

Let's Talk Lupus

August Monthly E-Newsletter

LUPUS
CANADA
Life Without Lupus



August is here and that means summer break is nearing its close. Those hot summer nights will start to become more brisk and the long sunny days will become shorter. While the warm weather is still here however, be sure to take advantage and put time aside to de-stress. Do this by getting involved in some late summer activities in your local community or engaging in other self-care practices that will work for you!

In this month's newsletter, we have included some important information for lupus patients. Navigating the medical system as someone living with lupus can be very difficult, especially when having to communicate about your health to multiple physicians, specialists and other caregivers. It is important that you advocate for yourself to ensure that you are being supported in whichever way you need. Take a look at the article "Be Your Own Advocate" to understand why this is important and how you can take steps towards personal advocacy!

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New Research Opens the Door to Personalized Medicine for Lupus Patients

Classification and diagnosis of lupus has been an ongoing challenge for SLE doctors and researchers, due to the wide variation in how lupus presents in patients. In a new study published in Nature Scientific Reports last month, researchers have made significant headway in classifying lupus by studying gene data. The study involved applying a *machine learning approach* to three data sets from SLE patient blood samples. This study importantly, could open the door to personalized treatment of SLE, for example, potentially developing a single blood test to predict or monitor lupus activity and providing decision support for drugs prescribed based on an individual's genes. To learn more about this exciting research, visit: <https://www.nature.com/articles/s41598-019-45989-0>

Being Your Own Advocate with Lupus

Source: <https://lupus.newlifeoutlook.com/be-your-own-advocate/>

When it comes to your physician and the team of doctors that manage your treatment plan for lupus, it can sometimes feel like you are the only one who truly understands this chronic disease.

Short of finding yourself a doctor who also has lupus, there are some ways you can advocate for the best possible care, no matter what lupus is doing to your body right now. Being your own health advocate is a tough job, but it is vital for us lupies.

Sadly, I believe many doctors do not know all they could and should about this complicated and multi-faceted disease, and that means some of the burden of proof and explanation falls upon us, the patients.

Why It Is Hard to Advocate for Yourself

You may feel that having to argue or stand up for better care is not in your nature and should not be required; I totally sympathize. I tend to avoid conflict more than I should and I really take it personally if I feel a doctor is dismissing a symptom I feel is important.

I even once had a primary care doctor who said my hair loss, rash and fatigue were caused by stress and getting older. His response to most of my concerns, including a bout of sudden and severe chest pain was: "Lupus does not do that. It is stress or depression — are you depressed?"

Meanwhile, I was thinking, "Um, no, only angry about your lack of concern and dismissive attitude over this crushing pain every time I inhale."

Once I felt humiliated and dismissed enough that I got angry, I took action. Sometimes it takes outrage to stir me into proper action.

So I switched doctors, twice, until I found someone who listened, showed genuine concern and took what I said and searched for answers if she did not have them off the top of her head. She was the real deal — my medical detective and I believe the needle in a haystack of doctors who only know the basics about lupus.

My new doctor confirmed I had pleurisy (swelling of the lining of my lung due to lupus) and also sent me to a rheumatologist who she trusted and recommended. He re-confirmed my lupus diagnosis, began a treatment plan of medication (Plaquenil), pain relief options and diet modifications (no processed foods) to avoid flares.

He listened and explained things and addressed my previously dismissed concerns with, "Yes, lupus hair loss is quite common in lupus patients." Finally.

We Are Not Crying Wolf

So, this brings me to my mission: to get you to advocate for your own better care and acknowledgement from the doctors that are supposed to be watching out for you. You may have a team you trust and who are amazing, but the odds are you may not.

When a new lupus flare arrives at your door you need doctors who do not assume you are crying wolf. The lupus wolf is real and dangerous and the last thing someone battling this disease needs is to be dismissed by a doctor because of their lack of knowledge.

If this is happening to you, you need to advocate for better treatment, more tests, different medications — whatever it might take to ease your pain and perhaps even save your life. You may need to switch doctors, and keep switching until you find one that is well educated about lupus and right for you.

How to Be Your Own Advocate

The first step in advocacy is knowledge. Knowledge is power. Knowledge gives you confidence.

Research as much as you can and educate yourself on lupus. The Lupus Foundation of America has a wealth of information on its website (there are many other organizations as well) where you can learn about the many health issues lupus can cause, the symptoms and [treatments for lupus](#). This will give you the power to argue with facts rather than blindly trusting your doctor when they brush off a major symptom.

The second step is to ask questions. Yes, we all ask the obvious questions, but what about when what your doctor says does not add up in your mind?

He works for you and should be doing so with kindness and respect for your concerns. If your doctor says something that does not make sense, ask him to clarify what he means.

