HOPE
life without lupus

LET'S TALK LUPUS

July 2023 E-Newsletter

LUPUS CANADA
Life Without Lupus

For more information visit www.lupuscanada.org

Happy Canada Day!

Since 1868, on July 1st Canadians across the country celebrate Canada's history, culture and achievements. To learn more about the history of Canada Day or events taking place in your city please visit https://www.canada.ca/en/canadian-heritage/services/canada-day-history.html.

Lupus Canada wishes everyone a safe and happy Canada Day.

For parents who have children who live with lupus, the summer can bring additional anxiety. For most children, the summer means spending days outside with friends, going to summer camps, and enjoying unstructured days. It might be difficult to communicate to your child about the importance of managing their lupus and why they may need to take extra precautions.

To learn more about how to manage autoimmune flare-ups in hot temperatures visit www.autoimmuneinstitute.org/articles/living-well/how-do-hot-temperatures-affect-autoimmune-disease/.

We want to thank our loyal supporters who allow us by way of their generous donations to continue to make an impact within the lupus community.

DONATE NOW
your gift makes a difference

A LOOK INSIDE

LUPUS CANADA NEWS

Lupus Canada is pleased to welcome Benoit Ferland and Mauricia Ambrose to the Board of Directors. We look forward to working together to make a difference in the lives of those living with lupus. Learn more about their expertise, experience, and why they hope to make an impact below.

Benoit now runs the Lupus Quebec funds in association with CHU de Quebec, where Dr. Boilard and Dr. Fortin are leading researchers in the field of lupus research and development.

Benoit states, "I was inspired by the commitment to the cause and ability to make lupus visible in honour of my best friend who lives with lupus."

Mauricia Ambrose was diagnosed with lupus in her last year at university and after almost 25 years of surviving lupus, lost her kidneys in 2015. In 2023, Mauricia won the International Women's Day speaker competition at RBC where she had an opportunity to tell her story to approximately 8,000 of her colleagues. Because of their response, she felt driven to do more for individuals struggling with this invisible illness. She has joined the board of Lupus Canada to help others survive as she has.

Read about Mauricia in the *My Lupus Journey* section of the e-newsletter.

To learn more about Benoit and Mauricia visit www.lupuscanada.org/about-us/our-team/

LET'S TALK LUPUS

Lupus Canada is pleased to present the

Let's Talk Lupus

Disease Awareness Webinars

An informative and interactive series of webinars for all Canadians impacted by lupus. Each month we will offer a new topic. To learn more about our upcoming webinars please visit www.lupuscanada.org/webinars/

