



Let's Talk Lupus

February Monthly E-Newsletter

LUPUS
CANADA
Life Without Lupus

Time is one of the most precious things in our lives and with Valentine's Day and Family Day being this month, it is a perfect opportunity to take the time and send love or express affection to those who are important to you. Perhaps the only thing of greater importance is to remember to also love yourself this month. Take time to recognize your strengths, accomplishments and positive attributes!

Additionally, February 17th is Family Day so ensure to spend the day sharing thoughts and feelings and developing strong relationships with those you love. For ideas on how to celebrate Family Day we have included an article from guest writer Florence Tewogbade. Florence also shares her journey with lupus in this month's edition of our e-newsletter.

With both Family Day and Valentine's Day this month we are focusing on the significance of family, friendship and love, and the benefit of 'communication'.

We hope you enjoy this month's e-newsletter!

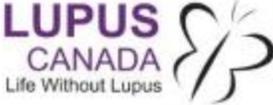
DONATE NOW

your gift makes a difference



Lupus News

LUPUS
CANADA
Life Without Lupus



LAUGHS FOR LUPUS
MAY 7 • 2020
AVENUE BANQUET HALL
CONCORD, ON
\$80 PER PERSON



IN SUPPORT OF THE THOUSANDS OF CANADIANS LIVING WITH LUPUS

Help us move the dial forward and make a difference in the lives of Canadians living with lupus!

Laughs for Lupus is an evening to showcase Lupus Canada's commitment to broaden lupus awareness and increase our funding capabilities. Championed by our dedicated Celebrity Ambassadors, Patrick McKenna and Debra McGrath along with Canadian talent, Two for the Show, Dave Hemstad and Linda Kash we invite you to join us for an evening of laughter.

Tickets this year are \$80 per person. Each ticket includes entry to the show, one drink voucher and an array of delicious hors d'oeuvres.

For more information please visit www.lupuscanada.org/laughsforlupus/ or

Contact us at 1-800-661-1468

You won't want to miss this spectacular event!



LUPUS CANADA SCHOLARSHIP PROGRAM

Lupus Canada is proud to support students living with lupus through our Scholarship program. Since 2013 we have provided Scholarships to over 26 students living with lupus.

For more information on our 2020 Scholarship program please visit our website at www.lupuscanada.org/lupus-canada-scholarship-program/



Lupus Canada Partners with the Lupus Foundation of America to Advance Lupus Research

On February 3rd, 2020 the Lupus Foundation of America (LFA) announced their partnership with Lupus Canada to fund innovative lupus research through the Lupus Canada Catalyst Award. The award supports research projects that have the potential to significantly advance the field or impact the lives of people with lupus.

"In order to accelerate lupus research to improve drug development, find better treatments and ultimately discover a cure, we must work together. Collaborating with Lupus Canada allows us to join forces to increase the impact of lupus research in North America and work towards our common goal of improving the lives of people with lupus and ending this disease," said Stevan W. Gibson, president and CEO, Lupus Foundation of America.

The Lupus Foundation of America's research program has contributed to every lupus research breakthrough of the past 40 years. The LFA is dedicated to uniting lupus experts and groups throughout the world to identify the cause, control the symptoms of and ultimately discover a cure for lupus.

"Lupus Canada is fiercely committed to improving the lives of Canadians living with lupus by funding the best and brightest lupus researchers in Canada. By partnering with the Lupus Foundation of America we will be able to further our mandate and bring greater attention on a global perspective to this debilitating disease," said Tanya Carlton, volunteer President, Lupus Canada.

The Lupus Canada Catalyst Award is available to a Canadian researcher at any stage of their lupus research career and provides support for high caliber start up projects for one year. Applications for the Lupus Canada Catalyst Award are now open until April 17, 2020.

In addition to this award, the Lupus Foundation of America has also opened its request for applications for its Gary S. Gilkeson Career Development Award and the Gina M. Finzi Memorial Student Fellowship Program Grant. Applications will be accepted until April 17, 2020. To learn more about these three peer reviewed grant programs, visit

<https://www.lupus.org/research/apply-for-funding> .

