



Let's Talk Lupus

Monthly E-Newsletter

This month, we will start to see the leaves turn and the temperatures drop. However, our hearts can remain warm knowing that we have Thanksgiving to look forward to on October 8th. This is such a great time of the year to spend with family and reflect on what you are grateful for – Happy Thanksgiving!

A couple days later on October 10th is World Mental Health Day. According to the World Health Organization, the goal of this day is to recognize and support mental health issues around the world and work towards a more accepting society.

For this month's newsletter we wanted to focus on a lupus patient's overall wellbeing and start a discussion on the impact lupus has on one's mental health. Many lupus patients experience difficulties both mentally and emotionally due to the toll that the disease has on every day life. Being aware of where those feelings are coming from may give you a better idea on how to address them going forward, and think of ways to implement coping mechanisms. Take a look at the article included in this newsletter to read more on this topic.

Happy Thanksgiving and Happy Halloween!

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Lupus Awareness Month

October marks Lupus Awareness Month

Lupus Awareness Month is such an important time of recognition for lupus patients nationwide as it places a much needed spotlight on an under-funded and under-recognized chronic disease. It has always been our hope to spread the word about

lupus to as many Canadians as possible because advocacy should be for everyone, not just those who are living with lupus.

Celebrating lupus awareness month has allowed for great leaps in lupus advocacy across the nation and created ample opportunity for discussion about the disease. We are very excited about the potential reach this month will bring. A large part of what we do is bring awareness and attention to this disease that is otherwise unknown to so many, despite 1 in 1000 being diagnosed. While this month is so crucial to lupus patients around the country, the attention should not stop at the end of the month. Our hope is that everyone across the country will continue to fight for those living with lupus all year round and work towards a life without lupus.

Together we can make a difference!

RESEARCH NEWS

<http://www.jrheum.org/content/early/2018/08/27/jrheum.171459>

As an initiative of the Canadian Rheumatology Association and endorsed by Lupus Canada and the Canadian Network of Improved Outcomes in SLE, the Canadian SLE Working Group has recently published new recommendations for the assessment and monitoring of lupus patients in Canada. This working group includes 23 adult and 4 pediatric rheumatologists, 1 immunologist, 4 general internal medicine and rheumatology trainees, and 1 representative from the Canadian Arthritis Patient Alliance. These recommendations are meant to help lupus healthcare providers in the evaluation of their patients, and help identify how and what to assess over time. These are the first lupus recommendations internationally to use a method called GRADE (Grading of Recommendations, Assessment, Development and Evaluation). This method carefully looks at the evidence behind each recommendation, and considers how it benefits or harms the patient, what resources would be required and if it is something that can be delivered equally to patients across the country. The working group looks forward to considering future recommendations in lupus treatments as a next step.

These recommendations confirm things that we already knew - that patients need to ensure their lupus healthcare provider is performing a thorough assessment per visit. In some cases, patients might notice over time that the practitioner is using a score to quantify this, which they can compare over time. The recommendations also help remind everyone how important heart health and the annual flu shot is. The recommendations do suggest that cervical cancer screening (aka PAP smears) should be done more frequently (eg. annually) rather than every 3 years as is stated in the Canadian guidelines for the general population. Pregnancy is definitely highlighted in these recommendations, with a strong recommendation to ensure a special set of antibodies called anti-Ro and anti-La have been done to evaluate the risk for a rare but important problem called neonatal lupus, where babies can have a serious problem known as congenital heart block. Close monitoring of women during the pregnancy period with coordinated care between physicians including obstetricians,

maternal-fetal-medicine and other specialists and the lupus healthcare provider are encouraged.

My Lupus Story by Carla Cavinta

At 16, I was diagnosed with Rheumatoid Arthritis. While my friends were worrying about the school dance, I was worried about my joint health (I was a cool kid, as you can imagine.) Fortunately, my symptoms were mild and managed by drugs until my early 20's.



