



Lupus Canada

Get in the Loop

summer 2007

A new lupus publication for youth

Volume 1, Issue 3



Summer lovin'

Look your best and feel your best
shopping for the latest trends
(Yes, it is possible!)

ALSO INSIDE :

FOOD

Quick and simple recipes
to beat the heat

FITNESS

Discover a surprising addiction
that's actually good for you

OPINIONS

Reach out to others living with lupus
from the comfort of your own home

Letter from the editor

Dear Readers,

I write to you from the confines of my bedroom. Yes, just when I thought things were going great for me lupus-wise, I got hit by a bad case of shingles. (Basically, it's a variation of the chicken pox virus.)

This not only caused me to once again seclude myself temporarily from the rest of the world, but it also reminded me that when we are not concerned with lupus, we should be wary of other conditions and ailments that we are vulnerable to.

But, as always, I am in high spirits. Being at home allows me to put the finishing touches on the newsletter . . . between naps of course.

The summer issue is full of updates within the Lupus Canada circle over the past few months as well as events to look forward to.

Opinions will focus on the benefits of using the Internet to meet others with lupus, while our Healthy Eating section offers some treats for the barbeque.

Of course, we can't forget to talk about sun safety and lupus. Our new reader, Jessica Kundapur, has also offered some tips on looking great during the hot summer months.

I hope you enjoy this issue, a lot of extra effort was put into making it happen.

And as always, we are looking for our readers to get more involved and write for us; so when I do fall ill, I can sit back, relax, and know that the newsletter is in good hands.

Charlene Johnson

Get in the Loop is a new publication for youth with lupus that strives to connect young people across Canada who are living with this disease. It is organized and published by young people with lupus, in conjunction and with the support of Lupus Canada. The opinions expressed in Get in the Loop are in no way a substitute for advice from medical professionals.

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.

LUPUS CANADA

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Sun Safety

Visit <http://lupuscanada.org/pdfs/SunSafety.pdf>

for more sun safety facts by Lupus Canada

WHY IT'S IMPORTANT TO PROTECT YOUR SKIN

Excess exposure under the sun's rays can lead to new skin lesions (e.g. rashes) or flares of internal lupus, including joint pain and fatigue
Forty to seventy percent of people with lupus are "photosensitive" to ultraviolet rays

Sunscreen

Think of 3 H's ...

Hypoallergenic
Have broad spectrum UV protection
Have an SPF of 30 or greater

Check the expiration date!

Store away from heat

Reapply every 2 or 3 hours

Hot tip: Reapplying 20 min. after being in the sun can reduce UV exposure by 40 percent!

OTHER SUN STRATEGIES TO TRY

Avoid sun exposure between 10am to 4pm and plan activities in the early morning or late afternoon • Keeping a scarf, sunscreen bottle or sun umbrella can come in handy • Even on cloudy days or stormy weather, harmful rays can shine through • Window glass still allows UV rays to come through at full strength • Check with your doctor or pharmacist if your medication may cause additional sun sensitivity

Hats and Clothing

Four-inch (10 cm) brim provides maximum protection

Wearing hats with a downward brim protects the face and neck

Best everyday clothing to look for is loose-fitting, thick, dark, and woven tightly

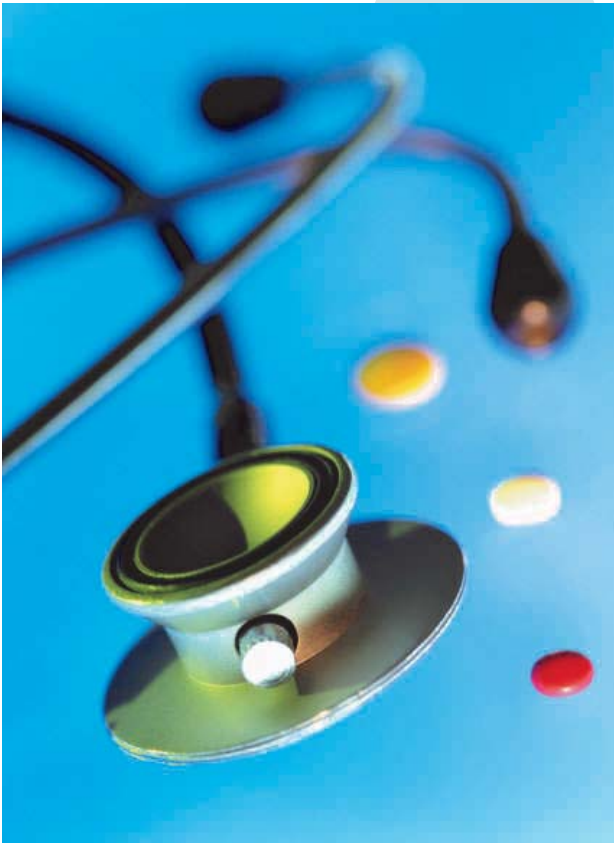
Lycra, polyester, and nylon are the best fabrics for UV protection; cotton is the worst

