

LUPUS
CANADA
Life Without Lupus



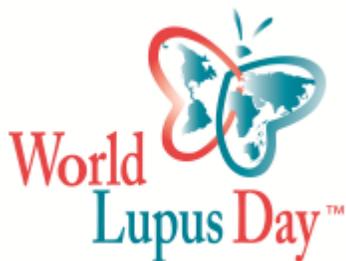
What's your lupus story? We'd love to hear it. *Send us your thoughts and experiences to be featured in Lupus Canada's national monthly e-newsletter. Email your stories to leanne.mielczarek@lupuscanada.org*

Making a Difference Together

APRIL E-NEWSLETTER

April is a busy time for everyone here at Lupus Canada as we gear up and prepare for World Lupus Day and Put on Purple next month! These are key dates to help make Canadians aware of lupus and shine a light on a disease that does not get nearly as much attention that it should. Help us on our mission of awareness for people living with lupus all over the country by interacting with our Facebook page, Instagram and Twitter! If you want to support individuals living with lupus, please consider donating to Lupus Canada with a one-time, in-honour, in-memory or monthly donation. No matter how big or small the donation, it may make a huge difference in the lives of many Canadians. Visit <https://www.lupuscanada.org/ways-to-donate/> for more information on how you can help!

On Sunday April 1st, many people will celebrate Easter with friends and family while many kids will try to add some flare by celebrating April Fool's Day! Like any other major celebration, this time of year can add some extra-long days to your itinerary. Take a look in this newsletter to read more about why sleep is so important for you and how it will help your lupus symptoms.



Make sure to mark your calendars because next month on May 10th we will celebrate World Lupus Day!

Lupus Canada Announces 2017-18 Catalyst Grant Program Recipients

Lupus Canada is proud to announce funding for three Catalyst Grants this year! In the second year of our funding program, we are thrilled to highlight the depth and diversity of Lupus research across Canada. Congratulations to:

- Ann Clarke and team at the University of Calgary for their project, "Enhancing the working life of individuals with SLE while promoting public understanding: an integrated knowledge translation approach"
- Joyce Rauch and team at Research Institute of the McGill University Health Centre, for their project, "RIPK2: A novel therapeutic target in SLE"
- Zahi Touma and team at Toronto Western Hospital, UHN, for their project, "Improving the assessment and care management of everyday living limitations in adults with lupus related cognitive impairments: a multi-methods examination of activities of daily living"

The Catalyst Grant Program was launched to support high calibre start-up projects that have the potential to significantly advance the field or impact the lives of persons living with lupus and their families. To learn more about the projects, please visit www.lupuscanada.org.

My Lupus Story by Marie-Josée Biallas



It all started 15 years ago with the flu, after having my flu shot (as I do every year) this time the pain spread to every inch of my body which landed me in bed for 2 weeks. After that the skin rash came with the spring sun. It grew and grew, on my arms on my chest to finish on my face. No one seemed to know what was happening to me. I got tired, lost all energy, it took all I had to do anything, but life with a child doesn't stop because mommy is "tired". Work, school, after school activities they don't stop. The dog still needs walking and the bills keep coming, no option but to keep going.

By the time October came around I didn't know how I was going to continue. We learned my mother was dying and every day I felt sicker. Of course, there was nothing they could find wrong with me to

explain it. Got another cold and that did me in. My chest was hurting so much I was walking bent over to keep the pressure off. Made it to work but when my best friend saw me walking she lost it. Even if I knew it was a waste of time to go to the doctor, they never had any answers for me, she convinced me to go.

Well this time I fell on the right doctor. I will always be grateful to her.. First, I got hospitalized with pericarditis. After the meds started to do their magic on the pain we had a long conversation. By the end she said "I believe you may have lupus. Let's do a few more tests." LUPUS??? What is she talking about and what is that, never heard of it. More blood work and BANG the diagnosis I was waiting for all year came down, I had lupus.

