



In May we recognize and celebrate Lupus Awareness Month with a variety of significant events throughout the month.

May 10, 2020 - World Lupus Day which serves to call attention to the impact that lupus has on people around the world. This month holds great significance to so many impacted by lupus not only within our communities but across the globe.

This year on May 10th we also celebrate **Mother's Day**. While physical distancing impedes in-person celebrations, there are many other ways to express your love and appreciation to your mother. It can be as simple as having a cup of tea or enjoying her favorite meal together via Facetime. However you plan to spend time with your Mother this Mother's Day we hope it is extra special, and remember to take time for yourself!

May 15, 2020 - Put on Purple for Lupus (POP) On this day, we encourage all Canadians to join us in wearing purple and show your support for lupus awareness and lupus patients. Remember to share your photos on social media and be sure to tag @LupusCanada! To get your POP t-shirt please contact us at info@lupuscanada.org or order online www.lupuscanada.org/POP/

Word of the Month - Advocate

Lupus Canada is fiercely committed to advocating and 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.



DONATE NOW

your gift makes a difference

#GivingTuesdayNow is a new global day of giving and unity that will take place on **May 5, 2020** – in addition to the regularly scheduled Dec 1, 2020 #GivingTuesday – as an emergency response to the unprecedented need caused by COVID-19.

On **May 5th**, join us and support others on #GivingTuesdayNow.

***We're all in this together,
so let's do some good
together!***

To support Lupus Canada on #GivingTuesdayNow please visit www.lupuscanada.org/givingtuesday/



Together we give ❤️ Together we stand ❤️ Together we thank
Together we help ❤️ Together we heal ❤️ Together we ...

Lupus Canada is working tirelessly to advocate for all Canadians living with lupus during COVID-19.

For up to date information on COVID-19 visit www.lupuscanada.org/COVID19/



A MONTH OF ADVOCACY AND RECOGNITION:

Raising awareness of lupus is essential to help people afflicted by lupus and to improve early diagnosis. Lupus Awareness Month allows us to put a spotlight on the many faces of lupus and ensure that people are aware and receive the support and resources they need. On average, it takes nearly 6 years for people with lupus to be diagnosed from the time they first notice their lupus symptoms. In spite of how many people it impacts, lupus is not well-known in Canada. This means that lupus gets less attention and less funding, which restricts the development and treatment that could be life-changing for people with lupus.

World Lupus Day was created in 2004 to raise awareness of this little-known disease that can have devastating effects on sufferers and their families. On May 10th, we take to our communities and to social media to let people know what lupus is, how it affects us and what we can do about it. Together we can make lupus an international health priority and to ensure that people with lupus around the world are diagnosed and treated effectively.

You can also go to the World Lupus Day's official website and sign an awareness pledge (<https://worldlupusday.org/sign-the-awareness-pledge/>) where you pledge to help the plight of those affected by lupus get more attention from the medical community and politicians.

For more information on World Lupus Day please visit www.worldlupusday.org



World Lupus Day

All over the world, lupus patients and supporters will be celebrating World Lupus Day. Get in touch with your local lupus organization to learn how you can advocate for greater recognition of lupus!

May 10

GET READY TO CELEBRATE: PUT ON PURPLE

LUPUS CANADA Life Without Lupus **MAY 15TH**

ENCOURAGE YOUR FRIENDS, FAMILY & COLLEAGUES TO PUT ON PURPLE #POP TO SHOW THEIR SUPPORT FOR #LUPUS

Show your support in finding a cure and help those living with lupus by wearing purple on May 15th!

Share your photos or videos on Twitter, Instagram or Facebook and tag @LupusCanada. Don't forget to send us your photos, email them to info@lupuscanada.org

HOW TO BE A LUPUS ADVOCATE:

Source: <https://www.lupuscanada.org/resources-advokit/>

Advocacy is not a science. It requires persistence and patience.

