

June Newsletter

Special Thanks to Fathers

Summer is always an exciting time as we get to spend quality time with our families. The school year is coming to an end, summer vacations are about to begin, you enjoy the warmth of the summer sun and finally start to enjoy outdoor bbq's. Always remember while you are outside to always protect yourself and your loved ones from the harmful effects of the UV rays.

To learn more about the sun and its effects please watch Let's Talk Lupus series "The Effects of UV" video on our website. <http://www.lupuscanada.org/video/>

FATHER'S DAY



On Sunday June 18 we celebrate fathers who give unconditionally of their time, love and support to their families. Thank you for what you do! Happy Father's Day from Lupus Canada

2017 SCHOLARSHIP

Lupus Canada is proud to announce the 2017 Lupus Canada Scholarship program. We will be offering five (5) one-time scholarships of \$2,000 CAN to students diagnosed with lupus, who are entering into, or currently enrolled in, a post-secondary educational institution.

Lupus Canada has been helping lupus patients with their post secondary education through our Scholarship program for the past four years. We are always happy to share stories from past recipients how our Scholarship has helped them.

The Lupus Canada scholarship was not only a great help to me financially, but it was also incredibly encouraging. Entering into university is daunting as it is, but knowing that there are people out there who understand what its like to live with Lupus, and

who are rooting for my success really means the world to me. This kind of support is invaluable in terms of building a foundation of support for students living with Lupus. I am very thankful and honored that I was chosen for this scholarship.

Shelby Brown, past Scholarship recipient

Selection of award recipients will be at the sole discretion of the Lupus Canada Scholarship Selection Committee. Recipients will be notified in the month of August 2017 via a personal telephone call and a confirmation letter. After a recipient's educational enrollment has been verified for the fall 2017 semester, the scholarship will be made payable directly to the educational institution. The scholarship of \$2000 CAN will be awarded to cover the recipient's tuition and/or educational materials and expenses. **Thank you to everyone who applied.**

RESEARCH

Catalyst Grant info – deadline June 1

MyLupusGuide



World Lupus Day Messages Reach Millions of People around the Globe

World Lupus Day 2017 was a big success. Together with our colleagues across the globe the hashtag #WorldLupusDay generated 44.5 million impressions. More than 6,200 individuals made 14,300 posts on social media during World Lupus Day. A search on Google returned more than 4,000 web pages with references to World Lupus Day.

In comparison to 2016 where 25 million impressions were generated. It is very exciting to see that we almost doubled the number of impressions which translates to almost double the public awareness for this disease

Thank you to everyone who tweeted using the #WorldLupusDay hashtag. Together we are making a difference!

“Lupus Knows No Boundaries e-Report”

The World Lupus Federation wishes to say thank you to GlaxoSmithKline and So What Global for working with us to produce the first-ever e-report on lupus. The e-report tells the story of people living with lupus and those who treat and care for them. More than 10,000 people viewed the [e-report page on the World Lupus Day website](#).

The 37-page e-report includes comments by 22 people from 14 countries on six continents. The document includes 11 videos, 30 illustrations, 70 photos, and more than 10,000 words of text.

The e-report is available online at www.worldlupusday.org/e-report.htm

Twitter Chat

Recently, as part of the World Lupus Federation, Lupus Canada participated in a #LupusChat on Twitter with @GSK and @TiffanyandLupus to discuss the results of the recent Twitter Poll. To read a transcript of the #LupusChat click on the below.

<https://storify.com/TiffanyAndLupus/challenging-misconceptions-breaking-down-barriers->

PUT ON PURPLE (POP) – FRIDAY MAY 19, 2017

Thank you to those who showed their support in finding a cure and help those living with lupus by wearing **purple** on **May 19**. Together we helped raise awareness for this under-funded and under-recognized disease!

