

**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](mailto:leanne.mielczarek@lupuscanada.org)*

## Celebrating World Lupus Day

MAY E-NEWSLETTER

May is an exciting month filled with special events for lupus awareness – these give us an opportunity for us to show our support for individuals living with lupus. On May 10<sup>th</sup>, Lupus Canada, along with many more organizations around the world will celebrate the 15<sup>th</sup> annual **World Lupus Day!** There is no boundary to the impact of lupus. Lupus is a global health problem that affects people of all nationalities, races, ethnicities, genders and ages. Lupus can affect any part of the body in any way at any time, often with unpredictable and life-changing results. World Lupus Day is so important to so many people around the world, country and within our own communities. It helps bring much needed attention to the effects that this illness may have on an individual and the need for increased medical sponsorship and services. Learn more at [www.worldlupusday.org](http://www.worldlupusday.org).

On May 18, we will also join in celebrating **Put on Purple!** On this day, we encourage you in joining us to wear purple and show your support for lupus awareness and lupus patients all over the world! Help raise awareness and rally public support for this under-funded and under-recognized disease. Mobilize individuals, corporations, physician offices, hospitals, people with a connection to lupus and the general community to get the word out about Put On Purple day and build excitement and interest.

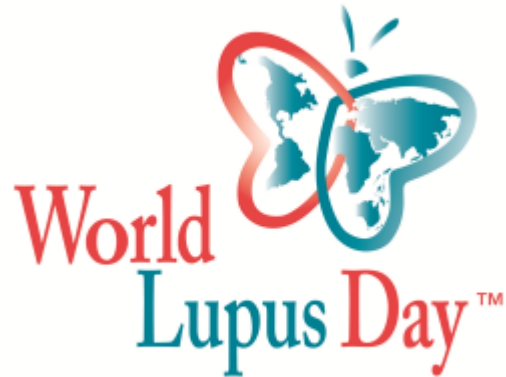
Celebrate  
with Lupus  
Canada!



## ***World Lupus Day***

Thursday May 10, 2018 marks the 15th World Lupus Day, a global awareness day which serves to unite people affected by the disease and lupus organizations around the world for the common purpose of raising awareness of this disabling and potentially fatal autoimmune disease.

For more information on World Lupus Day please visit [www.worldlupusday.org](http://www.worldlupusday.org)



**ON FRIDAY, MAY 18**

**I AM PUTTING ON PURPLE  
FOR LUPUS AWARENESS!**



On May 18 **Put on Purple (POP)** to show your support for those living with lupus. To purchase a t-shirt please contact Lupus Canada at 1-800-661-1468.

## My Lupus Story by Alexandra Cunningham

When you're living with lupus, there are a lot more questions than answers.

My lupus journey began in the three long and very painful years it took for me to get diagnosed. Years of living with sharp pains in my chest, debilitating migraines and severe arthritis - yet I was just 22 years old!



At first my doctors thought I was just reacting to the stress of going to university. But then one morning I awoke, and my first breath brought an excruciating pain and pressure in my chest like I'd never felt before. I had to call my parents to help me get out of bed and take me to the hospital. Doctors told me I had *pericarditis*, an inflammation of the lining of the heart. This symptom eventually helped lead to my lupus diagnosis.

Six years later, I'm still learning about lupus at every medical appointment. I have so many questions, and there's not always an answer. Often it seems the doctors are still learning too! There's just not enough information available about lupus, even though it affects 1 in every 1000 Canadians and *eight times* more women than men.

Today, I have more questions than ever. Many of my questions right now have to do with the fact that my husband, Shane, and I are expecting our first child! She's due to arrive on Mother's Day and we couldn't be more thrilled.

But I'm scared too.

While pregnancy can be challenging for any woman, it can be especially difficult for women living with lupus.

When I was diagnosed at 22 years old, the first rheumatologist I visited greeted me this way: *"You've been diagnosed with lupus. Just so you're aware, you may never be able to have children."*

In my early twenties I wasn't thinking about having kids, but I was brought to tears upon hearing those words. The diagnosis was given so bluntly and coldly. The rheumatologist went on to tell me that it would be very hard for me to conceive, and if I had a baby it would likely have heart problems, or worse.