Sponsored By AstraZeneca GSK

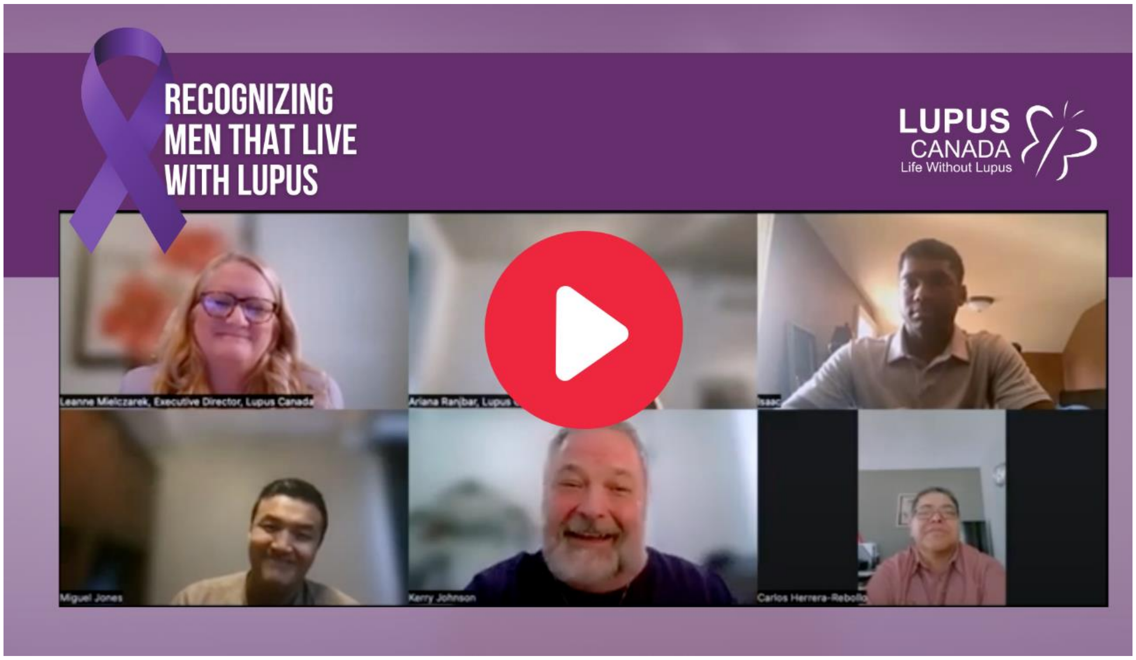
Fatigue Management Webinar

Lupus Canada is happy to be collaborating with Jennifer Tabrizi, a certified yoga teacher, personal trainer, and nutrition coach, in July to present a webinar discussing **Fatigue Management and Autoimmune Disease**.

Date: Thursday, July 20th • **Time:** 6:00 PM - 7:00 PM (EST) • **Location**: Online Webinar on Zoom

Lupus is a lifelong, incurable autoimmune disease that may require lifestyle changes and adjustments. For many people living with lupus, fatigue is one of the most common symptoms. To register click here.

LET'S TALK LUPUS
RECOGNIZING MEN THAT LIVE WITH LUPUS



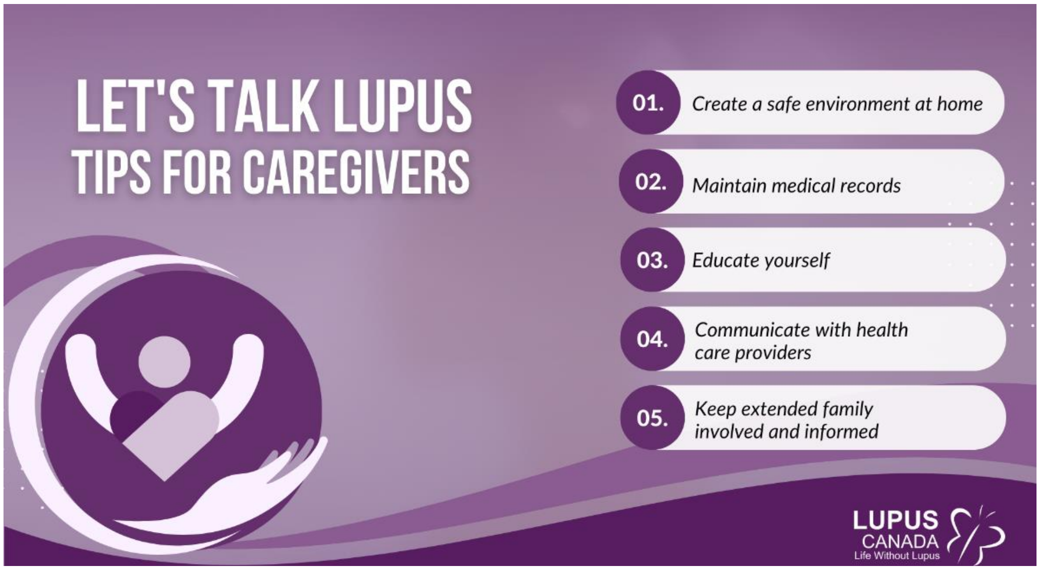
Recognizing Men Living with Lupus Podcast

Living with lupus can be isolating, especially as it is generally referred as an invisible disease. Lupus can affect anyONE at anyTIME in their lives and as such it is our hope to bring awareness and inclusivity to lupus.

