



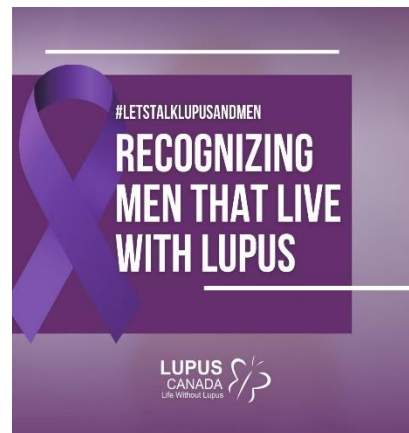
LET'S TALK LUPUS
June 2023 E-Newsletter



For more information visit www.lupuscanada.org/

Living with lupus can be isolating, especially as it is generally referred as an invisible disease. Lupus can affect anyONE at anyTIME in their lives and as such it is our hope to bring awareness and inclusivity to lupus.

Men living with lupus may be unsure as to how to communicate about lupus with colleagues, friends, and family. Many people do not know what lupus is and as it is an invisible disease, they may not understand why it may be difficult to carry out daily tasks. On **June 18th** let's recognize and celebrate all of the wonderful fathers in our community. Being a father living with lupus can have its own set of challenges.



Investing in Research, Advocacy, Public Awareness & Education

Thank you to our loyal donors for their ongoing support. As an organization whose mission is to improve the lives of all Canadians living with lupus, Lupus Canada is uniquely placed to invest its resources in areas where it can make the greatest difference; investing in research, advocating for lupus patients and their families, creating the much-needed awareness for this debilitating disease, and supporting students living with lupus to achieve their academic goals.

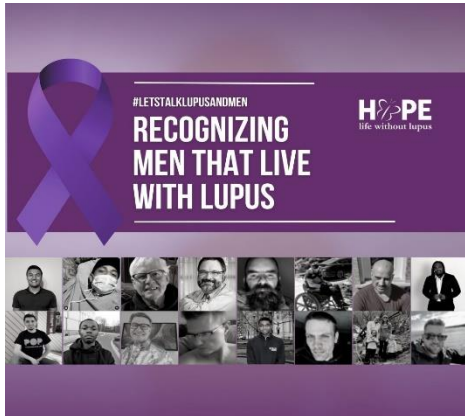
For more information on how your donation can make a difference visit <https://www.lupuscanada.org/get-involved/howyourdonationhelps/>

Help support Lupus Canada by donating below!

DONATE NOW
your gift makes a difference



LET'S TALK LUPUS AND MEN



Living with lupus can be isolating, especially as it can be generally thought of as a disease that primarily affects women.

Men living with lupus may be unsure as to how to communicate about lupus with colleagues, friends, and family. Many people do not know what lupus is and as it is an invisible disease, they may not understand why it may be difficult for you on some days to perform daily tasks such as, jobs around the house, going to work, picking up your children from school or social activities, or socializing with friends.

With the summer season approaching it can also be difficult for men living with lupus as there are assumptions that everyone wants to spend time outside in the sun. When you live with lupus it can be difficult enough to manage your disease, however, if you are also a parent living with lupus this can bring additional challenges. Specifically, society's expectations of a few of a father's role can include taking the kids to the park or barbecuing on the weekends. However, photosensitivity, or increased sensitivity to sunlight, is common among people who have systemic lupus erythematosus, or lupus. Sun exposure can cause rashes (including the butterfly or malar rash) and lesions or trigger flare-ups of the disease that could affect internal organs.

Remember that there are still ways to have fun in the warmer weather while making your health your priority. Enjoy the summer evenings, spend time in the shade or go for a scenic drive or have a dinner picnic. These are just a few of the many summertime activities that are still available to you and your family. For more information on lupus and sun safety visit www.lupuscanada.org/resources/fact-sheets/photosensitivity-sun-safety-and-lupus/.

Systemic lupus erythematosus (SLE), or lupus, is far more common in women (affecting approximately nine women for every man) but men do get lupus. Most women are diagnosed with lupus during childbearing years, but for men the onset of symptoms may occur at any age including childhood.