Advocacy is persuading a person with influence, the public, businesses, organizations, or governments to change attitudes, policies and/or practices about a certain issue. There are several types of advocacy:

- Individual Advocacy
- Third-party Advocacy: when a person or organization, not directly involved in the issue, represents a person or group in advocating for change
- Systemic Advocacy: aimed at changing legislation, policies, regulations or attitudes in order to benefit a group

WHY ADVOCATE?

Even in a perfect world, where systems work, and needs are met, there will always be people whose voices remain unheard and their need unrecognized. Advocacy is based on principles that each of us have the right to be heard and control how we are treated. Often, getting what we need is simply a matter of knowing where to go for advice or an answer, or finding what is available. There are situations when getting what we need requires that we convince someone or defend our rights and challenge a system that is rigid and archaic. In these situations, changes are needed. The way to make these changes is advocacy. This may mean, raising awareness or educating the public.

There are many different ways to advocate. Some people are good on the telephone, while others deal better with difficult situations face to face. Some people are more comfortable writing letters. Among an advocate's best tools are information and having a plan. Through planning, you are more likely to succeed in putting your point across.

EDUCATE YOURSELF

Your best tool as a person with lupus is to educate yourself about your disease and be able to educate the people around you. Go to www.lupuscanada.ca to learn more about lupus, lupus research and about Lupus Canada. Often, your first and best resources will be your doctor. You may want to ask your doctor for a special appointment to discuss your condition in further detail.

When advocating, the more you know, the more intelligently you can advocate. This is your best tool for dealing with government, private organizations, services or agencies.

ADVOCACY PLAN

It is not always easy to deal with government, private organizations, services or agencies. To help with your own advocacy, it is good to come up with an advocacy plan. Below are steps to help with your own advocacy plan. Remember: keep details of everything you do and every conversation you have. These notes will come in handy.

Define the problem, simply and specifically

Often, the problems or challenges that individuals are advocating to change are complex and multifaceted. By clarifying the problem, you make your argument easier and more time can be used to discuss solutions rather than explaining the problem.

List possible solutions

It is easiest to advocate for yourself when you are armed with potential solutions. Collaborating and working together with governments and organizations can produce solutions, but this takes time. Often those advocating need changes made quickly. Coming to the table with possible solutions indicates that you are ready to work now.

Collect information for each option

Remember, the more you know, the better you can advocate. By having all the information ready at your arsenal, you can challenge institutions that may not want to help. Often, government may not see your problem as their problem. By having information at hand, it is easier to persuade people to your cause.

Consider the options and decide

After listing all your solutions and gathering the relevant information, you may find that one of your solutions is not feasible. This is okay. By having several possible solutions, you can pick the best ones that will help you achieve your goal.

Consider further action

At this point, you may find some obstacles to your problem. Maybe you need some help from Lupus Canada? Maybe you need to partner with another organization? Remember, there is always help for your advocacy needs.

This is the time to find out who to take your problem too. Governments are becoming much more accountable and transparent. If you don't know where to go, checking out a government website. Often, they will have a directory where you can find a chain of command within the government. Unfortunately for private corporations and services you may have to call a generic number and be bounced around before you find the appropriate authority for your problem.

Other questions you should answer include:

- What should I say to ensure that I my problem is simple and specific and capture all the relevant information?
- What is my best argument?
- Should you request a meeting with the relevant authority?
- Should you write a letter to an organization?
- Should I involve a political figure to move this forward?
- Can Lupus Canada help?
- Take Action!

For more information on Advocacy visit www.lupuscanada.org

BEING A MOM WITH LUPUS:

Source: <https://www.momtastic.com/health/554455-feels-like-mom-lupus/>

If you are diagnosed with lupus in your mid-twenties you can learn tactics to hide what you are going through, whether that be canceling plans or leaving get togethers early. It also means tons of guilt and feeling like I could not always be relied upon, even though I wanted to be. As a working adult, wife and mother I have had to learn to give myself some grace, while still being accountable for those who need me.

