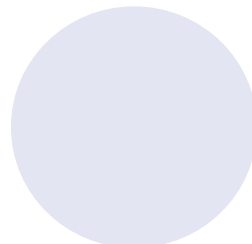
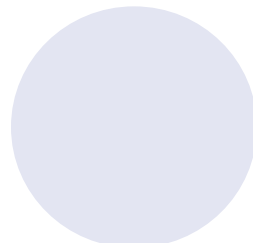


Get in the Loop

A new lupus publication for youth



Newsletter Date– October 2006

Volume 1, Issue 1

Special points of interest:

- Back to school (post-secondary education)
- Fitness
- Healthy Recipes
- Personal stories
- Much More

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Letter from the editor

It is with great pleasure that I present the first issue of *Get in the Loop*, Lupus Canada's newsletter written by and for young people with lupus. First, I should start by giving myself a little introduction. My name is Charlene Johnson and I am 24 years old. I was diagnosed 7 years ago with lupus, when I was 17. After 3 flares, and tons of meds, I am happy to say that I am feeling much better and getting back to doing the things I aspire to do. I'm majoring in French and Spanish at Glendon College, York University. That's right, I speak 3 languages :) I hope to be a kindergarten teacher someday. Besides learning new languages, I also enjoy writing, (hence the newsletter), and music. I've been studying classical violin on and off for 14 years.

I hope this newsletter will help you all feel the same way I did when I received a TLC newsletter after being diagnosed with lupus. Feeling alone and very scared, TLC (Taking Life as a Challenge)

reminded me that there are young people out there like me, who actually know what I have to deal with. Reading the newsletter may not sound like much, but it was very comforting and inspiring in its own little way. After reading it, I knew that despite my illness, I am very much like everyone else. Hopefully you will all feel this way after reading the first issue.

And I hope you will all continue to read the issues. A lot of hard work and care went into making *Get in the Loop* a reality. But, of course, we are open to suggestions and comment. If you feel something should be changed or added, let us know. If you would like to write for us, we'd also love to hear from you. We want this newsletter to meet your needs, so please let us know what those needs are.

I can't forget to thank a few special people without whom this newsletter would not have been published. Special thanks goes to everyone at head office (Judi Farrell, Pamela Bowes, John Studiner, and Karen Furlotte) for supporting this endeavour. And of course, I have to thank my **predecessors**, those who have set the example for me, especially Andrea Ou-Hingwan, founder of TLC, and Jaclyn Law, former editor.

Once again, I hope the newsletter is as informative and fun for you as I aspire it to be. And as time passes, and I get older, I hope that some of you will become inspired to carry on the torch!

Enjoy,

Charlene Johnson



Fitness is important—see page 3

The importance of having a support group

By Jen Huska

Hello and welcome to the new newsletter for youth with lupus! We write this newsletter in the hopes of getting more people involved in this fight to conquer lupus. Since this is the very first edition, I, Jen Huska will write a little something about myself and what the past TLC issues have meant to me.

When I was about 14, I started having some severe pain and swelling in my right arm. At first everyone just thought maybe I was playing too hard in gym class, but thankfully my parents were concerned and took me to the emergency room. That is how my journey began. By April of 2000 or 2001, I was sent to Bloorview MacMillan Centre where from there they sent me to the Toronto Hospital for Sick Children.

At Sick Kids, I went through an array of tests. Finally, the doctors sat down with my parents and me and said, "Jen, you

have lupus, and we can help you". Although I was one of the older patients, being 16, I still felt so very welcome there.

After many tests, and hospital stays, I was introduced to the TLC newsletter. There I found comfort in knowing I was not alone, was not the only teenager suffering from this strange disease and that there were others who wanted to talk! I jumped at the chance of meeting others my age. I contacted Charlene and today we are great, great friends. She's come to my brother's wedding and we've visited each other at houses and various events. It's been exciting to have a friend going through the same thing as me, though different in some ways, the same in many aspects. We can talk and understand each other. I feel so blessed to have found Charlene. Online, I also talk to over a dozen youth and older people who have lupus. When you find that person who can just talk and listen you will feel so much better.



