

Let's Talk Lupus

Monthly E-Newsletter

After a month of awareness and giving thanks, November is a time for many Canadians to take some time to breathe before the end of the year. This month also marked with a sense of reflection as we observe Remembrance Day on November 11th. With many Canadians donning their red poppies, we remember those who have sacrificed so much for our freedom – we thank you and we honour you. Also early this month on November 4th, don't forget to set your clock back one hour as Daylight Savings Time ends. This means an extra hour of sleep for us all!

This month's newsletter provides some information of how to apply for disability. For many individuals, their lupus prevents them from being able to work and carry out some daily activities. Lupus Canada wants to be sure that you are equipped with all of the information that you need to seek out these means.

Support Lupus Canada with Giving Tuesday

This November, Lupus Canada will be celebrating **Giving Tuesday**. On November 27th, after the Black Friday and Cyber Monday madness, we will be taking part in this global recognition of giving and supporting our favourite causes. As the national organization dedicated to lupus in Canada, we would like to take this opportunity to thank you for the continued support and emphasize how important donations are to maintaining our work. Giving Tuesday provides us with the chance to unite with other organizations, charities and people in empowering each other to make a positive change.

GivingTuesday



November 27th 2018

If you would like to participate in Giving Tuesday, please consider donating to Lupus Canada by visiting our website [here](#). If you would like to learn more about this global day of recognition, click [here](#). We thank you in

advance for your contribution. Let's work together towards Life Without Lupus!

DONATE NOW

your gift makes a difference

Lupus Canada Launches Next Competition for Catalyst Grants



This month Lupus Canada is launching the next round of our highly successful Catalyst Grant Program. Grants of up to \$35,000 will be awarded to Canadian lupus scientists to initiate high calibre research projects that will impact the lives of persons living with lupus and their families. Our hope is that these grant recipients will have greater success in obtaining larger multiyear grants from national funding bodies. Grants will be awarded in the Spring of 2019 after adjudication by a committee comprised of both lupus experts and informed patients.

To apply or find out more about the Catalyst Grant Program, visit our website www.lupuscanada.org/resources/catalyst-research-program/

Lupus Canada visits Germany



At the end of August Lupus Canada's Board member Kerry Johnson participated in a patient advisory committee meeting in Mainz, Germany. As part of the meeting, participants from France, Spain, Portugal, Greece, European Union, United Kingdom, United States, and Canada shared their personal experiences with SLE and lupus nephritis. In addition, attendees shared what each of their organizations have been doing in support of lupus

awareness, advocacy, and patient support. Participants were also given the opportunity to provide input on what would attract lupus patients to participate in clinical trials and the barriers to participating in clinical trials.

For Lupus Canada, we were happy to have the opportunity to share our activities and experience as well as learn from our colleagues on how they promote lupus awareness, advocacy, and patient support.

Lupus Fundraiser - DaSilva Racing/OMC

On Sunday October 14 DaSilva Racing and the OMC held a cruise to Niagara Falls with proceeds going to Lupus Canada and Princess Margaret Hospital.

Together they raised a total of \$2510.00! The donations were split, with each charity receiving \$1255.00.

Lupus Canada is honoured to have such a special group raise funds and awareness for those living with lupus!



My Lupus Story

My name is Glynis Sharpe and this is my lupus story.

It's easy for me to know where to start because my diagnosis was very clear. I had 10 of the 11 criteria used to screen for SLE.

It's 1991, my family is posted in Niamey, Niger. Probably Africa's hottest Saharien country with an average daytime temperature reaching 40 degrees in the spring. I got very sick, very suddenly. Over two weeks I had lost an excessive amount of weight, my joints were too stiff for me to put on my own socks or brush my teeth. I had a rash that ran across my cheeks and nose that was puss infected and peeling. And all I wanted to do was sleep. My mother drove me to the French Embassy as they had an on-call physician. That doctor, back in 1991, told us it was lupus! After blood work, he confirmed his diagnosis.



My parents decided to fly me back to Ottawa where I was admitted to CHEO and my lupus diagnosis was confirmed.

I was eleven.

Oddly enough, I feel like being diagnosed at a younger age has allowed me to better understand my lupus. Everyone's lupus is unique to them and this is key in understanding how your illness can progress in any direction, like growing branches of a tree.

Fast forward to 2018, it would be an understatement to say that I've had a hard time with everything lupus has thrown my way.

My high school years were defined by high doses of steroids and hospital visits. On the side, I was learning to recognize flares. I missed three months of senior year but still made it to prom.

University however was my rebel period. A period of pushing myself to be just like everyone else. Going out late and studying all night with pots of coffee. It did backfire and after a total of 17 months of cyclophosphamide (8 in 1998 and 9 in 2003), a total right hip replacement from AVN, loosing my hair and it never growing back and some much needed therapy, I made a promise to myself. If I was going to make it, I had to be in tune with what my body was telling me. By that time, I knew that stress in my environment was a major contributing factor to my flares and my migraines so I changed my career goals (air traffic controller to office job).