Get in the Loop

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Plaquenil

a.k.a Hydroxychloroquine

Originally used to treat malaria, Plaquenil has been used for many years as an *immunosuppressive* drug for lupus. Immunosuppressive drugs work by shutting off the immune system, thus preventing it from attacking foreign bodies, or with lupus, the body itself.

Dose is determined by the weight of the patient, and can take several weeks to produce a response. For lupus, Plaquenil has been shown to provide relief from skin rashes, hair loss, joint pain, mouth sores, and can prevent flares. Lupus patients generally take Plaquenil on a long-term basis.

Side effects are numerous and should be reported to the rheumatologist to help determine an alternate dose or treatment. Side effects may include acne, anemia, mouth blisters, itching, hives, problems with vision, and muscle weakness. It is also known to increase eye toxicity and may cause serious eye conditions. Patients, therefore, usually undergo a vision field test regularly (every one to two years) to ensure it is not affecting their eye health.

An enzyme deficiency known as G6PD – most common in people of African descent – may cause severe anemia, and should be monitored while taking Plaquenil.

Tasty summer treats

Fruit Kabobs with Strawberry Margarita Dip

- 1 pkg (250 g) of Philadelphia Strawberry Light Cream Cheese Spread
- 1 cup thawed Cool Whip light whipped topping
- Grated peel and juice from one lime
- 2-1/2 cups (370 g) cubed cantaloupe (about 24 cubes)
- 2-1/2 cups (400 g) cubed honeydew melon (about 24 cubes)
- 24 strawberries, washed, hulled

Mix cream cheese spread, whipped topping, lime peel and juice; cover. Refrigerate at least 1 hour.

Meanwhile, thread fruit evenly onto 12 wooden skewers; place in airtight container or resealable plastic bag. Store in refrigerator until ready to use.

Serve kabobs with the dip.



*Recipe and photo courtesy of KraftCanada.com

Got a great recipe to share for the Fall issue?

Send recipes to
getintheloop@gmail.com

Be *cool* with the *ho*

Most people anticipate the summer season, but for others living with lupus the sensitivity and body issues. Luckily, this season there are plenty of summer clothes to choose from. You deserve to look good and have fun! You deserve to love summer!

After all, summer only happens once a year.



Tip-Top Shape

According to the *Vogue* magazine website, the shapes for shirts for spring/summer 2007 are **softly contoured**. Think light and airy. Also, the new length is longer, and this slimming upgrade is available on almost all tops this summer. Check out www.sunveil.com for sun-protective clothing ideas.

TIPS WHEN SHOPPING:

- ✓ Only go shopping when you are feeling good
- ✓ Take a supportive friend/family member with you
- ✓ Well-fitting clothes are important; the size number is not
- ✓ Find a tailor; almost any garment can be altered your specific shape
- ✓ Be open to trying new styles and shapes
- ✓ When shopping online be familiar with the return policy



Bottoms up!

Capri-length bottoms are back again! Choose from styles ranging from casual cargo looks to sleek and sophisticated. Speaking of sleek, another sun-protective option is the *Bermuda short*, with a hemline that stops at the knee. Both of these longer short styles cover up most of the leg and are quite flattering.