Okay now we know what it is, what's the cure? Well we don't she said, we don't have a cure, but we can maintain it. I had tons of questions, she helped me so much to understand the disease, how it affects me and how to deal with it, it's going to be a lifetime battle, I better get ready. And I did. One of the best advise she ever gave me was "Never stop, tired or not, get up and move. Once you stop it will get harder for you to get up again." I never did. I admit some days it's hard and I need help, but I don't stop. Over the years I received help and support from my wonderful daughter, my family and friends, I could not have made it alone. I now have a great husband who lets me know when it's time to slow down or give me a boost when needed, he's my barometer!

There were a few scares over the years, cancer, more pericarditis, skin rashes, but I didn't stop, I figure I have lupus it won't get me.

Today after all those years it grew into much more than just lupus we added hypothyroidism, Raynaud's, sjogren's, celiac and lactose intolerant. But hey those are the cards I was given, I make the best of it. I now bake for my family, what can be made with gluten I will make it without, no complaints so far, even turned it i to a small side business. But most of all I still listen to my doctor. I'm active, stronger and more determined than ever to keep it at bay as long as I can. I do more now than ever before, crossfit, hot yoga, hiking, cycling and skiing. I live in BC, a natural playground year long and I take advantage of it.

That's my story, it's not finished, these are a few chapters, I have lots more left in me.

Marie-Josée Biallas

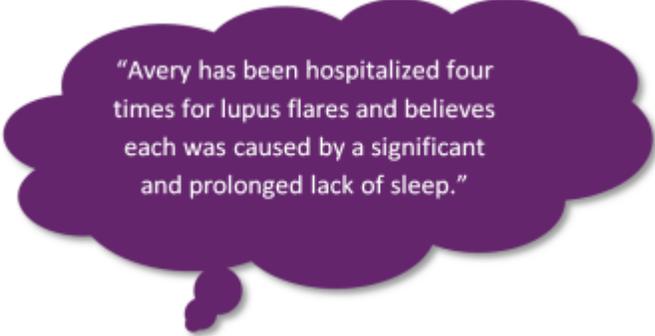
Why Sleep is Essential for Lupus

Taken from Lupus.org

Autoimmune diseases, including lupus, run in Karen Avery's family. "My brother has discoid lupus, and I lost my cousin to lupus three years ago. She was only 42—the age I am now," she says.

Avery was diagnosed with lupus in 1989 while in college. "I remember vividly the day I got sick; I fell asleep in class, and when I woke up my hands were blue. I stood up from my desk, and I was in so much pain, I thought, 'I must have the flu.' I have always had sleep issues and great difficulty sleeping at night. Plus, I wasn't eating right, I wasn't exercising; I was running myself into the ground," she says.

Today, Avery is a managing director for Marsh & McLennan Companies, an insurance brokerage and consulting firm based in New York City; she runs a global consulting firm for the company. As if that were not enough, she is a new single mother of one-year-old fraternal twin girls, Erika and Eden.



"Avery has been hospitalized four times for lupus flares and believes each was caused by a significant and prolonged lack of sleep."

Although Avery has, for the most part, been successfully managing her disease for years, she has been hospitalized four times since her diagnosis with lupus flares. She believes every flare was caused by a significant and prolonged lack of sleep. For her, getting the right amount of sleep is essential.

What's in a zzz ...?

According to the National Institutes of Health (NIH), approximately 70 million people in the U.S. are affected by a chronic sleep disorder or intermittent sleep problem. NIH reports that women suffer from lack of sleep more than men do; these sleep problems increase in frequency as women age.

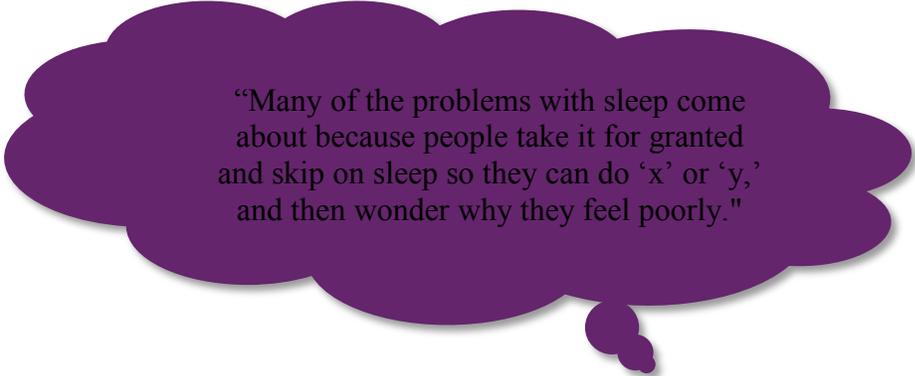
The 2015 Sleep in America™ poll, conducted by the National Sleep Foundation (NSF), found that pain, stress and poor health are key correlates with poor sleep quality and shorter sleep duration.

