

# July E-Newsletter

## Safe and Enjoyable Summer

Happy Summer! The sun is shining and the temperature is quickly rising - this may sound ideal for many people, but for lupus patients, this season can be extra stressful. Despite this, there are so many fun activities to participate in while remaining completely safe. This newsletter has some great information on protecting yourself and your body in the sun to help prevent flares; taking advantage of the warm, summer nights is one way to do just that. Especially with International Self-care Day on July 24<sup>th</sup>, we encourage you to celebrate YOURSELF and realize the importance of leading a healthy lifestyle, both physically and mentally. Living with lupus should not deter you from enjoying everything that the season has to offer, and joining the world in practicing self-care is a great start!

On July 1<sup>st</sup>, Canadians around the country will celebrate Canada Day. This holiday helps us to recognize the amazing privilege we have to live this great nation – Happy Canada Day from Lupus Canada!



“ Self-care is not about self-indulgence  
It’s about self-preservation ”  
-Audrey Lorde

**Lupus Canada Updates:** Happy Summer! The sun is shining and the temperature is quickly rising - this may sound ideal for many people, but for lupus patients, this season can be extra stressful. Despite this, there are so many fun activities to participate in while remaining completely safe. This newsletter has some great information on protecting yourself and your body in the sun to help prevent flares; taking advantage of the warm, summer nights is one way to do just that. Especially with International Self-care Day on July 24<sup>th</sup>, we encourage you to celebrate YOURSELF and realize the importance of leading a healthy lifestyle, both physically and mentally. Living with lupus should not deter you from enjoying everything that the season has to offer, and joining the world in practicing self-care is a great start!

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## My Lupus Story by Sue-San King

I wish to share my lupus story during this time of grieving for the recent loss of my beloved uncle, Mr. Clair Goodwin. He passed on May 16, 2017.

I wrote him a letter while he was in hospital, detailing my journey with lupus that he was not aware of. It was written to encourage him while he struggled with his health ordeals and give him insights into what it is like living with a chronic health condition.

**Dear Uncle Clair,**

I have always found writing to be therapeutic. With pen in hand, I allow myself to go deep into my emotions. A form of freedom of expression.

As you now find yourself on your own health journey, I wish to share with you my lupus story. For we are more similar in our health struggles than you may know. Both of us on warfarin and thyroid pills, bruise easily, permanent swelling in the lower legs so we have to wear support stockings. And most crucially, we must learn to live with chronic, life-long health conditions. What a pair we are, ha! This is the first time I've ever written about my lupus to anyone. So I begin to tell my truth.....

At 33, my life changed forever. After two years of mysterious illnesses and blood clots in my legs over this period, I was officially diagnosed with lupus in 2008. Lupus is an autoimmune disease where the body turns on itself and attacks healthy areas. It can affect the skin - called discoid lupus- in which large, red welts appear on the body. It can also affect any vital organ. It primarily strikes women between childhood to age 50 and there is no cure. Now, extensive research has come a long way so that someone with lupus can, generally, live a normal lifespan.

In my case, which is common, I had inflammation of my kidneys. This was discovered through a biopsy. I remember my anxiety waiting for the test result.....the scary thoughts that ran through my mind: If it's severe, would I need life-long dialysis or even a transplant? My symptoms prior to diagnosis were sun sensitivity, poor circulation, blood in my urine, achy body, and very fatigued all the time. I went from being a person with excellent health all her life to someone on 8 medicines and endless doctor appointments and blood tests. I've lost count how many needles have been poked into me and how much blood has been sucked out of my body. Essentially, I became another number in the health care system.

Physically, the worst pain I experienced was two issues. I developed intense leg muscle cramps. It felt like having a Charlie horse that never ends; a searing hot knife stabbing through my calves. I could find no relief and had to wait it out, as I lay on the couch crying in pain. Sometimes it was so bad, I thought maybe I wouldn't be able to walk properly again. Often, it would wake me in the middle of the night, as I twisted in agony. The other incident was suddenly getting (what I thought) was severe migraines. My head would explode in excruciating throbbing in one area. I would sit wailing, holding my head in my hands, desperate to make the pain go away.

When it became unbearable, I went to emergency where I was given a cat scan. I had a subdural hematoma, which is bleeding under the skull but outside the brain. I was admitted overnight and I found myself, like you, in a thin hospital gown with nurses constantly poking at me at all hours. In the morning I awoke to a doctor and his team of 8 medical students all staring at me in their white coats and holding clipboards. I felt like an alien species that they gawked at. Your dignity gets thrown out the window.

Emotionally, I felt disbelief and the unfairness of having lupus. The day I was diagnosed, I went home, filled the bath tub, and lay in the hot water for a long time. I didn't cry, but I was lost in my own sadness. Over time, it became a loss of many things: my physicality and strength diminished, I could no longer be out in the sun without burning, I could no longer run, I couldn't walk long distances with always having to sit down. I wasn't allowed to play contact sports due to bruising easily or anything that could further injure my legs. Most evidently, my energy level was permanently lowered. I can't remember what it feels like anymore to have 100% energy.

It caused me to isolate myself. I withdrew from friends. I lacked confidence to do normal activities. I was embarrassed if I couldn't keep up with my friends. I was ashamed of how physically weak I could be, even with simple chores. This disease struck me in my child-bearing years and it was too risky to have children at the time. Indeed, I felt so different from other people who were "healthy", while I had entered the realm of "the sick ones". A friend told me that once you wear the crown of health problems, you are forever changed.

Thankfully, I have been in remission for the last 7 years, meaning I no longer have inflammation and my symptoms are manageable with medicines. But I have had to undertake lifestyle changes, whereby I should create a stress-free, low-key existence. I laugh sometimes because simply living is stressful!! Life is not for the weak; there are constant struggles. I have come to a place of acceptance and choose to remain positive instead of cynical or self-pitying. If I feel down, I remind myself that there are millions who suffer much greater afflictions than me.

