

Let's Talk Lupus

August Monthly E-Newsletter

LUPUS
CANADA
Life Without Lupus

In a few weeks we will be saying goodbye to summer break. As you start to prepare for the start of a new school year most of you are left with the uncertainty around what this will look like due to COVID-19. As more information is available as September draws closer, it is important to communicate with your school administration to determine the safest method of return especially when living with an autoimmune disease.

On August 12th, we celebrate International Youth Day, an opportunity to promote lifelong learning opportunities, an inclusive and accessible community for all, and the development of education so that it remains a powerful tool. Therefore we have dedicated this e-newsletter to the importance and value of the world's youth, with a primary focus on youth by building 'awareness' for children with lupus.

DONATE NOW

your gift makes a difference

LUPUS CANADA NEWS/EVENTS:

HELP US REACH OUR GOAL!

GET INVOLVED



LOONIES FOR LUPUS

Help Lupus Canada improve the lives of people living with lupus!

Lupus Canada understands that during these unprecedented times it may be difficult to make a one-time donation. Well here's a little something different and fun for everyone. To get started with 'Loonies for Lupus' all you need is a jar and some spare change! Consider throwing in a loonie into the jar when you couldn't get that morning coffee, ice cream with the kids or lunch with a friend/colleague.

For every \$50 donation or greater to the Loonies for Lupus campaign Lupus Canada

will send you a special edition Lupus Canada mini flashlight as our way of saying thank you. But wait... it gets even better....

You Could Win a \$25 Tim Horton's Gift Card!

As part of the ***Loonies For Lupus*** campaign we encourage you to get creative with your jars. Until August 21st Lupus Canada will be hosting a contest to spread awareness for the ***Loonies For Lupus*** fundraiser. Please follow the instructions below for a chance to win a \$25 Tim Hortons Gift Card!

INSTRUCTIONS FOR CONTEST:

Show off your creativity by decorating your 'Loonies For Lupus' Jars.

- Take a picture with your jars.
- Tag @LupusCanada with the hashtag #LooniesForLupus
- Include and complete the sentence, "My loonies are for (i.e. my mother who lives with lupus)."

The staff at Lupus Canada will select the winner based on the most original jar. We cannot wait to see your jars! For more information visit our website

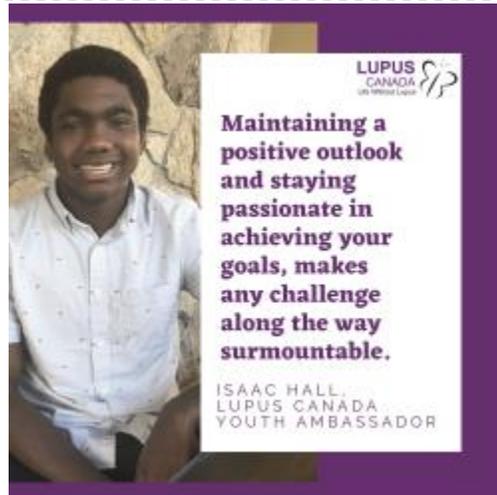
<https://lupuscanada.org/looniesforlupus/>

Every loonie is a step towards a 'Life Without Lupus'!

LUPUS CANADA YOUTH AMBASSADOR

Lupus Canada is fiercely committed to improving the lives of all Canadians living with lupus, their families and their loved ones by investing in the initiatives that bring us closer to dedicated treatments, and ultimately a cure. Given lupus can affect anyONE at anyTIME Lupus Canada recognizes that it is critical that we engage the youth demographic living with lupus across Canada. As part of this initiative we are honoured to welcome Isaac Hall as Lupus Canada's Youth Lupus Ambassador.

Isaac who is now 17 years old and living well with lupus first showed signs of this debilitating disease at the very young age of 4 years old. Both Isaac and his family appreciate the importance of the work Lupus Canada is doing and through his role as our Youth Ambassador Isaac will help us to ensure youth living with lupus have a voice by sharing his journey, knowledge and experience with lupus.



Welcome Isaac, we are thrilled to have you as part of our team!

To learn more about Isaac's story please visit <https://lupuscanada.org/living-with-lupus-isaac/>

TEENS WITH LUPUS:

Source: <https://kidshealth.org/en/teens/lupus.html>

Normally, a person's immune system works by producing immunity cells and antibodies, special substances that fight germs and infections. When a person has lupus, the immune system goes into overdrive and can't tell the difference between some of the body's normal, healthy cells and germs that can cause infection. So, the immune system responds by making autoantibodies that attack the body's normal cells.

Some teens work with a health care team, getting help from a rheumatologist, a nephrologist (a doctor who specializes in kidney problems), a nurse practitioner, and a social worker. Because lupus can differ from one person to another, **the team will create a special treatment plan based on someone's individual needs.**

Smoking, drinking and drugs are a bad idea for teens with lupus.

