

LET'S TALK LUPUS

March 2023 E-Newsletter

March is here and with it the hope of Spring!

It is the beginning of a new season, warmer weather and the blooming of flowers. Be sure to wear layers as March often holds both warm and cold days. Spring symbolizes hope, resilience and happiness. Let's hold onto these attributes as we enter a new season. Take time to enjoy the little things of life such as the melting of the snow and the budding of plants.



March 8th is International Women's Day. Lupus Canada celebrates the strong, intelligent and wonderful women lupus warriors of the world. We encourage you to celebrate the special women in your life today and everyday. For more information go to <https://www.internationalwomensday.com/Theme>.

March 12th is Daylight Savings. Don't forget to move your clocks forward one hour. Some folks may experience negative side effects from this adjustment, consider taking some time to reset and check in on yourself. For more information on how Daylight Savings may affect your sleep and some additional tips please visit <https://www.sleepfoundation.org/circadian-rhythm/daylight-saving-time>.

On March 20th we encourage you to celebrate the International Day of Happiness. This is a day in which to celebrate the things and people that bring you joy and find ways to spread joy into the lives of others. Let's set an example of kindness this month! To find out more about the happiness movement go to <https://www.dayofhappiness.net>.

We want to thank our loyal supporters who allow us to continue to make an impact within the lupus community.
Help support Lupus Canada by donating below!

DONATE NOW
your gift makes a difference

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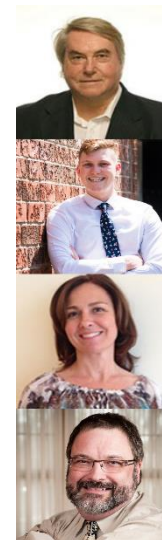


Board of Directors Updates

We would like to thank Malcolm Gilroy for his many years of service with Lupus Canada. Malcolm donated his time and expertise to the organization for 8 years. Malcolm first joined the Board as a Director, then took on the role of Treasurer which then led to his most recent role as the President of the Board. During Malcolm's tenure with Lupus Canada, we have seen significant growth in awareness for this debilitating disease. Malcolm has made a meaningful impact to the organization, and he will be missed.

With Malcolm Gilroy stepping down as our President, we are pleased to welcome Thomas Simpson to the role of Chair. Thomas brings many years of experience with the organization as he has previously held the roles of Advocacy and Governance committee Chair in addition to the role of Vice President. Thomas's dedication to our mission and vision of improving the lives of Canadians living with lupus through his continuous efforts to advocate for those living with lupus is unparalleled.

We are also pleased to share that Holly Jones Taggart will be taking on the role of Vice Chair. Holly has been with Lupus Canada for 4 years and has made a significant



impact as the Research Chair during her time at Lupus Canada. We welcome Holly to this new role.

Kerry Johnson, who served on the Board of Directors for 6 years, has stepped down from his role at Lupus Canada so that he can enjoy retirement. Kerry's passion to help others impacted by lupus is shown by his ongoing commitment to the Lupus Canada Scholarship program and always ensuring those with lupus have a voice.

We would like to thank our team of very dedicated and passionate Board of Directors. We wish both Malcolm and Kerry all the best and thank them for all their years of service to our organization. Together we have made a difference!

Give12 - Lupus Canada's Monthly Donor Program

A special and heartfelt thank you to our current monthly donors. Your ongoing support has been instrumental in helping us to continue working on our initiatives. Lupus Canada is making great progress and we thank you for being a part of our monthly donor program.

Your monthly contribution through Lupus Canada's Monthly Donor Program (**Give12**) directly supports vital research, advocacy, public awareness and educational initiatives.

Benefits of becoming a Lupus Canada Monthly Donor



- *It is convenient for you. Monthly giving is a great way to include charitable donations in your yearly budget.*
- *Giving a small amount such as \$10 each month feels more palatable than making a one-time gift of \$120.*
- *Monthly giving helps our organization further cut back on administrative costs.*
- *Monthly giving is convenient and customizable to your budget.*

In recognition of your monthly commitment to helping those impacted by lupus, we will send you a special lupus pin to wear proudly as a **Give12** donor! You will also receive a consolidated tax receipt at the end of December.

Together, we ARE making a difference.

We are excited to share that throughout the month of March when a new monthly donation of \$20 or more is made through @canadahelps they will make a one-time gift of \$20 in support of Lupus Canada.

