

## LET'S TALK LUPUS

January Monthly E-Newsletter



2020 was a challenging year for all Canadians and especially those living with lupus. Time spent with extended families and friends was limited at best, children's school years were disrupted, sports and other extracurricular activities were taken away, all to ensure everyone's well-being.

But there is hope! With new vaccines to combat COVID-19 we look forward to a better 2021. Those long-awaited visits to finally hug your family again will be possible in the not too distant future.

Charities definitely felt the impact of this pandemic. Lupus Canada worked tirelessly to still deliver on our initiatives. This was only made possible with the ongoing support of our very loyal donors.

We cannot thank you enough for your support. Together, we have made a difference and will continue to do so until a cure is found!

- ***With your support***, Lupus Canada worked tirelessly to ensure no lupus patient would be without Hydroxychloroquine (HcQ). While researchers worked to find medications of optimum benefit for those battling COVID-19.
- ***With your support***, Lupus Canada supported various research programs in 2020. Including funding a study to better identify how the problems of pregnancy happen in women with lupus and APS, so we that we can better predict who may get problems and then study targeted therapies to improve outcomes for mothers and their babies (for more information please visit <https://www.lupus.org/advancing-research/2020-recipients-of-the-lupus-canada-catalyst-award>).
- ***With your support***, Lupus Canada supported 8 students living with lupus through our Scholarship program.

- ***With your support***, Lupus Canada helped raise the much-needed awareness of this under-funded and under-recognized disease through our various Public Awareness initiatives.
- ***With your support***, Lupus Canada advocated on behalf of lupus patients to Government officials across Canada to enhance policies and legislation affecting people living with lupus.

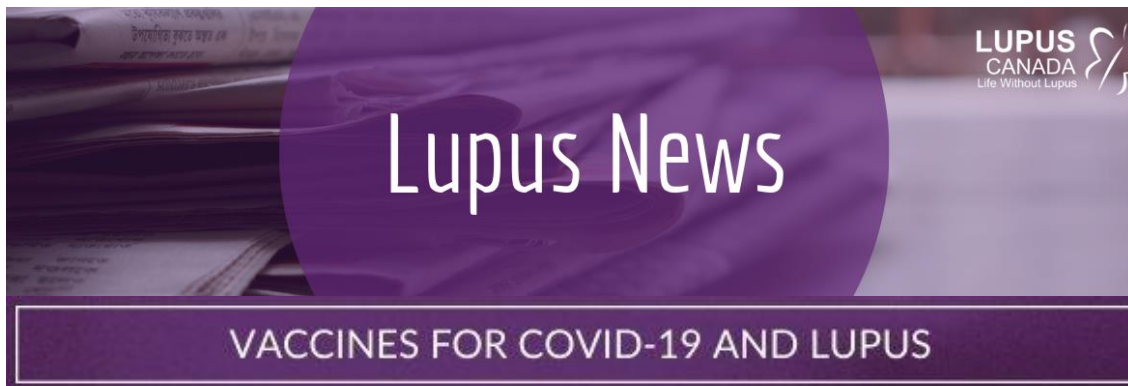
On behalf of the Board of Directors and Staff at Lupus Canada, thank you for your continued support. We look forward to 2021 with great hope and immense gratitude!

# THANK YOU!

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# Lupus News

## VACCINES FOR COVID-19 AND LUPUS

Lupus, and some of the medications used to treat lupus, lowers the immune system's ability to fight infections, including COVID-19. This means people with lupus may be at higher risk of severe illness from COVID-19. *For this reason, current recommendations are for adults with lupus to be immunized against COVID-19 when it becomes available.* (The vaccines have not yet been tested or approved in children or pregnant women).

The vaccines for COVID-19 help protect against COVID-19 by imitating an infection and allowing you to safely develop immunity to the virus. The vaccine causes the immune system to produce cells that will learn and remember how to fight that disease when you are exposed to it in the future.

Because the vaccine imitates a very mild version of an infection, but rarely causes illness, sometimes you might get minor symptoms such as a fever. This is a sign that the body is building up immunity to the disease. Like any medication, vaccines can cause side effects, but serious side effects are very rare. For most people, side effects are mild such as soreness at the spot where a shot was given.