Some mornings I wake up and I can complete all the tasks from getting out of bed, tend to my daughter, take my baby for a walk, make dinner, clean the kitchen and spend time with my husband. But then there are other days. There are mornings when I wake up and my breathing is tight, my joints hurt, my feet are swollen, and I feel embarrassed. As a mom I want to do everything for my child, and I do not want to have to lean on my husband. I try to keep a brave face for my girl but its hard, there are moments when I need to tuck away and cry, yes, I can take care of my child, but the energy and pain associated with everything surrounding it is

scary.

The reality of being scared to take my 8-month-old on a walk is probably the scariest part of all. I have had to find my grown-up hacks to get through it. Fashion is important to me, but I keep back ups like flats and gloves. Also, I communicate clearly to those closest to me- they understand everything about my disease. I try to do the most I can independently on the good days so that on bad days when I ask my husband to do something he knows why and just does it.

Being a mom with a chronic illness means sometimes I have to miss out on things. Now that I have my daughter, living with lupus is better and easier, even as it is harder. Now I have a beautiful, spirited, young lady who looks up to me. She needs her mama to be strong.

I carve out the time that I need to do the things I have to do. I have learned how to take care of myself. As moms, we want to put everyone else first all the time. Having a chronic illness has taught me that one way I can put them first is to make sure I am okay too.



Source: <https://worldlupusday.org/lupus-facts-and-statistics/>

"Did you know there are four different forms of lupus?"

Systemic lupus accounts for approximately 70 percent of all cases of lupus. In approximately half of these cases, a major organ or tissue in the body, such as the heart, lungs, kidneys, or brain will be affected.

Cutaneous lupus (affecting only the skin) accounts for approximately 10 percent of all lupus cases.

Drug-induced lupus accounts for about 10 percent of all lupus cases and is caused by high doses of certain medications. The symptoms of drug induced lupus are similar to systemic lupus; however, symptoms usually subside when the medications are discontinued.

Neonatal lupus is a rare condition in which the mother's antibodies affect the fetus. At birth, the baby may have a skin rash, liver problems, or low blood cell counts, but these symptoms typically disappear completely after six months with no lasting effects.



Salmon Burgers

Serve these burgers over a bed of greens or tucked into a crisp lettuce wrap. Top with freshly squeezed lemon juice and a dollop of Avocado Garlic Sauce.

Ingredients:

For the Salmon Burgers:

- 12 oz. wild-caught salmon, baked and chopped
- 1/2 lemon, juiced (~2 Tbsp.) + 1/2 tsp. lemon zest
- 1 small shallot, minced (*may substitute 2 cloves garlic, minced*)
- 2 green onions, sliced
- 1 Tbsp. fresh dill, chopped (*may substitute 1 tsp. dried dill*)
- 2 tsp. Dijon mustard
- 1/4 tsp. salt
- 1/4 tsp. pepper
- 2 egg
- 1/4 cup almond flour
- 1 tbspc coconut oil or ghee/clarified butter



For the Avocado Garlic Sauce:

- 1 medium avocado, halved and pit removed
- 1/4 cup extra virgin olive oil
- 1/2 lemon, juiced
- 1 tsp. Dijon mustard
- 1 Tbsp. fresh dill (*may substitute 1 tsp. dried dill*)
- 2 garlic cloves, minced
- 1/4 tsp. salt
- 1/8 tsp. pepper

How to Make It:

For the Burgers:

Step 1: Combine all of the salmon burger ingredients, except the coconut oil, in a large bowl and mix well. If mixture is pretty wet, add additional almond flour 1 Tbsp. at a time.

Step 2: Form into 6-8 patties. Patties easily fall apart until they are cooked. Handle with caution.

Step 3: Heat coconut oil on a griddle or pan to medium-high heat.

Step 4: Once hot (oil must be hot), carefully add burgers to pan and cook for 5-6 minutes on each side or until cooked through. Patties should sizzle when added to pan.

Step 5: To serve, top with 1-2 Tbsp. avocado garlic sauce and tuck into a lettuce wrap if you

wish.

For the Avocado Garlic Sauce:

In a food processor or blender, combine all of the ingredients and process until smooth.

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


Source: <https://therealfoodrds.com/salmon-burgers/>


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