To join **Give12**, our monthly donor program please visit <https://www.canadahelps.org/en/charities/lupus-canada/>



Research



Advocacy



Awareness



Education



LUPUS NEWS

SAPHNELO has received a positive recommendation to reimburse from CADTH (Canadian Agency for Drugs and Technologies in Health) and INESS (Institut national d'excellence en santé et en services sociaux) for adult patients, in addition to standard therapy, for treatment of active SLE. Pending negotiation with government funding groups and the individual provinces, we hope that Saphnelo will be accessible to patients through public coverage by 2024.

About SAPHNELO

SAPHNELO contains anifrolumab, a monoclonal antibody (a type of specialized protein) that blocks the action of a group of proteins called Type I Interferons (IFN). Type I Interferons are found at high levels in people with lupus and blocking them can reduce the inflammation in your body that causes the signs and symptoms of lupus.

SAPHNELO may help to reduce your lupus disease activity and the number of lupus flares you are experiencing. If you are taking medicines called 'oral corticosteroids', using SAPHNELO may also allow your healthcare professional to reduce your daily dose of the oral corticosteroids that are needed to help control your lupus.

BENLYSTA has received a positive recommendation to reimburse from CADTH (Canadian Agency for Drugs and Technologies in Health) for adult patients, in addition to standard therapy, for treatment of active lupus nephritis (LN). Pending negotiation with government funding groups and the individual provinces, Benlysta should be accessible to patients through public coverage by 2024.

About BENLYSTA

BENLYSTA, a BLYS-specific inhibitor, is a human monoclonal antibody that binds to soluble BLYS. By binding BLYS, BENLYSTA inhibits the survival of B cells, including autoreactive B cells, and reduces the differentiation of B cells into immunoglobulin-producing plasma cells.

BENLYSTA has been available in Canada as an intravenous infusion since 2011 to reduce disease activity in adult patients with active, autoantibody-positive systemic lupus erythematosus (SLE). It was the first SLE-specific treatment approved in over 50 years. BENLYSTA was approved for subcutaneous injection in 2018. Following Health Canada approval for lupus nephritis in 2021, it became the only treatment indicated for both SLE and LN in intravenous and subcutaneous formulations.

Did You Know?

May is International Lupus Awareness Month, and every year we encourage Canadian landmarks to illuminate in the colour purple to show support and raise awareness.

ARTICLES

If You're Thinking COVID Is Over... Here's What I Wish You Knew



"I have had moments when I've wondered if life is worth living like this."

For most people, the COVID-19 pandemic is effectively over. But this is not so for the 2.7% of Americans — approximately 7 million people — who are immunocompromised.

To read more visit: https://www.huffpost.com/entry/is-covid-over-immunocompromised-lupus_n_63de6f6ce4b0c2b49ae331ea

The Four Subgroups Of Systemic Lupus

Although all Lupus Warriors stand together under the same banner, understanding the differences between the subtypes of SLE can help us understand and better treat lupus.

Lupus is an inflammatory disease that effects organs throughout the body through immune system cells called "auto-antibodies."



There are many types of lupus:

- Cutaneous lupus affects the skin
- Lupus nephritis attacks the kidneys
- Drug-induced lupus occurs as a reaction to certain medications
- Neonatal lupus is a lupus-like condition that occurs in newborns
- Systemic Lupus Erythematosus, which affects organs throughout the body, and can occur alongside other forms of lupus. SLE is the broadest type of lupus. Women less than 40 years of age with high levels of anti-nuclear antibodies (ANA) are most likely

to develop SLE, and though they will often have symptoms in common, each patient has a set of symptoms unique to them.

Early on, however, doctors determined that these symptoms of SLE are not completely random. There are distinct patterns: Some people with full systemic lupus have more severe kidney problems. Others will have more symptoms related to the muscles, bones, and joints, or they might experience more neurological symptoms.

What are Autoantibodies?

Antibodies are key to lupus and autoimmune diseases in general. They are immune system cells that attach to invading cells such as bacteria and viruses. These act as “flags” that signal the immune system to attack and destroy these cells. Autoantibodies mark the body’s own cells to be attacked by the immune system.

Autoantibodies are not always bad. Healthy people have autoantibodies available, and they help fight diseases that involve the body’s own cells, such as viruses and cancer. Normally, though, most autoantibodies are “filtered out.” In SLE, this filter seems to not be working properly for a variety of reasons.