During puberty, about 25 percent of people diagnosed with lupus are young men, and in later years, about 20 to 40 per cent of the newly diagnosed lupus patients are men. There are an estimated number of about 5,000 men living with lupus in Canada. Systemic lupus in men can present similarly to lupus in women. This can include skin rashes, pleurisy, fatigue, neurological illnesses such as peripheral neuropathy (inflammation of the nerves in the arms and legs), joint pain, kidney disease, Raynaud's phenomenon and vasculitis (inflammation of the blood vessels).

Discoid lupus erythematosus (DLE), which is non-systemic, involves localized skin rashes (coin-shaped scaly lesions generally found on the scalp, face, cheeks and nose). DLE is

usually painless, but for some may be quite painful. Patients with DLE may be very photosensitive, and need to limit their sun exposure to reduce lesions and possible scarring.

Drug-induced lupus (DILE) Drug-induced lupus is the result of certain medications that cause lupus symptoms such as joint pain, muscle pain, fever, arthritis and inflammation of the heart and lung. These symptoms can be mild, moderate, or severe. More men develop DILE than women, probably because more men seem to be prescribed medications that produce DILE. The most common drugs that result in drug-induced lupus include medications for heart disease, and high blood pressure. After discontinuing the medication, lupus symptoms gradually disappear, but this may take many days, months or longer to disappear.

Diagnosing men with lupus

In order to diagnose lupus there needs to be comprehensive history and physical examination and investigations, such as blood tests. The American College of Rheumatology for research purposes had identified 11 diagnostic criteria some of which pertain to findings in the skin, blood, joints and organs. The presence of at least four of the criteria indicates a diagnosis of SLE by this standard. However, it is possible for a rheumatologist to confirm an SLE diagnosis in some patients, even if the patient does not meet ACR research criteria. Common manifestations include rash, oral ulcers, and inflammatory arthritis. There are other organs that can be involved including the kidneys, lungs and brain.

Hormones and SLE It has long been thought that hormones may play a role in the prevalence of lupus in both men and women. Studies have found that:

Young men with lupus have been found to have normal levels of Testosterone (a male hormone), however there is some evidence that lower levels of testosterone in both young and older men may predispose these men to autoimmune-like diseases

There is no increase of estrogen (a female hormone) in men with lupus. More research is being done on the hormone androgen. It has been found that women with lupus metabolize androgen at a faster rate than women without lupus, and thus have a lower amount of this hormone in their body. This is of interest, as androgens have been shown to have some immunosuppressive properties. As well, researchers want to find out if androgens explain the lower number of men having lupus compared to women

Why do some men get lupus?

It is unclear why men get lupus, but it appears that in some animal studies on lupus, both men and women who have lower active testosterone levels at the cellular level may have an increased risk of autoimmunity or a lupus flare. Lupus may be caused by a combination of genetic predisposition with certain variables, such as a viral illness or stress or other factors that might stimulate your immune system to trigger an autoimmune reaction.

Will my children be at risk of lupus if I am a male with lupus?

Lupus rarely runs in families. Lupus occurs in about 1 in 2,000 people in the general population. In families of lupus patients there is an increased risk of lupus, rheumatoid arthritis, scleroderma, juvenile arthritis and polymyositis. However, this risk might only be 1 to 5 per cent which is higher than the risk for the general population, but not as strong a risk as that seen with genetic illnesses, which often have a 25 to 50 per cent risk. Therefore, men with lupus who would like to have children should not let lupus change their minds. Speak to your physician if you have other concerns regarding your health or how medications you may be taking could have an impact on your ability to be a parent.

Are there special treatments that men with lupus should have?

Men and women with lupus are treated in similar ways. Your physician will treat the signs and symptoms and monitor organ involvement and the severity of the lupus. Treatments

may include anti-inflammatory medications for the joints and antimalarial drugs for skin and joints. Immunosuppressive medications are usually reserved for significant internal organ involvement or sometimes in severe joint involvement.

Source: <https://www.lupuscanada.org/resources/fact-sheets/men-and-lupus/>



Lupus Canada is pleased to introduce Ambassador, Prosper Laguerre, more affectionately known as DJ Prosper, as our newest Lupus Canada Ambassador.

DJ Prosper is a talented host DJ and home game crowd motivator for the Ottawa Senators and has a true passion for music and entertainment as well as inspiring others. These innate skills will naturally support his role as a Lupus Canada Ambassador in spreading awareness about lupus, a disease he has managed for many years. You will find his story below.