Men living with lupus may be unsure as to how to communicate about lupus with colleagues, friends, and family. Many people do not know what lupus is and as it is an invisible disease, they may not understand why it may be difficult to carry out daily tasks.

During Men's Health Awareness Month in June Lupus Canada's Executive Director, Leanne Mielczarek and our Social Media Coordinator, Ariana Ranjbar had the opportunity to speak with Kerry Johnson, Isaac Hall, Miguel Jones, and Carlos Herrera about their lived experiences with lupus.

To view our Roundtable discussion please visit https://youtu.be/6p22EjV8eKA



01. Create a safe environment at home
02. Maintain medical records
03. Educate yourself
04. Communicate with health care providers
05. Keep extended family involved and informed

Welcome to Called to Care: A Guide for Family and Friends

This booklet is for individuals who provide care for a family member or friend. Even if the assistance you provide seems limited–perhaps mostly helping your mother purchase and organize her medications, or taking your friend to his medical appointments–you play a critical role in health care today. The care that doctors, nurses and other health professionals provide is essential, but so is the care that family and friends give at home.

We know that most people who are called to care–whether it is because of a loved one's injury, a short-term illness or a long-term medical condition–have had little preparation for many of the tasks they take on. And providing this care can be physically and emotionally demanding. It often means sacrificing some of your own interests and not paying enough attention to your own health. However, with the right resources and support, you can be an effective caregiver, and maintain your own physical and emotional health.

As you navigate the world of caregiving, this booklet will provide you with valuable information and resources to make your journey as easy as possible. More importantly, it will remind you that you are not alone. Just as you are there to care for your loved one, there are many individuals and organizations available to help you.

To access the booklet visit https://www.hopkinsmedicine.org/about/_downloads/called-to-care/C2C_called_to_care_booklet.pdf

Parenting With Lupus

When you have lupus, taking care of yourself can be hard enough. If you're a parent — dealing with rheumatology appointments on top of dirty diapers and school bake sales — it may quickly become overwhelming for everyone.

"A parent's lupus will have an impact on their kids," says Robert Katz, MD, a rheumatologist and associate professor of medicine at Rush Medical College in Chicago. "It's a disease that affects the whole family."

There are techniques that will help make parenting with lupus easier, he says. Many parents with lupus — and their children — learn ways to thrive despite the illness. Here are some tips for parents with lupus, followed by advice on how to talk to your children about your condition.

Tips for Parenting with Lupus

- **Make your own health a priority.** As a parent with lupus, you may feel guilty about prioritizing your own wellness — shouldn't your kids always come first? But it's not selfish. If you wear yourself out taking care of everyone else, you could wind up sick with a lupus flare. "You can't be superwoman all the time," Katz says. Remember the advice you get on the plane: in emergencies, put the oxygen mask on yourself first, then your kids. So get enough rest, reduce stress, and see your lupus doctor regularly. "If you focus on taking care of yourself first," Katz says, "you'll be better able to care for your kids."

- **Create new traditions with your children.** If you’re a parent with lupus, you might not be able to do all the things you used to do with the kids. Don't get discouraged. Instead, connect with your children through new family traditions. Make them low-stress, so you can participate even when you're feeling crummy. Try to set aside a night each week for a family movie or board game.

- **Let your family know how you're feeling.** As a parent with lupus, one day you might feel terrible and the next day you might feel pretty good. It can be hard for your family to keep up. Try using a number to express how you feel, with 1 being poor and 10 great. Then write the number on a white board in the kitchen when you get up, says Dawn Isherwood, RN, house educator at the Lupus Foundation of America. Your family will know how you're doing at a glance and can adjust their expectations.

- **Stop feeling guilty.** Parents with lupus often feel like they "should" be doing more. Some blame themselves for their lupus symptoms, feeling that if only they tried harder they would be more active, "better" parents.

When you start to feel this, ask yourself: would you think this way if you broke your leg? Or had cancer? Lupus is just as real and often just as debilitating. Going through life feeling guilty and self-critical won't help you. What's more, it won't help your kids either.