My parents are blessed to have met Charlene's parents because they all talk about the different symptoms we have and how much support each person is to each other.

Now I'm excited to become a part of Get in the Loop for youth with lupus.

Have faith, believe in yourself, and don't be afraid to lean on people for support, and try to have some fun. I may be almost 21, but I am still able to relate and to hopefully comfort anyone who turns to me for support and advice.

"Have faith, believe in yourself, and don't be afraid to lean on people for support."



Charlene Johnson and Jen Huska, summer 2004

By Jodie Nimigon

The recommendation to stay active is one that we have all heard, numerous times, not only from our specialists, but from everyone else – teachers, family, friends, and the media.

The challenge of staying active when one is trying to battle arthritic pain, chronic fatigue and to decrease his or her stress load seems to be a bit of an oxymoron. Trying to add physical fitness to the list of things to do, when you have a school assignment to complete, a family function to attend, or a luncheon with your girlfriends planned, and you would already feel like you are dragging your feet, despite sleeping eight hours the night before.

However, the rewards of being even moderately active are positive all-around. For patients with chronic back pain, instead of bed-rest, daily moderate physical activity is now recommended to strengthen and stretch the back and shoulder muscles. The same advice applies to those patients with chronic fatigue syndrome: regular physical activity is recommended to help set a regular sleeping pattern by triggering sleep hormones.

For those of us with lupus, regular physical activity is recommended not only for the same reasons mentioned above, but to also help with the body's absorption and circulation of medication, as well as to help combat some nasty side-effects like water retention and decreased bone density.

Following a knee injury last fall, I was forced to hang up my gym shoes and to take up the traditional physical activity of walking. However, much to my chagrin, I enjoyed my 30-60 minute daily walks around my neighbourhood in Montreal. I discovered much that I didn't know existed, while taking in a breath of fresh air (or as much that is possible in a large city). I soon couldn't wait for my daily excursion, particularly on those days where my body was dragging when my hips or knees had sharp pains.

After a brisk walk, I was always left clear-headed, ready to tackle some more schoolwork; I also felt a lot looser in my joints, often with less pain than when I had set out 45 minutes earlier. This is not to say that I did not take some days off when I absolutely did not feel up for it, or when I didn't have enough time the day before an exam, however, it quickly became a part of my weekly routine.

Walking is the best and easiest exercise for people of all fitness abilities to participate, and it can be modified to increase or decrease levels of difficulty. People who experience different levels of (chronic) pain are typically still able to walk. It is the cheapest of exercise activities that is comparable to running, which requires a lot higher fitness level from participants and is not as inclusive.

Taking a walk is also super easy to do in groups, which is a great motivator to get out on a "bad" day, and it

is a great way to get to know your neighbourhood, particularly for university students who tend to move every year. It is an excellent way to connect with nature, to distance oneself from the busy-ness of life and to de-stress.

Just remember your water bottle to stay hydrated if you are planning on being out on a hot day and/or longer than 30 minutes.

So put on your most comfortable pair of shoes, gather a few friends or family members and get out there, preferably on a regular basis.



People who experience different levels of (chronic) pain are typically still able to walk.

Get in the Loop

By
Char-
lene Johnson

Heading to college or university? There's a lot to consider when taking that big step from being a high school senior back to first-year freshman. But students with lupus have many other things to consider.

After two years of university, I have learned a few things that will help any student with a disability do well in their program while maintaining their health. Here are my 10 best tips to doing well in school while living with lupus.

1. Health is your first priority. Whether we like to admit it or not, managing our health should be our top priority. Having a flare-up or just feeling ill can have a huge impact on our progress in school and our grades, which is why it's important to continue doing the things that help us feel well. Going to college/university may actually make it easier to get some exercise between classes, as most schools have an athletic centre or gym on campus that offers discounts to student members. Eating well, taking meds on time, going to checkups and doing regular blood work are all things that also shouldn't be neglected for studies. And don't fall in the habit of pulling all-nighters to complete assignments.