In autoimmune diseases such as lupus, these antibodies latch onto the body’s healthy cells, and the immune system starts attacking organs and tissues throughout the body. The damage releases particles that signal that the body is under attack, and that causes more immune system activity. This feedback loop causes the disease can become more entrenched or worsen over time, especially when it is triggered.

Researchers have determined what types of autoantibodies are involved in lupus, and what their targets are. There are certain patterns of autoantibodies that show up in people who develop autoimmune diseases. ds-DNA antibodies, anti-ribosomal antibodies, anti-histone antibodies, and anti-phospholipid antibodies, for example, target parts that healthy and unhealthy cells have in common.

There are several blood tests for autoantibodies, such as C-reactive protein tests which assess nearly 15 different immune system proteins responsible for causing immune system reactions, and ANA Tests, measures the level of antinuclear antibodies, which target proteins found in the nucleus – the center – of healthy cells.

What are the Four Subtypes of Lupus?

Systemic Lupus Erythematosus (SLE) is a broad term, encompassing any form of lupus that effects organs throughout the body. It is so broad that, as research has progressed, it has become clear that SLE is not a single disease, but a collection of different conditions with similar symptoms, involving different types of autoantibodies.

SLE has long been recognized as having two distinct types: Type 1 and Type 2, but because several different routes may lead to SLE, many researchers sought to break these types down further. Initially, researchers thought that there were three subtypes, but recent research implies that there are actually four! These four subtypes are physically different from each other, involving different types of autoantibodies and affecting the body in different ways. Researchers think that these four subgroups indicate that SLE has at least four different disease pathways, or ways that SLE can arise in a person.

Different levels of the common antibodies have been found between different people with lupus. It has been difficult to find differences between the symptoms that people experience and break it into groups in that way, but looking at the autoantibodies themselves, at least four different types of SLE have been revealed.

The Four Subtypes of Lupus

In a study involving 911 patients in the US and Sweden, researchers assessed data involving blood samples, clinical manifestations, self-reports of symptoms and symptom intensity. Autoantibodies were determined for all of the patients by analyzing their blood samples and then putting these samples through genome sequencing. The subgroups occurred evenly in the study group, and very likely is evenly distributed in the general population as well.

Subgroup 1: The primary antibodies are Anti-SSA/Ro60/Ro52 and Anti-dsDNA and Anti-RNPA. Subtype 1 made up 29.3% of the study population. This subtype is similar to the autoantibodies found in Sjogren's syndrome; an autoimmune disease sometimes found alongside lupus.

Subgroup 2: The primary antibodies are anti-nucleosome, anti-SmRNP, anti-dsDNA, and anti-RNPA antibodies. People with Subtype 2 were diagnosed as young adults (ages 27-31.) Subgroup 2 comprised 28.7% of the people in the study. Most (13% of the population) male patients with lupus in the study population had subgroup 2 SLE and were more likely to have lupus nephritis. Although the subtypes were equally represented, the researchers believe that subtype 2 is the form of SLE most commonly diagnosed as SLE, since it was associated with many of the common symptoms that people report.

Subgroup 3: The primary antibodies are anti-CL/IgG/IgM and anti- β 2GPI/IgG. 23.8% of the people in the study had subgroup 3, and shared some features with primary antiphospholipid syndrome, also known as pAPS. anti- β 2GPI is associated with a lot of cardiovascular symptoms, which means that it will be important to identify this subgroup early and begin treatment to protect the heart. People with lupus are at more than twice the risk of ischemic stroke (Blood clots) and are at three times greater risk of hemorrhage (brain bleeds.) These types of symptoms can be devastating, but when caught early, they can be controlled and prevented.

Subgroup 4: The primary antibodies are this group had patients who were negative for all 13 of the autoantibodies the researchers were looking for. 18.2% fell into this group and were diagnosed in early middle age (32-45) more often than the others and had the lowest numbers of males (7.3%.) Disease symptoms were generally milder, but serositis and arthritis occur in a higher proportion.