THE BENEFIT OF COMMUNICATION:

Source: <https://www.lupusuk.org.uk/lupus-and-relationships/>

Communication enables people to transfer information, to understand others, and to be understood. People communicate through different outlets, whether it is verbally, behaviourally, or visually. It is important to take the time and explore your emotions and which outlet you communicate with most and which you have difficulty understanding. Being aware that people communicate differently is essential as it avoids frustration and leads to more positive interactions.

Understand that communicating entails confronting both positive and negative feelings. Being transparent, although may be difficult, is always best. Sharing with others your thoughts and feelings will allow you to have long and trusting relationships. Some people feel as though avoiding communicating negative emotions is better, however, it can be more damaging to relationships than just expressing yourself. Remember there is a difference between communicating your thoughts and having a confrontation or being rude. Trust that the person you are communicating with, will understand your perspective and validate your feelings.

More specifically, people who live with lupus may find it hard to communicate with others. Try to be clear and direct about your needs and wants because, unfortunately, most people do not know or understand. Get those who are close to you involved, maybe ask them to go to appointments with you so they can try to understand more about what you are going through.

LIVING WITH LUPUS AND BEING IN A RELATIONSHIP:

Source: <https://www.lupusuk.org.uk/lupus-and-relationships/>

Often, people living with lupus become frustrated with those around them as it is

difficult to communicate what they are going through or they do not feel understood. It is important, if you have lupus that you try to understand that not a lot of people are aware of what lupus is. Although this is aggravating, try to accept that it is not their fault.

Lupus can have a significant impact on a relationship and many people with lupus have very happy, successful and fulfilling relationships. It would be entirely wrong to believe that because a person has lupus, they can never experience a happy and fulfilling relationship or that the relationship that they were in before they were diagnosed is doomed to failure.

Being diagnosed with lupus can put a great deal of pressure on a relationship. It surprises many people to know that it is often the person with the disability that brings about the end of a relationship after they become disabled – they often feel that their partner 'should do better' or that they are now 'holding them back'. This kind of situation is by no means inevitable, but it does demonstrate the need for good communication through the transition period so that each person understands the motives for the other's actions and understands their expectations and hopes for the future.

Lupus will almost certainly bring change to a relationship – simple physical changes to what you do and how long it takes to do things if nothing else – and you will need time to adjust to those changes and to understand them fully.

Due to lupus often being invisible, it may be difficult for your partner to understand what you are experiencing. It is possible that they may doubt your illness, believing it is all in your head. This can be extremely painful and frustrating, causing anger and resentment. You may not be able to care for your home or family the way you or they are used to, and that can lead to feelings of depression, and even guilt.

Chronic illness can often shift the balance of a relationship. The more responsibilities one of you needs to take on, the greater the imbalance. If you have been diagnosed with lupus and you're receiving care, you can feel more like a patient than a partner. A shift like this can threaten self-esteem and create a huge sense of loss. If your partner is providing care for you they may start to feel overwhelmed and resentful so it is important that their needs and wellbeing are also looked after.

FIVE WAYS TO EXPRESS AFFECTION:

Source: <https://www.focusonthefamily.com/marriage/communication-and-conflict/learn-to-speak-your-spouses-love-language/understanding-the-five-love-languages>

When someone in a relationship, whether it is a family member, friend or partner has lupus it is important to remember the different ways that you can communicate your affection and love to them. Whether it is you that is living with lupus or you care for

someone who does, take the time to communicate with them as they may be feeling depressed, insecure in their relationship or distant. You do not have to express your love in all these different ways; however, it is important to be mindful of how you show or communicate your affection and how the other person likes to receive love. Below are five different manners someone can show their love and affection:

Words of Affirmation

Many people don't understand the power of verbally affirming each other. Verbal compliments or words of appreciation are powerful communicators of love.