Knee-length fuller skirts are stylish, comfortable and a hot-ticket summer item. According to the *What Not to Wear* website, a fuller-cut skirt that flares (no pun intended) away from the body balances the frame and flatters every figure.



ottest summer looks

The arrival of sunny days aren't greeted as joyfully. There are concerns about sun-
sting styles that are the perfect fit for your health state and body type. Be creative and
look and feel good every day!

...and then before you know it, it's...winter.

FOR THE BOYS

Lightweight button-down shirts are everywhere!

Blazers are once again very in demand

Lightweight casual and dress pants are both modern and classic

Shorts have a golf, military and beach-inspired look

There's more out there than just baseball hats: Check them out!



The Bold and the Beautiful

Funky jewelry completes any outfit, expresses your individuality and focuses attention where you want it.



Fabulous Hats are in! For maximal sun protection and fashion savvy, choose a dense material and a brim is bigger than 8cm.

Big Sunglasses (think Jackie O.) can help protect against the sun's rays. Read labels to ensure UV protection.



Summer Jackets made with lightweight materials are modern and flattering.



Fitness – Weight Training

BY JODIE NIMIGON
FITNESS EDITOR

I decided to venture a little deeper into fitness issues for this edition by broaching the big, bad “w” word: Weights. Although I have always been an avid exerciser, I readily admit that I was not always so fond of lifting weights. I was intimidated by strength training. I was scared of hurting myself, of doing something wrong, of looking silly.

But those anxieties quickly faded when I was diagnosed with osteoporosis in my lower back in February 2002, likely due to extensive prednisone intake over a number of years. (I am sure that many lupus patients can relate.) I was prescribed leg and arm weights, and was strictly instructed against abdominal and back strengthening exercises. Apparently, using both my upper and lower limbs increases strain on the lower back and would be counter-productive.

“The new challenges were invigorating, and also helped to increase my self-confidence.”

To my own surprise, after following the doctor’s orders, I quickly became quite addicted to lifting weights. I was instructed to use squats, pliés and lunges for my legs as well as shoulder presses, push-ups, triceps push-backs, and bicep curls for my arms. For my abdomen, I not only continue to do regular crunches but include regular and sideways planks and upper-back lifts. Now, I feel rather lethargic if I do not maintain my regular routine on a weekly basis.

A few summers ago, I even registered with a personal trainer to teach

me a few new tricks because I was no longer feeling tired after my workouts. She got me doing my leg exercises from a jumping position, on and off stairs and with a “bosu” (which is half the size of an exercise ball). We also incorporated a stability ball and the bosu into arm exercises.

The new challenges were invigorating, and also helped to increase my self-confidence. I still laugh about the first time that I had the courage to ask a huge football player if he was done with a particular piece of equipment – little me, at five-foot-one! Similarly, five years prior I never would have imagined myself being able to complete 12 push-ups off a stability ball!

I have to admit that I have faltered some this past year: trying to balance my part-time job with full-time classes and placement made working out my last priority. My body lets me know when it needs attention, though . . .

my knees start to ache! This is a sure sign that I haven’t been to the gym enough, or recently. Once I am at this point, it can be a real challenge to get back into a regular routine because my knees typically get worse before they get better. I push this pain though by slowly re-building my strength and endurance, knowing that in the end my body will thank me.

So, for all you weight-training newbies, give it a shot! My key word of advice: Everyone else who is at the gym is concentrating on themselves, believe it or not, and won’t notice if you are only lifting three pounds and/or if you are making funny faces while you are at it. Besides, being good to your bones and complimenting your calcium intake, you will be surprised just how far you can push yourself!



Higher confidence and energy levels are just a few of the benefits to a regular fitness routine.

Opinions – Lupus shouldn't lead to loneliness

BY FRANCES OLIMPO
ASSOCIATE EDITOR

Lupus is a disease that affects more than just your body. Sudden flares or fatigue brought on by lupus can take you away from your friends and activities, leaving you in the confines of your home.

Fortunately, there are ways to overcome these obstacles to your social life, thanks to the wonderful invention known as the Internet (is there anything it *can't* do?).

For example, the hugely popular peer networking site, Facebook, has been a place for many people diagnosed with lupus to connect and share their stories.