"Live" vaccines are contraindicated in some lupus patients; none of the vaccines currently approved or in development for COVID-19 are live vaccines.

The two vaccines that have been approved for COVID-19 have been tested in thousands of people, and their safety and effectiveness has been carefully evaluated by Health Canada, the FDA, and other national oversight bodies. Long term monitoring will continue to detect any long-term safety concerns. So far, there are no serious safety concerns for these two recently approved vaccines for COVID-19. While we don't yet have a lot of information about the safety and effectiveness of these vaccines in lupus patients, so far there do not appear to be any specific concerns. This will be carefully watched and studied in the coming months and years.

For additional information on the COVID-19 vaccine please visit <https://www.canada.ca/en/health-canada/services/drugs-health-products/covid19-industry/drugs-vaccines-treatments/vaccines.html>

## LUPUS CANADA INFORMATIONAL SURVEY RESULTS

Lupus Canada shared a survey with our lupus community to gather information about lupus patients experiences with symptoms of lupus. This information is not for research but will be used to support and inform applications to Health Canada by pharmaceutical companies as part the regulatory requirements to bring drugs to market. The survey results are summarized without identifiers. This data will be shared with pharmaceutical companies to support applications for drug approval to Health Canada. The survey results may help regulators and health technology assessment bodies to understand what the benefit of new treatments is and who would benefit most from them, thereby improving their ability to make new treatments available for people with lupus.

To learn more about the survey results please visit <https://lupuscanada.org/news/whats-new/>.



Source: <https://herviewfromhome.com/self-care-is-an-act-of-survival/>

As women, we're naturally nurturing and don't even think twice about caring for those around us before our ourselves.

We'll give every part of ourselves to keep the house clean (or at least picked up), give attention and show love to our partner and children, take on extra responsibilities at work or volunteer in the community.

But what happens when we're constantly taking care of everything outside of ourselves? We become overwhelmed, overworked, burned out and frazzled. We begin to lose sense of self.

When was the last time you gave yourself attention or showed yourself some love?

We tend to make self-care the last priority because our schedules are already overflowing. Who has the time or energy for a massage, a workout, a date night or snuggling up with a book?

And then there's the guilt. Most of us will break down from exhaustion before caring for ourselves because we feel so guilty caring for our own needs.

One of my favorite quotes is, "I have come to believe that caring for myself is not self-indulgent. Caring for myself is an act of survival." – Audre Lorde. It's so powerful when we begin to think about self-care as part of our survival.

When I began making self-care a daily practice, my entire life changed. I have more energy, I'm more inspired, I'm happier, I'm healthier, I'm kinder to my partner, I'm more motivated and so much more.

We think of self-care as being this time-consuming and expensive thing that will take so much extra energy. But when you shift your mindset about self-care, creating a daily practice will become easier.

Self-care is as simple as waking up 15 minutes before the rest of your family and enjoying a few minutes alone sipping your coffee.

Self-care is hiding in the bathroom for five minutes breathing with your eyes closed or listening to a short meditation on your phone.

Self-care is feeding your body a nourishing meal or snack.

Self-care is using your favorite body scrub for a few extra seconds in the shower.

Self-care is calling or texting a friend to connect with someone important to you.

Self-care is kissing and hugging your partner when they return home from work.

Self-care is wearing clothes that make you feel confident and beautiful.

Self-care is lounging on the couch under a fuzzy blanket with a glass of wine after the kids go to bed.

Take a moment to visualize yourself doing one or two of these acts of self-care each day. How would you feel? How would it change your day?

## NEW PROTOCOL FOR DIAGNOSING LUPUS

Source: <https://kaleidoscopefightinglupus.org/new-protocol-for-diagnosing-lupus/>

The American College of Rheumatology's (ACR), in 1997, approved a specific set of criteria for the diagnosis of systemic lupus erythematosus (SLE). Recently, however, in collaboration with the European League Against Rheumatism (EULAR), these criteria have been significantly revised. Read on to learn more about these important changes and how they can affect how lupus is diagnosed.