You can imagine the fear and uncertainty we felt when Shane and I decided we wanted to start a family in spite of the challenges. Thankfully, we didn't have trouble conceiving. The first few months of my pregnancy, however, were fairly difficult. I

experienced the full-range of pregnancy symptoms, everything exacerbated by my having lupus (especially the *extreme* fatigue)!

At about four months into the pregnancy, some challenges did come up. I tested positive for anti-Ro antibodies, which can pass through the placenta of lupus patients to the baby. Additional tests showed our baby might develop prenatal lupus, which appear in the best case scenario as a body rash, and the worst, as congenital heart block. For now, all we can do is take each day at a time and trust that everything is going to turn out okay.

When you're pregnant, your body is going through so many changes. But for me, every time something happens I have a little panic in my head wondering, '*is this a normal pregnancy symptom, or is this lupus?*'

I wish I'd known about Lupus Canada sooner. It was my incredibly sweet and supportive husband, Shane, who first connected us with this amazing organization.

When we found out I was pregnant, Shane took it upon himself to create a special fundraising project called the #ISangforLupusChallenge. It's a social media campaign where people upload a video of themselves singing their favourite song, and then challenge three of their friends to do the same within 72 hours. It's been very successful so far in raising awareness about lupus, which is such an unknown and misunderstood disease.

Shane started the challenge in the hopes that there will be more advances in the way lupus is diagnosed and treated, so that as we get older, our daughter and I can live the best lives possible.

Because I have to admit, I do worry...a lot.

I try to stay positive, but I'm worried about my baby. I'm worried about how this disease could affect her, especially since ***eight times*** more women than men are diagnosed with lupus. And, there is no cure. Lupus is a chronic disease, with very few options for treatment.

I desperately want that to change. For me, and for my baby.

Lupus is called "the disease with a thousand faces" because the symptoms are so wide-ranging. It often takes many years to receive a diagnosis, just as it did for me.

My grandmother had the same experience. She'd been struggling with pain for much of her life, particularly in her older age, seeing doctor after doctor. None of them could figure out what was wrong. Strangely, just a few months after I was diagnosed, she too was diagnosed with lupus, at the age of 82.

It pains me that she had to suffer for so long without being diagnosed and treated. I

believe that the last years of her life would have been very different if she could have been diagnosed sooner.

I hope you agree that his has to change.

We simply must find ways to diagnose people with lupus faster, to improve quality of life and reduce suffering for so many. I'm confident we will – when we join together in support of Lupus Canada.

It took me a while to realize that nothing I did resulted in me being diagnosed with lupus. It's not my fault - there's nothing I could have done differently. I am learning each day to deal with it in the best way I can.

For now, Shane and I are looking forward to welcoming our sweet baby girl into this world – getting to know her and creating our life as a family of three.

I know that we'll stay involved and connected with Lupus Canada. I'll continue to share my story in every way I can, both online in my new photo blog (@thisfamilytree on Instagram) and in other ways. I'm determined to inspire others who are struggling, to show them that it's possible to be happy, and to have a great life while living with this disease. Sure, we're all going to have good days and we're going to have some pretty bad days too – and that's okay, because we'll get through it together.

## Lupus Flares: Triggers & Prevention

Source: <http://www.mollysfund.org/2013/07/lupus-flares-recognizing-one-triggers-and-prevention/#3>

### ***What is a lupus flare and how do I recognize one?***

Unpredictable and debilitating bouts with symptoms of the disease are known as flares.