Acts of Service

Acts of service refers to doing things you know your loved one would like you to do. You seek to please them by serving them, to express your love for her by doing things for her. Consider actions such as cooking, cleaning, and picking up medication. They require thought, planning, time and effort.

Quality Time

Quality time does not mean simply watching television together but looking at each other and talking. It is time when devices are put away and you are giving each other your undivided attention.

Receiving Gifts

For some, receiving gifts, visible symbols of love, speaks the loudest. A gift is a symbol of thought. It is the thought expressed in securing the gift and giving it as the expression of love.

Physical Touch

Physical touch is also a powerful vehicle for communicating love. Holding hands, kissing, embracing are all ways of communicating love. Some people do not need to touch, and others feel secure in love with it.

COMMUNICATING - WHAT IS LUPUS?:

Source: <https://www.lupus.org/resources/coping-with-lupus-guide>

It's important for family and friends to understand lupus so they know how they can help. But since lupus has so many different symptoms that come and go — which may range from manageable to life-threatening — it can be hard to describe.

You may want to start by explaining what lupus is not:

- Lupus is not contagious — you can't "catch" it from someone or "give" it to someone.
- Lupus is not like or related to cancer.
- Lupus is not like or related to HIV or AIDS.

Then, you can talk about what lupus is:

- Lupus is an autoimmune disease — the immune system attacks your own healthy tissues because it mistakenly sees them as foreign invaders.
- Lupus is a chronic disease — people who develop lupus will have lupus for the rest of their lives.
- Lupus has many different symptoms and affects each person differently.

Explain that lupus is unpredictable. Symptoms can appear, disappear, and change. Knowing this may help other people understand your ups and downs, and also the changes that you may have to make in your life.



Source: <https://www.bcm.edu/news/skin-and-hair/facts-you-should-know-about-lupus>

"Did you know that it is believed that lupus is influenced by genetics and environmental factors, such as being triggered by stress, sun exposure, and medications?"

"It's a combination of both genetic and environmental factors, but we haven't really identified all of the aspects," Dr. Kalpana Bhairavarasu said. "Two people, even twins, could have the exact same antibodies and still have different clinical presentations and response to treatments. There is a genetic component but there is still a lot of work going on for gene studies to see what dictates the different clinical response."

FAMILY DAY:

Family Day Fun by Florence Tewogbade

Family Day is a time that allows loved ones to drop everything and spend some quality time together. This holiday gives us all the opportunity to celebrate the real

meaning of family while taking part in any number of various family-oriented activities.

While this day is often filled with outdoor activities like skating, skiing and sightseeing, those with lupus may feel left out and have a difficult time participating. Overly strenuous activities coupled with the cold winter air are a poor combination for those who have lupus. The good news is that there are plenty of activities that can be done as a family that everyone can enjoy, including those with lupus.

The Museum/Art Gallery

Going to the museum or the art gallery are excellent Family Day activities. With the benefit of being both fun and educational, visiting either of these two establishments on Family Day allows you to expand your knowledge and your mind in a diverse setting. Both the museum and the art gallery may offer the option of taking either a guided tour or engaging in some self-exploratory activities. For someone with lupus, keeping up with a guided tour may prove to be stressful and tiring. In contrast, exploring on your own and at your own pace will allow you to take your time and rest as needed without the pressure of keeping up with a group.

Go to the Movies/See a Live Show

Taking in a movie on Family Day is a fantastic activity that everyone can enjoy. Not only do you get to watch the latest and greatest movie with your loved ones, but you also get to sit back and relax without the worry of physical fatigue. Many theatres offer family-specific movie times that are focused on creating a comfortable environment for families with young children. These types of screenings are beneficial for both families with young children and people with lupus, as they provide a comfortable environment where you can easily step outside of the theatre if need be without the worry of disturbing another moviegoer. Establishments like Costco offer discounted family vouchers that include movie tickets as well as snack vouchers. If you know that your family will be spending Family Day at the movies ahead of time, consider taking advantage of such discounts so that you can keep a few extra bucks in your pocket.

