

# 2016 E-Newsletter September

**Subject: *Back to School/Back to reality***

**INTRO:** This month starts to bring many things such as colorful leaves and stressful times. Now that summer has passed school is right around the corner and with school comes responsibility and stress. The most important thing anyone can do this month is to learn how to manage stress levels. We have included in this edition of our e-newsletter two articles that we hope you will find helpful when dealing with the stress that September can bring. ***Managing Lupus Stress More Effectively by Changing Thoughts and Actions*** explains how people living with lupus can manage their stress more effectively, ***College With Lupus - Being a Student with Lupus*** is written from a student's perspective who has lupus and how she managed her school stress throughout the years of college.

## ***Let's Talk Lupus***

The September edition of Let's Talk Lupus will be available on Monday September 14. Dr. Matsos will discuss how to minimize the risk of flares. We hope you find the video informative.

## ***October is Lupus Awareness Month!***

You asked and we listened! Lupus Canada will have some exciting news to share with everyone in October.

Join the Canada wide effort this October to help raise the much needed awareness and funds for lupus through campaigns like #GivingMonday [www.lupuscanada.org/givingmonday](http://www.lupuscanada.org/givingmonday)





## *My Lupus Story by Nancy Le*

**M**y name is Nancy and I am 33 years old. Like many with lupus it was not an easy diagnosis. My initial symptoms included joint pain and fatigue which my doctors accredited to my lifestyle of competitive dancing. Then I had hair loss, extreme mouth sores and a red scaly skin rash on my hands, feet and face and finally after months of bloodwork and seeing countless specialists I was finally diagnosed with lupus at 15 years old. Like a flip of a switch, my life had changed completely. I wasn't allowed to dance anymore, I was prescribed a concoction of medication, herbal supplements and cortisone creams, I lost so much hair that I had to wear a wig and I was taken out of school due to my extreme fatigue. Further testing showed the lupus affecting the function of my kidneys and I was sent for my first kidney biopsy. It took well over a year to get the disease into a managed state with the right amount of prednisone and plaquenil at which point I was allowed to go back to school and had to adjust to my new life.

The next few years my body learned to respond to the medication and the disease remained managed. In early 2005 shortly after getting engaged, I had a serious flare-up in my kidneys which was also accompanied by joint pain and the red scaly rash on my face, arms and chest. The kidney biopsy results were so severe that the only solution to avoid permanent damage to my kidneys and possible kidney failure was cyclophosphamide aka chemotherapy. At 21 years old, it was extremely frightening and I can remember many nights crying myself to sleep because I was so scared. I was naïve and only knew chemotherapy to be used with cancer, did this mean I was dying? After given some time to digest what the situation was and understanding how the treatment would help me, I was put through 12 rounds of cyclophosphamide. And just in time for my wedding in the summer of 2006, my kidneys were doing better, the skin rash had

subsided but left some scarring and I no longer had any joint pain. Considering where I was a year prior, I felt and looked the best I possible could.

I was prescribed cellcept post treatment and was responding well, the disease was once again being managed. Family planning was important to my husband and I, so my doctors came up with a plan to slowly switch me from cellcept to imuran so we could proceed with starting a family in June 2008. Unfortunately, my body did not respond well and it went into a flare and proceeded to get worse over several months despite efforts to put me back on cellcept and higher doses of prednisone. I remember the skin rash being so red and raw all over my face, arms, chest and back that I had to wear bandages because some areas would often start to bleed if not covered. Finding ways to cover the rash was challenging and even a simple shower stung so badly at times. My eyesight also was affected and I was taken off plaquenil, unfortunately the side effects were permanent and I now have difficulties with my vision. Family planning was put on an indefinite halt until the lupus could be put back into a managed state which at this point because I wasn't responding to any other medication, more rounds of cyclophosphamide was prescribed.

I was referred to the fertility clinic to discuss freezing my eggs because my doctor knew family planning was extremely important to me and the amount of cyclophosphamide (which adversely affects my egg supply) I would need was undetermined. It took 5 years of kidney biopsies, several rounds of cyclophosphamide and trying different medications for my disease to get back into a state of "remission". At one point, some of my doctors suggested that we should look into alternative ways to have a family which devastated me, for as long as I can remember I wanted to bear and have my own children, I had no idea lupus could possible take this away from me.

When I was finally well enough to discuss family planning again, my nephrologist wanted to try a new medication called rituximab that was considered "safer" in pregnancy. We didn't want to go down the same path again with imuran and have another 5-year setback so we approached the transition plan very cautiously. My body responded well to rituximab and I was given the go ahead to start our family. I was given all the precautions of lupus in pregnancy and we reviewed all the risks and dangers that could arise to me and my baby during pregnancy. We decided since my disease was in remission and I had the best possible care with my team of doctors we would go ahead and try. In December 2013, we welcomed the most perfect baby girl and she has brought more happiness to us than we could ever imagine. My lupus has been in remission since pregnancy and has been that way for two years now. I really couldn't have asked for more since my dream of becoming a mother had come true and I was in remission.

