

LET'S TALK LUPUS

August Monthly E-Newsletter



Lupus Canada wishes you a happy August! As we enjoy the remainder of the summer, we hope you find things to do while staying safe, for example enjoy an evening walk or a picnic (remember to wear your sunscreen and try to avoid exposure to the sun). Make sure that you and your family have enough time to transition to a school mindset. Try creating a little bit of a routine before school starts, or setting a regular bed time. These small adjustments can help create a positive attitude and allow your child to become motivated for the year ahead.

Additionally, on **August 12th**, **Lupus Canada celebrates International Youth Day!** This day is dedicated to promoting lifelong learning opportunities and an inclusive and equitable community for all. By encouraging youth and giving them the tools they need, they will create a powerful legacy and a bright future for all.

DONATE NOW
your gift makes a difference

Mark your calendars this
AUGUST
and Let's Talk Lupus



Mark your calendars this August and Let's Talk Lupus!

As the only national organization dedicated to lupus research, advocacy, public awareness and patient support, Lupus Canada plays a leadership role in drawing upon the best resources from across the country and focuses on priorities that benefit all Canadians and their families who are impacted by lupus. No other organization provides a bigger opportunity to make an impact on lupus and those who live with it.

A recent survey conducted by Lupus Canada revealed that 58% of respondents believed that their lupus strongly impacts their ability to participate in daily life. In response to this survey Lupus Canada is launching, **Healthy Living With Lupus**, an awareness and fundraising campaign. This campaign aims to focus on how Canadians living with lupus can improve their physical and mental health to better participate in their daily lives. The Healthy Living With Lupus campaign will take place from *August 3rd 2021 to August 27th 2021.*

Lupus Canada would like to collaborate with Canadians living with lupus to help promote healthy living and wellness. With your assistance Lupus Canada will engage with our communities and provinces across Canada to discuss the importance of living a healthy lifestyle with lupus, mentally and physically. Due to the nature of this debilitating disease living a healthy lifestyle will look different for each person.

This virtual campaign is crucial to supporting those who live with lupus, as well as, working to create more resources for those in need. Lupus Canada hopes to use our social media reach to promote this campaign. **#HealthyLivingWithLupus seeks to gather 1,000 photographs of people living with lupus around the world to raise lupus awareness.** Lupus is known as the "Disease of a Thousand Faces" due to its wide-ranging symptoms and ability to mimic other diseases.

Help Lupus Canada and join the movement by taking a picture* of yourself so we can showcase the many faces of lupus and email info@lupuscanada.org or tag Lupus Canada on social media! It is easy to compare your health and body to others but remember that living a healthy lifestyle is

about YOU and your journey. *By gathering 1,000 pictures of people living with this complex disease, Lupus Canada wants to showcase that healthy living looks and is different for each body.*

We hope that the Lupus Canada community will help us to move the dial forward and make a difference in the lives of Canadians living with lupus.

Janice LeBlanc, a Registered Psychotherapist with over 20 years of clinical experience will be assisting Lupus Canada with a social media giveaway. Please keep an eye on our social media as we release more information.

** Lupus Canada will use the pictures with the purpose of putting together a final poster of all the submissions once the campaign is finished. Please note that we will not be posting individuals pictures of each submission on our main social media feeds.*

Healthy Living with Lupus Campaign Collaborations



Steve Ramos is owner and founder of Daily Fitpak. He is a certified personal trainer who focuses on strengthening both body and mind. Through his own experiences, he has found that to live a happy and meaningful life we need to heal ourselves physically and mentally. That is how we become the best versions of ourselves. Steve is a: Certified Personal Trainer, Movement and Mobility Specialist, Mindset and Meditation Trainer, and is Durability Certified.

Steve will be co-starring in Lupus Canada's, *Living a Healthy Lifestyle with Lupus*, series that will entail three videos that focus on how lupus patients can strive to live a healthy lifestyle, mentally and physically, while living with lupus. To learn more information please visit Steve's Instagram page @FitPak.