- **Be willing to say no.** There will be times when you'll be too sick to do things that your kids want or expect. It will be hard to disappoint them and they might be angry. Acknowledge their feelings and tell them why you had to say no. "If you can explain, even grumpy and cranky teens can be more understanding than you expect," says Katz.

Parenting with Lupus: How to Get Support
If you're a parent with lupus, you're going to need help from a lot of different people. Here are some pointers on how to get it.

- **Have scheduled help**. Don't get extra help on a casual, as-needed basis. Build support into the week. Maybe it means getting a nanny. Maybe it means asking your sister to take the kids grocery shopping once a week. Maybe it means hiring a 12-year-old girl from the neighborhood to be a mother's helper after school. However you do it, parents with lupus need to have regular, scheduled help, Katz says.
  "You must have time to yourself that you can depend on," says Katz, "time when you can take a nap or take a walk and know that your kids will be OK."
- **Plan for emergencies.** Most people with lupus do quite well with treatment. Even so, parents with lupus should all have a disaster plan in case they ever get seriously sick or hospitalized, Katz says. Make sure close friends and family know what they would need to do. Not only will a plan help things run more smoothly if you have a health setback, it will reduce your anxiety now.
- **Don't let your kids get overburdened.** If you have lupus, your kids will probably have to help out more around the house than they would otherwise. That's to be expected. Just be careful not to put too much on your children's shoulders. "You don't want your kids to grow up feeling like a semi-parent," says Katz.
- **Consider seeing a therapist.** Being able to express your concerns to a therapist — about everyday hassles as well as serious health anxieties — will help you feel better and more in control. A therapist can teach parents with lupus practical techniques to manage the day. Family therapy can be a good idea too. It will allow your whole family to express themselves freely in a safe, controlled environment.
- **Strengthen your relationship with your partner.** If you're raising kids with a spouse, the two of you need to have a solid relationship. Inevitably, your lupus will put extra stress on your partner. It’s important that you not let your relationship deteriorate so

that you're the "sick one" and your partner is the caretaker, Katz says. "Even if you're worn out, there are still ways you can support your spouse," he says. "Give him or her a chance to talk about their day or their stresses. Do little things to help your spouse feel better."

Parenting with Lupus: How to Talk to Your Kids
You might feel uncomfortable talking to your kids about lupus. Lupus is unpredictable, and you may not be sure of your health in the long-term. It's tempting to avoid the subject. But that won't work for long. Even young kids will sense that something is wrong. If you don't talk about it, your kids might not ask — but they might worry in private.

As a parent with lupus, the best you can do is reassure your kids, realistically, about your health. Here are some tips for the conversation.

- **Explain the basics.** The specifics depend on your kids' age and your health. Talk about how lupus affects you, says Lisa Fitzgerald, MD, a rheumatologist at the Lupus Center of Excellence at the Beth Israel Deaconess Medical Center in Boston. It might make you tired, achy, forgetful, and cranky. Stress that you're getting good treatment and most people with lupus do well. Make clear that lupus is not like cancer — it doesn't get worse and worse. Instead, it's unpredictable — you'll have good days and bad days.

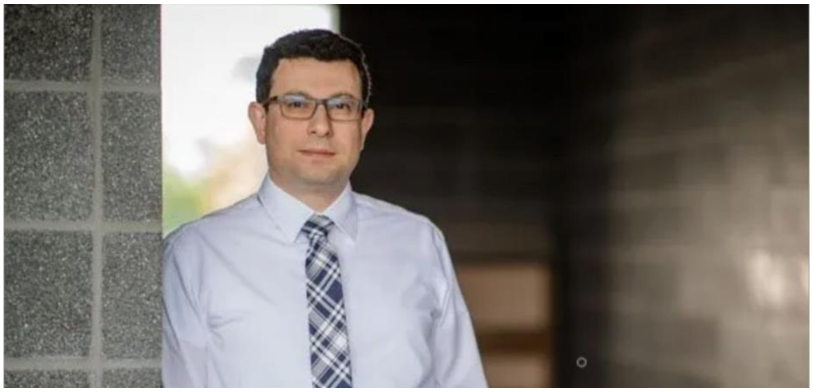
- **Let them ask questions.** Don't feel obligated to tell your kids everything about lupus, Katz says. Let your kids guide the conversation with their questions. If they ask about the scary stuff — like whether you might die — answer them in a reassuring way. But you're not obligated to talk about unlikely worst-case scenarios if they're not asking, Katz says.