I recently took my wellness for granted and have been dealing with a nagging cough for over 9 months that would not go away despite trying several different medications. It was really starting to affect my quality of life and becoming really exhausting. It was not until my 3<sup>rd</sup> chest x-ray where areas of concern in my lungs were presented which further resulted in me going for an emergency CT scan and a bronchoscopy. The results of the bronchoscopy showed no firm explanation for my cough other than it being a cold virus which was extremely frustrating since a cold virus can't really be treated though it is better than having lupus in my lungs which was what was initially thought. The doctor explained that the medication I was on to keep my lupus managed had made me so immuno-suppressed I had no B-cells or antibodies to fight anything. Basically someone with a cold could simply breath on me and if I were to catch the germs, my body is not equipped with anything to fight it off. I was prescribed some antibiotics to clear out any bacteria in my lungs and help it from spreading any further but

my body would have to try to recover on its own while waiting for my B-cells to regenerate.

This episode had me really think and remind me of what it is like to live with an auto-immune disease. Explaining to others what it truly being auto-immune is also important, it's not as easy as taking more or different medicine or getting more sleep or eating more vegetables. One is never 100%, my best possible self is probably about 80%. The physical, mental and emotional stress of coping with an auto-immune disease is challenging everyday, there are good days and there are bad days. I need to remember to take care of myself, my body is at constant battle with itself whether I feel it or not. A positive attitude and surrounding myself with loved ones gets me through, I don't want to let lupus define who I am, it is merely just a part of me.

## ***Managing Lupus Stress More Effectively by Changing Thoughts and Actions***

"This illness will never go away;"  
"Flares will cause complications or even kill me;"  
"People will reject/abandon me;"  
"I won't be able to take care of myself;"and  
"I can't" (fill in the blank, e.g. I can't do my job anymore or go on a trip or lift the laundry, etc.).

These negative thoughts can affect behavior and cause negative feedback loops. For example, fear of being dependent may prevent you from accepting needed and offered assistance from people who love you. This causes you to have feelings of isolation that your behavior - not the disease - caused. Or fear of not being able to climb a hill leads you to not going on a trip that you would really enjoy - even if you have to sit out the part where others climb a hill. Or fear of being rejected leads you to put up a wall so that you don't give relationships a chance.

Negative thoughts often exist for a reason, although sometimes we have been thinking that way for so long that we forget the reason why they arose. And negative thoughts are very hard to give up. So they must serve some positive role, such as helping us deal with fear of change or failure. But when you are consumed with negative thoughts and have a vision of a sad past, negative present and unhelpful future - when you feel stuck - it's a form of depression. You don't know what it's like to step out of that rut. Yet it's 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 can 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's our thoughts and belief systems that often cause us upset - that is, not just the event that occurs but how we think about that event that troubles us. Here's how that might happen:

- a. The initial stressor may be that
- b. someone invites you to a party.
- c. 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.
- d. The bad consequence is that you don't go to the party, stay home alone, and feel lonely.

Clearly, the bad consequence arises not from the party invitation but your negative fears about it. Instead of enduring that upset, you can look at the possibility of challenging your own thoughts and changing the sequence of events. You can tell yourself that you will enjoy being among interesting people and that you will take it easy - not dance every dance - so that you don't get over-tired. Then you might go to the party and enjoy yourself. You might even meet someone who returns your interest!

Consider another sequence:

- c. You're having a bad flare and are too fatigued to go shopping.

- a. Your negative thoughts tell you that friends will reject your request for help - so you don't ask for it.
- b. The consequence is that you don't get the nutrition you need or you spend money you can't afford getting groceries from a more expensive store that delivers.

Again, the bad consequence arises not from the flare and fatigue, but your negative thoughts about how friends might react to it. Instead, you could tell yourself that "helping each other is part of what friends are for," and then ask for their help. Then, they would likely be glad to shop for you - and feel good about themselves for being helpful. They would be glad that you feel close enough to them to ask for help and, along the way, learn to understand what lupus is about - which will help your relationship and lead them to have more realistic expectations from you in the future.

Some of our negative thoughts relate to fear of losing control. Control is a very appealing illusion that we maintain, but it is an illusion. Life after being diagnosed with lupus is different. You are still the same person, but now you know there are some things you cannot control. So you need to look at your life through a different lens. And all the big events in our lives are similar - we remain the same people but we are changed in some way. We need to learn to see differently when we look through a different lens. It can be frightening - and that can lead to negative thoughts unless we look very carefully and evaluate our new reality carefully.

So we need to learn to react for reality, rather than to 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's meaningful and emotionally rewarding for you in life.