If he says something that seems to be misinformation, mention your research and ask for more details on the “facts” that he knows. A good doctor may look into the latest information and admit he might not know all there is to know.

The next step is to get your medical history with lupus onto paper. Create a complete list of your conditions, medications, all of the doctors you see, past treatments and their outcomes and include general dates. This will help if you start with a new physician or if you go to the hospital for an issue.

Next in advocating for yourself is a tough one — something we all dread doing. If a current doctor does not seem to take your symptoms seriously or does not seem to understand lupus or offer much in the way of treatment, find another doctor.

Do not feel guilty or ashamed. This is your health and your life. You deserve to be taken seriously and be provided with the best in care.

Find a new doctor and seek different or additional treatment options, which were not discussed by the previous physician. Plan out your questions for the new doctor before your first visit and have it written down so you will not forget these questions and concerns. Be organized, detailed and to the point. Expect the same in return from your new doctor.

When asked, “What brings you here?” don’t bash the previous doctors you have had.

This tends to make other doctors nervous that maybe you just cannot be satisfied. You want to be taken seriously.

Keep your comments factual, without emotion, as to why you are seeking a new doctor. Simply explain: "I had concerns that there were possible avenues of treatment and aspects of the disease, because of its complexity, that were not being explored by my previous physician. I am here because I am seeking the best possible care I can find."

This is a credible and reasonable concern for anyone battling a chronic illness. No doctor can blame you for seeking the best care.

Finally, be sure to ask for and collect your medical records from your previous doctor and have them sent to the new one at least two weeks before your appointment. Many doctors will review the new patient records and be better prepared for your first appointment.

Becoming your own advocate is a vital step to take when battling lupus. You cannot always trust that you are getting the best treatment or the proper level of concern regarding your symptoms. Follow your gut instinct. If you feel there is a lack of action from your doctor, be willing to express your concerns and advocate for yourself. Facing the wolf requires bravery and sometimes facing your doctor requires it as well.

How to Advocate for Yourself with a Federal Election on the Horizon

With a Federal Election on the horizon in Canada it is important to know how to advocate for yourself and/or your loved ones living with an episodic disability. Elections offer an unique opportunity for folks to influence public policy and budget decisions. Over the course of the month of August Lupus Canada will share with you how we plan to advocate for those living with lupus. Thomas Simpson, Lupus Canada's Advocacy Chair will also share with you some professional insight as to how to be your own best advocate. Together we can make a difference! For more information and to receive updates on Lupus Canada's advocacy initiatives please be sure to follow Lupus Canada on Twitter (@LupusCanada) and on Facebook (@LupusCanada).



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Lupus and the Toronto Argonauts!

Lupus Canada in partnership with Lupus Ontario is proud to share this exclusive offer. On August 16 join us at a Toronto Argonauts football game. Not only will you have a fun evening you will also be supporting those living with lupus. Come for the day as your ticket purchase also allows for free entry to the opening day of the Canadian National Exhibition. Remember to wear the appropriate clothing and apply sunscreen should you plan to do some of the outdoor activities. Special rates for children 18 years and under.

To purchase your tickets visit www.argonauts.ca/ticket-pass and use code LUPUSARGOS. Don't forget to wear purple and help us create awareness for this under-funded and under-recognized disease.

For more information please contact Lupus Canada at 1-800-661-1468 or info@lupuscanada.org

My Lupus Story by Jackie Dailleur

I started showing symptoms about 20 to 25 years ago. Then in November of 2003 I had an impacted wisdom tooth and ended up having all four of my wisdom teeth removed under anaesthetic in the OR. The dental surgeon was mystified as to my complaints after the surgery. I started having major headaches, ending up in the ER twice to be medicated for them. Then over the next several weeks I started getting sicker and weaker. My blood work started coming back completely abnormal. My family physician suspected, because of my pain complaints, that I had Fibromyalgia. I had asked if it could be lupus. She said in order to diagnose Fibromyalgia she had to rule everything else out. So, she sent me for more blood tests. A few days later I received a phone call at home from my



family physician. She apologized and told me that it was lupus. She based on my symptoms and the fact that I had a positive ANA she was certain of this. She then referred me to Rheumatologist.

