



Let's Talk Lupus

Monthly E-Newsletter

After a very successful Lupus Awareness Month, we would like to extend a huge thank you to all of our supporters. Together, we are making a difference in the lives of so many Canadians and working towards Life Without Lupus. During the month of May we celebrated Put on Purple and World Lupus Day and held our inaugural fundraising and awareness event, ***Laughs for Lupus***.

On the 21st of June, summer officially begins. While this means more sunshine and warmer weather, it is often a stressful time for lupus patients as managing symptoms and preventing flare-ups become even more difficult. Unusual or extreme reactions to sunlight are very common with lupus and so, it's important that with the onset of summer, those living with lupus take measures to ensure protection of their skin.

DONATE NOW

your gift makes a difference

Laughs for Lupus



Lupus Canada held its Inaugural Fundraising and Awareness event, ***Laughs for Lupus*** on May 9, 2019 at the Second City in Toronto. On hand were some of Canada's Top Researchers, representatives from several Pharmaceutical companies and lupus patients. We also helped launch MyLupusGuide, the first interactive website developed specifically for people with lupus.

It was wonderful to see the lupus community come together.

World Lupus Day 2019

World Lupus Day, observed on May 10, serves to call attention to the impact that lupus has on people around the world. The annual observance focuses on the need for improved patient healthcare services, increased research into the causes of and cure for lupus, earlier diagnosis and treatment of lupus, and better epidemiological data on lupus globally.



Together we can make lupus an international health priority and to ensure that people with lupus around the world are diagnosed and treated effectively.

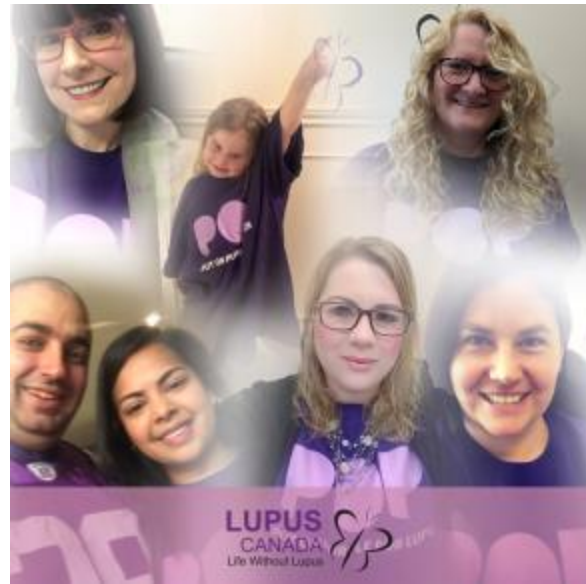
Special Note of Thanks....

Lupus Canada would like to thank the provinces of British Columbia, Manitoba, Saskatchewan, Nova Scotia and Ontario for being champions for lupus in Canada and recognizing May 10 as World Lupus Day.

Put On Purple for Lupus

On Friday May 17 we asked people to show their support in finding a cure and help those living with lupus by wearing purple. We asked people to not only wear purple but to also share their photos via social media to help raise lupus awareness and support efforts to advance lupus research.

Thank you to everyone who **Put on Purple** on Friday May 17 and shared their photos.



Lupus Canada Announces Catalyst Grant Program Recipients

The Catalyst Grant Program was launched to support high calibre start-up projects that have the potential to significantly advance the field or impact the lives of persons living with lupus and their families. To learn more about the projects, please visit

<https://www.lupuscanada.org/resources/catalyst-research-program/>



Dr. Joan Wither and team are awarded a grant for their project, "Using CyTOF to dissect the interplay between Type I interferon and autoantibody production in Systemic Lupus Erythematosus"

Dr. Murray B. Urowitz and team are awarded a grant for their project, "Identifying Antimalarial-Induced Heart Damage in Systemic Lupus Erythematosus"



MyLupusGuide™

MyLupusGuide (MLG) is the first interactive website developed specifically for people with lupus. This website provides free access to reliable information for all ages and stages of lupus. Comprehensive in its scope, MLG provides a wide variety of information about lupus and also addresses important lupus-related issues including, pregnancy, dealing with work, explaining lupus to family and friends and much more. For more information please visit <http://mylupusguide.com/main/en/signin?> (Access Code: lupuscanada)

WaterLupus Hackathon

Lupus Canada Board Members, Vinita Haroun and Thomas Simpson, were proud to represent Lupus Canada at the University of Waterloo's WaterLupus hackathon. Five teams of students worked over a weekend to come up with policy, research and practical applications to improving the economic lives of people living with lupus. Congrats on the winners **Shine On**, who pitched their idea to collaborate with non-specialized brands to increase both the accessibility and affordability of sun protective clothing suitable for a range of events and environments, including work and school. We are excited for the winning team to continue to work with researchers at the University of Waterloo to make their plan a reality





Special thanks to Jodie Nimington-Young! Jodie designed and created the purple butterfly bracelets to recognize World Lupus Day and Lupus Awareness Month in Canada. Jodie raised \$890 for Lupus Canada. Thank you Jodie!