There are fabulous groups that you can join on Facebook for encouragement and support, particularly if you are new to the disease and need more information. You can chat with other women about the challenges faced and overcome in a group called "Hot Chicks with Lupus," or you can find out more



about it in general in other groups like "I Have Lupus — What's Your Excuse?" or "Fight Lupus!" The list is endless.

Similar to MySpace, Facebook users sign up for free and post their own individual profile for other fellow members to see (with optional privacy settings, if preferred). Users can start special groups and chat with each other online in forums about anything from sex to politics to religion, as long as differences of opinion are respected.

But as great as Facebook sounds as a social tool, there are also potential dangers in using the site as

well. Options such as publicly posting information about yourself such as your birthdate, the schools you've attended and your job experiences can lead to identity theft. Photos of yourself with your friends or family can be viewed, copied, and used by strangers.

The bottom line is that while it is great to meet new people, staying smart and keeping personal information limited is always better. Use common sense and listen to your radar if things get creepy (e.g. never give anyone your address information if they want to meet).

Keeping these things in mind, also remember that many people connect with each other online everyday. One of the greatest things about the web is the exchange of ideas; sharing your thoughts with others living with lupus might be just what the doctor ordered.

We hope that you, our readers, will join our Facebook group by emailing getintheloop@gmail.com. We are looking for all young Canadians living with lupus in the hopes of bringing everyone together across the country. Support is only a click away!

In the Know

World Lupus Day

On May 10, people around the world commemorated World Lupus Day since it was officially declared in 2003. Although it is not well-known, momentum is growing with each passing year. There is a call to action, to recognize lupus as a serious disease that affects millions of people worldwide. Lupus patients often commemorate the day by educating others about the disease and by contacting their local government to have declarations made in legislature.

Public Service Announcement

Global Television, in conjunction with Lupus Canada and its member organizations, produced a public service announcement to increase lupus awareness across Canada. The advertisement features the host of ET Canada, Cheryl Hickey, as well as actress Rachel Blanchard. Blanchard, whose mother was diagnosed lupus

since she was a little girl, has become a spokesperson for lupus awareness. This brings us one step closer to eliminating the question: "What is lupus?"

Lupus Canada Symposium, Winnipeg 2007

This past April, people living with lupus, their loved ones, and volunteers involved with the cause gathered together in Manitoba to share ideas and gain valuable information about the disease. Presentations were held by medical professionals and people living with the disease, in an effort to share valuable tips and resources for maintaining and controlling lupus. As always, those who attended left feeling satisfied that they learned a bit more about this complex autoimmune disorder.

Upcoming Events

Lupus Canada Symposium 2008

Lupus Quebec will be hosting the Lupus Canada AGM in Montréal on **May 31, 2008**. The symposium features keynote speakers that discuss topics related to living well with lupus. It promises to be a worthwhile and informative event. Details are to follow in our next issue.

First Anniversary issue

Our next issue will also be our first anniversary issue. We want to celebrate by giving the newsletter a new logo, a title for the French edition, and have a special section featuring stories from significant others about their thoughts on knowing someone who has lupus. This can include boyfriends, girlfriends, parents, siblings, and friends. Send all submissions to getintheloop@gmail.com. There will be prizes for the best submissions.

Get in the Loop is on Facebook!

For all the latest news on what's happening with Get in the Loop, join us on our Facebook group. You can also make suggestions on what you would like to see happen with the group or the newsletter. Hope to see you soon.

Walk A Block 2007

Get your walking shoes ready. The fifth annual Walk A Block for Lupus fast approaching, Lupus Canada hopes to make it the most successful fundraiser to date. In keeping with the theme of allowing walkers to choose a distance they can manage, participants can choose between their own walk in their neighbourhood or a community walk by organizers set for **Oct. 21, 2007**. On this national kickoff date, people living with lupus can get together with others who are enthusiastic about fighting for a cure.



*This could be you!
Walk A Block for
Lupus Canada*



*The Khan Family
Winnipeg, Manitoba*



British Columbia 2005



*Walk A Block in Toronto
October 2006*

To learn more about how to get involved with the Walk A Block and to register your team online, visit

http://www.lupuscanada.org/english/involvement/wab_2007.html