## Distorting Reality with Negative Thinking

A first step in doing that is looking at the different ways we distort reality with our thinking (called cognitive distortions).

3. All-or-Nothing Thinking: You see things in black-and-white categories. If your performance falls short of perfect by even one tiny notch, you see yourself as a total failure.
4. Over-generalization: You see a negative as a never-ending pattern of defeat.
5. Mental Filter: You pick out a single negative detail and dwell on it exclusively so that your vision of all reality becomes darkened, like the drop of ink that colors the entire beaker of water.
6. Disqualifying the Positive: You reject positive experiences by insisting that they "don't count" for some reason or other. In this way, you maintain a negative belief that is contradicted by your everyday experiences.
7. Jumping to Conclusions: You make a negative interpretation even though there are no definite facts that convincingly support your conclusion. This category includes: mind-reading, in which you arbitrarily conclude that someone is reacting negatively to you and don't bother to check it out; and fortune-telling, in which you anticipate that things will turn out badly and feel convinced that your prediction is an already established fact.
8. Magnification (Catastrophizing) or Minimization: You exaggerate the importance of things, or you inappropriately shrink things until they appear tiny. You tend to magnify the negative and minimize the positive.
9. Emotional Reasoning: You assume that your negative emotions always reflect the way things really are - "I feel it, therefore it must be true." - and you never really check it out.
10. Should Statements: You try to motivate yourself with "shoulds" and "shouldn'ts," as if you had to be whipped and punished before you can be expected to do anything. "Musts" and "oughts" are also offenders (related to all-or-nothing thinking). The emotional consequence is guilt when you do it to yourself - or anger, frustration, and resentment when you direct these expectations at others and they don't perform your "shoulds".

1. Labeling and Mislabeled: This is an extreme form of over-generalization that involves describing an event with language that is highly colored and emotionally loaded. Instead of describing your error, for example, you attach a negative label to yourself -- "I'm a loser." Remember: labels belong on jars, not people.
2. Personalization: You see yourself as the cause of some negative external event for which, in fact, you were not primarily responsible. You personalize everything. (In general, women tend to personalize and internalize events - "I should have...," whereas men tend to externalize them - "Oh, that was just bum luck.")

## Changing Automatic Negative Thoughts

Recurring negative thoughts that you have every day - "I'm never going to get over this flare, I'm never going to be able to work again, I'm never going to have a boyfriend," etc. - 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 can't change all our negative thoughts at once, but we can work on one or two of them at a time. Ideally, you 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'll never get out of the house." This represents four different types of negative thoughts: catastrophizing, jumping to conclusions (fortune-teller error), over-generalization, and all-or-nothing thinking." Consider the reality and how to dispute that negative thinking.

Instead, here are some more rational responses to consider: "Since my lupus sometimes flares in the summer heat and sun, I'm 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. And when I do go out in the day time, I will wear a lightweight, long sleeved shirt and a big hat or carry an umbrella."

Now it's your turn. Think about your negative thoughts. Make a list of them. Note which types of negative thinking they represent. Then try to come up with rational responses - instead of those cognitive distortions.

Note: The ten cognitive distortions above, as well as some of the theories in this session, were drawn from *Feeling Good: The New Mood Therapy* (3rd edition) by David Burns (New York: Avon Books; 1999). It's an excellent book for helping you identify your negative thoughts and talk back to yourself to improve your mood.

Source: [https://www.hss.edu/conditions\\_managing-lupus-stress-more-effectively.asp](https://www.hss.edu/conditions_managing-lupus-stress-more-effectively.asp)

## **College With Lupus - Being a Student with Lupus**

Managing university when you have lupus can be an extreme challenge – and even that is kind of an understatement.

I made it through my university career with lupus and though it wasn't easy at all, it was doable. So doable, in fact, that I ended up getting two Masters degrees and I'm now pursuing a PhD on top of it. I guess I am kind of a glutton for punishment.

As part of my PhD, I sometimes teach students and have had chronically ill students in my courses. So, as someone who has been there and done that (and purchased many university t-shirts) I have a few tips for helping you stay on top of your work and college life when lupus is in the mix, from the perspective of both teacher and student.

## **Keep Communication Lines Open**

Don't go into a class and hide your condition because you're embarrassed. Your lupus may not be something you want to shout from the rooftops, but it is better to disclose early than let it become a problem later on in class.

Most teachers and professors are understanding about things like this, as long as you're able to get the work done, but telling them early is important. Why? Because excuses begin rolling in near a due date, and even if yours is legit it will be overshadowed by all of the others coming in.

It is easy for a teacher to be less sympathetic when they've already dealt with eight other people with "grandmothers in the hospital" or "a two-week case of food poisoning."

I have always been much more accommodating to my students who reveal they are having family difficulties or health struggles early on in the course, or when these issues appear.