Prosper, Welcome to Lupus Canada. To read more about DJ

Prosper click [here](#).

My Journey – Prosper Laguerre

I was diagnosed with lupus after I was having multiple issues with my heart and bones. For almost 2 years I was misdiagnosed before finding out I had systemic lupus. It all started when I was at work and I couldn't even walk to my car. All my bones were aching and then shortly after my breathing was severely affected. After several chest X-rays they realized I had litres of fluid in my lungs and around my heart and that is when I went through the right process to find out I had systemic lupus.

This is when my life completely changed. I couldn't explain to people that I wasn't feeling well because on the outside I looked fine. I was diagnosed in 2013, and for the first four years every winter I had to go on disability from work because my flares were so bad. I slept in a chair sitting up for months to protect my breathing at night, and often had a home nurse come to drain fluid off my lungs. The conditions I faced made it difficult to live a full and productive life, however, the "world" perceived me as being



healthy because I always showed a smile. Often people will say "You don't look sick" when I am taking 17 pills in order to function each day.

Lupus and its treatments can impair mental & emotional health. Pain, fatigue, and other physical symptoms. Simply trying to live with pain and other symptoms every day can wear you down. One of my scariest attacks was when I got severely hit with a flesh eating disease due to a mix up with my meds. My entire body was attacked and I was hospitalized for days and the doctors had a hard time trying to figure out a solution or a cause.

Despite this battle, one thing that I've always tried to be extremely intentional about is maintaining a normal life.

In 2020 my wife and I decided to start the process to adopt. In 2022, we were matched with two beautiful children and then one month after they moved in we became pregnant after 16 years of trying to have a family. This has been the biggest blessing of my life to have three children, but it has also been the hardest challenge with such a major lifestyle change. In the last year my flares have inflamed my kidneys and I'm currently in treatment. I decided to become an ambassador for lupus because I want to show my children how to fight back when life hits you down. This is not easy but I believe by speaking out you can also encourage yourself to keep fighting. Nothing can dim the light that shines from within and living daily with routines, tasks, and responsibilities is my way of shining my light to my family.

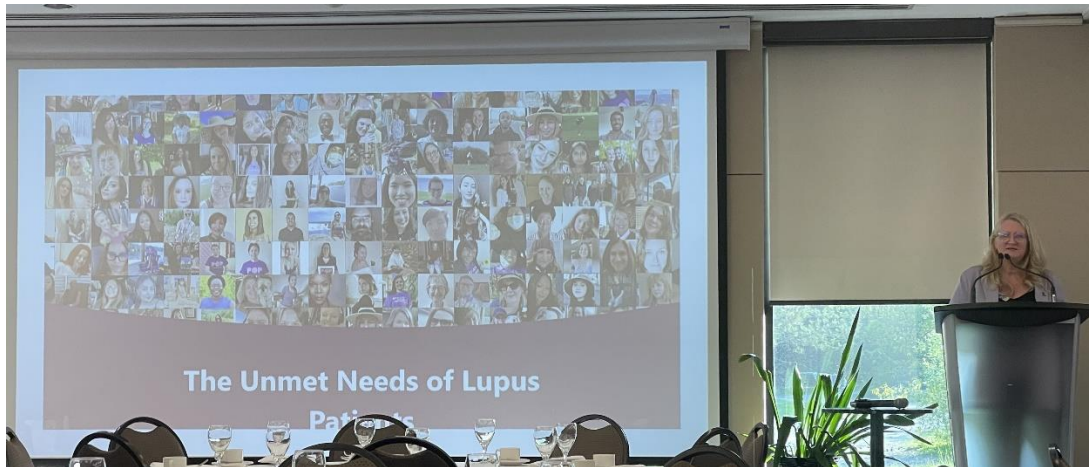
Every day I may not feel good, but there is something good in every day. Having a good support system that helps is everything. My wife pushes me to still pursue all my dreams, and helps me make them possible. My three miracle children motivate me to live to inspire and one day I hope they will say, because of you, I didn't give up Dad.