Alcohol can throw off the balance of certain medications, a dangerous situation for someone with lupus. **Tattooing and body piercing are also risk** because of an increased risk of infection. Some of the medications doctors prescribe for lupus suppress the immune system and do not allow the body to fight infections as it usually would.

Doctors also advise that teen girls with lupus stay away from birth control pills containing the hormone estrogen, particularly pills with high-dose estrogen. Researchers believe that the extra estrogen in the pills can make symptoms worse. Some females with lupus can safely take low dose estrogen pills. The doctor can do blood tests to determine which are safe for a patient. With the right medicines and by paying attention to their health habits, **most teens with lupus can go to school, enjoy many activities, play sports, and hang out with their friends.**

LUPUS AND KIDS:

Source: <https://www.nationwidechildrens.org/family-resources-education/700childrens/2017/09/lupus-and-kids-understanding-child-onset-disease>

SLE is seen worldwide in both children and adults. Childhood onset SLE (CSLE) represents 15 to 20 percent of all SLE patients, affecting about ten out of one million children per year. Onset of SLE is rare before five years of age and is more common in children of African American, Hispanic, Asian and Native American origin. Children with lupus may have similar manifestations as adults. However, childhood onset lupus is usually a more severe illness and

has greater disease damage over time. Kids with lupus may develop kidney and or brain disease with the first 2-3 years of the diagnosis- lupus has a lifetime burden.

YOUNG LUPUS WARRIORS:

Source: <https://lupuscorner.com/juvenile-onset-lupus/>

Childhood-onset lupus, also known as juvenile-onset lupus erythematosus (JSLE), often has more severe symptoms than SLE. The 5,000 – 1,000 children and teens fighting the disease are more likely to suffer from lasting kidney, brain, and damage to other organs and to have life-long consequences. Childhood lupus is very similar to SLE and has many of the same symptoms, including:

- Pain.
- Itching.
- Weight gain.
- Oral ulcers.
- Fatigue.
- Gastrointestinal symptoms including stomach pain.
- Cutaneous lupus.
- Lupus nephritis.

In addition to these traditional indications of lupus, children are more prone to brain and nervous system-related symptoms than adults. These symptoms can include:

- Seizures.
- Loss of vision.
- Higher risks of depression and anxiety.
- Hemiplegia (on one side) or iplegia (equally on both sides).
- Sides of the body are paralyzed, stiff, or numb.
- Caused by lupus attacking the child's growing bloodstream and restricting blood flow to the brain.
- Spasms similar to cerebral palsy or a stroke.

Fortunately, children with lupus do not typically suffer from intellectual disabilities, though they may require some level of special accommodations. Most researchers think that stress, hormone changes, pollutants, infections, and other outside factors may lead to childhood lupus. There is also a genetic component, and a family history of lupus does increase the risks.

Why is Childhood Lupus More Severe?

Researchers are not sure why childhood lupus presents with more severe symptomatology.

It may be more aggressive with a younger immune system or have a larger effect on the small and still-developing organs of children. It may also react to changing hormones as these children go through puberty. Because lupus is so rare in children, doctors will often attribute the symptoms to something more likely, including stress, puberty, sports-related injury,

dehydration, poor nutrition or eating habits, or depression and anxiety. They will also typically treat these symptoms first.

It is only when there is serious organ damage, especially kidney involvement, that doctors will look towards lupus as a possibility and perform the appropriate blood and urine tests. Another factor in the damage that childhood lupus causes are the medications itself. Because the child's lupus symptoms will often be very severe, they will generally be prescribed high doses of medications such as corticosteroids to bring their lupus back down. These high doses work well to bring lupus under control, but they come with serious side effects, can interfere with growth & development, and can leave lasting damage.

Treating Childhood Lupus:

Medications for childhood lupus are the same as those for SLE, such as immunosuppressants. Initially, children with lupus are given higher doses to bring their lupus down. After their symptoms have subsided, they may be tapered back to a lower dose appropriate for their age and size. Regular exercise and vitamin D supplements help children build strong bones and can help make up for lack of sun exposure related to photosensitivity. It is important for children with lupus to have a sturdy support network of doctors, psychiatrists, and education professionals to help them deal with the challenges of lupus. This helps them both grow up resilient and be able to handle their disease. Transitioning them from childhood care to adult care is also vital. Their lupus treatment team will be able to help.



Source: <https://www.everydayhealth.com/lupus/how-systemic-lupus-affects-children.aspx>

"Did you know in adults, lupus is 9 times more likely in women than in men, and among children, girls are affected 4 times more frequently than boys?"