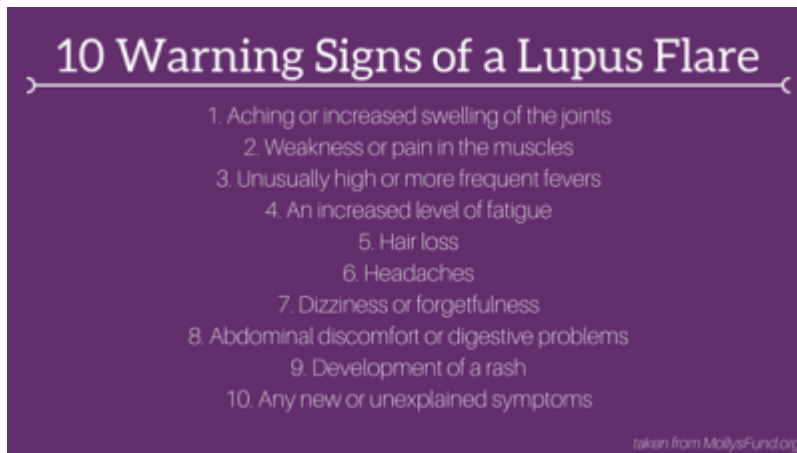
At times, lupus patients may have periods with few to no symptoms, commonly called remissions. Some physicians are uncomfortable with the term "remission" as lupus symptoms rarely disappear completely. They may, instead, choose to use the term "quiescence" (pronounced: kwee-ess-ence.) At other times the patient may have high disease activity which include unpredictable and debilitating bouts with symptoms of the disease.

Flares can be classified as mild, moderate, or severe. For example: A mild flare could perhaps be signaled by a lupus rash, moderate flares could include the rash, fatigue, and joint or muscle pain, and severe flares could potentially cause damage to the organs including fluid buildup around the heart or even kidney disease or failure

(called lupus nephritis), which would require immediate medical attention.

### ***So how is a lupus flare recognized?***

Most lupus patients will have symptoms of muscle and joint pain as well as fatigue regularly, so what makes a flare different? Here are some warning signs of a pending lupus flare:



It is important to keep in mind that a flare can look different for every lupus patient

### ***What can trigger a lupus flare?***

Lupus is an auto-immune disease. This means that the immune system, when activated, creates auto-antibodies that attack not only an invading virus, but will turn and continue to attack healthy cells and organs, thus causing inflammation. Therefore, anything that stimulates activity in the immune system can cause a lupus flare. Here is a list of potential flare triggers:

1. Infections, like a cold or the flu, can activate the immune system and trigger a flare
2. Stress flares are common after either emotional or physical trauma
3. Pregnancy flares are common as well as, directly after the birth of the baby
4. Sunlight
5. Starting or stopping a new drug

### ***Can anything prevent a lupus flare?***

Your physician has probably created a specific plan of treatment that was created specifically for you and your lupus symptoms. The most important thing is for you to completely understand this plan and the steps needed to keep your disease under control and avoid a lupus flare. Your plan may include some or all of the following:

- Take your prescribed medications as indicated by your physician
- Physical and emotional rest
- Aggressive treatment of infections
- Exercise
- Good nutrition
- Avoidance of direct sunlight and other sources of ultraviolet light, see our blog on photosensitivity.
- Watch for stress. Having a chronic illness can understandably cause anxiety and depression which can lead to stress. Finding ways to manage stress is very important. This is often called a mind/body balance.

Sometimes, despite you and your medical caregiver's best attempts, you may still experience a lupus flare. If you suspect that you are having a flare, please contact your physician immediately so that any adjustments to your treatment plan and medications can be made.

[Read More](#)

## Recipe: Stuffed Zucchini

### Ingredients:

- 3 zucchini
- 1 pound lean pork sausage
- 1 cup dry bread crumbs
- 1 clove garlic, minced
- 1 (32 ounce) jar spaghetti sauce
- ½ cup grated low-fat Parmesan cheese
- ½ cup shredded mozzarella cheese



### Directions:

1. Preheat oven to 350 degrees F (175 degrees C).
2. Trim stems from zucchini and slice lengthwise. Scoop out seeds and put in bowl. Mix seeds with sausage, garlic, bread crumbs, and parmesan cheese. Stuff squash with sausage mixture and place in 9x13 inch baking pan. Pour sauce over squash and cover pan with foil.
3. Bake in preheated oven for 45 minutes, or until sausage is cooked. Remove foil and cover with mozzarella cheese. Cook until cheese is melted.

***The recipes used by Lupus Canada have been reviewed and approved by***

**Heather Penney, Registered Dietitian.**


Source: <http://allrecipes.com/recipe/24162/stuffed-zucchini/print/?recipeType=Recipe&servings=4&isMetric=false>


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