The reason why people give up so fast is because they tend to look at how far they still have to go, instead of how far they have gotten. For the last ten years I've come far and I lean on my faith. I get up daily and I look in the mirror and speak life into my body. Spirituality brings comfort and peace and provides a place to unload my worries. You don't have to control your thoughts. You just have to stop letting them control you. Make up in your mind that you will fight to make your life the best you can.

The best way out is always through. We may live with a chronic illness, but we can beat it if we fight through the storms to the other side.



Lupus Canada was pleased to present at the 2023 ORA Annual Scientific Meeting on Sunday May 28th to address the unmet needs of the lupus patient



Lupus Canada is thrilled to be welcoming back Emma Blachar this summer as a Research & Fundraising Assistant



"I recently graduated from University with a double major in International Relations and Political Science. An avid volunteer, I have assisted in a variety of fundraisers predicated on supporting my community and the vulnerable people in it. My studies and volunteer work, coupled with the practical experience that I gained working for Lupus Canada last summer, solidified my desire to pursue a career in the not-for-profit field. I am thrilled to be returning to Lupus Canada as a Research and Fundraising Assistant. Lupus Canada does integral work, and I am excited to join the team and assist in their projects and campaigns. This is a great opportunity to enhance my research, fundraising, and advocacy skills while working with a supportive team. I am looking forward to all that we can accomplish this summer."
Emma Blachar



LUPUS AWARENESS MONTH RECAP

Lupus Awareness Month was every success we had hoped for and more. Special thanks to my wonderful team at Lupus Canada for all their hard work and dedication and to our many supporters. Whether you organized a fundraiser, helped us provide valuable information to our community, donated to our cause or shared our posts, we are truly thankful! It is your generosity and advocacy that is driving awareness and change.

But let's not stop here, together let's keep the momentum going as we ARE making a difference.

Leanne Mielczarek, Executive Director

"Never doubt that a small group of thoughtful committed individuals can change the world. In fact, it's the only thing that ever has." Margaret Mead

Spotlight on Fundraisers

Lupus Awareness Month is an important time for so many Canadians impacted by lupus as it places a much needed spotlight on an under-funded and under-recognized disease. We would like to recognize the following fundraisers and extend our thanks to the individuals, communities, media and celebrities that helped us make a difference this Lupus Awareness Month. Your contribution to raising awareness for lupus is greatly appreciated.