"We see systemic lupus in girls at the age of puberty where the disease is similar to adult lupus, but we also have patients as young as 4 to 6 years old. In these younger patients, males are more likely to be affected than in adult lupus. Just as in adult lupus, pediatric lupus is more common in African Americans,' says Emma Jane MacDermott, MD, who specializes in pediatric rheumatology at the Hospital for Special Surgery in New York City. Systemic lupus has been diagnosed in 5,000 to 10,000 children and teenagers in the United States. In adults, lupus is 10 times more likely in women than in men, and among children, girls are affected 4 times more frequently than boys. The average age of diagnosis for pediatric lupus is just over the age of 12."



RESEARCH & RESOURCES:

RemeGen's "Telitacicept"

Source: <https://www.prnewswire.com/news-releases/fda-grants-fast-track-designation-to-remegens-telitacicept-as-a-treatment-for-systemic-lupus-erythematosus-301041049.html>

Telitacicept, a recombinant fusion protein for the treatment of Systemic Lupus Erythematosus (SLE), has received a fast track designation from the US Food and Drug Administration (FDA).

Telitacicept is a novel recombinant fusion protein that is produced by RemeGen Ltd for treating auto-immune diseases, such as SLE. Previously, in [research studies](#), Plasma and B cells were implicated in the manifestation of SLE, through secretion of auto-immune elements. Telitacicept has a dual-targeting mechanism, which can inhibit the survival and development of both Plasma and B cells.

For certain drugs that treat a life-threatening condition and fill an unmet medical need, such as Telitacicept, for SLE, the US Food and Drug Administration (FDA) expedites the development and review of selected drugs. The high frequency of communication between RemeGen and the FDA will ensure quick resolution for any issues on the drug development. The fast track selected drugs can often lead to early approval and patient access.

Janssen has announced the discontinuation of Phase III clinical trial of STELARA® (Ustekinumab), a human IL-12 and IL-23 antagonist, in the evaluation of Systemic Lupus Erythematosus.

The Janssen Pharmaceutical Companies of Johnson & Johnson manufacturers STELARA® (Ustekinumab). STELARA® is a human IL-12 and IL-23 antagonist approved by the US FDA for treating psoriatic arthritis, ulcerative colitis, and Crohn's disease. IL-12 and IL-23 have also been implicated in Systemic Lupus Erythematosus (SLE).

In 2015, Janssen Pharmaceutical started a [clinical phase II](#) study to evaluate the efficacy of ustekinumab in SLE. Results from the study demonstrated that adding ustekinumab to the standard-of-care treatment resulted in [better efficiency in clinical](#). To further assess the efficacy and safety profile of ustekinumab in SLE, a clinical phase III study named "LOTUS" was initiated. However, recently Janssen announced the discontinuation of the "LOTUS" clinical trial based on the interim efficacy analysis and the consistency of the known safety profile of STELARA.

Source: <https://www.jnj.com/janssen-announces-discontinuation-of-phase-3-lotus-study-evaluating-ustekinumab-in-systemic-lupus-erythematosus>

RECIPES:

Garden Veggie Vegan Buddha Bowl

Ingredients

- 2/3 cup to 1 cup cooked rice (blended wild and white or brown)
- 2/3 cup to 1 cup cooked quinoa
- 1 cup whole radish (about 5-6)
- 1/2 cup crunchy spicy peas or chickpeas (see notes roasted spicy peas for homemade version)
- 1/4 cup roasted pumpkin seeds
- 1/3 cup raisins or dried berries
- Two cups (bunched) watercress
- One shallot sliced
- Fresh basil
- Sea salt and pepper to taste
- One tbsp Oil and vinegar or my goddess dressing (see notes for link to recipe)
- Optional – 1/2 tsp crushed garlic mixed in rice or with dressing



How to Make It:

Step 1: First make sure your rice and quinoa are cooked. Follow instructions according to package or just use leftovers from another dish. I like to place a mix of quinoa and rice in the rice cooker and use throughout the week. See my notes in post.

Step 2: Next slice your radishes and shallots.

Step 3: Clean and remove stems from watercress.

Step 4: Arrange all ingredients in one big bowl or two smaller bowls.

Step 5: Garnish with basil, sea salt, and pepper.

Step 6: Drizzle with 1 tbsp olive oil/vinegar and enjoy!

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

Source: <https://lupusrebel.com/grilled-lemon-chicken/>

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STAY CONNECTED:



 615 Davis Drive Suite 306
Newmarket, ON L3Y 2R2

 Toll Free: 1-800-661-1468
Local: 905-235-1714

 info@lupuscanada.org

 www.lupuscanada.org

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Lupus Canada
306-615 Davis Drive, Newmarket, ON L3Y 2R2