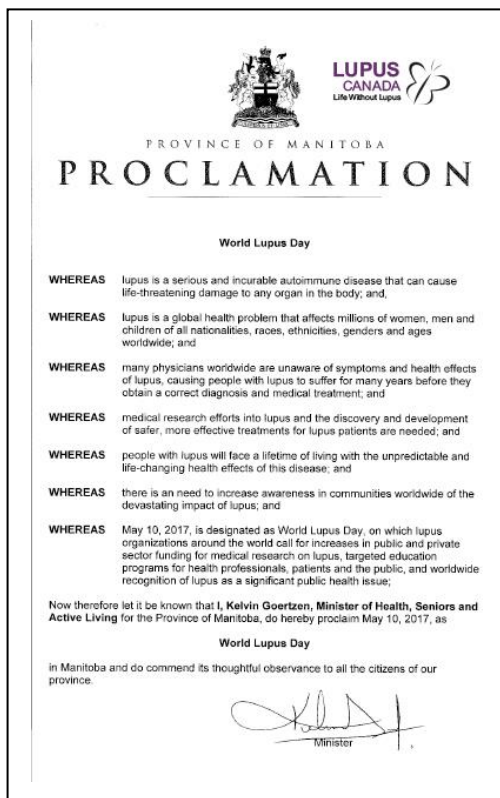
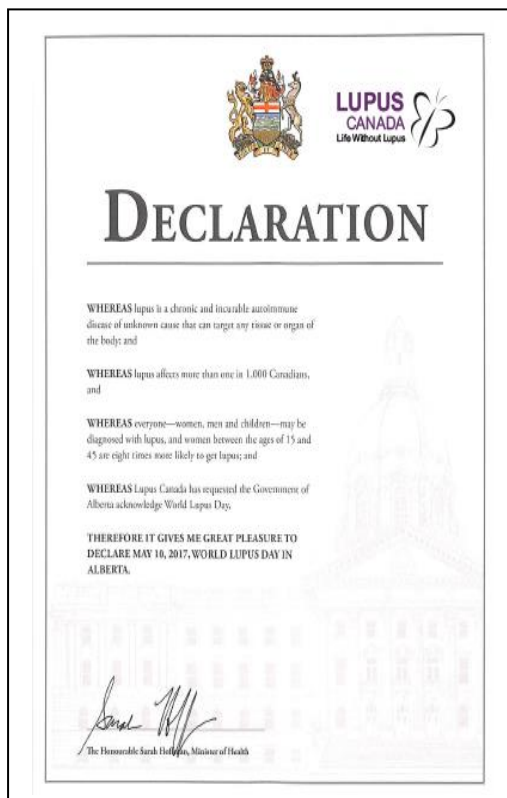
Don't forget to share your photos or videos on with us by emailing them to info@lupuscanada.org.

POP t-shirts are still available. To purchase please contact our office at 905-235-1714 or 1-800-661-1468 to order.

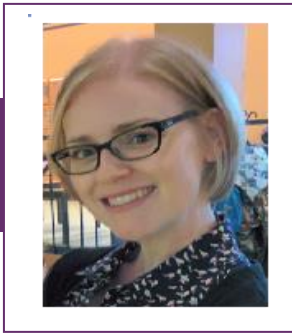


A Special Note of Thanks . . .

A special thank you to the Honourable Sarah Hoffman, Minister of Health, Alberta and the Honourable Kelvin Goertzen, Minister of Health, Seniors Active Living, Manitoba for being champions for #lupus!



We would also like to thank the Honourable Jane Philpott, Minister of Health for acknowledging Lupus Canada's commitment to raising awareness for lupus.



My Lupus Story by Kim Desmarais (past Lupus Canada)

The worst thing to happen to an overly driven person like me is a chronic illness that slows me down. I was diagnosed with SLE during the last year of my undergraduate degree. Initially, I had a difficult time coping with my condition. I read too much about Lupus and its manifestations; Google was my enemy! I saw others with SLE who experienced lung disease, kidney disease, and those who were robbed of their mobility. I was terrified at what my future would be in the face of a disease that changes at the drop of a hat and can go from mild to severe. A disease that has no cure and would have an impact my life. A disease in which your body is not always able to meet the expectations of your brain. I wondered if I would still be able to pursue higher education, have a family, and all the other goals I wanted to accomplish. I felt ashamed by my condition and wanted to hide it from others. I did not want to be viewed with pity. Socially, I began to isolate myself. I had trouble seeking support from family and friends who continually reached out. I also did not know how to explain the impact of this disease to others as, on the outside, I looked fine.

A few months after being diagnosed, I came across the "Spoon Theory"* by Christine Miserandino, which gave me way of explaining SLE to those I love. I began sharing it with my friends and family and it became part of the way we communicate. To this day, I find it comforting when I'm speaking with my spouse and he asks if I have enough spoons to complete some unnecessary tasks in my day. Or when my best friend offers to do groceries so I can "save some spoons". In speaking with others, I also learned to accept that the condition was a part of my life, but was not a part of me. Lupus does not define me, and though I may have to work somewhat differently, I am still able to reach my goals. I am still learning to cut myself some slack, realizing that things do not always need to be perfect. Learning to cope with Lupus is ongoing, following the peaks and lows of my illness.

Eventually, I finished my undergraduate degree and went on to complete my Master's. The journey was long and difficult. Like many people with Lupus, I received additional diagnoses and experienced many set backs resulting in longer delays than I would have

liked. While attending school, I dealt with several hospitalizations, multiple invasive procedures, surgery, and frequent changes in medications with their accompanying side effects. The additional health concerns took their toll on my emotional and physical well-being, and I often thought of giving up.

I thought of pursuing simpler goals that would be easier to balance with the demanding nature of this disease. Knowing I would regret not trying to do the most I could, I fought through it. It was one of the most difficult things I have ever done but, at the end of the day, I am proud of what I have accomplished despite everything that was thrown at me. I am currently completing my doctoral degree to become a pediatric neuropsychologist. While I'm sure more obstacles will present themselves as I finish this degree, I am confident that I will attain my goal.