- **Ask them what they know about lupus.** You really can't predict what your child might have picked up about lupus, Katz says. Your son might wonder why you seem so rundown compared to apparently healthy celebrities who say they have lupus. Or he might be terrified because he assumes lupus is a death sentence — all because a friend told him his grandmother died from it 20 years ago. Find out what they know and correct any misconceptions.

- **Make it an ongoing conversation.** When your discussion is winding down, make clear that it's not over. Tell your kids that they should come and ask you questions as they think of them. It might take some time for them to process the information and figure out what they want to know.

Source: https://www.webmd.com/lupus/features/parenting-with-lupus

RESEARCH



Doctor’s Orders: Lupus puts people at higher risk of organ damage, depression and cognitive impairment

Despite the challenges of treating lupus, Dr. Zahi Touma is hopeful for the futures of people living with the complex autoimmune condition.

"Healthing spoke with Dr. Zahi Touma, a rheumatologist and clinical epidemiologist with the University Health Network in Toronto, and a professor and scientist at the University of Toronto. His research is focused on patients with SLE and measurement science for assessing disease activity, patient-reported outcomes and cognitive function."

To read the full article visit www.healthing.ca/diseases-and-conditions/lupus/autoimmune-uhn

Survey Opportunity

A team of researchers from the University of Toronto are conducting research to help people with invisible disabilities, including lupus. In this survey, they are studying how people with invisible disabilities navigate the workforce.

If you are interested in taking part in this survey, they would greatly appreciate your participation. The only requirement to take part is that you have an invisible disability. To participate in the survey please click here.

The survey will take you approximately 5 minutes to complete. Please feel to reach out to the primary researcher, Chloe Kovacheff (chloe.kovacheff@rotman.utoronto.ca), with any questions.

RESOURCES

LUPUS 100

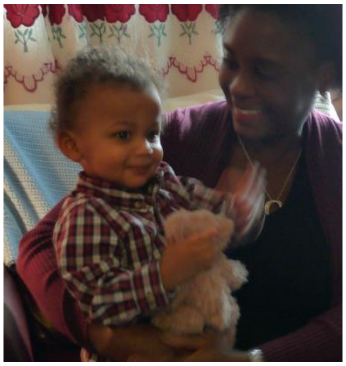
Answers to the most important questions about lupus, verified by world renowned lupus doctors.

https://lupus100.org/en/100-questions

MY LUPUS JOURNEY

with Mauricia Ambrose

Your struggles shouldn't define you; they should motivate you.



What would you do if your kidneys failed three years after adopting a child as a single parent? It was 2015. I had been waging an all-out war against lupus for 26 years up to that point. I was constantly fighting back against my body's determination to destroy itself. I knew lupus was attacking my kidneys. What I didn't know was, a simple turn of events would upend my almost perfect existence.

Systemic Lupus Erythematosus or SLE is an autoimmune disease that has no cure. My immune system attacks my internal organs because it can't tell the difference between my normal cells and foreign bodies. Lupus is also called the disease of a thousand faces because every person is affected differently, and we all represent the many faces of this disease.

In most cases, doctors treat the symptoms and never the root cause. It can take years to diagnose the actual disease and by then the organ being attacked may be irreversibly damaged. I was lucky that my diagnosis came in 1989 when my kidneys were still functioning.

I was in my last year at university when I was diagnosed and by then I had spent years going from one doctor to another, trying to understand what was happening to my body. I was in constant pain. I was photosensitive and always fatigued. By that last year my hair was falling out in clumps and I was struggling to keep my head above water. I could have said, "this is too hard" and simply quit, but I persevered.

