



Let's Talk Lupus

March Monthly E-Newsletter

LUPUS
CANADA
Life Without Lupus

Happy Spring! This season represents positive change as the flowers begin to bloom and the days get warmer and longer. As you close your eyes you can smell the beautiful scents that arise from gardens and hear the bees buzzing. As the clocks go forward and this beautiful season begins, let us remind ourselves to wish our friends and family a season of happiness and strength.

Already we are approaching March Break and we here at Lupus Canada hope you have an enjoyable and well-deserved break. Remember to take time to relax, refuel and refresh. People can find themselves exhausted by the end of winter, so we would like to shed some light on an occasion occurring this month, 'International Day of Happiness'. This global celebration on March 20th focuses on the pursuit of happiness and the desire to spread joy as far and wide as possible. Let's try to be happy together, find commonalities, and sympathize with one another. That said, the word of the month is 'positivity'.

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Lupus News

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Meet the Lupus Canada Board of Directors

Please meet the very dedicated Board of Directors who give of their time to help make a difference in the lives of the thousands of Canadians living with lupus.



Tanya L. Carlton, President

Tanya joined the Board of Lupus Canada in order to bring both her personal interests and professional skills to the Board. Tanya was diagnosed with Discoid Lupus in 2009 and SLE in 2010, and after a few years of trying to get her lupus under control, is finally in a position to give back to the community that helped her in her times of need. Tanya is a mother of two teenage boys and a lawyer who practices in the areas of not-for-profit and charity law. Prior to being a lawyer, Tanya taught high school math and chemistry for several years, and then took a hiatus and started a family. Throughout this time, while maintaining her status as an Ontario Certified Teacher, she worked in the dental field and served as a Municipal Councillor.

She has also served as a board member and chair of several other smaller not-for-profit organizations throughout the years and is excited about the opportunities ahead for Lupus Canada.



Shane Dungey, Vice President

Shane spent 19 years in capital markets with extensive experience in institutional asset management, institutional sales and trading, equity financings, private placements and institutional equity research. Currently VP of Investor Relations for The Green Organic Dutchman (TGOD), the global leader in cultivating premium, certified organic cannabis. Prior to working with TGOD Shane was a Managing Director, Institutional Trading with AltaCorp Capital Inc. working in Calgary Alberta. Previous to joining AltaCorp, Shane was Vice President, Institutional Trading at Macquarie

Securities, and prior thereto, Tristone Capital Inc. since 2008. Before moving to Calgary, Shane was Head Trader and Portfolio Manager of Passive funds at AEGON Capital Management in Toronto. His volunteer commitments include Play4Kids, a non-profit organization founded by the Dungey Family that aims to improve the lives of children through PLAY . Shane holds a Hons BA in Political Science from York University. Subsequent to joining industry, he played professional hockey throughout Europe and the minors in North America.



Malcolm Gilroy, Treasurer

Malcolm is a seasoned financial services executive with extensive African experience. He has recently returned from Nigeria where he lived for eight years. Initially he was sent to Nigeria as a Technical Advisor to the World Bank Group, mandated to review the financial landscape of the country and to advise the Nigerian Government on ways to rejuvenate their dormant bond market. He continued to work in Nigeria as an investment banker and consultant. Prior to going to Nigeria Malcolm had a successful career as a bank treasurer and investment counsel in Canada. He is currently a Principal of Pax Terra Inc. a Washington based development and private equity consultant and is also an associate of Logan Wealth Management, a Canadian based Investment Counsel. In addition to Lupus Canada, Malcolm sits on the Boards of The

Jane Goodall Institute of Canada and CSCDL Funds (Nigeria) and is a former Chair (President) of the ALS Society of Canada.



Thomas Simpson

Thomas has several years of experience in government relations, advocacy and stakeholder engagement for a national non-profit and the federal government. Currently, Thomas is the Head of Public Affairs for the Canadian National Institute for the Blind (CNIB). He leads CNIB's national government relations and advocacy efforts. He works to break barriers and promote accessibility, inclusion and equity for the lives of Canadians with sight loss.

In the past, Thomas has worked for Health Canada and the Canadian Nuclear Safety Commission where his work focused on policy research and analysis, regulatory program support and stakeholder management. Thomas graduated from the University of Ottawa with

an Honours Bachelor of Social Science Specializing in Political Science with a Minor in History. He is currently working towards a Graduate Certificate in Public Relations through the University of Victoria.