2. Get a doctor's letter. This is your golden ticket to accessing disability services at your school. Without proper documentation stating that you have lupus, you will not be able to receive accommodations. Don't forget to have your rheumatologist update the letter every few years.

3. Find out where the disability centre is located. Visit the centre, become acquainted with the counsellors and the services they provide, and never hesitate to ask questions. Most students wait to see them only when a problem arises, but getting to know them beforehand can help anyone in the long run.

4. Choose your courses based on lupus activity. It may sound silly, but think about it . . . why burden yourself with a full course-load when you're flaring? Taking a reduced course-load when the lupus is still active allows you ample time for extra rest and doctors appointments, while allow-

Back to School

ing and you to study complete quality work. Also look into distance courses, which bring some more flexibility. I actually completed my first course at home, when I was recovering from a flare-up and wasn't very mobile. I liked being able to plan my studying according to how I felt that day, without worrying about commuting to class in crowded buses.

5. Ask for accommodations. This can include things like having a notetaker or writing tests in a separate room, and it may also include extensions or deferrals when you miss deadlines because of illness. Accommodations are arranged with your disability counsellor and are sent to all your professors on an annual basis; a new appointment must be made each year. As for your confidentiality, your medical condition is never disclosed to your profs (unless you tell them yourself), and they do not have the right to discuss your issues with anyone else.

6. Seek advice when problems arise. Sometimes problems do arise between students and professors in regards to disability accommodations, and other academic issues. Never hesitate to make an appointment with your counsellor if you have any questions or concerns, or simply want to talk about what's bothering you. That's what they are there for. Unresolved issues can have a negative effect on your ability to concentrate on your studies.

7. Get to know your profs. Regardless of policy, profs are more understanding with accommodations when they know who they're giving it to. Corresponding by email is not enough. Make an appointment to meet your prof, or get a quick work-in after class. Explain your situation and show them that you genuinely want to do well in the course. Demonstrating your study habits makes things easier for both sides, especially if you do become ill and miss classes.

8. Look into tech aids. Things we use everyday can actually help us keep up with our studies. PDAs can help forgetful minds keep track of important dates and deadlines, and the omnipresent computer can help fatigued or achy fingers when multi-page assignments are due. A voice recorder can be helpful with taking notes during lengthy lectures and tutorials. Speak with your disability counsellor; they may have these devices available for short-term loans.

9. Join social activities. Don't forget to take time for social activities. Join a club, a group, or a sports team, something that interests you – there are lots to explore. The key here is to have fun, make friends, and to find something you enjoy doing when taking a break from schoolwork.

10. Enjoy college/university life! This is a time to discover new things and learn more about yourself. Making this transition can be challenging at first, but it is also quite rewarding. You will likely take a more active role in your health care and in managing your lupus, so remember to continue doing the things you did before, even if you are feeling well. And if your health doesn't go as well as planned, don't hesitate to take a step back to recuperate. School will always be there when you're ready to go back.



Happy
Study-
ing!

“...become acquainted with the counselors and the services they provide, and never hesitate to ask questions.”

Here are some yummy recipes that you can enjoy morning, noon, and night.

Breakfast

Pineapple Smoothie

Servings: 1

Tip: This dish is great with some cinnamon French toast or an omelette. Don't forget to be creative. Other fruits can be used as well!

Ingredients

- ½ cup pineapple chunks in light syrup, drained
- ¼ cup plain low-fat yogurt
- 2 tbsp orange juice or pineapple juice
- 2 ice cubes

Instructions

1. Place all ingredients in blender container. Blend until smooth.
2. Serve immediately.

Lunch

Mini Tuna Pitas

Servings: 2

Tip: This recipe is great to carry to school. For a tangier taste, substitute mayonnaise with Ranch or Creamy Cucumber Dressing. Remember to use a little less, to prevent pitas from getting soggy. Tuna can be substituted with flaked chicken, turkey, or deli meats.