Naina's Fundraiser

BigBunz Scrunchies Fundraiser

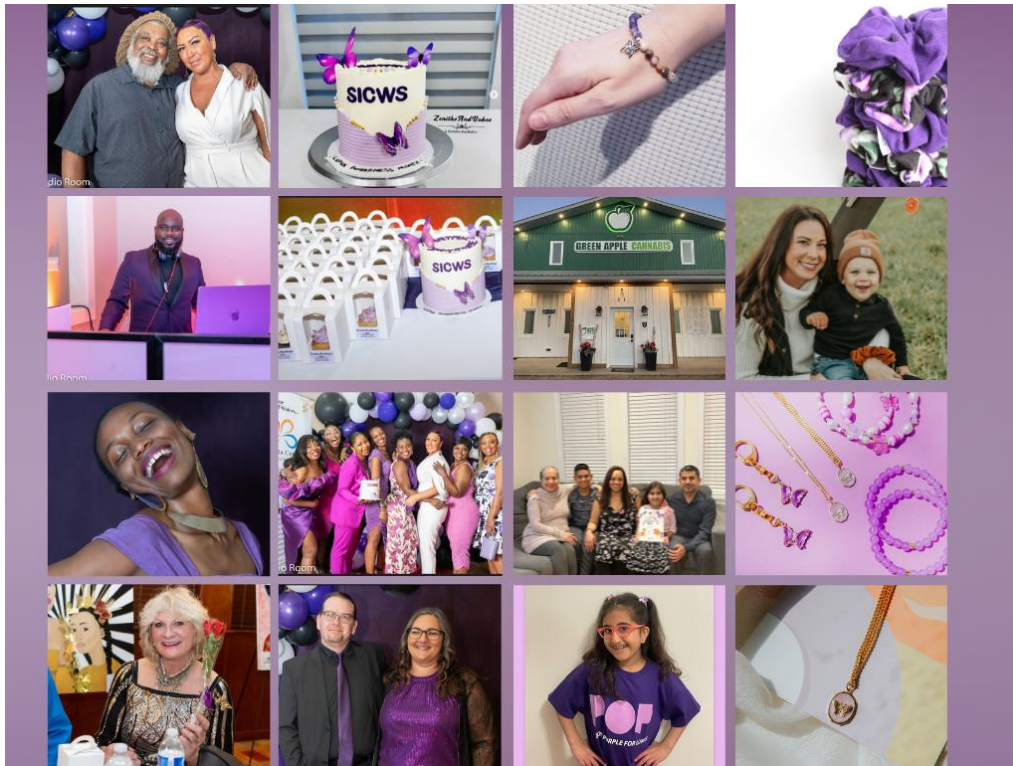
Jamie Tees Fundraiser

Haley Made Shop Lupus Jewelry Collection Fundraiser

Essence of a Butterfly presented by ArtfulXistence Fundraiser

Sisters in Canada Wellness Society & Zenith and Bakes

Green Apple Cannabis Fundraiser



Essence of a Butterfly presented by ArtfulXistence Fundraiser

Sisters in Canada Wellness Society & Zenith and Bakes

On May 13th, Artful Xistence presented Essence of a Butterfly in Surrey, BC in support of Lupus Awareness Month. Their evening started with a red carpet, included art by Kiyari as well as a one of a kind art piece raffle, entertainment, sweet treats and great company. Their thanks, as well as ours, is extended to the Sisters in Canada Wellness Society as well as Zenith and Bakes who helped to make this event the success that it was. Thank you all!

Green Apple Cannabis Fundraiser

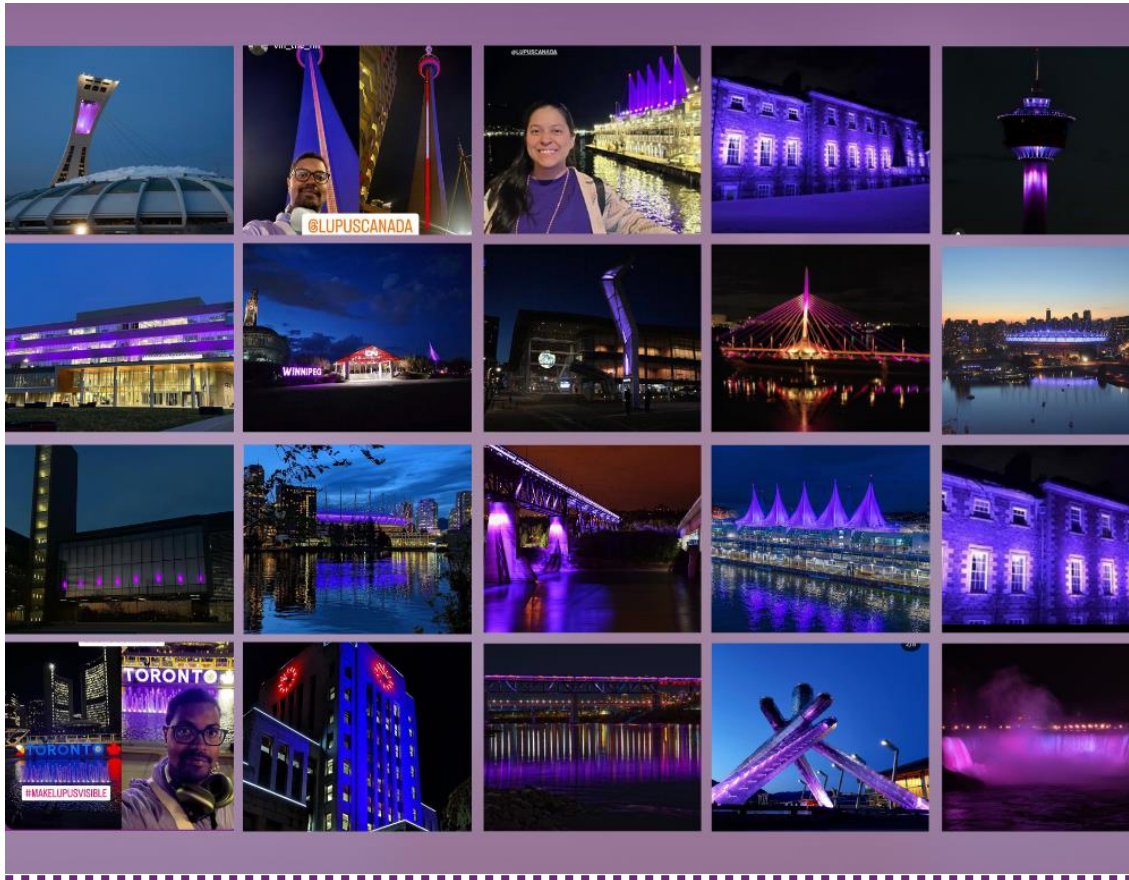
Throughout the month of May the town of Burk's Falls, Ontario launched into Lupus Awareness Month action led by local business, Green Apple Cannabis. Donations were accepted at various retailers and restaurants, a May long weekend event was hosted and the community came together to create awareness and raise funds for Lupus Canada. We often communicate that Together We Can Make a Difference and to the community of Burk's Falls, you certainly did!