No one knew what I was going through because I looked perfectly normal, maybe a bit chubby because of my medications, but otherwise healthy. Lupus is one of the many invisible illnesses that, unless you mention it, no one would know and sometimes they would even doubt its existence. I come from a large Caribbean family where you learned to be independent at an early age. Because of that, it was difficult for me to ask for help. So, even after university when I had flare-ups and, because of inflammation, I could barely lift my legs to get dressed, I kept going on my own.

At one point I made a crucial mistake. I stopped taking my medication. I was convinced that God would heal me. Like the story of the man in the storm, I continued to say" God will save me". I eventually lost the use of my limbs and was bed-ridden for 6 months. I could have given up but my nephrologist assured me that my paralysis was temporary so, I did everything I could to regain my strength.

I was slowly regaining the use of my legs when, one morning, while I was getting ready to take a shower, my legs collapsed beneath me. I fell to the floor with a loud thump and had to call out for help. I was living at home with my parents and my father came running into the bedroom. He picked me up and gently put me in bed, never saying a word, knowing how I must have felt. I was devasted and embarrassed as he lifted me up, half-naked and helpless. I realized at that moment, that it wasn't going to be as easy as I thought. Challenges have never deterred me, but living with lupus has been the challenge of a lifetime. I eventually regained the use of my arms and legs but this wasn't the final battle I had to fight.

When I moved to Canada in 2000, I hadn't had a flare-up for some time and I lived like any normal person. However, life as a lupus survivor is never simple. I had multiple episodes of flare-ups and unexplainable illnesses, much of which I attribute to stress. Working as a black professional in corporate North America, how I experienced stress was very different from what you might expect. It came in the form of micro-aggressions and racial bias. This along with a heavy workload made living with lupus almost impossible to bare. There were times when I simply wanted to give up but I had made the difficult decision to leave my home and make a life for myself here in Canada and there was no turning back.

I got married in 2006 and we were happy, however, I couldn't have children and we eventually got divorced. I always wanted to be a mother so in 2010 I decided to submit my application to the Children's Aid Society (CAS) to adopt as a single mom. Almost exactly two years later I was blessed with a fifteen-month-old baby boy. We were blissfully happy. Nothing could destroy the cocoon of unconditional love that we were creating in those first few months together.

Unfortunately, during that time, my lupus started flaring up again. All indicators were deteriorating rapidly. My doctors wanted me to have a kidney biopsy but I resisted. I was afraid of anything invasive that could potentially take me away from my son. I pushed away the thought that what I was going through had anything to do with him - not when his presence in my life brought me so much joy.

Then one morning my doctor called in a panic. I needed a dialysis catheter immediately. He had just gotten my most recent test results and was trying to convince me that I needed to get to the O.R. right away. But I continued to resist. I didn’t have a will. I was a single mom with no one to take care of my son. What if I died on the operating table or couldn’t take care of my son anymore? I couldn’t do this now. I had to talk to my rheumatologist because I believed I just needed to increase my dose of immunosuppressant medication, prednisone. My rheumatologist had the same diagnosis. I had to go on dialysis immediately, so an O.R. date was set.

This is where my story takes an unusual turn. One morning while taking my medication, I noticed that the label said 1mg rather than 5mg. It turned out that I was taking the wrong dose of my medication for months. My doctor immediately increased my dose of prednisone and things went back to normal, except for the fact that my kidneys were now permanently damaged and I had to go on dialysis.

Life can change in the blink of an eye. I have learned how to live one day at a time, accepting the good and the bad as they come. I have learned how to listen to my body and love it with all its complexities. I am on dialysis now but I haven’t let my illness define who I am. It may have taken control of my body but I am in control of my life. I travel with my son every year and we make beautiful memories together. I will continue to find balance, so I can give my son the life he deserves.