### **What needed to change?**

Several lupus research centers across Europe worked on this international initiative, with the ACR and EULAR, to analyze the existing criteria and write new ones. According to Dr. Jack Cush of RheumNow – Rheumatology News and Information the study was conducted in four phases:

- (1) Assessing the feasibility of including antinuclear antibody (ANA) as new criteria. Researchers analyzed several databases that included over 13,000 individuals from several studies and found a 97.8% ANA sensitivity, convincing researchers of the necessity of ANA inclusion in the new classification.
- (2) Determining how to reduce criteria. The number of criteria was reduced from 43 to 21. This simplified things, but also included differentiating between "required" criteria – those that were absolutely necessary for a lupus diagnosis – and others called "additive" criteria.
- (3) Discussing how to define and weigh new criteria. A group of SLE patient advocates, a steering committee and international SLE experts collectively determined how to redefine and weigh the final reduced list of criteria through "[achieving] consensus on classifying a case vignette as SLE."
- (4) Deciding how to refine weighting and threshold scores with a new cohort of subjects. Experts determined a "data-driven threshold for classification" and evaluated information on individuals thought to have SLE but who were below the threshold and "misclassified" against individuals who unequivocally had SLE yet still missed classification requirements. Experts again refined the proposed weighing system, rounding the weights to whole numbers, according to the findings from their evaluation. A steering committee "unanimously endorsed" the new system.

The new classification reflects the "largest international, collaborative SLE classification effort to date." Twenty-three international lupus research centers engaged in this study and subsequent revisions, each selecting individuals with SLE and those without to partake in the research. A group of 1,001 individuals were reviewed using the proposed new criteria while

a group of 1,270 individuals were reviewed using existing criteria in order to compare the difference in diagnoses from one set of criteria to the other.

According to an article published in the September 2019 issue of *Annals of the Rheumatic Diseases*, the study took place in the Department of Rheumatology, Hopitaux Universitaires Paris Sud, which is a reference center for "rare systemic autoimmune disease."

#### **What are the significant changes from 1999 to 2020 criteria?**

Dr. Cush notes the following significant changes to the new criteria:

- Criteria is chosen from seven clinical categories including: constitutional, hematologic, neuropsychiatric, mucocutaneous, serosal, musculoskeletal and renal.
- Criteria is chosen from three immunologic categories including: antiphospholipid antibodies, complement proteins and SLE-specific antibodies.
- Criteria is weighted from two to ten.
- Derivation and validation sensitivity and specificity percentages have increased from the previous criteria.
- Individuals with  $\geq 10$  points are classified as having SLE.

The 1997 classification outlined 11 criteria that are common to SLE. If an individual met at least 4 of the criteria, the likelihood was high that they had SLE, prompting their healthcare practitioner to perform additional tests and create treatment plans based on the analysis. Researchers of the 2019 study published in the journal *Annals of the Rheumatic Diseases* note that the new criteria was developed with "multidisciplinary and international input," and has "excellent sensitivity and specificity."







## Vegan White Bean and Kale Soup

PREPARATION: 10MIN

COOKING: 20MIN

SERVES:10

### INGREDIENTS

- 2 tablespoon extra-virgin olive oil
- ½ large white onion (1.4 lb or 1 cup diced)
- 2 large carrots (1.4 lb or 1 cup diced)
- 2 large celery stalks (1.4 lb or 1 cup diced)
- 5 cloves Garlic finely chopped
- One 28 oz cans Diced Tomatoes
- Two 15 oz cans White Cannellini Beans (drain and rinse)
- 4 cups Vegetable Broth
- ½ teaspoon Kosher Salt
- ½ teaspoon Italian Seasoning
- ¼ teaspoon Crushed Red Pepper (optional)
- 4 cups Kale or Spinach (2 oz chopped)

### DIRECTIONS: SOUP STOVE INSTRUCTIONS

- 1** In a 3 qt soup pot on medium-high heat, heat OLIVE OIL until it shimmers (about 2 minutes)
- 2** Add ONIONS, CARROTS, CELERY, and GARLIC; sauté a few minutes until slightly tender, stirring as needed
- 3** Stir in TOMATOES, VEGETABLE STOCK, BEANS, SALT, ITALIAN SEASONING, and (optional) CRUSHED RED PEPPER
- 4** Bring the bean soup just to a boil then lower heat and simmer 10 minutes, stirring as needed
- 5** Add KALE to the pot and continue simmering until kale is wilted

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

*Source: <https://thekitchengirl.com/instant-pot-vegan-tuscan-white-bean-kale-soup/>*

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