These autoantibodies are similar to each other, and a few are different forms of the same autoantibody. They each target something present on healthy cells, such as proteins in the cell membrane or normal cell DNA. These apparently small differences can be quite profound:

People with lupus use a wide range of different medications, and often go through several combinations before finding the combination that works for their symptoms. Determining the subtype might lead to more efficient and targeted treatment at the start. For example, Subtype 1, which may be Sjogren's like, may benefit more from medications that block the activity of interferon, which are made by the immune system to target viruses. Other

subtypes may benefit more from drugs involving the immune system's ability to regulate itself.

Limitations of the Study

Only people of white/European origin were in this study, and 911 people is a relatively low number of patients for a study. These two traits limited researcher's ability to find differences between the four types.

However, it is a hint as to what the patterns might be. The four distinct autoantibody-defined phenotypes appeared to be associated with certain clinical manifestations and symptoms. There are differences in genetic background, cytokine levels, disease activity, and the organs effected.

There are also studies that indicate that there may be many more subtypes that have yet to be found.

A Lupus Warrior's Takeaway

The more we learn about the autoantibodies involved in lupus, the closer we come to therapies that can send lupus into remission and better understand how to diagnose and treat lupus. Different subtypes may explain why some people do well when tapering off of medications like hydroxychloroquine and why some do not.

Knowing these subtypes might also help to make better monoclonal antibody therapies. Essentially, these lab-produced artificial antibodies target the autoantibodies themselves, marking them for destruction! The immune system "learns" these new targets and can start clearing out the autoantibodies. While current monoclonal antibody therapies are imperfect, they are a valuable tool for dealing with lupus.

Source: <https://lupuscorner.com/the-four-subgroups-of-systemic-lupus/>



MY LUPUS JOURNEY WITH DANICA A.



I was diagnosed with lupus about 8 years ago. I experience all the hallmark symptoms of lupus: lung issues, malar rash, raynauds, fatigue, headaches, brain fog and joint pain, etc.

My disease progressed a lot within my twenties. It has been an ongoing journey to find the right dosage/ combination of medications to curb my flares. I'd say the last two years have by far been the worst for my illness, many of my symptoms accelerated and worsened, but it has taught me a lot about the importance of self care and being aware of my own body, disease triggers and personal limitations.

As someone who is naturally prone to pushing past my limit, I was often my own worst enemy for my disease. Creating unnecessary expectations of myself and trying to take on too much. Whether at work or personally.

I really have had to really reorient myself and realize that it was okay for me to slow down. To stay home from the gathering, or make the choice to work from home so I could accommodate my symptoms. I am still a work in progress, but I feel like I have gotten a lot better at accepting when I feel sick, and immersing myself into a process of healing rather than pushing through. Although I still get super frustrated as a composer when I can't play piano because of my joints! (Pet peeve)

Recently, I have made the effort to find Instagram pages and support groups for lupus online and I have found it to be really helpful. I don't know why I never did before. Lupus can feel so isolating as so few people understand what it feels like to live with. Even just seeing someone post something that you experience as well... It really helped me realize that none of us are actually alone.

Moving forward, I really want to be more active in terms of spreading awareness and embracing community. I hope I am able to help others the way reading stories of fellow lupus warriors has helped me.



Spotlight on Community Fundraisers

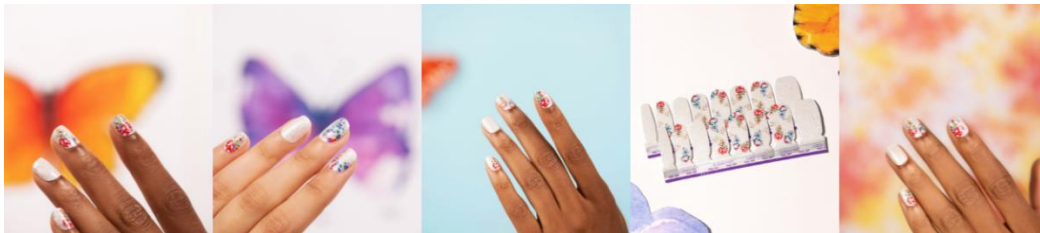


Color Street Foundation

This March, the Color Street Foundation is promoting Autoimmune Disease awareness, research, and patient support. The limited edition nail strip "Infinite Hope," a white glitter with multicolored abstract butterfly motifs, honors autoimmune disease warriors and helps spark a conversation about the 100+ autoimmune

diseases that affect this community.

