



Let's Talk Lupus

Monthly E-Newsletter

April is upon us and that means spring is in full swing – hopefully we will start to see the end of that cold Canadian weather and instead, see some colourful flowers blooming!

For this month's newsletter, we wanted to shift the focus towards the champions and supporters of lupus patients. For family members, parents and friends, it can be very difficult to understand what daily life with lupus is like if you yourself don't have lupus. This makes helping out and lending a hand so tough because we often don't know what we can do, if anything at all. The first step is always asking: don't assume how someone else wants to be taken care of or checked up on and remember, it never hurts to ask. This small act can go such a long way and make a huge difference in someone's life! Check out this month's articles detailing ways to support a friend, child or partner living with lupus. If you know someone who could benefit from this information, don't be afraid to forward them this email and share these insights.

DONATE NOW

your gift makes a difference

Lupus Awareness Month is just around the corner...

We also want to remind everyone that next month is Lupus Awareness Month! During the month of May, we will be joining the rest of the world in celebrating World Lupus Day on May 10th as well as, Put on Purple Day on May 17th! Advocating for lupus and the lupus patient is one of our biggest focuses and May gives us a great opportunity to do so. Lupus does not discriminate and it's important that more people hear about this under-funded and under-recognized disease. If you would like to show your support for lupus, be sure to get your very own POP shirt here www.lupuscanada.org/POPtshirt or call 1-800-661-1468



Get a Put on Purple t-shirt to show your support for lupus!

order online or call us at 1-800-661-1468

LAUGHS FOR LUPUS TICKETS ON SALE NOW!

LAUGHS FOR LUPUS LUPUS CANADA
LAUGHS FOR LUPUS LUPUS CANADA
LAUGHS FOR LUPUS LUPUS CANADA

LAUGHS FOR LUPUS LUPUS CANADA
MAY 9 • 2019 Life Without Lupus

GUESTS OF HONOUR
PATRICK MCKENNA
DEBRA MCGRATH
COLIN MOCHRIE

DOORS OPEN AT 7PM SHOWTIME AT 8PM
SECOND CITY TORONTO • 51 MURGER ST
VISIT LUPUSCANADA.ORG
FOR MORE INFORMATION

TICKET PRICE \$150

Laughs for Lupus is Lupus Canada's inaugural fundraising and awareness event in support of the thousands of Canadian men, women and children living with 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 afflicted by lupus. No other organization provides a bigger opportunity to make an impact on lupus and those who live with it.

Lupus Canada is fiercely committed to improving the lives of people living with lupus, their families and their loved ones, by investing in the initiatives that bring us closer to dedicated treatments and ultimately a cure.

Lupus Canada is putting the spotlight on the many faces of lupus. Despite of its widespread nature, lupus isn't an easily recognizable disease. Join Patrick McKenna, Colin Mochrie and Debra McGrath, along with some of the top Canadian Lupus Researchers as we come together raise money and awareness for those who are impacted by this debilitating disease. To purchase your tickets please visit our website at www.lupuscanada.org



Lupus Patient Resource

Would you like to learn more about important lupus research news that matters to you? Visit Lupus Foundation of America's Inside Lupus Research

Inside Lupus Research, powered by the Lupus Foundation of America, is your one-stop location for learning about the

most important lupus research news that matters to you – whether it's early discoveries from clinical trials or new treatment breakthroughs.

<https://www.lupus.org/news/inside-lupus-research>

HAVE YOU RECENTLY BEEN DIAGNOSED WITH LUPUS NEPHRITIS?

Lupus Nephritis is one of the most severe forms of systemic lupus characterized by inflammation of the kidneys. Current treatment with immunosuppressant's and steroids may help, but the need to find new treatments is high. If you have been diagnosed with Lupus Nephritis, a new research study may be an option.

Centers in Canada are currently conducting a research study in people with Lupus Nephritis to compare the effect of a new investigational drug (BI 655064) and placebo and are looking for participants.

Qualified Participants Must:

- *Be 18 to 70 years of age*
- *Be recently diagnosed with Lupus Nephritis*
- *Not have acute or chronic infections including HIV, Hepatitis B or C*
- *Additional Criteria may apply*

Make a difference. Help us in the search for improved lupus treatments today!

To learn more about this study, please contact:

Dr. Paul Fortin

Centre de recherche du CHU de Québec

CHU de Québec - Université Laval

418 525-4444 X48280

Dr. Murray Urowitz

Centre for Prognosis Studies in Rheumatic Disease – Toronto Western Hospital

416 603-5800 X3259

Further information is available at:

<https://clinicaltrials.gov/ct2/show/study/NCT02770170>

If Your Child Has Lupus

Source: <https://www.lupuscanada.org/how-to-advocate/>

For the parent of a child with lupus, information is equally important. Everything – symptoms, medications, side effects, sun sensitivity – will affect what you and your family can do together. It is easier to cope when everyone is informed about what they are dealing with.

Children react to peer pressure, and some of the difficulties that arise can be as much age related as lupus related. But either way, a chronic condition alters everyone's perspective.

A parent needs to be aware of how sisters or brothers are dealing with the illness, and how they are affected by the attention the child with lupus is getting. The child may be unwilling to accept the reality of the disease and the routine of treatment and medication. Denial – by the child or others in the family – may require counselling, perhaps for the whole family.