Add lupus to the mix, and the importance of good sleep takes on an even more important role.

Is sleep related to disease?

Sleep deprivation can be harmful to the immune system. Research done through the National Institute of Neurological Disorders and Stroke has shown that neurons that control sleep interact closely with the immune system. For example, as anyone who has had the flu knows, infectious diseases tend to make us feel sleepy. This probably happens because cytokines—chemicals that the immune system produces while fighting an infection—are powerful sleep-inducing chemicals. Sleep may help the body

conserve energy and other resources that the immune system needs to mount an attack.



“Many of the problems with sleep come about because people take it for granted and skip on sleep so they can do ‘x’ or ‘y,’ and then wonder why they feel poorly.”

Daniel McNally, MD, a pulmonologist and director of the University of Connecticut’s Sleep Disorders Center, agrees that people with a chronic illness, especially those who live with chronic pain and must deal with sleep-disrupting effects of medications, are likely to have more sleep problems on average. “Being able to help these people with ways to sleep better may give them a bit of relief,” he says.

The most recent Sleep in America poll found that only 31 percent of Americans had ever discussed sleep with their doctor. Meanwhile, 67 percent reported being somewhat or very concerned about the consequences of poor sleep on their physical health. McNally is not surprised.

“Many of the problems with sleep come about because people take it for granted and skip on sleep so they can do ‘x’ or ‘y,’ and then wonder why they feel poorly. I’m always frustrated when someone who should be getting adequate sleep says, ‘Can’t I just take more vitamins?’ ”

OK, so how much sleep do we need?

How much sleep we need depends on many factors, including age. While teenagers need about nine hours of sleep, seven to eight hours of sleep a night appears to be the best amount for most adults. The amount of sleep a person needs also increases if he or she has been deprived of sleep in previous days. Getting too little sleep creates a “sleep debt,” which is much like being overdrawn at a bank. Eventually, your body will demand that the debt be repaid.

We don’t seem to adapt to getting inadequate sleep, either; we may get accustomed to a sleep-depriving schedule, but our judgment, reaction time, and other functions are still impaired.

What’s worse, the practice of “burning the candle at both ends” that is common—and even respected—in Western industrialized societies has created so much sleep deprivation that what is really abnormal sleepiness has become the norm.

But sleep deprivation is dangerous: Sleep-deprived people who are tested by using a

driving simulator, or by performing a hand-eye coordination task, perform as badly as or worse than those who are intoxicated.

Don't put off taking control of your sleep

When Avery decided to have her children, she vowed to take control of both her work hours and her sleep hours. To be sure to get enough sleep to prevent her lupus from flaring, Avery has implemented a variety of strategies.

"Without sleep I will have a lupus flare, so sleep is critical for my overall health and well-being," Avery says. "The quality of my life has really improved over the last six, seven, eight years, because I really took control," she says. "I said, 'I'm going to get more sleep, I'm going to exercise, I'm not going to be too dependent on medication, although I have to take it sometimes; I'm really going to force myself to do these things,' and it's made a huge difference."

[Read More](#)

Recipe: Wild Rice Salad

Cook Time: 25 mins

Serves: 6

Ingredients:

- 400 g mixed rice, such as Camargue, wild and long-grain
- 150 g mixed nuts
- ½ a bunch of fresh basil
- ½ a bunch of fresh mint
- 75 g dried apricots
- extra virgin olive oil



Directions:

1. Cook the rice according to the packet instructions until tender. Drain, then allow to cool.
2. Roughly chop the mixed nuts, pick and roughly chop the basil and mint leaves, then roughly chop the apricots.
3. Combine with the rice, season with sea salt and black pepper, then drizzle with oil. Serve with grilled meat or fish

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

Source: <http://www.jamieoliver.com/recipes/rice-recipes/wild-rice-salad/>

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