Those of us who live with chronic health problems are faced with unsettling questions: Who am I now? What are my physical and emotional limitations? Where do I find my purpose anymore if I can't work or enjoy my regular activities? How do I obtain a good quality of life with these new changes? The answers only come, in time, with each individual. The road is long and the struggles are plenty.....Do we break like a dry twig in a storm or bend like the willow reeds in the wind? This I know: *that which doesn't bend shall break.*

Know that I am here for you during your recovery and beyond. You are not alone. When I am not physically present, I am always supporting you through encouraging and loving thoughts. You are my teacher, a role model, and my friend.

*So take my hand and let us sway in the winds of life. We will not be broken!*

I love you forever & always.

**Your niece, Sue-San xoxo**

## Lupus Keeping You Indoors This Summer?

Source: <http://www.lupusil.org/lupus-keeping-you-indoors-this-summer.html>

Lupus and the sun is viewed by many in the lupus community as compatible as oil and water. It is well known that the sun can cause a lupus rash and a flare-up of systemic lupus with joint pain and internal manifestations. Studies have shown that about 40% of lupus patients are sun sensitive, but, of course, some are more sun sensitive than others.

Those with a history of rashes over sun-exposed areas such as the face need to be particularly careful about the sun and other sources of ultraviolet light. Some lupus

Patients are may be too worried about sun exposure.

If sun exposure has not caused a flare-up in the past, people with lupus usually need not worry. Some rheumatologists advise strict adherence to sun avoidance, whereas others are more lax, but most lupus flare-ups are not associated with sun exposure. Lupus patients shouldn't become hermits, afraid to venture outside.

That said, sun protection is important for everyone. Sunblock, including make-up with sun block, can be protective. But how much sun block is necessary?

The protective factor for sunblocks is decided by the company that makes the product rather than the FDA or another regulatory organization. Companies are incentivized to beef up the protective factor score for sunblocks, and so, in testing situations, they tend to glob on huge amounts of sunblock that form a very thick layer and then do the test for the sun protective factor - providing an inaccurate score.

The FDA has new rules governing sun block, which go into effect in about one year, that will ban certain labels such as "sunblock", "waterproof", and "sweatproof" because these words apply a false level of protection. One of the FDA rules is that to use the term "broad spectrum" the sunblock must cover UVA and UVB radiation adequately. (There are two kinds of solar radiation: UVB rays cause burning while UVA rays cause wrinkling. Both types can cause cancer.)

For now, in general look for products with a sun protective factor between 30 and 50 and with the words "broad spectrum." Sunblocks should be water resistant, and reapplied after about one hour, depending on the product. Wearing hats and staying out of the sun especially the mid-day sun, are advisable. Currently, sunblock products with SPFs over 50 can expose people to additional irritating sunscreen ingredients, but do not necessarily provide meaningful added protection.

When the new FDA rules go into effect, a sun block with a sun protection factor of 15 or higher will be able to claim a reduction in risk for skin cancer and early skin aging. Consumers will be better able to choose a sunscreen based on the SPF number and make sure that it is broad spectrum.

Sunscreens do prevent squamous cell skin cancer and melanoma. Melanoma is the most serious type of skin cancer. Sunscreens may not protect against the first case of basal cell carcinoma, but appear to delay recurrences of basal cell cancer.

Because humans often sweat off part of the sunscreen and also do not use the same quantities as in testing situations, the sun protective factor is only a guide to the strength of the sunblock lotion or cream. Nonetheless, sunblock is very helpful, but should be reapplied on hot days when people perspire a lot. Protective clothing including hats, longer sleeves, long sleeves, and long pants are also advisable for some certain patients.

If a lupus patient does get a rash provoked by the sun, usually steroid creams and, occasionally, oral prednisone are used for treatment. Stronger skin steroid creams can cause mild skin atrophy with prolonged use. For longer use on the face, hydrocortisone 1% cream is recommended. For short-term use, stronger steroid preparations can be used.

There are other forms of skin lupus aside from the systemic lupus rash, which often involves the face and frequently the hands and other sun exposed areas. These include discoid lupus, in which there are disc or plate-shaped scaly lesions on the skin, and a form of skin lupus called subacute cutaneous lupus with extensive skin lesions. It is less clear that these other forms of skin lupus are directly related to sun exposure, though it seems wise to avoid prolonged sun contact in patients with these conditions.

## Recipe

### Linguine with Tomatoes ,Baby Zucchini and Herbs

#### Ingredients:

- 1 pound tomatoes, cored and finely chopped
- 1 tablespoon chopped basil
- 1 tablespoon chopped parsley
- 2 garlic cloves, minced
- 2 teaspoons kosher salt
- 1 small red chile, seeded and minced
- 1/3 cup extra-virgin olive oil
- 12 ounces linguine
- 3 baby zucchini, thinly sliced
- 1/4 cup freshly grated Parmigiano-Reggiano cheese, plus more for serving

**Time: 25 minutes**

**Serves: 4**



**Directions:**

1. In a large bowl, toss the tomatoes with the basil, parsley, garlic, salt, chile and olive oil.
2. In a large pot of boiling salted water, cook the linguine until al dente; drain well. Add the linguine to the bowl along with the sliced zucchini and toss. Add the 1/4 cup of grated cheese, toss again and serve in bowls, passing more cheese at the table.

*SUGGESTED PAIRING*

Cooked tomato sauces are a great match with high-acid red grapes like Barbera and Sangiovese, but a raw tomato sauce such as this one calls for something more delicate, like a dry rosé.