Parents are encouraged to get together with other parents and exchange information about how they have dealt with various situations. It's always good to know that you are not alone with your problems.

If there are peer groups of children with chronic illnesses, you might encourage your child to meet with them, both to recognize that others face similar issues and to learn new coping skills.

If Your Partner Has Lupus

Source: <https://www.lupuscanada.org/how-to-advocate/>

Often in a relationship where one partner has a chronic illness, we forget that the other person suffers too. While medical attention is paid to the person with lupus, life can change drastically for both partners.

Roles may be reversed – wage earning, household chores and family connections may fall to the caregiver. There are mood swings, medications and medical

appointments to sort out, and a broad range of symptoms, fatigue on both sides.

Because a person with lupus often looks well, family and friends fail to understand or accept how serious the problem has become. Change is hard to cope with, and tension in the household can escalate as everyone tries to deal with the illness and the desire to get back to what used to be normal.

Not every situation will be the same, but there is no question that lupus calls for flexibility.

If Your Friend Has Lupus

Source: <https://lupusnewstoday.com/2017/08/22/ways-to-support-a-friend-with-chronic-illness/>

1. Show up

Something about my strongest friendships that I adore is when someone reaches out to me, and says they would like to come over and just spend some time with me. It is that understanding that I may be too sick to go out, or not have enough energy to shower, get dressed and leave my home for hours, that is crucial. So, my friends and I often will make a cup of tea and sit on my patio.

We may dive into a variety of topics, or say nothing at all. Those actually are the moments that mean the world to me. In those moments, I am reminded of Job in the Bible. Job suffered so much at one point that his friends came and just sat with him in silence to show their support. Sometimes our suffering is so great, there are no words that can make it better. But support, love and the gentle "I get it" glance of someone you love can be worth a thousand words.

2. Offer an act of service

There have been times I needed a ride to a doctor's appointment, help getting groceries, or getting a nutritious meal into my stomach. One of the most thoughtful things my friends can do is send me a text saying, "I'm at the grocery store. What can I grab for you?" or "I'm off next Friday; do you want me to come over and bring lunch/help you with errands?" We may not ask you for anything, but sometimes just knowing someone cares enough to put themselves out there is enough.

3. Recognize silence and be understanding

Sometimes I am so sick that if I brush my teeth and go down the stairs to get food, I've accomplished something. And in those seasons, I have a tendency to withdraw. This happens often with people who have chronic illness. It isn't because we are trying to be aloof or unresponsive to texts, calls or emails. It is literally because we barely have enough energy to keep our head above water.

In the past, I've had people get angry because I didn't respond for a while;

sometimes I would learn these individuals were incapable of understanding chronic illness and how erratic it is. Those friendships didn't last long. But the people who do understand often will send a text or leave a voicemail that says something to the effect of: "You probably aren't feeling well this week. I'm here – call me if you need something or just want someone to be there with you." There is such relief in that one little statement. It tells me someone cares, I am loved, and someone is concerned they haven't heard from me. It offers a positive moment in the often negative experience of being ill.

Recipe: Orange Sesame Salmon with Quinoa & Broccolini

Ingredients:

- 1 cup quinoa
- ½ cup orange juice plus ⅓ cup, divided
- 2 scallions, sliced
- 1 bunch broccolini, trimmed
- 1 tablespoon extra-virgin olive oil
- ½ teaspoon ground pepper, divided
- 3 teaspoons toasted sesame oil, divided
- ¼ teaspoon garlic powder
- 4 4-ounce portions wild salmon
- 1 teaspoon black sesame seeds
- 1 tablespoon minced fresh ginger
- 1 tablespoon reduced-sodium tamari
- 1 teaspoon cornstarch



Directions:

Prepare quinoa according to package directions, substituting ½ cup orange juice for ½ cup water. Remove from heat and stir in scallions. Cover to keep warm.

Preheat oven to 450°F. Line a rimmed baking sheet with foil.

Toss broccolini with oil and ¼ teaspoon each salt and pepper in a large bowl. Transfer to the prepared baking sheet. Roast for 8 minutes.

Meanwhile, combine 2 teaspoons sesame oil, garlic powder and the remaining ¼ teaspoon each salt and pepper in a small bowl. Brush the mixture on salmon.

Push the broccolini to one side of the pan and place the salmon on the other side. Bake until the salmon is just cooked through, 5 to 8 minutes. Sprinkle the salmon with sesame seeds.

Whisk the remaining ⅓ cup orange juice, 1 teaspoon sesame oil, ginger, tamari and cornstarch in a small microwave-safe bowl. Microwave on High for 1 minute. Divide the quinoa, broccolini and salmon among 4 plates. Drizzle with 2 tablespoons sauce each.

Tips: Turn leftovers into a salmon & spinach sandwich with wasabi mayo for lunch: Whisk 1 Tbsp. reduced-fat mayonnaise with 1 tsp. wasabi powder. Spread on 1 toasted whole-wheat burger bun. Top with a leftover portion of salmon and ¼ cup baby spinach.

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


Source: <http://www.eatingwell.com/recipe/256509/orange-sesame-salmon-with-quinoa-broccolini/>


Visit Our Website

[Home](#) | [Contact](#) | [About Us](#) | [Make a Donation](#)

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

Working together to conquer lupus

[Privacy Policy](#) | [Unsubscribe](#)

[Lupus Canada](#)
306-615 Davis Drive, Newmarket, ON L3Y 2R2