Michelle Gazze is a purpose driven Communications and Community Engagement professional with over 10 years of experience leading strategy, development and execution of social impact initiatives and campaigns for non –profit, private and public organizations. Managing sponsorships, events and building community partnerships for True North Sports & Entertainment, CBC Manitoba and diverse not for profits has provided Michelle with a unique perspective in philanthropy, donor relations and community investment.



Diagnosed with Lupus in 2016, her commitment to help advance awareness of Lupus leads her to share her own healing journey and the integrative approaches she has explored to help manage her Lupus through meditation, nutrition, lifestyle and mobility. Michelle Gazze will be co-starring in Lupus Canada`s, *Living a Healthy Lifestyle with Lupus* video series.

LOONIES FOR LUPUS

In 2020 Lupus Canada launched the Loonies For Lupus campaign as a creative/unique way to help FUNdraise for such a special cause. Last year we raised over \$1,100! We are happy to once again present this campaign from August 3rd to August 20th and hope that everyone is as excited as we are to see the creativity of the jars and watch the them fill up! To watch Lupus Canada`s Loonies for Lupus promotional video please click [here](#).

To get started all you need is a jar and some spare change! Consider throwing in a loonie into the jar for those moments when you couldn't get that morning coffee, ice cream with the kids or lunch with a friend/colleague or just have some spare change floating around.

This year as part of our Health and Wellness Summer Campaign our goal is to raise \$1,000 in recognition of the *thousand faces of lupus!* 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. It gets even better, submit a photo of your jar and you will be entered to win a lupus gift pack!

Every loonie is a step towards a 'Life Without Lupus'. We are grateful to have a community of people such as yourselves who support us and are committed to bringing awareness and increasing research opportunities to lupus especially during these unprecedented times. Together we can make a difference.

We hope you will share photos of your jars with us!

Please follow the instructions below for a chance to win a lupus gift pack! The winner will be decided based on the most original jar! We cannot wait to see your jars!

INSTRUCTIONS FOR CONTEST:

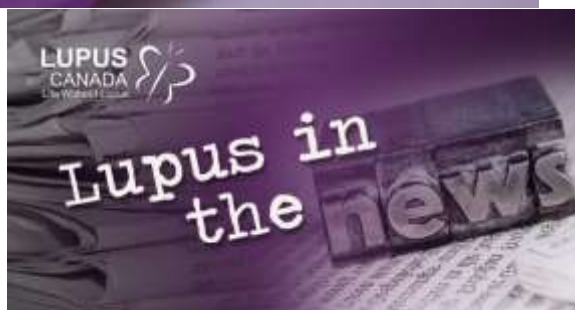
- Show off your creativity by decorating your 'Loonies For Lupus' jars
- Take a picture with your jars
- Tag @LupusCanada with the hashtag #LooniesForLupus
- Include and complete the sentence, "My loonies are for (i.e. my mother who lives with lupus)

Thank you for your support!



BENLYSTA now approved in Canada in addition to standard therapy for treatment of active lupus nephritis in adult patients

BENLYSTA (belimumab) has been approved in Canada for the treatment of active lupus nephritis (LN) in adult patients.[i] BENLYSTA is available as an intravenous infusion and a subcutaneous injection.



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. Since then, BENLYSTA has also been approved for subcutaneous injection. The recent approval extends the indication in Canada to include both LN and SLE.

BENLYSTA, a human monoclonal antibody, is the first and only biologic approved in Canada for systemic lupus erythematosus and lupus nephritis. This approval follows recent approvals in the US and EU for a similar expanded LN indication.