In 2013, shortly before my 25th birthday, I woke up one morning and my hands looked like balloon animals (the poodle, to be exact). They felt like they were: 1) on fire and 2) being stabbed with steak knives. After some tests at Toronto Western Hospital, I was sent home with a healthy dose of steroids. A month later, I was told I was initially misdiagnosed - I in fact had lupus.

As a cruel joke from the universe, I found out that same day that an old friend had just died of lupus complications. As you can probably relate, I was feeling scared, overwhelmed, confused, and alone. Being a self-proclaimed nerd, I booked it to the hospital library to learn more about this disease of many faces.

Over the next five years I've experienced a spectrum of flare-ups ranging from mild to severe. The hair loss, weight gain, and acne was a huge confidence booster when trying to find Mr. Right in your early 20's (sarcasm). This was nothing compared to the recurring onslaught of joint swelling and pain, rashes from photosensitivity, excruciating headaches, and extreme fatigue. That said, the pericarditis (inflammation of the heart lining) definitely takes the cake. It's far too painful to lie down so you're forced to sleep upright. There's nothing like scaring your dad in the middle of the night because he thinks you're Dracula. All kidding aside, I consider myself extremely grateful because I know it could be far worse.

While I've experienced several challenges over the past few years, I'm happy to say that I'm in remission at the moment. I'm currently working as a Digital Marketing Manager at RBC and am starting my MBA at the Schulich School of Business in the fall. I will soon be married to a super supportive stud who helps me every day in my quest to balance nutrition, exercise, and stress management. I'm still on Prednisone and Plaquenil, but this is a far cry from the cocktail of drugs I used to be on. I still get flare-ups, but nothing can stop me from trying to live my best life!

What's your lupus story? We'd love to hear it. Send us your thoughts and experiences to be featured in Lupus Canada's national monthly e-newsletter. Email your stories to leanne.mielczarek@lupuscanada.org

Lupus and Mental Health Concerns

Source: <https://www.webmd.com/lupus/guide/psychosocial-aspects-lupus#1>

Living with lupus can have a profound effect on a person's mental and emotional well-being. You may have recently been diagnosed with lupus, or you may have been living with it for years. Either way, you are likely to have experienced mental and physical problems such as difficulty concentrating or sleeping. You are also likely to have felt emotions such as grief, fear, anxiety, and depression. These feelings are common. Understanding where they come from can help you develop techniques for coping with them.

Where the Feelings Come From

The feelings associated with lupus can have multiple causes, including:

Outward effects of the disease or its treatment. Visible problems such as a facial rash or weight gain from corticosteroids used to treat lupus can affect your physical appearance and self-esteem.

Work and activity limitations. Pain, fatigue, and other symptoms can make it difficult to do things you once enjoyed. The disease or its treatment may make it necessary to cut back at work or even leave your job completely. This can affect the pleasure you get from your job, your sense of purpose, and your income.

Pain, fatigue, and other physical symptoms. Simply living with pain and other symptoms every day can wear you down. Emotionally, this can lead to frustration and feelings of hopelessness.

Social isolation. When you feel bad or use all of your energy just to get through the day, social activities may be among the first things to go. Concerns about changes in your appearance may also cause you to withdraw.

Uncertainty about the future. Having a chronic, unpredictable disease can cause uncertainty and anxiety. You may wonder how the disease will progress, whether you will be able to stay independent, or how you will manage physically and financially.

Difficulty with family relationships. Having a chronic illness like lupus may make it difficult to take care of your home or family the way you would like to or feel you should. Because the disease may come and go and often shows no outward signs, your family may not understand why you can't do the things you used to do. They may even question whether your disease is all in your head.

Mental Effects of the Lupus Disease Process

Sometimes, the mental and emotional effects of lupus can be related to the disease process itself or medications used to treat it. Common problems that may be associated with the disease include:

Cognitive dysfunction. Many people with lupus experience a variety of related problems including forgetfulness or difficulty thinking. They may describe these problems as feeling "fuzzy-headed" or being in a "lupus fog." These problems often coincide with periods of increased disease activity, or flares. But cognitive problems can also be symptoms of depression.

