

LET'S TALK LUPUS

December Monthly E-Newsletter



It is time to enjoy this winter season! Do not let your busy school, work or family life get in the way of appreciating the white winter snow and all the festivities that come with this season. Take some time to sip your favourite hot chocolate, to bundle up and go for a nice walk, or to get wrapped up and watch your favourite movie.

This holiday season can also be a great time to think of doing a small act of kindness. Lupus Canada asks you to remember them in your holiday plans. To learn more about different ways to donate please visit our website <https://lupuscanada.org/get-involved/ways-to-donate/>. Donations this holiday season allow Lupus Canada to continue supporting students with lupus financially through our scholarship program, provide research grants, and continue to advocate for those living with lupus.



SUPPORT LUPUS CANADA THIS GIVING TUESDAY
ON DECEMBER 1ST DO A SMALL ACT OF KINDNESS FOR THE LUPUS COMMUNITY!

TODAY IS THE DAY! Lupus Canada is so excited to be participating once again in **Giving Tuesday** which is taking place today, **December 1st!** With over 6,500 partners across Canada, you will not want to miss out on celebrating Giving Tuesday, an opportunity to globally acknowledge hardworking charities.

Kindness can be seen in a variety of ways. Advocating and raising awareness for Canadians living with lupus can also be seen in a variety of ways. Participating in Giving Tuesday can mean: (1) Advocating and raising awareness about lupus, (2) Sharing our posts online (3) Initiating your very own Lupus Canada fundraiser and so much more!

The Board and Staff at Lupus Canada have a message for everyone! 2020 has been challenging for all of us. This year charities have been impacted significantly due to their inability to traditionally raise public awareness and participate in community fundraising events. To watch the video please click on the image below or this link <https://www.youtube.com/watch?v=9-63QUj4YAE&feature=youtu.be>

Join Lupus Canada
THIS GIVING TUESDAY!



Make kindness your priority and support Lupus Canada today on Giving Tuesday <https://lupuscanada.org/givingtuesday/>

DONATE NOW
your gift makes a difference

In Helping Others, You Help Yourself

Consider the positive feelings you experienced the last time you did something good for someone else. Perhaps it was the satisfaction of running an errand for your neighbor, or the sense of fulfillment from volunteering at a local organization, or the gratification from donating to a good cause. Or perhaps it was the simple joy of having helped out a friend. This “warm glow” of pro-sociality is thought to be one of the drivers of generous behavior in humans. One reason behind the positive feelings associated with helping others is that being pro-social reinforces our sense of relatedness to others, thus helping us meet our most basic psychological needs.

Research has found many examples of how doing good, in ways big or small, not only feels good, but also does us good. For instance, the well-being-boosting and depression-lowering benefits of volunteering have been repeatedly documented. As has the sense of meaning and purpose that often accompanies altruistic behavior. Even when it comes to money, spending it on others predicts increases in happiness compared to spending it on ourselves. Moreover, there is now neural evidence from fMRI studies suggesting a link between generosity and happiness in the brain. For example, donating money to charitable organizations activates the same (mesolimbic) regions of the brain that respond to monetary rewards or sex. In fact, the mere intent and commitment to generosity can stimulate neural change and make people happier.

Recent research suggests yet another way our well-being can benefit from practicing pro-social behavior: helping others regulate their emotions helps us regulate our own emotions, decreases symptoms of depression and ultimately, improves our emotional well-being.

Regulating each other's emotions

Our day-to-day lives offer plenty of opportunities for regulating our own emotions. When we are happy, sad, frustrated or anxious, we find ways of managing our feelings to meet the demands of our environments. At times, however, when the weight of our emotions becomes too much to bare, we turn to others for support. Social regulation of emotion is a key component of our relationships. Whenever we navigate children through tantrums, help a friend through a breakup, or rely on our partners for comfort after a challenging day, we often engage in social regulation of emotion. Whether we are the ones providing the emotional support or the ones seeking it, the 2 most common ways to help others regulate their emotions are through acceptance (showing empathy by validating their feelings) and reappraisal (helping others think about their situation in a different way). A recent study from Columbia University has revealed that when helping others navigate their stressful

situations, we are enhancing our own emotion regulation skills, and thus, benefiting our own emotional well-being.

The study

Over a three-week period, participants were provided with an anonymous online environment where they could share their personal stories of stressful life events. They could also provide emotional support to other participants by replying to their entries with short, empathetic messages. Participants helped each other by identifying potential distortions in thinking, suggesting reappraisal strategies or providing words of acceptance. Responses were rated for their degree of helpfulness and participants were given the opportunity to express their gratitude for the acceptance or reappraisal messages that they received from others.