Kerry Johnson

Kerry is a senior lecturer at the University of Ontario Institute of Technology (UOIT) in the Faculty of Health Sciences. His experience in the health care field includes over 30 years of experience as a Health Information Management (HIM) professional, mostly in hospitals. His education includes a masters and doctorate in the field of education, with a focus on adult education, distance learning, and educational technologies. Diagnosed with lupus at a young age, Kerry has lived with lupus for 45 years. The unusual circumstance of a white male with lupus has given Kerry an appreciation for men with lupus and some of the challenges living with a life-long chronic illness. With his experience in the health care field, Kerry also has

developed a strong perspective regarding the patient's and care providers' points of view in managing chronic illness.



Lauren Isherwood

Lauren is a Chartered Professional in Human Resources (CPHR) currently working for a large consulting engineering firm. Lauren's past volunteer work includes local community associations, a publishing society, and the Lupus Society of Alberta. Lauren was diagnosed with Lupus in 1995 and is passionate about making a positive contribution to the lives of others living with lupus.



Nicholas Baingo

Nicholas has more than 15 years of non-profit management and volunteer experience, and currently works in the tech sector. His non-profit experience includes a two-year term on the Board of Directors of the Lupus Society of Alberta, and a two-year term as the Executive Director of the CKXU Radio Broadcasting Society. Past volunteer experience includes work with seniors, youth groups, and local community associations, as well as coordinating (with Lauren Isherwood) two annual Step Out for Lupus fundraising and awareness events in Lethbridge, Alberta. His past work experience includes business development and web services roles with Amazon, IBM, Xerox, and leading his own technology startup.



Dr. Holly Jones Taggart

Holly is an associate professor in the Faculty of Health Sciences at Ontario Tech University and the director of the Medical Laboratory Sciences program. Her teaching expertise is in the area of human genetics and she has collaborated on teaching innovation projects to develop novel approaches to learning in the classroom. Her research focus is laboratory based and her students currently investigate the molecular mechanisms of cell behaviour in health and disease. Holly joined the board of directors at Lupus Canada to help advance research and education that affects the lives of persons living with lupus and their families.



Vikas Tiwari

Vikas is an experienced Wealth Management professional. In the early stages of Vikas' career he held several roles across two of Canada's largest banks. During this time he developed a focus on wealth advisory, with a specialization in investments. Presently, Vikas manages an independent wealth advisory practice with clients based throughout North America. He established his educational foundations with a Bachelor's degree in Economics and advanced them through earning the Chartered Investment Manager (CIM) designation. Vikas has come to understand lupus through his experience as a primary care giver and advocate. His foremost goal is to help the organization better the lives of

those affected by lupus.

LAUGHS FOR LUPUS
MAY 7 - 2020 THE AVENUE BANQUET HALL
 1600 STEELES AVE W • CONCORD • ON

LUPUS CANADA
 Life Without Lupus

PATRICK MCKENNA
DAVE HEMSTAD
DEBRA MCGRATH
LINDA KASH
TWO FOR THE SHOW

TICKET PRICE \$80.00

VISIT LUPUSCANADA.ORG
 FOR MORE INFORMATION

LAUGHS FOR LUPUS

Join us on **May 7, 2020** at **Laughs for Lupus!** Championed by our dedicated Celebrity Ambassadors, Patrick McKenna and Debra McGrath along with Canadian talent, Two for the Show, Dave Hemstad and Linda Kash. It's an evening to showcase our commitment to broaden lupus awareness.

Get your tickets today before they sell out at www.lupuscanada.org or contact our office at 1 800 661 1468.

Put on Purple T-Shirts Now On Sale!

Get your POP t-shirt in time for Put on Purple day on May 15th! To order yours please visit www.lupuscanada.org or call 1 800 661 1468.



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/

Marching towards Awareness-Spring is the time to "Talk Lupus"

With the warmer weather slowly making an appearance, consider hosting an event for Lupus Canada!

It could be as easy as a garage sale, bake sale, a dress down day at work, or a car wash! We are very supportive when members of our community want to help educate or create awareness around lupus!

If you need ideas on what type of event to organize or how to register your event with Lupus Canada contact Susan Smart, National Fundraising Manager at susan.smart@lupuscanada.org or 1-800-661-1468

THE BENEFITS OF POSITIVE THINKING:

Source: <https://www.adventhealth.com/blog/how-positive-thinking-affects-your-health>

In some circumstances, being positive can seem impossible and challenging. Nonetheless, positive thinking and optimism has benefits. Positive people tend to be healthier, more relaxed and have a greater well-being. Whether it is one thing that has affected your mentality or a sequence of events that have taken a toll on you, make a conscious effort to reject those negative thoughts or it will become a habit.

