

### President's Message

from Julia Kane

After a wet and dreary spring, we hope summer is about to shine it's face. I remind you to be "sun aware" and protect yourself at all times. Use twice the sunscreen and apply it twice as often as you think you should. (Lac Hydrin for skin tone is not a sun screen)



Lupus Ontario AGM 2011

Lupus Ontario has had a busy few months with a well-attended Annual General Meeting April 2 & 3 where we introduced two new Board Members, Tom Mather from St. Catharines as Vice President (Lupus Foundation of Ontario) and Janice Locke from Ancaster who is Secretary and the new Lupus Canada Delegate. In the afternoon we had an inspiring support leaders training session, thanks to the hard work of Cathy Ferren Palmer, Juanita Butler and our guest facilitator Katherine Tomkinson. The comments back were that it was very worthwhile. We are fortunate to have so many volunteer leaders who care about others with lupus in their communities and give such precious gifts of time and self.

Lupus Ontario presented the SLE UPDATE, **Toronto Lupus Clinic at 40 Years** with 5 wonderful speakers including the newest **Geoff Carr Fellow** recipient, **Dr. Amanda Steiman** who will be working with Drs. Urowitz and Gladman at the Toronto Western Lupus Clinic 2011-2012. The day was topped off with a tremendous talk by Dr. Murray Urowitz on Current Therapies in SLE which left us all with a great deal of hope for the future. The same weekend Dr. Urowitz was honored this weekend at a Gala celebrating his 40 years of dedication to lupus care and research. We are all his biggest fans.

The Lupus Walk throughout the province in May was a great success for all who participated. The money raised from this event will help fund the Geoff Carr Fellowship, some CaNIOS research as well as Lupus Ontario's Programmes. We have committed to make next years' walk even better and iron out some of the wrinkles that caused confusion, on line and off. Nicole Wright, our Lupus Ontario Walk /Events Coordinator was well organized and motivating and did a great job.

The Yard Sale June 18<sup>th</sup> raised over \$1200 dollars and again was only possible because of the tireless work of Karen, Nicole and Juanita and many volunteers. A special Thank You to Judy Clement and **Bristol Truck Rental**, 9205 Yonge Street in Richmond Hill, for the donation of a cube Van to pick up and store items for the sale. Your generosity was greatly appreciated. We couldn't have managed it without the truck. Thanks to the Durham Lupus group for the loan of tables and canopy and Laverne Nimigon for the transportation.



Lupus Ontario Yard Sale

On a more somber note, we have noticed that our general donations are down and we are keeping costs as low as possible. We will do a mailing in August and also will have a 2012 Calendar available "**Butterflies for Lupus**" in a CD type case for sale. Please remember every penny counts with Lupus Ontario and give generously if you are able. Donate online @ [www.lupusontario.org](http://www.lupusontario.org) or by calling 1-877-240-1099

Research Continues to Fuel our Hope for a Cure

### IN THIS ISSUE

- President's Message
- Keeping you in the loop!
- Ignite your Passion
- Durham Walk for Lupus
- Events, Events & more Events!
- Upcoming Events
- Ready for a Challenge
- iGive.com
- HBC Rewards
- Shoppers Optimum Points
- Contact Information

# Keeping you in the loop!

## Are You Making These 6 Medication Mistakes?

By Jaclyn Law

Like many people with lupus, I take several medications to manage my disease. And, even though I've been doing this for nearly half of my life, I occasionally goof—I run out of pills or lose track of my doses (“Did I take my drugs this morning?”). I bet I'm not alone, so I asked Delia Brereton, Shoppers Drug Mart Associate Owner in Parry Sound, Ont., for advice on common medication mistakes.

### **Mistake #1: Not following doctors' instructions**

This is by far the biggest problem, says Delia. She sees many people who take too much or too little of a drug, or take it more or less often than they should. Still others don't take a drug for as long as prescribed, or they follow a friend's advice instead of their doctor's. “Not all things work for all people the same way,” cautions Delia.