The results showed that helping others to regulate their emotions predicted better emotional and cognitive outcomes for those participants who were giving the help. Moreover, because heightened levels of self-focused attention are common in depression, the more people helped others, the more their helping behavior predicted a reduction in their own depression, thanks to the use of reappraisal in their own daily lives. Follow-up analyses further showed that this increase in reappraisal in people's lives also affected their mood and subjective happiness. Interestingly, messages that used other-focused language (e.g., second-person pronouns such as you and your) were considered more helpful and garnered more gratitude from participants. In fact, using other-focused language not only helped the people in need, but also those who were helping. This finding suggests that when providing emotional support to others, trying to fully take on their perspective can increase reappraisal and lead to better psychological outcomes for those who are providing the support.

Next time you find yourself helping someone with regulating their emotions, consider how your efforts may be providing you with an opportunity to practice for future situations at a distance, and consequently, improving your emotional well-being. Thus, when it comes to the benefits of social emotion regulation, St. Francis of Assisi's words ring especially poignant: For it is in the giving that we receive.

Source: <https://www.psychologytoday.com/ca/blog/between-cultures/201805/in-helping-others-you-help-yourself>

ASKING FOR HELP

Source: <https://lupusla.org/asking-for-help-3/>

Most of us don't like to ask for help. The more stressed we feel, the more likely we are say (or feel): "Oh, I'll just do it myself!" These are generally the reason people think they can't ask for help:

They fear looking "weak." Asking for help is human. It is not a sign of weakness.

They worry about having to "owe" a favor. Most people don't keep score. Many subscribe to the thought of "paying favors forward." If they help you, you'll help someone else another

time. But if someone does ask for a reciprocal favor, it may make you feel better about asking them another time.

They worry about “bothering” someone. Honestly, your good friends or co-workers will be delighted to have you specify what they can do to help. Those around you are generally aware if you’ve hit a bumpy patch. If you let them help you out, they’ll be delighted for guidance as to what they can do. Asking for help is such a big issue that the Stanford Graduate School of Business has undertaken studies about it.

“Our research should encourage people to ask for help and not to assume that others are disinclined to comply,” says Frank Flynn, associate professor of organization behavior at Stanford GSB. “People are more willing to help than you think.”

The Best Way to Ask

Whether or not we have lupus, everyone hits a time when it is so much better to take a breath and ask for help. Here’s how to do so effectively:

Be specific. Don’t assume they’ll notice you are struggling.

If you’ve been sick, ask a neighbor if they could stop by the pharmacy to pick up a prescription your doctor has called in for you. Ask a neighbor who loves cooking, if she would mind putting together a meal for you—it can just be extra of whatever is being prepared for the family. Ask your teenager to walk the dog or unload the dishwasher. Teenagers are notorious for being oblivious to the world around them. Tell your son or daughter exactly what you need them to do. (Some families do well leaving reminder notes.) When you ask for help, you are actually creating an opportunity for someone else to feel good. Many people actually feel happier when they are giving or receiving a gift or aid of some type. They will be glad you spoke up about what you needed.

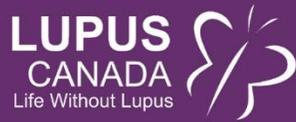
Asking for help doesn’t mean you’re weak, it only means you are wise.



Yukon Event in support of lupus, invisible illnesses and autoimmune diseases



Lupus Canada would like to thank Anne H. for organizing this fundraiser that happened on October 25 in Yukon! Anne has been living with lupus nephritis for 13 years and together with her peers she hosted a talk and walk session for lupus awareness! This event was dedicated to lupus, invisible illness and autoimmune disease and they were thrilled to have a total of 12 participants, and with some individuals within the lupus community. This fundraiser consisted of discussing lupus and then proceeding to doing a 45 minute walk! Raising approximately \$270 was not the only success of this event but raising awareness and educating people about lupus who had maybe not heard about this disease. We are so grateful for everyone who participated!



**Looking for
that perfect
stocking
stuffer? We
have unique
gifts for that
special
someone.**



Don't miss out on ordering some Lupus Canada merchandise this year for some easy stocking stuffers! From toques to masks to flashlights we have a variety of options that everyone in your family may enjoy!

Visit our website to scroll through our merchandise
<https://lupuscanada.org/merchandise/>



Highlights from American college of Rheumatology Annual meeting 2020

DxTerity Diagnostics develops a new Immune-profiling test for RNA based precision medicine.