Ingredients

- 1 pkg mini-pitas
- 1 can chunk light tuna, drained
- 1 celery stalk, chopped
- 3 tbsp light mayonnaise
- 1-2 lettuce leaves

Salt and pepper for taste

Instructions

1. Slice pitas open wide enough to stuff ingredients.
2. In a medium-size bowl mix tuna, chopped celery, mayonnaise and salt and pepper. (Mix with a fork to flake the tuna.)
3. Cut lettuce to about the size of the pitas, then stuff them in with the tuna mixture.

Dinner

Vegetable Lasagna

Servings: 4-5

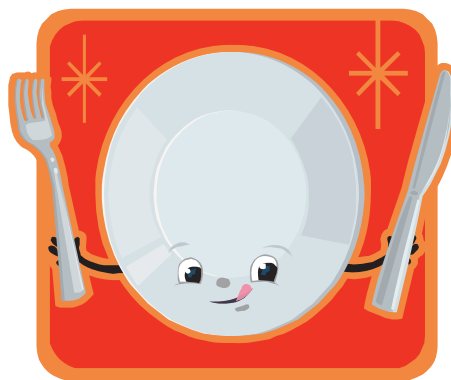
Tip: To speed up cooking time, use oven-ready noodles, you don't need to boil them. Use leftovers for microwave lunch the next day.

Ingredients

- 1 pkg lasagna noodles
- 1 can (680 ml) pasta sauce
- 2 cups shredded mozzarella cheese
- 2 cups chopped zucchini, carrots, red peppers
- 2 tsp chopped onions

Salt and pepper for taste

1. Boil noodles according to instructions on package, drain.
2. In a large pot, add onions, vegetables, and pasta sauce over medium-high heat. Add a full pasta can of water. Simmer for 10 min.
3. Cover the bottom of a 13" x 9" casserole dish with 1-2 spoons sauce. (This prevents the noodles from sticking.)
4. Line the bottom with one layer of noodles and a layer of sauce mixture. Add another layer of noodles, and sprinkle cheese.
5. Repeat step 4 until you reach the top of the pan (about 2 veggie layers/ 2 cheese layers). Sprinkle remaining cheese on top noodle layer.
6. Cover with foil and bake at 350° C for 20 min. Remove foil and bake for an additional 10 min. Cut in 12 squares. Serve with garlic bread and salad.



Got a great recipe

to share? Email it

to

chars.j@gmail.com

Get in the Loop

By Jodie Nimigon

Hi there! I hope you will enjoy this first edition of the youth magazine, and hope that this initiative will continue. I am one of the youth representatives listed on the Lupus Ontario website (although you may recognize my last name, since my father is the head of fundraising on the Ontario board of directors). After my diagnosis 12 years ago, there was a support group and magazine for youths which helped me realize two important things: having lupus wasn't the end of living just like every other teenager and it wasn't the end to my career or life goals.

For those of us lupus patients who hadn't yet turned 18 and went to the Sick Kids clinic, on clinic days we often met in a spare examination room and chatted about life, sometimes had lunch, and maintained regular contact. During annual conferences for lupus held in the Toronto area, there would also be youth-oriented activities organized by one of the youth representatives.

When I moved to Ottawa to pursue my first undergraduate degree in psychology, these were aspects of what I had come to associate with my lupus "experience" that I missed the most. So naturally, I was thrilled that, in the same year, I was approached to be a youth representative for Lupus Ontario. Unfortunately, university proved to be very busy and although I was able to provide some individual counselling to newly-diagnosed youth and their families, I was not able to continue working for the newsletter and help organizing conferences for the TLC youth group. (This was also complicated by the fact that I was no longer close to the city of Toronto.)

I was fortunate to only encounter a small flare during my second year, and I have since then earned an Honours Bachelor of Arts in Psychology from the University of Ottawa and, (as of last June) a Bachelor of Arts in Social Work from McGill University.