Special thanks to Green Apple Cannabis, Yeti's Pizza, Jude's Country Diner, Haye's Service Centres, Yolande's Hairstyling, The Mag, Gateway Arms, Sandra's Spuds and Mill Bay Market.

For more information please visit <https://www.lupuscanada.org/lam-fundraisers/>

Together We Made Lupus Visible on World Lupus Day

Thank you to all those who visited one of the 68 landmarks that were illuminated on May 10th and to those who tagged us on social media or sent us pictures of the landmarks. We look forward to continued success in 2024.



World Lupus Day Proclamations

Special thanks to the provinces that declared May 10th, 2023 as World Lupus Day.

Michelle Thompson, Minister of Health and Wellness of Nova Scotia

Tom Osborne, Minister of Health and Community Services, Newfoundland and Labrador

Paul Merriman, Minister of Health, Saskatchewan

Audrey Gordon, Minister of Health, Manitoba

Adrian Dix, Minister of Health, British Columbia



World Lupus Day X Suncor Energy Well-Being Café



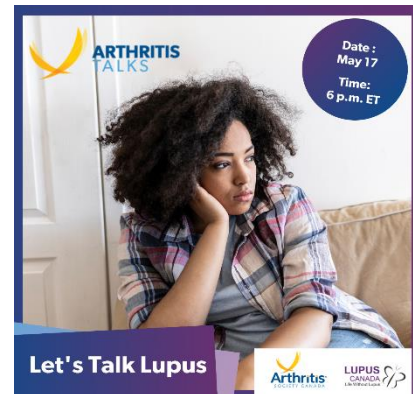
Lupus Canada had the privilege to meet with Suncor on World Lupus Day 2023 to present on Autoimmune Disease and most specifically, lupus. Suncor's Health & Wellness Team was instrumental in making this internal webinar the success that it was! We thank you for this public awareness opportunity.

Members of Suncor's Health & Wellness Team

Arthritis Talks: Let's Talk Lupus

On Wednesday, May 17, 2023 the Arthritis Society Canada in partnership with Lupus Canada hosted Arthritis Talks: Let's Talk Lupus, a webinar which discussed the many complexities of lupus to help you better understand the disease. Lupus expert, Dr. Christine Peschken, touched on topics such as:

- Early signs of lupus, symptoms and risk factors
- How lupus is diagnosed
- What makes it so complex and why it is different than other forms of inflammatory arthritis
- Advancements in lupus research and treatment



For the video recording of the webinar visit <https://www.lupuscanada.org/webinars/>

Lupus In The News



[Tony Van Bynen Member of Parliament Newmarket-Aurora May 23, 2023 Newsletter](#)



[A Fierce Commitment to Improving the Lives of Lupus Patients](#)



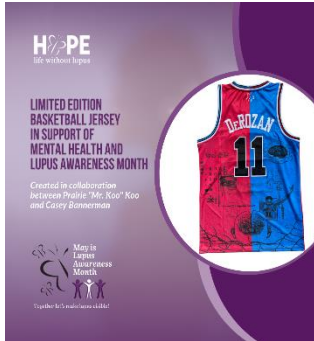
[Shining a light on lupus](#)



[Life without lupus is the goal of Lupus Canada](#)

Limited Edition Basketball Jersey In Support of Mental Health and Lupus Awareness Month

Created in collaboration between Prairie "Mr. Koo" Koo and Casey Bannerman



"Lupus Canada is honored to partner with DeMar DeRozan to help bring much-needed awareness to Lupus, a disease very close to his heart. By raising our voices together through initiatives like the Compton Prove 'em Jersey, we hope to create a better world for those living with Lupus," said Leanne Mielczarek, Executive Director, Lupus Canada.