Long term use of Prednisone has a big price tag. I've never been off Prednisone, not in 27 years. I could definitely go one and one but anyone taking Prednisone gets me

on this.

My husband and I were blessed in 2009 with the arrival of our son Caleb. I had an emergency c- section at 26 weeks because of pre-eclampsia. Our little miracle is a healthy nine year old today!

In my personal lupus journey, kidney failure and dialysis was my trickiest hurdle. The greatest of all gifts is the gift of a kidney. My best friend literally gave a piece of herself to me. A healthy kidney that has changed my life. The donors are the hero's in our stories.

It's been seven months already and I am back at work and enjoying all that a healthy kidney has to offer.

As I gaze into the future, my mantra " let's do this" gives me hope.

In 1991, when I was diagnosed, only 3 pamphlets explaining lupus were available to take home. They all stated that life expectancy with SLE was 10 years.

There are foreseeable hurdles down the road, Lupus is a part of my story but it does not define me. I am more than lupus and my amazing healthcare team is a part of my journey. Working as a team is my best advice. Your doctors have to know YOU in order to know YOUR 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

Applying for Disability for Your Lupus

Source: <https://www.resolutelegal.ca/blog/winning-disability-benefits-for-lupus>

Are you not able to get back to work because of lupus? Is chronic lupus preventing you from living a normal and comfortable lifestyle?

If you have been considering applying for disability benefits for lupus, you are well aware of the obstacles that you will face along the way.

There are specific requirements that insurance companies have for qualifying for these benefits. In addition, you must demonstrate that the severity of your lupus is seriously preventing you from working. The whole application process for qualifying is quite tedious and can be difficult.

Figuring out how to navigate through the various roadblocks and obstacles to get approved only makes life tougher for you. The goal of this article is to offer a

summary of the cumbersome process of applying for disability benefits for lupus in Canada. If you follow the guidelines we outline, you will be well on your way to being granted the benefits you need.

Knowing Your Lupus Symptoms And Their Severity

Before embarking on the quest for winning disability benefits for lupus, you must know if your symptoms and their severity meet the requirements for qualification. The most important symptoms are pain and fatigue. To qualify for benefits, you must have disabling pain that is preventing you from working.

Likewise, chronic fatigue also presents a strong case for qualifying for benefits. Ultimately, you have to ask yourself if the problems you are facing are disabling you from performing your duties at work. Once you come to this conclusion, you should look at the options for disability benefits available to Canadian residents. Identifying the best option for you will give you a clearer path to winning your benefits.

Which Disability Benefits For Lupus Do I Qualify For?

When it comes to claiming long-term disability benefits, you might be eligible for one of two types of disability benefits if you are a worker. These are the Canada Pension Plan (CPP) disability benefits and the long-term disability insurance benefits.

- [The Canada Pension Plan Disability Benefits For Lupus](#)
The CPP, designed to support you after retirement, also covers disability benefits that start once you become disabled and last until you are 65. After that, these disability benefits are converted into regular pensions. In order to be eligible for the CPP disability benefits, you have to have worked for four out of the past six years and paid payroll taxes. The CPP requires you to prove that your disability is both prolonged and severe, leaving you unable to work.
- [Long-term disability benefits for lupus](#)
Group disability insurance policies are the most common type of disability insurances in Canada. If your employer has insured you as part of a group, you are receiving your disability insurance through your job. These group disability insurance policies provide both long-term and short-term disability benefits. If you are suffering from a chronic form of lupus, you can apply for the long-term disability benefits if eligible. If successful, these will provide you with monthly income payments during long absences from work to take the financial pressure off you.

Steps You Need To Take To Get Disability Benefits For Lupus

[1. Obtaining a specific diagnosis from a qualified physician](#)

The most important part of putting yourself in a position to win disability benefits for lupus is getting a specific diagnosis for it. If you cannot get a doctor to give you a legitimate diagnosis, you will have no case to provide to insurance companies.

The disease is often difficult to diagnose because there isn't a standalone test that can determine whether you have it or not. To have the best chance of getting

properly diagnosed, you should see a Rheumatologist.

These doctors specialize in autoimmune disorders like lupus. They use a list of eleven criteria for lupus to assist them in making the diagnosis. In general, if you have four or more of the criteria, you can be diagnosed with systemic lupus. The different criteria go as follows:

- Butterfly (malar) rash on the nose and cheeks.
- Raised red patches on the skin called discoid rashes.
- Skin rashes that come from sunlight.
- Ulcers in the mouth or nose.
- Nonerosive arthritis in multiple different joints.
- Inflammation of the lining around the lungs or heart called cardiopulmonary involvement.
- A neurotic disorder, such as seizures.
- Renal disorder, which is excessive protein in urine.
- Low white blood cell or platelet count, known as Hematologic disorder.
- Immunologic disorder which affects antibodies.
- Antinuclear antibodies.