If a student tells me after a test has already been graded that they are battling an illness or something else is happening in their personal life, it is unfair to make concessions for them – no one else was granted leniency or a second chance.

Source:

<http://lupus.newlifeoutlook.com/college-with-lupus/>

## RECIPE: Kale Chips



Source:

<http://www.vergiespeed.com/baked-kale-chips/>

### Ingredients:

- 1 bunch kale
- 1 tablespoon extra-virgin olive oil divided
- 1 tablespoon sherry vinegar
- 1 pinch sea salt

**Prep:** 15 min **Cook:** 35 min **Ready in:** 50 mins

### Directions:

1. Preheat an oven to 300 degrees F (150 degrees C).
2. Cut away inner ribs from each kale leaf and discard; tear the leaves into pieces of uniform size. (pieces about the size of a small potato chip.) Wash torn kale pieces and spin dry in a salad spinner or dry with paper towels until they're very dry.
3. Put the kale pieces into a large resealable bag (or use a bowl if you don't mind getting your hands oily). Add about half the olive oil; seal and squeeze the bag so the oil gets distributed evenly on the kale pieces. Add the remaining oil and squeeze the bag more, until all kale pieces are evenly coated with oil and slightly 'massaged.' Sprinkle the vinegar over the kale leaves, reseal the bag, and shake to spread the vinegar evenly over the leaves. Spread the leaves evenly onto a baking sheet.
4. Roast in the preheated oven until mostly crisp, about 35 minutes. Season with salt and serve immediately.

Source:

<http://allrecipes.com/recipe/214784/kale-chips/?internalSource=search%20result&referringContentType=search%20results&clickid=cardslot%202>

## Blue Heron Blitz Fundraiser in support of Lupus Canada

The Blue Heron Blitz 5km /10km run/walk takes place in Windsor Ontario at the Blue Heron Park on the Civic long weekend each year. The race is unique and sells out each year due to the fact that it starts and finishes at the top of the Blue Heron Hill. The running course follows fine crushed stone pathways through trees, and a paved pathway around a small lake with plenty of wildlife to keep a person's attention during the run. Each participant gets a Blue Heron Blitz race T-shirt for signing up, along with a Custom 3" Finisher Medal when completing the race. Blue Heron Blitz provides pizza, water, bananas at the finish line for everyone, music, water stations around the course, and prizes to the top finishers.

Ryan's mother has lupus, which is the reason that Lupus Canada was the charity he chose to raise awareness for. Ryan also set up a donation page for any participants or sponsors of the race that would like to donate to Lupus Canada. The other goal of the race is to keep people active in the community. Having a fun oriented run gives families in the area something to look forward to, something to train for, getting them outside or on the treadmill, some family bonding time, along with a way to get the community together in a healthy active atmosphere.

This was the 3<sup>rd</sup> annual run for the Blue Heron Blitz and it was a great day. Ryan is always looking to improve and grow the event, with the focus of bringing people together and raising awareness in the Windsor area for lupus.

Lupus Canada thanks Ryan and his team for their continued support and congratulate them on another great fundraiser!



## envirofilms /Lupus Canada Partnership

One environmental factor that is proven to trigger SLE is ultraviolet (UV) light. Envirofilms window film for sun protection has been recommended by physicians nationwide as a skin safe preventative measure for patients with solar sensitivity, skin related diseases and cancers of the skin.

Did you know that window film can help provide sun protection not only for your skin but also for your interior furnishings? Most people do not realize that harmful UV rays can pass through glass. The deep-penetrating Ultraviolet A (UVA) rays in particular can reach you behind a glass window or door in your home or office. Damage from UVA rays is cumulative as they penetrate deep into the skin and can silently accelerate the aging process, cause wrinkles and even skin cancer.

UVA rays account for 90% of the sun's most damaging rays. While it's rare to get sunburned through your car windows, harmful ultraviolet (UVA) rays that contribute to premature aging and skin cancer can still reach you. UVA rays streaming through glass not only can damage your skin and may contribute to wrinkles, photo damage, or worse, cancers of the skin, they also adversely affect fabrics and furnishings. Envirofilms window film product blocks up to 99.9% Ultraviolet Rays.

Lupus Canada is excited to partner with Envirofilms to help people living with lupus have a way of protecting themselves from these harmful UV rays. We have partnered with Envirofilms because they are specialized in providing window tinting services for homes, commercial buildings and autos in the Ottawa region. Their knowledgeable staff will recommend the right film for comfort, protection and to save energy. Envirofilms carries a film for just about everything!

Should you not be in the Ottawa area, contact Lupus Canada for a company in your area.

**5% of every sale will be donated to Lupus Canada**

For more information on Envirofilms and the products they provide please visit [www.envirofilms.ca](http://www.envirofilms.ca)