"Approximately 40% of patients with systemic lupus erythematosus develop active lupus nephritis, which causes inflammation in the kidneys and can lead to end-stage kidney disease. BENLYSTA is the first medicine approved to reduce SLE activity and treat adults with active lupus nephritis. This approval symbolizes new hope to many of the thousands of Canadians living with lupus, a complex and incurable autoimmune disease," said Marni Freeman, Interim Country Medical Director at GSK Canada. "We're proud to bring forward this important treatment advance, not only for Canadian lupus patients seeking options but also for the healthcare professionals who treat them."

"This represents a critical step forward for lupus patients in Canada, many Canadian patients with systemic lupus erythematosus and active lupus nephritis should enjoy healthier and more active lifestyles with this new treatment alternative," said Leanne Mielczarek, Executive Director, Lupus Canada.

To read the full Press Release please visit <https://www.newswire.ca/news-releases/benlysta-now-approved-in-canada-in-addition-to-standard-therapy-for-treatment-of-active-lupus-nephritis-in-adult-patients-815017415.html>



Self-Advocacy 2021 Live Webinars

Thank you Abby Charles for joining Lupus Canada at our sixth Self-Advocacy Webinar, 'Tips For Being Your Own Best Advocate... Lived Experience With Abby Charles' that took place on July 22nd. To watch Abby Charles' presentation, please click [here](#).

Don't forget that you can watch any of the video recordings of the Self-Advocacy webinars by visiting <https://lupuscanada.org/resources/advocacywebinars/>.

Do you have an advocacy topic you want to learn more about? Please be sure to email us at info@lupuscanada.org

QUOTATION OF THE MONTH

"Do what you feel in your heart to be right-
for you'll be criticized anyway."

—ELEANOR ROOSEVELT



ARTICLES

How To Advocate For Yourself

There are many different ways to advocate. Some people are good on the telephone, while others deal better with difficult situations face to face. Some people are more comfortable writing letters. Among an advocate's best tools are information and having a plan. Through planning, you are more likely to succeed in putting your point across.

Educate Yourself

Your best tool as a person with lupus is to educate yourself about your disease and be able to educate the people around you. Go to www.lupuscanada.org to learn more about lupus, lupus research and about Lupus Canada. Often, your first and best resources will be your doctor. You may want to ask your doctor for a special appointment to discuss your condition in further detail.

When advocating, the more you know, the more intelligently you can advocate. This is your best tool for dealing with government, private organizations, services or agencies.

Advocacy Plan

It is not always easy to deal with government, private organizations, services or agencies. To help with your own advocacy, it is good to come up with an advocacy plan. Below are steps to help with your own advocacy plan. Remember: keep details of everything you do and every conversation you have. These notes will come in handy.

Define the problem, simply and specifically

Often, the problems or challenges that individuals are advocating to change are complex and multifaceted. By clarifying the problem, you make your argument easier and more time can be used to discuss solutions rather than explaining the problem.

List possible solutions

It is easiest to advocate for yourself when you are armed with potential solutions. Collaborating and working together with governments and organizations can produce solutions, but this takes time. Often those advocating need changes made quickly. Coming to the table with possible solutions indicates that you are ready to work now.

Collect information for each option

Remember, the more you know, the better you can advocate. By having all the information ready at your arsenal, you can challenge institutions that may not want to help. Often, government may not see your problem as their problem. By having information at hand, it is easier to persuade people to your cause.

Consider the options and decide

After listing all your solutions and gathering the relevant information, you may find that one of your solutions is not feasible. This is okay. By having several possible solutions, you can pick the best ones that will help you achieve your goal.

Consider further action

At this point, you may find some obstacles to your problem. Maybe you need some help from Lupus Canada? Maybe you need to partner with another organization? Remember, there is always help for your advocacy needs. This is the time to find out who to take your problem too. Governments are becoming much more accountable and transparent. If you don't know where to go, checking out a government website. Often, they will have a directory where you can find a chain of command within the government. Unfortunately for private corporations and services you may have to call a generic number and be bounced around before you find the appropriate authority for your problem.

Other questions you should answer include:

What should I say to ensure that I my problem is simple and specific and capture all the relevant information?