While it is okay to not always be in a good mood, it is important that being negative does not become a permanent state of mind. Whenever you have a harmful or discouraging thought stop and think if there is another perspective or way you can think about it. Through time you will begin to recognize a pattern and form healthier thoughts. A good exercise one can do to negate destructive thoughts is the 'sandwich method', think of something positive, negative and end with something uplifting. This will allow you to acknowledge and communicate your emotions but also make you think of positive factors as well.

Actively working on positive thinking will make it more natural over time and will make you look at challenges with a fresh perspective. According to research, here are some of the many health benefits that stem from positive thinking:

- Increased life span.
- Lower rates of depression.
- Lower levels of distress.
- Greater resistance to the common cold.
- Better psychological and physical well-being.
- Better cardiovascular health and reduced risk of death from cardiovascular disease.
- Better coping skills during hardships and times of stress.

MANAGING LUPUS STRESS AND BEING POSITIVE:

Source: https://www.hss.edu/conditions_managing-lupus-stress-more-effectively.asp

People with lupus often have recurring negative thoughts, such as: "People will reject/abandon me", "I won't be able to take care of myself" or "I can't do ____". These negative thoughts can affect behaviour and cause negative feedback loops. For example, fear of being dependant may prevent you from accepting needed and offered assistance from people who love you. This causes you to have feelings of isolation that your behaviour- not the disease- caused.

Negative thoughts often exist for a reason. Sometimes we have been thinking that way for so long that we forget the reason why they arose. We should allow negative thoughts to have a positive role in our lives such as helping us deal with fear of change or failure. Having negative thoughts is like being in a comfort zone because it may protect you from risk, such as the risk of failure or rejection.

Developing Awareness of Negative Thoughts:

The first step in dealing with negative thoughts is to develop our awareness of them. Then we must think about whether we are willing to risk changing one or more of them in order to open ourselves up to a fuller and more satisfying life. It is our thoughts and belief systems that often cause us to be upset- that is, not just the event that occurs but how we think about that event that troubles us. Here is how that might happen:

- *The initial stressor may be that someone invites you to a party.*
- *Your negative thoughts say that you will get too tired from partying and go into a flare, or that you will meet someone who does not return your interest.*
- *The bad consequence is that you do not go to a party or social gathering, stay home alone, and feel lonely.*

Instead of enduring that upset mindset, you can look at the possibility of challenging your own thoughts and changing the sequence of events. We need to learn to react for reality, rather than the fears in our minds. Your willingness to look at how your thoughts may be shaped by your interpretation of reality can be a big challenge- but a worthwhile one- a path to finding what is meaningful and emotionally rewarding for you in life.

Changing Automatic Negative Thoughts:

Recurring negative thoughts that you have everyday can become automatic thoughts. They come to our minds immediately without our awareness. In order to help better manage our stress we need to become more aware of such thoughts and learn to challenge them with a healthy dose of reality and be able to change them. We cannot change all our negative thoughts at once, but we can work on one or two of them at a time.

Choose one or two that you feel have the best chance of success for changing your life with lupus in some positive way. For example, you might think: "The weather's getting warm early; my lupus will probably flare all summer, and I will never get out of the house." Consider the reality and how to dispute this negative thought. Consider these more rational responses, "Since my lupus sometimes flares in the summer heat and sun, I am going to try to pace

myself by doing cool indoor things like going to the movies and to avoid being out for long in the hottest time of the day."

POSITIVE AFFIRMATIONS AND LUPUS:

Source: <https://lupuscorner.com/positive-affirmations-and-lupus/>

Positive affirmations and positive thinking are two powerful strategies that can help lupus warriors improve self-esteem, manage stress, and get motivated to take on challenges. Staying positive and motivated when dealing with lupus is a challenge, and overtime it is easy to find yourself in a funk.

Research has shown that positivity is a powerful force that can help with many aspects of life including motivation, activity levels, eating habits, and mental health. And, as a stress management tool, positivity can decrease the risk of lupus flares. An exercise to prevent yourself from being the best version of yourself is through positive affirmations.

