupus Story by Dallyn Giroux

Well, let me start by saying that this is proving to be a lot harder than I had anticipated. How much of the dirty Lupus details should I share with you? Let's start with my early onset diagnosis at the young age of fifteen. Twelve years ago I was diagnosed with Systemic Lupus Erythematosus (SLE). Since then my life has been through a whirlwind of ups, downs, lifestyle changes, and most of all, overcoming huge adversities.



My initial diagnosis was the push I needed to pursue a healthy lifestyle. Despite hardly being able to get out of bed most days, the gym became my best friend. I found that even when I was in the worst of flare ups, if I could just get moving I knew I was going to be ok. Being witness to the direct effects that exercise and nutrition had on joint/muscle pain, fatigue, brain fog (shall I go on?) ... was enough proof that this lifestyle change was going to save my life.

Flash forward to today. I am now a successful Personal Trainer and CrossFit Coach with my own business called The Primal Movement. I am a competitive Olympic Style Weightlifter, and I lead a healthy lifestyle to support all of these things. I am currently getting over one of the longest, most debilitating flare ups that I have ever had. As I pull out another handful of hair and switch my icepack from left knee to right, I can tell you that this disease will NEVER slow me down

Living with SLE obviously hasn't been all sunshine and rainbows. "Lupies" have to fight a little harder; every - single - day. The average day to day stuff like opening a jar of pickles (don't get in the way of a girl and her pickles!), or tying your own shoes, suddenly become a lot harder with something like joint pain staring at you right in the face. These things, among SO MANY OTHERS (remember, lupus is the disease of many faces) are what make us so resilient. You can knock us down, but you better believe we will get right back up again!

There is a huge lack of research, funding, public awareness, and education about Lupus. My team and I at The Primal Movement and CrossFit Nanaimo recently put on a fundraiser to help create some more awareness at the very least. We called our fundraiser "Deadlift or Bust" and it was a huge success! People came out and donated \$\$/pound of weight that they deadlifted. Our members had seen how much I struggled during the months leading up to this fundraiser, so the amount of support that I received for it was quite overwhelming. I would like to give a huge shoutout to the members of The Primal Movement and CrossFit Nanaimo for their donations and kind words, and to my team mates Alana and Alex for being such a HUGE help when I wasn't able to step up!

Lastly, thank you to Lupus Canada for featuring my story for August. Together we can make living with Lupus better (or at the very least, more tolerable)!

Cheers, Dallyn

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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*

Allergies, Autoimmune & Chemical Sensitivity

Source: <http://lupuschick.com/allergies-autoimmune-chemical-sensitivity-overview-products/>

Both autoimmune disease and allergies can be classified as a hyper immune response. Hyper immune responses are characterized by the immune system attacking seemingly harmless substances in the environment. This is dangerous because the immune system can focus its energy on combating the perceived threat, resulting in symptoms like rash or inflamed sinuses. Times in which symptoms are present in result of these inflammatory responses are sometimes called "flare ups" or simply "flares". Allergy flare-ups have a few major differences from autoimmune flares.

So, what's the difference?

The easiest way to tell if you might be experiencing allergy symptoms or that of an autoimmune disease is to pay attention to the triggers of your flare up episodes. Allergies respond to external factors such as dust or pollen that the immune system sees as an attack on the body. Autoimmune conditions, however respond to internal triggers that the immune system mistakes as a foreign substance, even though they are normal and essential in the body's function. In Lupus patients, for example, certain organs including the lungs, brain, heart, blood vessels, or nervous system get attacked by the immune system, resulting in different symptoms such as a butterfly rash (a rash across the bridge of the nose and the cheeks), sunlight sensitivity, fever, inflammation of the joints, etc.

Technically speaking, the reactive mechanisms in the body are very different as well when comparing an allergic reaction to an autoimmune flare up. The specific immunological pathways activated in an allergic reaction to release histamine, are different from the pathways in which an autoimmune response is triggered.

The last major difference between autoimmune diseases, and allergies involve the

environmental substances that trigger a flare-up. Allergen triggers can be readily identified with lab tests, and treatments can be effectively determined. In autoimmune conditions, there is not yet a complete understanding of the diseases, making it much harder to diagnose and treat. As a result, the treatment plans for patients with an autoimmune disease tends to be much more broad, in order to cast a wide net over the different functions of the body that may be reacting or responsible.

Are They Caused by the Same Thing?