What is my best argument?

Should you request a meeting with the relevant authority?

Should you write a letter to an organization?

Should I involve a political figure to move this forward? Can Lupus Canada help?

Take Action!

You've considered the steps you need to take, now go forth and make it so. It can be daunting to get to this point and go forward. Hit send on that email. Make that call. You are ready to advocate! For more information please visit <https://lupuscanada.org/get-involved/advocate/how-to-advocate/>.



A recent online survey led by Drs. Ann Clarke (University of Calgary) and Susan Elliott (University of Waterloo) was conducted that aimed to investigate how individuals with Systemic Lupus Erythematosus (SLE) access and trust health information before and during the COVID-19 pandemic.

Along with patients from Lupus Canada, participants from 15 patient cohorts and four other patient advocacy organizations in Canada, Argentina, Mexico, Singapore, South Korea, Spain, and the US completed the survey. Data is still being collected at a small number of sites, and so far over 2000 patients worldwide have completed the online survey.

Canadian patients accessed lupus specialists, family physicians and pharmacists for their health information most frequently prior to the pandemic, and access to the news media increased by 7% since March 11, 2020 – the date the World Health Organization declared a global pandemic. International patients also accessed lupus specialists and family physicians most frequently before and during the pandemic, and their access to the news media increased by 9% since March 11, 2020.

Patients were also asked to rate their level of trust in each source of health information. The most trusted sources in Canada were lupus specialists, family physicians and pharmacists before and during the pandemic, and the most trusted sources internationally were lupus specialists, family physicians and advocacy organizations (before COVID-19) and lupus specialists, family physicians and pharmacists (during COVID-19).

In Canada and internationally, trust in the online news media decreased during the COVID-19 pandemic, and amongst the international participants, trust in other news and social media sources (e.g., newspapers, radio, television, Facebook, internet blogs) also decreased. Among Canadian and international participants, 12% reported that their health had been negatively impacted by the news media, and 10% reported that their health had been negatively impacted by social media.

We know that many of these sources can circulate a large amount of misinformation, and this finding emphasizes the need to ensure patients can continue to access their most trusted sources of health information like lupus specialists and family physicians in times of high stress and scientific uncertainty.

Thank you for your participation and interest in this research.

For more information please email fcardwell@uwaterloo.ca

RECIPES



Quinoa Avocado Salad

PREPARATION: 15MIN

COOKING: 20MIN

SERVES: 6

INGREDIENTS

Salad:

- 1 cup uncooked quinoa
- 1 cup grape tomatoes, halved
- 1 large cucumber, diced
- ¼ cup red onion, finely chopped
- 2 large ripe avocados, chopped
- ¼ cup chopped cilantro

Dressing:

- ¼ cup olive oil
- 1 tablespoon red wine vinegar
- 1 tablespoon lime juice
- 1 teaspoon Dijon mustard
- 1 garlic clove, minced
- ½ teaspoon salt

DIRECTIONS

Place the quinoa in a medium sauce pan over medium heat. Toast without oil or salt for 5-7 minutes until the seeds start to pop and become aromatic. Add 2 cups of water to the quinoa and bring to a boil, then turn down the heat to low. Cover and simmer the quinoa for 15 minutes. Remove from the heat and keep covered for an additional 10 minutes. Fluff with a fork and season with salt.

To make the dressing, whisk together the olive oil, red wine vinegar, lime juice, Dijon mustard, garlic and salt.

When the quinoa is cool, place it in a bowl and add all the ingredients for the salad on top. Pour the dressing on top and stir gently to combine. Serve at room temperature or chilled.

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

Source: <https://feelgoodfoodie.net/recipe/quinoa-avocado-salad/>

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PO Box 8, LCD 1
Newmarket, ON L3Y 4W3



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



info@lupuscanada.org



www.lupuscanada.org

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PO Box 8 LCD 1, Newmarket, ON L3Y 4W3