COMMUNITY ENGAGEMENT

Social Media Highlights

Thank you to our supporters who continue to spread lupus awareness. Here is a little recap of our favourite community posts in June. Keep tagging us in your posts for a chance to be featured in our Social Media Highlights.


courtneyschaosandcooking

Epic Life Challenge Day 6

Our morning started early on the soccer field, I brought my Superhero Breakfast Cookies, Cohen ate one too😋 anything mom has, he wants. Off we went to support Lupus & my beautiful aunt, the kids had cupcakes & got to play at a super cool park. Getting out & doing things as a family is what this challenge is all about. We're the cupcakes a good choice for the kids? Well, no but we skipped the drive thru to head home and make a healthy lunch.

@LUPUSCANADA
@EPICUREOFFICIAL


everydaylivinglupus

everydaylivinglupus What is a Malar Rash? Swipe To Learn More...


bigleaguemovers1

2nd Annual Luis Aguirre Memorial Golf Tournament

Powered by: Big League Movers

Saturday July 22nd
Puslinch Lake Golf Course
1:30 Shotgun Start
4-person scramble

$125 per player includes:
18 holes with cart
Post round dinner
Donation to Lupus Canada
On-course contests
Draw prizes

Proudly Supporting:

To Register your team, Sponsor or Donate contact:
jonathan@puslinchlakegolf.ca

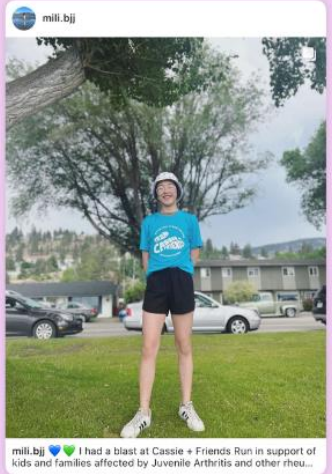
bigleaguemovers1 We are more than 50% full for the 2nd annual Luis Aguirre Memorial Golf Tournament!...


muacolleen._xo

muacolleen._xo If you been following me for a bit you may know that I suffer from an autoimmune disease called #lupus. This ill...


djprosper22

djprosper22 As a Lupus warrior with platforms opportunities to inspire others ,I decided to get out of my shell and inspire men...


mili.bjj

mili.bjj 💙💚 I had a blast at Cassie + Friends Run in support of kids and families affected by Juvenile Arthritis and other rheu...

RECIPES

Approved by registered dietitian Heather Penny

A Delicious And Healthy Meal

On The Menu:
Crispy Lemon Chicken

Ingredients

- 4 boneless, skinless chicken thighs (or 2 breasts) cut into bite-sized pieces
- 1 teaspoon sea salt
- ¼ cup tapioca or arrowroot starch
- ¼ cup coconut or avocado oil
- ¼ cup water
- 1 teaspoon arrowroot powder
- 1 teaspoon gelatin powder
- ½ teaspoon wasabi powder (*optional)
- 2 green onions, thinly sliced
- 1 lemon, zested and juiced
- 1 tablespoon honey

Instructions

1. Season the chicken pieces with salt, then toss with arrowroot powder.
2. Heat the oil in a medium skillet until it shimmers.
3. Fry the chicken on both sides taking care not to overcrowd the pan, if necessary cook in two batches. Set aside in a large bowl.
4. In a small bowl combine the arrowroot, gelatin and wasabi until there are no lumps. Add the water and let the gelatin bloom.
5. In a small skillet or saucepan heat the lemon juice and honey until the honey has completely dissolved.
6. Add the bloomed gelatin mixture to the lemon juice mixture and cook until thickened and syrupy.
7. Pour syrupy mixture over cooked chicken and toss to coat evenly.
8. Sprinkle zest and green onions over the top before serving.

Source: https://autoimmunewellness.com/crispy-lemon-chicken/

QUICK LINKS

Q&A's

All your lupus related questions answered by trusted professionals here.

Merchandise

Help support Lupus Canada by shopping our merchandise catalogue here.

Ambassadors

Take a look at our celebrity ambassadors here.

Visit Our Website

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Working together to conquer lupus

Lupus Canada

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