Great Canadian Giving Challenge - Help us win \$10,000!

Every dollar donated to Lupus Canada by an individual in June, through www.canadahelps.org or www.givingchallenge.ca, is an automatic entry for Lupus Canada to win a \$10,000 donation.

The Great Canadian Giving Challenge is (GCGC) a new initiative from GIV3 and CanadaHelps, the organizers of GivingTuesday Canada. The GCGC encourages Canadians to donate to charities in a typically low giving season, with the ultimate goal to benefit registered Canadian charities. The challenge runs from June 1 to June 30.

Every dollar donated to Lupus Canada by an individual in June, through www.canadahelps.org or www.givingchallenge.ca, is an automatic entry for the chosen charity to win a \$10,000 donation.

Source: <https://www.givingchallenge.ca/>

My Lupus Story by Yadira Castro

I was diagnosed with Lupus 6 years ago, after several misdiagnosis. I lost 38 pounds in three months, had severe joint pain, extreme fatigue and developed rashes along my face arms back and chest. I was first told I had leukemia and then went through a gallbladder surgery, however none of these diagnosis were correct.

After nine months I was diagnosed with Lupus SLE. My journey started with many different medications including high dosis of steroids(prednisone) As the years passed by I started to get organ involvement, I've been hospitalized numerous times with pericarditis an inflammation of the heart sac along with lupus nephritis where the lupus got into my kidneys and started to get renal failure.

By this time I felt very discouraged and my husband started looking for support groups where we came across the North York support group, where we were lucky to meet Dr. Tselios from the Toronto Western Hospital. From that day I switched rheumatologists and I'm now under the care of the Lupus Clinic under Toronto Western Hospital.

Last year I was hospitalized 7 times with numerous issues ranging from pericarditis, kidney infections , low blood pressure due to adrenal imbalance and sepsis. Out of those times I was in Intensive Care Unit four times where they had to use revival methods to stabilize me. After these episodes I developed depression and in November 2018 I became suicidal and tried to overdose myself with sleeping pills.

Now I'm under the care of a psychologist and a psychiatrist to help me cope with this along with antidepressants pills.

More recently I had to be hospitalized on April 10th and once again was admitted in the intensive care unit of Toronto Western Hospital to stabilize my heart rhythm as well as my blood pressure.

I recently started a new biological treatment Benlysta which is based on monthly infusions but still take over 21 pills a day. Due to the side effects of some of the lupus medications I've also damaged my eye sight where my optic nerve has been impacted with inflammation.

Lupus has not only affected me as a patient but has also had a big impact in my family, our finances ,as I lost my job and my children and husband have also needed psychological help to be able to cope with everything we've been faced with.

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: Turkey Taco Lettuce Wraps

Ingredients

- 1 tbsp olive oil
- 3/4 cup chopped yellow onion
- 1 lb 95% lean ground turkey
- 2 cloves garlic
- Salt and freshly ground black pepper
- 1 tbsp chili powder (preferably 2 tsp regular chili powder and 1 tsp ancho chili powder)
- 1 tsp ground cumin
- 1/2 tsp paprika
- 1/2 cup tomato sauce
- 1/2 cup low-sodium chicken broth
- Iceberg or Romain lettuce leaves, doubled up, for serving
- Shredded low fat cheese, diced Roma tomatoes, diced red onion, diced avocado, chopped cilantro, light sour cream, for serving



Directions

Heat olive oil in a non-stick skillet over medium-high heat. Add onion and saute 2 minutes. Add turkey and garlic, season with salt and pepper, and cook, tossing and breaking up turkey occasionally, until cooked through, about 5 minutes. Add chili powder, cumin, paprika, tomato sauce and chicken broth. Reduce to a simmer and cook about 5 minutes until sauce has reduced. Serve mixture over lettuce leaves with desired toppings.

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


Source: <https://www.cookingclassy.com/turkey-taco-lettuce-wraps/>


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