DxTerity Diagnostics has developing a new immune-profile test called "Modular Immune Profile Test" (MIP) which can detect the expression level of twelve gene, which play an important role in autoimmune diseases. These include

Type I and Type II Interferon, plasma and plasma blast cells, neutrophils, B cells, T cells, and T cell exhaustion. MIP used uses Chemical Ligation Dependent Probe Amplification

(CLPA) on small volumes of whole blood samples. MIP is being developed for longitudinal tracking of patient's immune response for on-site as well as remote monitoring of clinical trials.

At ARC 2020, DxTerity Diagnostics demonstrated the ability of MIP for detecting inflammatory biomarkers in the randomized, double-blind clinical trial assessed the effects of treatment with Iberdomide (Celgene) on SLE associated genes. Over-time the expression levels of the pro-inflammatory biomarkers were shown to subside.

An important area of application would be for at home-monitoring of immune biomarkers, thereby replace or supplement current testing methods. Inflammatory and auto-immune diseases such as SLE, Multiple Sclerosis, Inflammatory Bowel Disease, and Rheumatoid Arthritis could be monitored for therapy response.

Source: <https://www.biospace.com/article/releases/phase-ii-study-demonstrates-utility-of-dxterity-s-modular-immune-profiling-test-for-predicting-and-amp-monitoring-iberdomide-response-in-lupus-patients/>

Nektar Therapeutics presented additional clinical data for NKTR-358, a first-in-class T regulatory cell stimulator

Inflammatory and autoimmune diseases are caused by underlying immune process that lead to the formation of pathogenic T-cells. To counter these pathogenic T-cells, Nektar Therapeutics has developed a therapy called NKTR-358 which stimulates the IL-12 receptor and thereby leading to the production of T-regulatory cell. The T-regulatory cells help to counter the pathogenic T-cells and bring back the balance to the immune system.

In a Phase-1b clinical trial, three doses of NKTR-358 demonstrated adose-dependent reduction in CLASI-A (Cutaneous LE Disease Area and Severity Index) composite clinical scores in patients with mild-to-moderate SLE.

"We also observed dose-dependent biomarker changes associated with Treg activation including increases in Treg functional markers, changes in DNA methylation of the FoxP3 locus, and increased expression of Treg functional genes," said Jonathan Zalevsky, Ph.D., Chief Research & Development Officer at Nektar Therapeutics.

Highlights from the ARC 2020 presentation included, safe and well tolerated with a similar safety profile for single and repeat doses, Increases in Treg activation markers, Low-level increases in NK cell numbers occurred in most patients at the highest NKTR-358 dose and a dose-dependent reduction in CLASI-A¹ score.

Source: <https://ir.nektar.com/news-releases/news-release-details/new-clinical-data-presented-phase-1b-study-nktr-358-novel-t>

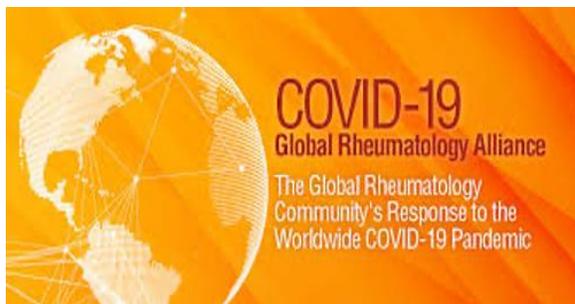
Kezar Life Sciences highlights the safety and therapeutic potential of KZR-616, a novel immunoproteasome inhibitor, in a Phase 1b clinical trial

Kezar Life Sciences has developed a novel immunoproteasome inhibitor with broad therapeutic potential across multiple autoimmune diseases, including SLE. Results from the pre-clinical results have shown the effectiveness in suppressing the pro-inflammatory elements, without causing an immunosuppression. In a Phase 1b clinical trial KZR-616 was

evaluated in SLE patients with and without lupus nephritis. KZR-616 administered subcutaneously (SC) once weekly has been consistently well tolerated for 13 weeks. KZR-616 has been studied at doses of 45 mg, 60 mg and 75 mg SC weekly. Encouraging trends were observed including early efficacy signals and improvement of SLE-specific disease activity scores and no new safety signals.

"The clinical data continues to show that KZR-616 is well-tolerated and improves multiple signs and symptoms of SLE. We continue to build a strong foundation for KZR-616 as a novel and important therapeutic for patients living with LN, dermatomyositis and polymyositis and other immune-mediated diseases," said Noreen Henig, M.D., Kezar's Chief Medical Officer.