Depression and anxiety. These can occur as a psychological reaction to having lupus or a side effect of treatment. They may also occur as a direct result of the disease process. Often it is difficult for doctors to sort out the actual cause.

Mood swings and personality changes. People with lupus may experience unpredictable changes in moods and personality traits. This can include feeling of anger and irritability. These may be related to the disease process or, in some cases, the use of corticosteroid medications.

Getting Help for the Emotional Effects of Lupus

If you are experiencing any of these problems, it's important to discuss them with your doctor. Your doctor can help you find solutions. These may include a change in medication to control your lupus. Or, the doctor may add medications to treat problems like anxiety and depression.

Your doctor may also refer you to a mental health professional, who will be able to help you identify additional ways to cope with lupus.

How You Can Help Yourself

There are steps you can take to cope better with lupus, including:

Educating yourself -- and others. Learn as much as you can about the disease and its treatment. Share information with friends and family members so they will better understand the disease and how it affects you. Their support is important to success in managing the illness.

Practicing healthy lifestyle habits. Exercise regularly; eat a healthy, balanced diet; get enough rest; and avoid alcoholic beverages, particularly if you are depressed. Alcohol is a natural depressant. It can markedly increase the severity of depression and its symptoms.

Learning stress-management techniques. Living with a chronic disease is stressful. A mental health professional can teach you techniques, such as progressive muscle relaxation, guided imagery, and meditation, that you can use regularly to cope with the stress of lupus. Other stress relievers you can try include listening to soothing music, taking a warm bath or a walk, or doing some gentle exercises.

Doing activities you enjoy. Lupus may limit some activities. So it's important to find things you enjoy doing and take time to do them. These activities can be as simple as reading a good book or doing thoughtful things for others.

Seeking support. When you are feeling down, talk with a trusted friend, clergy

member, or counselor. Consider joining a support group. To find a group for lupus patients near you, speak with your doctor or counselor or your local/provincial organization.

Appreciating yourself. Although you have lupus, you likely have many other things, such as pretty eyes, a friendly smile, musical talent, or a flare for Cajun cooking. Don't make lupus the focus of your life. Focus on your talents, abilities, and strengths.



Special thanks to Ryan Allison and his team for participating in the Blue Heron Blitz race again this year! Over the past 6 years their team has raised over \$7900 in support of those living with lupus.



Recipe: Roasted Fall Veggies

Ingredients

- 1 1/2 c. semi-pearled farro
- 2 c. butternut squash, cubed
- 2 c. baby bello mushrooms, quartered
- 2 c. Brussels sprouts, quartered or halved
- 6 tbsp. extra-virgin olive oil, divided
- kosher salt
- Freshly ground black pepper
- juice of 1 1/2 lemons
- 1 small clove garlic, minced
- 2 tbsp. tahini
- 1/4 c. fresh parsley leaves



Directions

- Preheat oven to 425° and cover two baking sheets with aluminum foil.
- Place farro in a large saucepan and cover with cold water. Let soak 15 minutes, then drain, return to pan, and cover again with water. Bring to a boil and let simmer 15 minutes. Drain and spread out on a paper towel-lined baking sheet to let cool.
- Arrange vegetables on prepared baking sheets and drizzle with 3 tablespoons olive oil. Season with salt and pepper and toss to coat. Roast until golden and tender, 18 minutes. Remove from oven and let cool slightly.
- Make dressing
- Meanwhile, in a mini food processor or blender, combine lemon juice, garlic, tahini, parsley, and remaining olive oil. Add 3 tablespoons water to achieve thinner consistency and season with salt and pepper.
- In a large bowl, toss together farro and roasted vegetables. Divide into serving bowls and drizzle with dressing.

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


Source: <https://www.delish.com/cooking/recipe-ideas/recipes/a44291/roasted-fall-veggie-bowl-recipe/>


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