A verbal exercise where you repeat positive phrases to yourself, out loud at least once a day. This encourages positive thoughts to grow and take charge. The affirmations you use are up to you. When selecting your personal positive affirmations, you can choose ones that:

- *Highlight your best traits.*
- *Encourage you to approach new experiences with an open mind.*
- *Psyche you up for the day.*
- *Control negative feelings, including anger and frustration (by rewriting negative self-talk in a positive light).*

Positive Affirmations and You:

When deciding on your affirmations, think about what you want to do and who you want to be. Wording does matter here: when making your own affirmations, try to use words with good associations wherever possible. You should also use words like "I choose," "I allow," or "I am willing" because this lets you "choose" that outcome, giving you agency. These kinds of phrases help to prime your brain to thinking the way you want to think and doing what you need to do. And, science says, it does much more than that. Here are three positive affirmations that may be helpful for lupus warriors:

- *I am making progress in my health, and I will keep making progress.*
- *I am strong, and I will do great things today.*
- *I am a master at managing my energy, and I will pace myself well today.*



Source: <https://www.sciencemag.org/news/2019/03/genetically-engineered-immune-cells-wipe-out-lupus-mice>

Genetically engineered immune cells wipe out lupus in mice

Lupus can be a stubborn disease to treat. Although many struck by the autoimmune condition live relatively normal lives, some suffer from kidney failure, blood clots, and other complications that can be deadly. Now, scientists have found that a novel treatment that wipes out the immune system's B cells cures mice of the condition. Though the work is preliminary, it has excited researchers because it uses a therapy already approved for people with blood cancer.



Lupus took away my childhood.

Now I'm helping bring an end to lupus

Lupus is serious and relentless... and so are we. Let's fight it together.

Hello I am Gemma. Back in 2012, when I was 12 years old, I became one of the youngest person to be diagnosed with lupus. Approximately 7 months before diagnosis I started to have pain in my joints and extreme tiredness which wouldn't go away regardless of how much I rested. During this time a rash began to develop on my nose, and I started suffering from hair loss. At the same time, I started to get constant mouth ulcers, having up to 8 at any one time as well as having deep lesions on my hands and arms which were reluctant to heal. When the weather turned cold my hands and feet frequently turned anything from white through to blue then purple because of poor blood circulation due to a condition known as Raynaud's. This continued and in the space of one month I had gone from a healthy weight to 18kg and the rash had spread across my cheeks. I needed to find out what was causing all of this and get a diagnosis.



When I was diagnosed the doctors were concerned that I might not survive due to the severity of my condition. I have had to have numerous blood tests, in the early stages one on every alternate day, with each test requiring several tubes of blood. The specific one for lupus needed 12 of these in one session, I had several intravenous steroid drips alongside the blood tests. To help manage my symptoms I have had to take anything up to 36 tablets a day with some of these being taken to manage the side effects of others.

After a period of 2 years the doctors managed to balance my medication and side effects to a point where I was reasonably stable. Although it is managed well, I still continue to experience fatigue and painful joints and take medication for this. The blood tests show that my lupus is

inactive and the doctors have diagnosed Arthrosis, which means that although I am in pain, there is no physical damage to my joints.

Until very recently, due to the pain, I have been unable to have hugs and when I was at school, I had to leave classes early to prevent me from being knocked (or even touched) by anyone.

I would love the opportunity to raise awareness of lupus, placing an emphasis on children and adolescents who have the condition. Due to the rarity, I have struggled to find individuals who have been diagnosed of a similar age to myself - I personally know 4 adults and a dog.

I would encourage everyone who suffers with Lupus (regardless of age) to go by my moto "I **have** lupus, lupus **does not** have me"

For this reason, I will be doing a skydive in Canada and the UK to show to others with the condition that there is light at the end of the tunnel, to spread awareness and raise money towards research into new treatments and hopefully a cure.

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



Purple Power Smoothie Bowl

Ingredients:

- 1 cup beets, peeled and diced
- 1 cup frozen blueberries
- 1 cup frozen raspberries plus more for topping
- 1/2 cup blackberries
- 1 cup carton coconut milk
- 1/2 medium banana fresh or frozen
- 1/2 medium avocado, skin and pit removed
- 1 Tablespoon
- pure maple syrup
- 2 ounces protein powder of choice, vanilla or chocolate optional

Toppings:

- Rolled oats or granola
- Coconut milk
- Unsweetened shredded coconut



- Additional blueberries, raspberries, or blackberries

How to Make It:

Step 1: In a blender, combine all the ingredients and blend until smooth.

Step 2: For an extra thick smoothie bowl and for additional protein, you can add a scoop of protein powder to this smoothie bowl if you like. Add the protein powder and blend again.

Step 3: Pour into 2 bowls and top with your choice of toppings. Serve immediately.

Step 4: Enjoy!

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

Source: <https://thefitcookie.com/purple-power-smoothie-bowls/>

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