If I could offer any advice to those who were recently diagnosed or who are struggling, it would be to seek support. Talk to your friends, family, or even the doctors, nurses, and psychologists who specialize in Lupus. In the face of chronic illness, your support system is of utmost importance. Whether it is the family you were born into or the one you created for yourself along the way, these people will be your most valued allies, rallying for you when you cannot. I am eternally grateful for my friends and family. Without them, I know I would not be where I am today.

Spoon Theory found at: <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

ARTICLE - **5 Fabulous Tips to Enjoy The Beach Without a Lupus Sun Flare!**

Doctors say that people with lupus cannot be in the sun. I still shudder when I hear the words, "You will never be able to be in the sun again." I remember hearing those exact words years ago in my rheumatologist's office and leaving in tears.

Being the ultimate sun worshipper, I took this as a life sentence. How could I possibly live only indoors? No more sun, no more beach. This was too much for me to bear. Hearing that I would forever have to worry about lupus sun flares was worse than my diagnosis. I felt like a prisoner.

Next, I had to buy dreary clothes and hats for sun protection, which didn't help the way I was already feeling about my body. Fat and in pain, I felt even worse in these awful-looking clothes.

That was 5 years ago. Today, I do go to the beach. I do not get a rash as I did initially. But I go to the beach *prepared*. For those of you contemplating a warm getaway in the midst of this long winter, you may want some tried-and-tested sun protection tips.

Here are my 5 beautiful options for those of you who love the outdoors and the beach:

1. Wearable sun protection. I've purchased clothes from <http://www.coolibar.com>; the styles have really improved in the past few years. This kind of sunwear protection is especially important for those of you who are newly diagnosed or who get a rash from being in the sun.

2. Gorgeous brim hat. Another deal I found on <http://www.coolibar.com>. I wear it all summer long, at the

5. Timing. Timing is everything, so I try to avoid the hottest and most potent sun exposure between 10:00 am – 2:00 pm and head outdoors after 2:00 pm. I won't lie and say that I've never stepped foot on the beach in Miami at 11:00 am, because I have, but I go prepared! All of the above goes with me and I rent an umbrella at the beach, too. Some may gasp at the fact that I am even writing about going to the beach.

beach or park. Most department store hats may not have the same level of sun protection as this one does – it shades your face as well. It's worth the investment.

3. SPF. Yes, that white pasty lotion. I wear 50 -100 SPF if I know my skin will have any sun exposure. I use this high SPF especially at the beginning of summer. This includes lip protection, at least 30 SPF. To make sure that you stay protected, reapply your sunscreen every two hours if you're walking or exercising outdoors. In general, individuals with lighter skin and light colored eyes have a higher risk of getting a sunburn.

4. Beach umbrella. I have one that I carry everywhere! If I take the subway to the beach, I drag my umbrella with me. It may seem high maintenance to some, but I love having my own portable shade! Use an umbrella while walking outdoors. You can make a fashion statement with it. Just choose the right fabric, color, and design and make sure that it has UV sun protection.

RECIPE:

Chicken Club Pasta



8 ounces corkscrew shaped pasta
¾ cup Italian style salad dressing
¼ cup mayonnaise
2 cups chopped, cooked rotisserie chicken
12 slices crispy cooked bacon, crumbled
1 cup cubed Muenster cheese
1 cup chopped celery
1 cup chopped green bell pepper
8 ounces cherry tomatoes, halved
1 avocado, peeled, pitted and

But I am here to share my journey with you.

Now, I am not saying run out in the sun and lay out! I know what your specialists have told you. I am also not taking medications that make my skin super sensitive to the sun.

Keep in mind that lots of medications taken during a flare – or even when not in a flare – will definitely cause a rash. I also don't think you should be out in the sun during a flare.

Please be mindful of the sun and its powerful rays – and definitely no artificial sun bathing! I learned the hard way.

If you really want to be tan (for a wedding or fun gathering), get a spray-on tan. It will last 7-10 days, longer if you avoid hot tubs and pools.

The best spray tans are done by a professional technician who sprays your body, rather than just standing in a booth and getting sprayed by a machine. Bronzing lotions are also quite nice, though it can take some time to build up to your desired color. If you start early in the summer and use it daily, color will accumulate over time.

Directions:

Prep 20 m | Cook 10 m | Ready In 30 m

Bring a large pot of lightly salted water to a boil. Cook pasta in the boiling water, stirring occasionally until cooked through but firm to the bite, 10 to 12 minutes. Drain and rinse under cold water.

Whisk Italian-style dressing and mayonnaise together in a large bowl. Stir pasta, chicken, bacon, Muenster cheese, celery, green bell pepper, cherry tomatoes, and avocado into dressing until evenly coated.

source:

<http://allrecipes.com/recipe/223380/light-and-easy-greek-potato-salad/?internalSource=previously%20viewed&referringContentType=home%20page>

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