Source: <https://www.biospace.com/article/releases/kezar-highlights-broad-therapeutic-potential-of-kzr-616-during-acr-convergence-2020/>

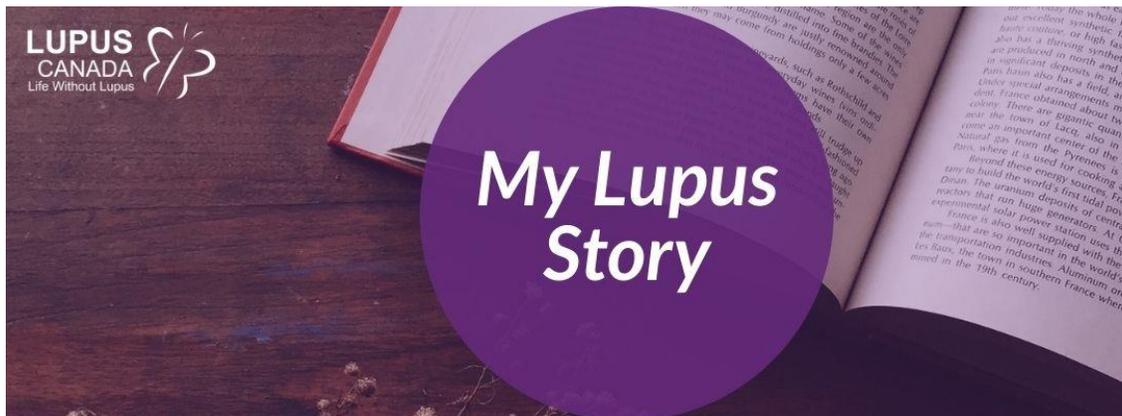


Lupus Canada is proud to be among the supporters of the **COVID-19 Global Rheumatology Alliance, an organisation** that unites rheumatologists and patients with rheumatic diseases worldwide to respond to the global pandemic.

The group's mission is to create a secure international data registry called the COVID-19 Rheumatology Registry. It is

designed for healthcare providers to share their experience treating specific cases of people with rheumatologic conditions such as lupus who develop COVID-19. Reporting will also record how common rheumatic medications like Plaquenil impact patients' outcomes and evaluate the risk of infection in patients on immunosuppression.

You can **view the latest updates from the COVID-19 Global Rheumatology Alliance including Plain Language Summaries** of The COVID-19 Global Rheumatology Alliance data.



Lupus Canada's Scholarship program helps students living with lupus to succeed in attaining a post-secondary education. Through the financial support of the Lupus Canada Scholarship,

we intend to recognize and raise awareness of the achievement of students living with lupus who have taken a positive and ambitious outlook in achieving their academic goals. Each month we will highlight one of our Scholarship recipients. This month we are honoured to share Amelia's story with you.

Living with Lupus by Amelia

In October 2015, I was diagnosed with lupus. In the summer, I had experienced troubling symptoms such as fatigue, skin rashes, hair loss, vomiting, painful joints, and severe weight loss. My symptoms started in grade seven in December 2014 and continued on until grade eight when I was diagnosed at SickKids Hospital. During my time at school when I was sick, I had trouble concentrating and faced intense anxiety. It was one of the most difficult times of my life and I felt trapped in a sickening hole with no one to help me. Eventually, I was diagnosed with lupus and got the treatment I needed to be myself again.

After I was diagnosed I missed two months of school. I was always a high achiever and I was afraid my chances at getting honour roll at my grade eight graduation were gone. In December when I fully recovered, it was difficult to catch up with everyone, but however, I was destined to get my life back on track. Throughout the school year I stayed optimistic and pushed through every assignment without letting my disease hold me back. I ended up not only achieving my goal of getting honour roll but I also received the English award and was the class valedictorian.

In high school I still suffered from anxiety and struggled with perfectionism. Specifically, in grade 9 and 10 I was always determined to get good grades that it mentally and physically impacted my health. Then, in grade 11 and 12 I stopped worrying as much with getting high grades and instead focused on just doing my best. I cannot explain how I stopped worrying, but I believe I suffered from senioritis and just stopped caring so much about how well I did on my assignments and more on just completing them. Due to my senioritis, I became the healthiest I have ever been as I was more self aware of how my actions were affecting my wellbeing. In addition, I still excelled in school as I have received honour roll and individual course awards in every grade. I have had arthritis and joint pain hold me back from physical activities at school. Nevertheless, I was not afraid to speak about my illness to anyone and tell them what I can or cannot do to plan out around any challenges that I had.