While waiting to get in to see the Rheumatologist I continued to get weaker and sicker. I started developing cold-like symptoms and would end up having to call in sick. At the time I worked as an RPN in a Retirement Home. I would work about two weeks and end up off sick for one week. Each time getting weaker and increased joint pain as well as pain in my back. I contacted the Rheumatologists office and was put on their cancelation list to get in to him quicker. One week before my appointment I ended up off work again, sick. By this time, I was also developing fevers. I also started vomiting uncontrollably and was told by my doctor's office to go to the ER. I was treated for dehydration and nausea and was put on an IV for 3 hours and then sent home. The next day (a Tuesday) I went into my doctor's office. I could no longer climb the stairs to her office so they had to give me the code for their elevator. She sent me to the lab at the hospital for more blood tests. Later that day she called me at my parents' place, where I was now living as she had told me I could not live alone anymore. She told me that in all good conscience she could not leave me until Friday, which is when I was to see the Rheumatologist. She called my pharmacy and order Prednisone 50 mg once daily for me. My Rheumatologist was not thrilled about this but said that based on my most recent blood work he understood why she did it. Of course, none of this was entirely clear to me even with my nursing background until several months later when I commented to my doctor that the Rheumatologist had not been happy about the early start of the Prednisone. She then informed me that had she not started me on it when she did I most likely would not be alive come Friday.

For the next 15 years my lupus remained under control with Plaquenil and Prednisone. (I was never able to get entirely off Prednisone.) Then a year ago last May, after accepting a new position at the college where I have been working for the last three years, I started putting on weight, getting short of breath, and getting weak again. My Rheumatologist, since the beginning of the year had been increasingly worried about my kidneys. More so than normal. He has always monitored my kidneys from day one. In April he had ordered a 24-hour urine test. In 24 hours, I managed to void only a half a cup of urine. Not good. He wanted to see me, so I went to his office. He was very surprised to see how "symptomatic" I was and sent a rush referral to the chief of Nephrology at University Hospital in London. By the end of May I was admitted to UH in Kidney Failure on IV Lasix and IV Prednisone. I was also now on sick-leave from the college. At first the Nephrologist said that the strange thing was that although I did have lupus there was no sign of lupus in my kidneys but that I had Minimal Change Disease. It was later determined, with the help of a Nephrologist, who had studied this for her Thesis in University, that I had a rare form of Kidney Disease called Lupus Podocytopathy. Most people with lupus who have Kidney Disease have Lupus Nephritis, but there are some of us who have this other type. It disguises itself as another type of Kidney Disease. Either Minimal Change Disease (MCD) or Focal Segmental Glomerulosclerosis (FSGS). MCD is the easier one to treat. I was told they are able to put it into remission in about 4 weeks. With FSGS they often have to resort to chemotherapy drugs.

Needless to say, I spent last summer recovering from this. I was again on Prednisone 60 mg for 2 months before they started weening me off of it. They had assured me that I would be back to work by September. I had my doubts as I was using a cane to walk and even with that could only walk very short distances. I found it difficult to do things such as wash my hair, take a shower, get dressed. I eventually found out that I was having side effects from the Prednisone. As they started weening me down on the Prednisone, I started getting stronger. By September, I was back at work, only using my cane to walk the halls and not the classrooms. By the end of the first term I was no longer using my cane at all.

My kidneys are still being closely monitored as I can slip out of remission very easily. The good thing is, is now that they know what it is, they know how to treat me to put me back into remission. I was also told that next time they have to up my Prednisone they will have to give me another medication to help me deal with the side effects. I continue to work; I do tire easily and only work part-time. I still live with my mother. Sadly, my father, who diligently took care of me when I was really sick the first time. Driving me to doctors and labs and hospitals passed away six years ago from cancer. I was able to spend the last five months of his life taking care of him like he took care of me. Something that brought us closer than we already were.

Since my diagnosis of Lupus Podocytopathy I found a t-shirt on-line. It says "Lupus Awareness – Not going down without a fight." I wear it at least once a week with pride and determination.

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

Recipe: Lasagna Stuffed Zucchini

Ingredients

- 4 large zucchini, halved lengthwise
- 1/2 onion, diced
- 2 cloves garlic, minced
- 1/2 lb. ground beef or turkey
- 1 c. jarred marinara
- pinch of crushed red pepper flakes
- 1 c. ricotta
- kosher salt
- Freshly ground black pepper
- 1 c. shredded low-fat mozzarella
- Chopped fresh parsley, for garnish



Directions

- Preheat oven to 350 degrees F. Score zucchini (like you're dicing an avocado) and scoop out insides into a large bowl.
- In a large skillet over medium-high heat, heat oil. Add onion and cook until soft, 5 minutes, then add garlic and cook until fragrant, 1 minute. Add ground beef and cook until no longer pink, 6 minutes more, then add marinara and stir until combined. Add crushed red pepper flakes.
- Stuff zucchini: Spread ricotta on bottom of each zucchini boat and season with salt and pepper. Spoon sauce over ricotta layer and sprinkle with mozzarella.
- Bake until zucchini is tender and cheese golden, 15 minutes.
- Garnish with parsley and serve.

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

Source: <https://www.delish.com/cooking/recipe-ideas/recipes/a48828/lasagna-stuffed-zucchini-recipe/>

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