I now live in Toronto and will complete my Master's Degree in Social Work at the University of Toronto this coming year, with a specialization in adolescent health. I hope to help

Personal Stories: Jodie Nimigon

chronically ill youth deal with depression, low self-esteem and body image as well as to assist them in setting life goals. I will also be looking for a professional job next summer – Does someone know anybody that's hiring a social worker or counsellor? Just kidding

As a lupus patient, I have been very lucky to not have experienced some of the more serious complications or symptoms, while having a supportive family and an understanding group of friends. However, after living with lupus for 8 years, I was diagnosed with osteoporosis in 2002 due to long-term prednisone use. I was told my bones were like those of a mature woman in her sixties. This happened despite taking calcium and vitamin D supplements, despite staying relatively active during high school and university by dancing full-time and later exercising with step class and elliptical.

Somehow, this second diagnosis was even harder than the when I was diagnosed with lupus, because it seemed to be preventable. I had followed all recommendations made not only by my specialist, but also by others in the medical community. I took a pro-active stance, really watched my diet, increased my weight training and ensured I participated in impact activities (where the feet make contact with the floor: running, walking, dancing, but not swimming, biking, elliptical).

I was told this was the only way to maintain the bone density that I had, and to not anticipate much re-growth given my age (I am now 25 years old), continued prednisone use (currently 5mg/day), small bone structure, and history with anorexia. I am no longer considered to have osteoporosis or osteopenia, although my bone density is still on the low end for individuals my age. But this statistic didn't matter to me; all my hard work and determination had paid off, and I had beaten the odds of re-growth.

Due to a knee injury last fall, my exercise routine was put on hold and walking was the only activity left that I could do without causing further damage while undergoing treatment. It was during the winter months that I tied on my boots, hat, gloves, scarf and walked around my Montreal neighbourhood, sometimes venturing to Mont-Royal. This made me feel very frustrated, given my life long dedication to active living and daily activity, among other things. This incident also made me realize how frustrated I was (and still am) with how few people take proper care of themselves and still end up



Jodie Nimigon (left) and her sister at the Madonna Concert in Montreal

with few health problems. However, I was proud that I was able to be so dedicated to my health to do whatever possible to maintain my bones, heart and weight.

It was finally, in June that I was ready to attend the gym on a regular basis, but was still not ready to run. Throughout this past summer, and since moving to Toronto in September, my efforts to slowly re-build my muscle strength and cardiovascular capacity have led to a re-discovery of my love for walking. Although it started partially out of necessity to learn where the different buildings are located on my campus and to relax before a busy semester begins, it was also out of interest in the beautiful architecture of the University of Toronto campus, and all it has to offer.

Much to my surprise – and that of my osteoporosis specialist Dr. Hawker, from the Women's College medical centre – the results from my annual check-up showed that I had regained *six times* the growth this past July.

That is me, in a nut shell, up to the moment, however, if you ever have any questions or concerns, or just need to speak about what you are experiencing (or have experienced), I would love to hear from you all.