I want to thank all the wonderful doctors at Sick Kids Hospital for taking care of my health. That goes out to the rheumatologists, phlebotomists, and the receptionists for being so nice and caring towards me. I am currently in my first year of university at the University of Toronto Scarborough and I am on track to pursue a degree in psychology. From my experiences with my disease and my anxiety, it has led me to help others in their fight against mental illness. Right now, university has been one of the biggest challenges yet on my health. Online school has been very stressful but I try to stay in the mindset of my grade 11 self and just do my best. I struggle with feelings of fatigue which makes me have trouble concentrating and feel unmotivated to work. I also feel pressured to work all the time and think if I do not work one hour I might fall behind. Mostly, I always feel if I start worrying and stressing a lot I would get sick and fall right back down again. My advice to anyone who is reading this is to just stop obsessing over things and go with the flow. In high school I was always caught up with the things I did bad on that I never focused on the good things. For example, I would always be sad that I got a certain question wrong on a test that I didn't focus on the fact that I got a 83% on it which is a pretty good mark. Although my advice is mostly related to school, it can be considered in other areas. You just have to sit back and examine your feelings and actions, and think how am I doing mentally, and

physically and are my actions in any way affecting my health? While my disease is a big part of me, it does not define who I am. I view my disease as a second chance at life and I am grateful to have the opportunity to continue to pursue my goals and sustain a longer, healthy future. I am thankful to Lupus Canada for this scholarship and the opportunity to share my story. I wish others with lupus to be strong and carry through with your life. When times are difficult, try to focus on the good and plan out how you will continue to build that goodness in your life to over power the bad. Thank you to everyone who took the time to read this.





ULTIMATE VEGETABLE LENTIL LOAF

PREPARATION: 15MIN

COOKING: 90MIN

SERVES: 6

INGREDIENTS

Loaf:

- 1 cup dry lentils (use green/brown)
- 2 ½ cups water or vegetable broth
- 3 tablespoons flaxseed meal (ground flaxseeds)
- 1/3 cup water
- 2 tablespoons olive oil or steam sauté using ¾ cup water
- 3 garlic cloves, minced
- 1 small onion, finely diced
- 1 celery stalk, finely diced
- ¾ cup oats
- ½ cup oat flour or finely ground oats
- 1 heaping teaspoon dried thyme
- ½ heaping teaspoon dried cumin, optional
- ½ teaspoon each garlic powder and onion powder
- ¼ - ½ teaspoon ground chipotle pepper, optional
- Cracked pepper and sea salt to taste

Glaze:

- 3 tablespoons organic ketchup
- 1 tablespoon balsamic vinegar
- 1 tablespoon pure maple syrup

DIRECTIONS

Prepare lentils: Rinse lentils. In large pot add 2 1/2 cups water/broth with lentils. Bring to a boil, reduce heat, cover and simmer for about 35 - 40 minutes, stirring occasionally. It's ok if they get mushy, we are going to roughly puree 3/4 of the mixture when cooled. Once done, remove lid and set aside to cool (there should only be a little bit of water so do not drain), lentils will thicken a bit upon standing, about 15 minutes is good. Preheat oven to 350 degrees.

Make flax egg: In small bowl combine flaxseed meal and 1/3 cup water, set aside for at least 10 minutes (preferably in refrigerator).

Saute vegetables & spices: In saute pan heat oil or water over medium heat. Saute garlic, onion, bell pepper, carrots and celery for about 5 minutes. Add spices mixing well to incorporate. Set aside to cool.

Mash lentils: Using a food processor, back of a fork or potato masher blend 3/4 of the lentil mixture. For me this was an important part, I tried it other ways and this worked to help as a binder.

Assemble lentil loaf: Combine sauteed vegetables with the lentils, oats, oat flour and flax-egg, mix well. Taste, adding salt and pepper as needed, or any other herb or spice you might like. Place mixture into a loaf pan lined with parchment paper, leaving it overlapping for easy removal later. Press down firmly filling in along the edges too.

Glaze: Combine all ingredients in a small bowl, mix until incorporated, recommend making each tablespoon heaping so you have plenty of the great sauce on top (if using tomato paste and mixture is too thick, add 1/2 teaspoon of water). Spread evenly over top the loaf.

Bake: Place in center of the oven, and bake in oven for about 45 - 50 minutes. Let cool a bit before slicing.

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

Source: <https://simple-veganista.com/the-ultimate-vegetable-lentil-loaf/>

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