Similar to going to the movies, seeing a live show or a musical is an activity that everyone can appreciate. Depending on the ages of your family members, there are several suitable shows to choose from. Tickets for live shows often sell out quickly, so planning ahead is crucial. Many live shows also offer intermissions. These breaks are fantastic as they allow you to stretch your legs, go to the washroom, and perhaps pick up a treat at the snack bar.

Cards/Board Games

Sometimes we can find plenty of fun right in our own homes. Cards and board games are always crowd-pleasers. They're interactive, fun, and in many cases, they can be educational too. Some great board games include Scrabble, Chutes and Ladders, Monopoly, The Game of Life, and many more. Kid-friendly card games include Crazy

Eights, Go Fish, War, and Old Maid. Card games are great as they enable you to play a variety of games with the same deck of cards.

For those with lupus, staying home and playing cards/board games has some excellent benefits. Not only do you get to spend time with your loved ones while having fun, but you also have the advantage of being in the comfort of your own space. Taking breaks and resting is much easier when you're able to do it at home.

If you don't have any board games or a deck of cards, you still have options. Heads Up, a family-friendly interactive game that can be downloaded right to your cell phone, is sure to give your family hours of laughter-induced tears.

Family Day shouldn't be stressful; this day is a time to enjoy the company of your loved ones while having some fun. With a little bit of planning, Family Day can be a fun and memorable occasion that the entire family can safely and comfortably participate in.



About the Author - Florence Tewogbade

Florence Tewogbade is a blogger and HR Professional in Toronto, Ontario. Her lupus journey began when she was a 14-year-old high school student. After falling ill, Florence went to The Hospital for Sick Children, where she was diagnosed with Lupus Nephritis.

After this diagnosis, Florence was placed on hemodialysis and prescribed several medications aimed at controlling her lupus. The aggressive treatment that she received was successful, as her kidneys regained their function, and she was able to stop dialysis.

Unfortunately, the treatment that she received came at a cost. The side-effects from the medications she took required medical intervention. This intervention included cataract removal surgery on both eyes, a hip replacement and a knee replacement. To help her cope, Florence started a blog, <https://www.flowonlupus.com>, to chronicle the struggles of dealing with this illness.

Several years passed, and Florence's kidneys failed for the final time. She resumed



dialysis, eventually turning to nocturnal home hemodialysis. Home hemodialysis enabled Florence to go to work and school during the day and do hemodialysis at night.

A few months after graduating from college, Florence received a living donor kidney transplant from her brother. She has been living well with her new kidney for eight years.

Today, Florence lives with her fiancé and works full-time as an Employee Policies and Programs Consultant in Toronto. Working from home a few times a week helps Florence maintain a healthy work/life balance while still managing her illness.

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



Red Beans and Cauliflower Rice

Ingredients:

- 2 teaspoons olive oil, or oil of choice
- 1/3 cup chopped white onion
- 1/2 cup chopped celery
- 1/2 cup chopped green pepper
- 1 large head of cauliflower (about 3 cups)
- 3 cans (15 ounce) cans red beans, drained and rinsed
- 1/2 teaspoon salt, or more if desired
- 2 teaspoons ground cumin
- 1 teaspoon paprika
- 1 teaspoon granulated garlic
- 1 teaspoon chili powder
- 1 teaspoon Italian seasoning
- 1/4 teaspoons black pepper
- Optional garnishes: cilantro, jalapeno, avocado, tomato



How to Make It:

Step 1: Heat a large pan over medium heat and add olive oil and onion. Cook for 2 minutes and then add celery and green pepper.

Step 2: Cook until vegetables are softened, 3-5 minutes.

Step 3: While vegetables are cooking, roughly chop cauliflower and throw it all into the food processor. Process until rice like, 30 seconds-1 minute.

Step 4: Add the cauliflower rice, beans and seasonings to the pan, stir until combined, and cook until cauliflower is tender, 7-10 minutes.

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

Source: <https://www.shelikesfood.com/30-minute-red-beans-and-cauliflower-rice/>

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