Although both conditions are a result of mistaken immune responses, the triggers are very different. As recently as the last few decades, researchers have started to uncover previously mysterious commonalities between autoimmune diseases and allergies. One commonly accepted hypothesis is the "hygiene hypothesis." This assumes that as medicine and sanitization methods have advanced, people have become too clean, getting rid of necessary protective bacteria and viruses, without understanding their importance to the immune system. This theory has been proven through the examination of bacteria in third world countries. In these countries with less focus on hygiene, there are far less allergies and autoimmune diseases present. The Clinical & Experimental Immunology journal published this article (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2841828/>) explaining that over time we have eliminated all traces of necessary bugs with the misunderstanding that all bacteria are harmful. In turn, our immune systems don't have enough targets to fight against, and turn against itself to keep busy.

Interestingly, a new gene has been identified called BACH2 that scientists believe to be the blueprint of both allergic reactions and autoimmune flare ups.

Do Different Seasons Flare Up Autoimmune Diseases?

The link between different seasons and allergies is commonly known and accepted. Many allergy sufferers experience worsened symptoms during the springtime when pollen is floating through the air. Some researchers have studied the link between autoimmune reactions and seasonal triggers. More compelling are testimonials from patients online that clearly indicate the connection. In some cases, for example, some pregnant women experience severe allergic reactions and develop autoimmune thyroid diseases after their pregnancy.

As suspicions develop regarding a link between environmental factors and autoimmune diseases, studies will continue to be conducted and every aspect of the link explored. Although it might not yet be accepted by everyone in the medical community, the link is clear through the personal stories of sufferers that detail their experiences online. The evidence can't be ignored and actions should be taken to alleviate autoimmune flare ups.

Helpful Lupus Resources

Lupus Chick

< <http://lupuschick.com>>

"Marisa Zeppieri is a journalist, chef, & the creative director/founder of LupusChick. LupusChick was birthed in 2008 to encourage those living with Lupus and other autoimmune diseases. Here, men and women can find information, advice, nutrition, recipes, coaching, humor, life hacks, true stories and more. Marisa's mission is to help others live the most vibrant, healthiest life possible despite chronic illness."

Sydney Davis – Writer on "The Mighty"

< <https://themighty.com/author/sidney-davis/>>

"Twenty-something male living and working with lupus in Washington, D.C. Web editor by day and actor/singer by night. Trying to navigate this hot-mess life one brunch at a time." Sydney provides a unique perspective for males living with lupus and uses comedy, combined with great information, to get his point across.

Thirty-Something With Lupus

< <http://www.flowonlupus.com/>>

"Lupus hit me in a strange (and quick) way. I had just graduated from grade 8 and was on top of the world. I'm 31 years old now. I'm now off of dialysis and I also graduated from college at the beginning of 2012. According to many people I know, I don't "look sick". Well, I'm glad I don't look sick, because I'm not. I may have Lupus, but as you can see, while Lupus may try, it DEFINITELY doesn't have me."

Molly's Fund Lupus Blog

< <http://www.mollysfund.org/blog/>>

"Here you will find a wealth of information on various lupus related topics. Molly's Fund Fighting Lupus is a nonprofit organization that is changing the way the health care community, pharmaceutical companies, governmental agencies, the general public and those living with lupus understand the disease, its diagnosis and its treatment."

Lupus Canada

< <https://www.lupuscanada.org/> >

We may be a little bit biased, but our website has great information, especially for Canadians living with lupus! "Lupus Canada is a national voluntary organization dedicated to improving the lives of people living with lupus through advocacy, education, public awareness, support and research." Our vision is a life without lupus, so join us in the fight!

Recipe: Omelet with Summer Vegetables

Ingredients:

- Cooking spray
- 2/3 cup frozen whole-kernel corn, thawed
- 1/2 cup chopped zucchini
- 3 tablespoons chopped green onions
- 1/4 teaspoon salt, divided
- 2 tablespoons water
- 1/4 teaspoon black pepper
- 3 large egg whites
- 1 large egg
- 2 tablespoons shredded smoked Gouda cheese



Directions:

1. Heat a small saucepan over medium-high heat. Coat pan with cooking spray. Add corn, zucchini, onions, and 1/8 teaspoon salt to pan; sauté 4 minutes or until vegetables are crisp-tender. Remove from heat.
2. Heat a 10-inch nonstick skillet over medium-high heat. Combine 1/8 teaspoon salt, water, pepper, egg whites, and egg, stirring well with a whisk. Coat pan with cooking spray. Pour egg mixture into pan; cook until edges begin to set (about 2 minutes). Gently lift the edges of omelet with a spatula, tilting pan to allow uncooked egg mixture to come in contact with pan. Spoon corn mixture onto half of omelet; sprinkle corn mixture with cheese. Loosen omelet with a spatula, and fold in half over corn mixture. Cook 2 minutes or until the cheese melts. Carefully slide omelet onto a plate.

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


Source: <http://www.myrecipes.com/recipe/omelet-with-summer-vegetables>


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