Jodie Nimigon

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Mind Games

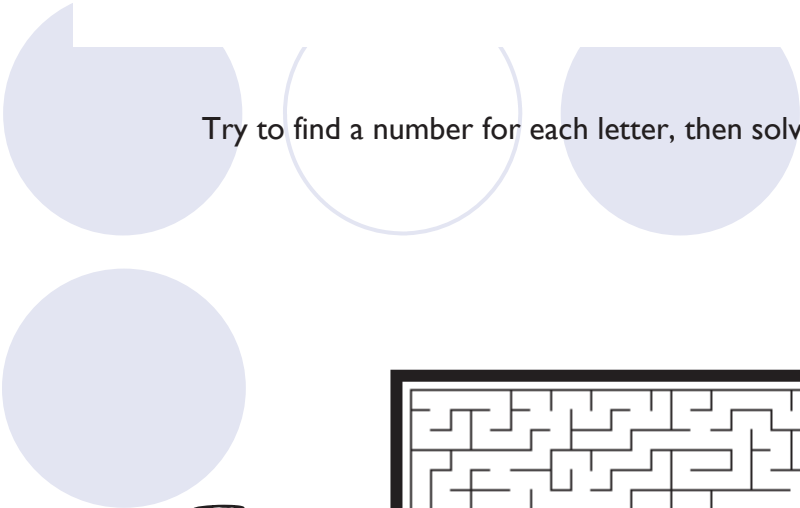


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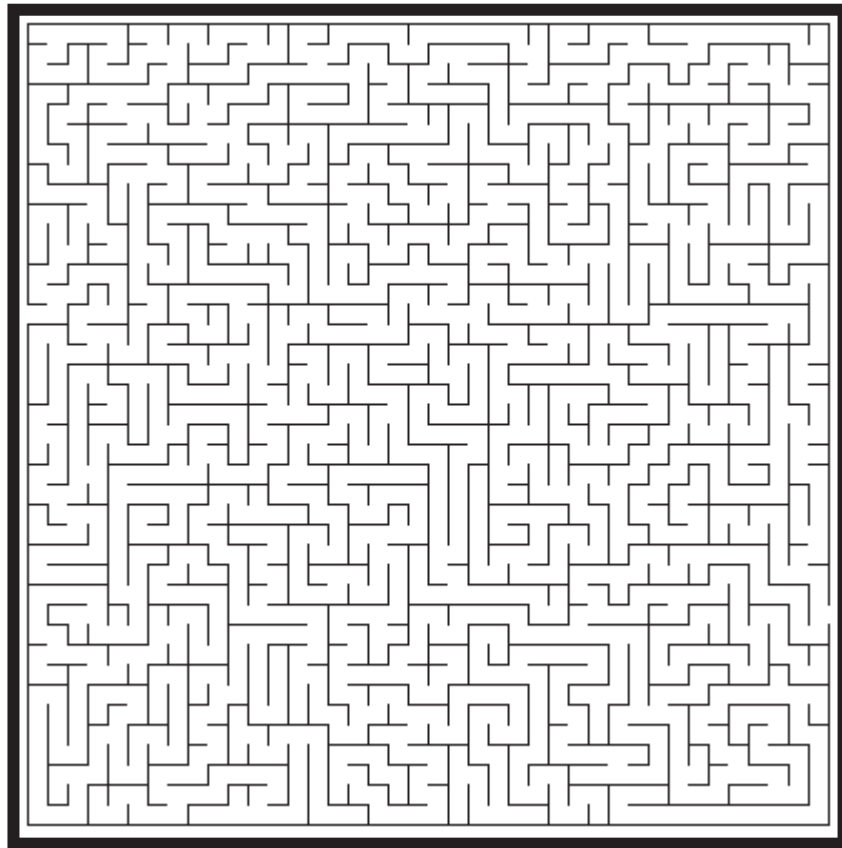
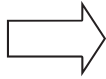
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Try to find a number for each letter, then solve the sentence.



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October is Lupus Awareness Month

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WE'RE ON THE WEB!

WWW.LUPUSCANADA.ORG

We need your help!

I hope you enjoyed reading this newsletter. A lot of time and effort was put in to making this happen. But what we really need is more help. We need your comments, suggestions, and even your submissions. We want to keep this going, and we want to make sure that you look forward to reading every issue. Let us know if our articles were interesting, and what we can write about in the future. And if you would like to write something, send it along, and it will get published. Get involved, and Get in the Loop!



Every October, thousands of lupus patients across Canada join together to bring awareness to the cause. There are tons of events taking place across the country, for people of all ages to get involved and help conquer lupus. For more information on events in your community, contact your provincial organization. Here are some examples of upcoming events:

- Walk A Block for Lupus: Nationwide, the entire month of October.



Co-Editors: Charlene Johnson and Frances Olimpo

Writers: Jen Huska,, Jodie Nimigon, Charlene Johnson

Lupus is an autoimmune disease that affects thousands of people in Canada, mostly women in their child-bearing years. Symptoms vary greatly from patient to patient and treatment is highly individualized. Patients are urged to contact their physician or health professional with any questions or concerns they might have. Opinions expressed on these pages do not reflect those of Lupus Canada.

Check it out

If you happen to have a bit of spare time on your hands, here are a few websites that are sure to puzzle your brain.

- www.sudoku.com

This number puzzle is sure to keep you occupied!!!

- www.jigzone.com

This website times how long it takes for you to complete the puzzle

- <http://puzzlemaker.school.discovery.com>

Here you can make and print your own puzzles.