The Color Street Foundation is pledging \$85,000 USD to 3 charity partners - *Autoimmune Association, Lupus Foundation of America, and Lupus Canada* - and raising awareness for the cause. Shop now on www.colorstreet.com



Lupus Canada and BigYellowBag Fundraiser

Lupus Canada is excited to share that we will be participating in the BigYellowBag Give & Grow Fundraising program. Gardening can do wonders for your well-being and is a hobby that has a variety of health benefits. With Spring right around the corner be sure to place your order early!

How Does It Work?

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 – it's that simple!

To learn more about the program please visit <https://bigyellowbag.com/>.



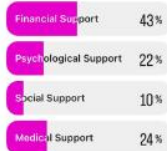
Social Media Highlights

Thank you to everyone for tagging us in their social media posts, here's a little recap of our favourite community posts from February! Keep tagging us in your posts for a chance to be featured in our Social Media Highlights.



HOPE
life without lupus

Help Lupus Canada continue to improve the lives of people living with lupus, their families, and their loved ones by answering what your unmet needs are as someone living with lupus.



Working together to conquer lupus



yconic
@yconicstudent

\$2000 Lupus Canada Scholarships

Six #scholarships awarded annually to students living with #lupus 'who have taken a positive and ambitious outlook in achieving their academic goals.'

studentawards.com/scholarships/L...
@lupuscanada

CLOSES MAY 31

Lupus Canada Scholarship Program

Lupus Canada @LupusCanada · 5d

"Watching my baby girl suffer and worrying that she might miss out on being a kid is devastating."

When a family member is diagnosed with lupus it can bring changes to the entire family.

Learn more about creating a new normal for your family 🏡 buff.ly/3HVE4c

DL-LupusWarrior
@canadian_girls

I was that kid, diagnosed at age 15, in 1985. Scared, worried and no real assistance from anyone back then...it was a real "unknown".

Accounts Of Interest

Dealing with chronic illnesses can be challenging, so we've provided some social media pages that you may find helpful and informative below.



[@hannahb_reed](#)

I've been connecting with others who also have lupus on my social media. It's nice to connect and have someone else to relate to. I document my journey on my page to help inspire others and bring awareness to lupus.



[@cafsociety](#)

Cassie + Friends Society (C+F) is the only charity in Canada dedicated 100% to transforming the lives of kids and families affected by Juvenile Arthritis and other rheumatic diseases through research, education, connection and support. Working together with youth, parents, healthcare professionals, researchers and other friends, we help children and families navigate day-to-day life with a chronic condition while never losing sight of our ultimate goal – a pain-free future for all kids living with rheumatic disease.



RECIPES

Approved by registered dietitian Heather Penny

A Delicious And Healthy Meal

On The Menu:

Peanut Butter Banana Pancakes

Ingredients

- 3 small ripe bananas (about 1 lb)
- 1/2 cup peanut butter
- 3 large eggs, lightly whisked
- 3/4 tsp baking soda
- 1 tsp vanilla extract
- 1/2 tsp cinnamon
- dash of sea salt
- *olive oil for cooking



Instructions

- 1** Mash banana with a fork in a medium mixing bowl until most lumps are gone.
- 2** Add peanut butter and mash again, smoothing mixture as much as possible.
- 3** Preheat griddle or skillet for cooking pancakes on medium to medium high temp (For the griddle I set it to 350 degrees). You need a bit more room to flip these only because they're much more delicate than standard pancakes, so I highly recommend a flat surface griddle if you have one.
- 4** Add eggs and remaining ingredients and whisk till well combined and mostly smooth.
- 5** Once pan or griddle is ready, lightly spray evenly with olive oil.
- 6** Use a 1/4 cup measuring cup to scoop out batter onto your pan.
- 7** Cook batter on pan about 3 minutes or until a centre bubble pops or you see the edges of the pancakes setting up well.
- 8** Very gently and slowly flip over pancakes (if you flip too fast they may roll on you) and cook for another 3 minutes on the 2nd side. (These pancakes are much more delicate than standard pancakes so just be gentle with your handling of them.)
- 9** Repeat cooking till batter is gone. (Using a griddle I can do this amount in 2 batches, a smaller skillet will require more batches.)

Source: <https://lupusontoast.com/dessert-recipes-for-people-with-lupus/>

QUICK LINKS



Q&A's

All your lupus related questions answered by trusted professionals [here](#).



Merchandise

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

LUPUS
CANADA
Life Without Lupus



Brochures

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

Visit Our Website

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