<https://www.lupuscanada.org/wp-content/uploads/Press-Release-DeMar-Jersey.pdf>

To purchase the Limited Edition Basketball Jersey please visit

<https://caseybannerman.com/collections/jerseys/products/demar-derozan-and-mr-koo-charity-compton-city-jersey>



Community Fundraisers

Big League Movers Golf Tournament @ Puslinch Golf Course - SOLD OUT

2nd Annual Luis Agurrie Memorial Golf Tournament, Power by Big League Movers – Saturday July 22, taking place at Puslinch Lake Golf Course 6527 Ellis Rd. Cambridge, ON N3C 2V4

While this year's tournament has sold out there is still an opportunity to support its success!

Check out their sponsorship options below and get your company's name out there at this incredible event in support of Lupus Canada. Please contact: Jonathan Petro, jonathan@puslinchlakegolf.ca, 519-212-7384

**Luis Aguirre Memorial Golf Tournament
Sponsorship Packages**

Package 1, Single hole sponsorship: \$100

- Company branding on the tee box of selected hole
- Company acknowledgement in tournament program

Package 2, Silver Sponsor: \$150

- Company branding on the tee box of selected hole
- Company branding beside registration table/ putting green
- Company acknowledgement in tournament program

Package 3, Putting Contest Sponsor: \$200

- Presenting sponsor of putting contest
- Company branding beside registration table and contest area
- Company acknowledgement in tournament program

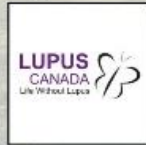
Package 4, Gold Sponsor: \$250

- Presenting sponsor of contest hole (Closest to pin/ Long drive)
- Company branding on tee box of contest hole
- Company branding beside registration table/ putting green
- Company acknowledgement on first page of tournament program

Powered by:



In support of:



For all sponsorship inquiries, please contact:
Jonathan Petro, jonathan@puslinchlakegolf.ca, 519-212-7884

**2nd Annual Luis Aguirre
Memorial Golf Tournament**

Powered by: Big League Movers

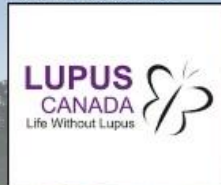
Saturday July 22nd

Puslinch Lake Golf Course

1:30 Shotgun Start

4-person scramble

Proudly Supporting:



\$125 per player includes:

18 holes with cart

Post round dinner

Donation to Lupus Canada

On-course contests

Draw prizes



To Register your team,
Sponsor or Donate contact:
jonathan@puslinchlakegolf.ca

BigYellowBag Give & Grow Fundraising Program

The first day of summer is on June 21st! Don't forget about the BigYellowBag Give & Grow Fundraising program. Use the code LC23 to save \$5 off a BigYellowBag of soil or mulch. Every time this code is used, BigYellowBag will donate \$10 to Lupus Canada. To place your order visit bigyellowbag.com. Don't forget to share with your friends and family.