In all of these situations, there is the potential for medication failure; patients' symptoms aren't alleviated, or they experience side effects. If you're fuzzy on any details related to your medication, or you have concerns about your drug regimen, talk to your doctor or pharmacist. Do *not* make adjustments on your own.

It's also a good idea to find out what to do if you miss a dose—different drugs have different recommendations.

### **Mistake #2: Sharing medications**

Some people take someone else's drugs because they can't afford to buy their own. “People think their husband or wife takes similar meds, so they'll take those. It happens all the time,” says Delia.

Sharing medications is a dangerous habit; only take those prescribed to you. If you can't pay for prescriptions, ask your doctor or pharmacist about funding options.

### **Mistake #3: Mixing up meds**

“When you have multiple medicines, common mistakes include taking the wrong one, or not remembering which ones you've taken,” says Delia.

To reduce errors, organize your drugs in an inexpensive Dosette, available at the pharmacy. There are different sizes, and they have labels such as the days of the week and times of the day. Your pharmacy may also package drugs in strips or blister cards to help you keep track.

### **Mistake #4: Mixing over-the-counter or herbal products with prescription drugs**

Tell your doctor and pharmacist if you're taking non-prescription therapies—they can identify potentially harmful drug interactions. Before starting new supplements, ask for advice; don't assume that just because something is “natural,” it has no side effects.

### **Mistake #5: Running out of medication**

If you often forget to order refills—or you tend to wait until the last minute and cross your fingers in hopes that the pharmacy has your drug in stock—you need a better system. If your drug-store has a reminder service, sign up for it. If not, add “order medication” to your day planner, calendar or smartphone.

### **Mistake #6: Not being informed**

If you have a question about your drugs or your health condition, ask! “If you're silent, you're not going to get an answer and you're not going to be informed. You need to take that step and ask—and don't be afraid to accept help,” says Delia. “Sometimes when patients are diagnosed with lupus and they don't know enough about it, they may be afraid to ask...but if they don't use the resources they need, they're not going to better their health. Knowledge is power.”

## ACT/UCT 2011 FLEA MARKETS

In support of Lupus Ontario



**Where:** 441 Gibb Street, Oshawa (In the Canadian Tire parking lot)

**Time:** 8:30 a.m. to 4:30 p.m.

**Dates:** Monday September 5, 2011 (Labour Day)

Monday October 10, 2011 (Thanksgiving)

## New Combination of Antibodies May Better Predict Childhood Neuropsychiatric Lupus

The role of measurement of serum autoantibodies in prediction of pediatric neuropsychiatric systemic lupus erythematosus.

Authors: Mostafa GA, Ibrahim DH, Shehab AA, and Mohammed AK. (2010). *Journal of Neuroimmunology*

Reprinted from: *Lupus Foundation of America* [www.lupus.org](http://www.lupus.org)

### What is the topic?

Neuropsychiatric lupus (NPSLE) is difficult to diagnose and can be present when disease activity in other organs cannot be identified. Gangliosides are fats on the outer covering of cells and are found throughout the brain. Some people can make antibodies (immune proteins) that target one of these fats, called ganglioside M1.

### What did the researchers hope to learn?

The researchers hoped to learn whether antibodies to ganglioside M1 could predict childhood NPSLE any better than standard laboratory measures currently in use.

### Who was studied?

The researchers studied 30 children with lupus (24 girls and 6 boys) between the ages of 8 and 16. For purposes of comparison, 30 healthy children with no immune or neuropsychiatric disorders were also included. Children who clearly had NPSLE at the start of the study were not included since the idea was to see if the test for antibodies would predict the onset of NPSLE.

### How was the study conducted?

All of the children with lupus were given the steroid treatment prednisolone (0.5 mg/kg/day), either alone or along with other immune-suppressing drugs such as intravenous cyclophosphamide. The children were tested for symptoms of NPSLE and overall lupus disease activity. Blood was drawn from each study participant to assess anti-ganglioside and anti-ribosomal P antibodies. Patients were then examined and tested for brain function (neuropsychological tests) every month for one year.