The criteria are quite specific, but each can be tested for, unlike lupus. After going through the many tests required for each of these symptoms, you can find out if you do have lupus. This will allow you to move forward in the process of winning disability benefits.

2. Show That You Have Gone Through Every Treatment Option Available

In order to receive disability benefits for lupus, you must have documented prove that you have done all the possible treatments to alleviate your lupus symptoms. Lupus is a tough illness to treat because the symptoms vary from person to person. Usually, a health professional will create a plan specific to your needs. The general categories of treatment for lupus are prescription drugs, living a healthy lifestyle, and having regular appointments with your doctor to make sure all of your symptoms are being treated correctly.

Prescription drugs have been developed that treat the most symptoms of lupus. There are anti-inflammatory drugs that are used to stop swelling and treat different forms of pain associated with lupus. Antimalarial drugs are another type of drug used to treat a variety of lupus problems.

Since there are no lupus-specific drugs available, you have to rely on your doctor's ability to identify where your problems are stemming from. Often, lupus patients may not see their symptoms completely subside with drug use. If this is the case, you strengthen your chances of receiving benefits.

While living a healthy lifestyle seems like a weak treatment plan, it is still important if you want to win disability benefits for lupus. If you have a history of substance abuse or obesity problems, you can be rejected benefits. You must show you are keeping

your body in the best condition possible to handle the disease.

You must make an effort to keep track of your healthy habits to give to insurance companies. You should maintain a healthy diet with documents on what kinds of food you eat throughout a normal week or have regular meetings with a dietitian. You should also keep a journal of your sleep patterns to show you are keeping a consistent and regular sleep schedule.

Try to keep documentation on everything so you can convince insurance companies you are living a healthy lifestyle. Being able to prove you are a healthy individual is crucial to winning your case.

Lastly, you have to make sure you can show you have been seeing your doctor consistently. This proves that you are serious about fixing your problem. If you have been working with your doctor to attempt every possible treatment option to alleviate your problems with lupus, you will be in a good position to receive disability benefits for lupus. Doctors will also be able to more accurately tell you if you have gone through every possible option you could have to treat your symptoms, which will help with deciding if you should apply for benefits. Doctors are a reliable and trustworthy source for insurance companies. Having plenty of documentation from your doctor gives insurance companies convincing information that can really help your case.

3. Keep Track Of Limitation In Your Daily Life Associated With Lupus

While actively trying to find treatments and being diagnosed are important steps in this process, it is crucial that you are able to prove your daily life is being heavily affected by the disease. The best indication of an inability to do work related tasks is any difficulties doing activities at home.

You must document the physical limitation you are having at home in great detail. You must also be able to discuss why these difficulties at home directly translate to problems in the workplace. In particular, an inability to maintain concentration, pace, or persistence in activities will help build a stronger case. Be consistent with your documentation and use a ton of detail in the description of how lupus is affecting your activity to give insurance companies the information they need to grant you disability benefits for lupus.

Recipe: Butternut Squash Carbonara with Broccoli

Ingredients

- 1 (3 pound) butternut squash, peeled
- 2 cups small broccoli florets
- 2 tablespoons extra-virgin olive oil
- ½ teaspoon ground pepper, divided
- ¼ teaspoon salt
- 2 large eggs, at room temperature
- ¾ cup grated low-fat Parmesan cheese, divided
- 4 strips bacon
- 2 large cloves garlic, grated
- ¼ cup low-sodium chicken broth



Directions

- Position oven racks in upper and lower thirds of oven; preheat to 400°F.
- Cut the neck of the squash from the bulb. Using the large noodle blade of a spiral vegetable slicer (or a julienne or regular vegetable peeler), spiralize (or cut) the squash neck into long strands. You should have about 10 cups of "noodles." (Reserve the bulb for another use.)
- Combine the spiralized squash, broccoli, oil, ¼ teaspoon pepper and salt in a large bowl. Divide the mixture between 2 large rimmed baking sheets. Roast until just tender, 12 to 14 minutes.
- Meanwhile, whisk eggs and ½ cup cheese in a medium bowl.
- Cook bacon in a large nonstick skillet over medium heat until crisp, 7 to 9 minutes. Transfer to a paper towel-lined plate. Remove the pan from the heat; add garlic and stir until fragrant, about 30 seconds. Stir in broth and the remaining ¼ teaspoon pepper. Transfer 3 tablespoons of the broth to the egg mixture, whisking constantly until smooth. Add the egg mixture to the pan; cook over low heat, stirring, until thick and creamy, about 45 seconds. Add the roasted vegetables and gently toss to coat. Transfer to a serving bowl.
- Serve topped with crumbled bacon and the remaining ¼ cup cheese


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


Source: <http://www.eatingwell.com/recipe/261170/butternut-squash-carbonara-with-broccoli/>

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Working together to conquer lupus