WENDY'S CORNER

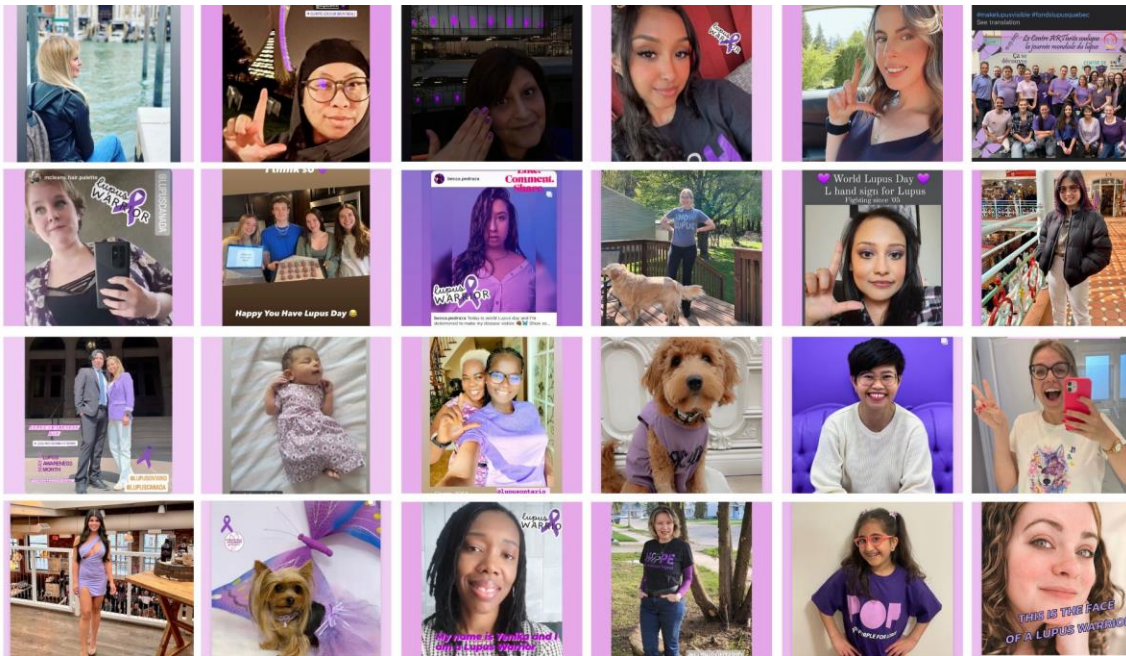


"Taking care of your skin under the sun should be like showering, eventually it comes naturally and becomes a habit. Be sure to apply suitable sun protective lotion every day."



Social Media Highlights

Thank you to all those who joined Lupus Canada in making lupus visible during Lupus Awareness Month and for tagging us in their posts. Below is a recap of our favourite community posts! Keep tagging us in your posts for a chance to be featured in our Social Media Highlights.





RECIPES

Approved by registered dietitian Heather Penny

A Delicious And Healthy Meal

On The Menu:

Gluten-Free Protein Donuts

Ingredients

- 1 1/2 cups Almond Flour
- 1 dash Salt
- 1 tsp. Baking Soda
- 3 tbsp Unsweetened Cocoa Powder
- 1 1/2 scoops Protein Powder
- 2 tsp. Vanilla
- 1/2 cup Maple Syrup
- 2 Eggs
- 2 tbsp Unsweetened Almond Milk
- 4 tbsp Coconut Oil melted and cooled

Glaze

- 1 tbsp Coconut Oil
- 1/2 cup EnjoyLife Dark Chocolate Chips



Instructions

- 1** Preheat your oven to 325 degrees and grease a donut pan with Coconut Oil spray. I used a standard size with 6 wells, but you can use a mini donut pan also.
- 2** Whisk your dry ingredients together, then add in your wet ingredients. Using a hand mixer, mix everything until you have a nice batter consistency.
- 3** Here's where things get fancy: Use a piping bag to pipe your batter into each well. Confession: a ziploc bag works just fine because that's what I used... Cut the corner after you put your batter in and bam.. makeshift piping bag. Bake for about 9-10 minutes, and let cool for a few minutes before removing them from the pan. This recipe made 12 so once your first batch comes out of oven and the donuts cool a bit so you can remove them, repeat the piping process for 5-6 more.

Glaze

- 4** After your donuts have been cooling for a while, prepare your glaze. Melt 1 tablespoon of coconut oil with 1/2 cup EnjoyLife dark chocolate chips over low to medium heat, and keep stirring.
Pour into a shallow bowl and dip donuts in the glaze.
- 5** Set on a rack or parchment lined dish, and go to town with your sprinkles.
- 6** Place the donuts in the refrigerator to harden for about 20 minutes, get your coffee or glass of milk, and get to snacking!

Source: <https://www.lupuslifebalance.com/donutkillmyvibe/>



QUICK LINKS



Celebrity Ambassadors

Take a look at our celebrity ambassadors [here](#).



Merchandise

Help support Lupus Canada by shopping our merchandise catalogue [here](#).



Brochures

Read and learn about everything lupus related [here](#).

Visit Our Website

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