### What did the researchers find?

12 of the 30 children with lupus developed some clinical evi-

dence of NPSLE during follow-up. Children with NPSLE had significantly higher anti-ganglioside and anti-ribosomal P antibodies than did healthy children or children with lupus that did not develop NPSLE. At the time of initial evaluation (and before NPSLE developed), 83% and 50% of children who later developed antibodies, respectively. Both antibodies were found together in 33% of those patients. All patients who developed NPSLE during the study follow-up had at least one of the antibodies. None of the 18 patients who did not develop NPSLE had either one of these antibodies.

Children with higher levels of anti-ganglioside M1 antibodies seemed to have weaker results on brain (neuropsychological) tests. A similar trend was observed for children with higher levels of anti-ribosomal P antibodies, but this finding was not statistically confirmed.

In children with lupus, overall disease activity level was not statistically related to levels of either anti-ganglioside or anti-ribosomal P antibodies. Levels of anti-nuclear antibodies or antibodies to double-stranded DNA were not statistically related to clinical evidence for NPSLE.

### What were the limitations of the study?

This small, preliminary study suggests that children with lupus may have anti-ganglioside M1 and anti-ribosomal P antibodies before developing NPSLE. This does not prove cause and effect and should be confirmed in a large group of children with lupus.

### What do the results mean for you?

This study found that anti-ganglioside M1 antibodies might help to predict NPSLE in children with lupus, especially when paired with anti-ribosomal P antibodies.

## Did You Know....

### ... 15 percent of people with lupus develop the disease late in life?

It is not uncommon for both men and women to develop systemic lupus after age 55. And it may even occur for the first time in people in their 80's. The average age of those who develop late-onset lupus is 62.

### ... late-onset lupus affects women and Caucasians more often?

Compared with younger people with lupus, late-onset lupus affects women eight times more often than men. Lupus occurs in all racial and ethnic groups, but compared with younger people with lupus, late-onset lupus affects a higher percentage of Caucasians.

### ... symptoms of late-onset lupus are not as serious as lupus in younger people?

The most commonly reported symptoms are muscle aches, arthritis, chest pain with deep breathing (pleurisy), inflammation of the sac around the heart (pericarditis), and dry eyes/dry mouth (secondary Sjogren's syndrome). But other symptoms typical of lupus, such as nephritis, may occur.

### ... lupus is less active in older people?

Those with late-onset lupus can usually manage their symptoms with minimal medication. However, because these older individuals may already have medical problems, the impact of the disease (and the medications used for it) may be significant; thus, careful follow-up is needed.

# Ignite your *PASSION!*

October is Lupus Awareness month and Lupus Ontario is requesting your support to bring more awareness to this under recognized disease.

Invite your workplace and your local businesses to show how passionate they are about finding a cure for lupus. Once you have their commitment pick a date in October and start the creative ball rolling. See below for suggestions and more details.

**Let's help those with lupus live longer and live better!**

## Dress in **RED** fundraising ideas:

Donate and wear red for a day  
Red hair/Red highlights/Red wig  
Bake sale with red goodies  
Ugliest red tie contest  
Car wash  
BBQ  
Potluck  
Pumpkin carving contest

*Challenge your  
neighbouring business!!!*

## *Be creative!*

Customize a poster to promote your fundraising day

Keep pledges available for donations

Ask Lupus Ontario for a donation box to keep in your business for the month of October

Make a personal donation to show your support

Ask your employer to make a "matching gift" donation



**YES!**

Our organization will be participating in "Dress in Red for Lupus"

\_\_\_\_\_ (provide date)

Organization's Name: \_\_\_\_\_

Dress in Red Coordinator: \_\_\_\_\_

Street Address: \_\_\_\_\_

P.O. Box: \_\_\_\_\_ City: \_\_\_\_\_ Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_

Number of pledge forms required: \_\_\_\_\_ Coordinator's Signature: \_\_\_\_\_

By mail Lupus Ontario  
2900 John St. Suite 301  
Markham, ON L3R 5G3

By fax 905-415-9874  
By phone 1-877-240-1099 or 905-415-1099  
By email [nwright@lupusontario.org](mailto:nwright@lupusontario.org)

*Thank you*

For making Lupus Ontario your charity  
of choice throughout the year

Charitable tax receipts will be issued for donations of \$20 or more.

**Please make all cheques/money orders payable to: Lupus Ontario**

Charitable Registration #88333 1472 RR0001

## My experience with lupus

By: Richard Wu

I was four when my father bought me my first box of crayons. It had only four basic colors, but that didn't matter. Each day, I would sit at my desk for hours, wielding each crayon like a wand, casting appealing colors onto my rather unappealing, formless drawings. And if there's one thing that I absolutely hated, it was losing my crayons. A blue sun just doesn't look that warm and a yellow field of grass just doesn't look that safe.

Eight years of professional art class eventually taught me the techniques I needed to refine my drawings. I was eventually selected to design school uniforms for my junior high. This time, I had a box of seventy-two crayons. But regardless of how many I had, or how refined my techniques were, losing any crayon would drive me nuts because each color has its blank space to fill; and each filled space gives the



This early interest in art eventually becomes ingrained to more than just a hobby, but an eventual artistic lens on life that helps me march through its difficulties. In March of 2008, in the midst of my final year in high school, I was diagnosed with Systemic Lupus Erythematosus. For an art fanatic who always aspired to become an architect, I was not prepared for the changes that the words "autoantibody" and "Reynaud's" were about to bring. It started from the body. Being a competitive badminton player in high school for three years, doctors advised me to refrain from playing due to potential joint damage. I abandoned my hobby of swimming, as my sensitivity to cold will cut off most of the blood to my extremities. Yet what pains the most, are never the Reynaud hands or the swollen joints, but the fear of waking up in the morning into a life that has been robbed of its necessary colors. Because a life without color is just like a box without its crayons, a blue-colored sun never looks warm, and a life that you have no control over will never feel like living. Just five months after, I was told that I should take a year off.

Driven by the same tenacity as the childhood me who treasured my crayons, what quickly ensued was an excruciating experimentation with naturopathic medicine. Apart from the prescribed medications, I plummeted myself into research, and even braved a trip to visit Dr. Sakic's lab to further my understanding of lupus. On Sundays, I would catch the earliest transit to a distant acupuncture clinic. I still remember the first time I laid there. The Zen music in the background was supposedly to relax me, but that first needle was met with nothing but a thick wall of tense muscle. I immediately shook, because it really hurt. My mind raced and I contemplated two options: should I escape from this difficulty to enjoy a momentary comfort, or to patiently endure, neglect the uncertainties and be hopeful that this tradeoff can lead to an eventual improvement of my health. The doctor waited for me to say something, but I shut my eyes and prepared for the second needle. It stung like a bee.

These past three years of consistently choosing that second option have strengthened me with unconditional perseverance and courage in spite of uncertainties. I continued to wage my war against lupus by unyielding to the confines of the disease, gifted myself the privilege to matriculate into university with others of my age. With the problem-based learning of the Health Sciences program, along with my personal experiences, my artistic aspirations slowly eroded to a growing interest in human physiology. And like the childhood me who just found my lost crayons, I would not let go. I continue to develop this new found color of my life by conducting physiological research with Dr. Kunze and Dr. Bienenstock in the Brain-Body-Institute. My first paper was eventually published in FASEB journal shortly after first year and received award of distinction at the CDDW conference. I'm now writing my second paper and being trained for my third project with the team. But, regardless how much I learnt through the science of research, nothing has impacted me more than the patient interactions at the hospital.

I like their stories, I value the familiarity and trust they give and more importantly, I treasure their sharing of their lifelong battle with diseases much more horrifying than my lupus. Yes, the nametag said "volunteer" and the application specified my "roles". But nothing was more enjoyable than to sit down beside an old friend, sharing each other's stories against a deadly disease, and worshipping each other's courage, determination and optimism. Because we both know how much harder it is, when you must walk this journey alone.

My journey eventually brings me to today.

Today, I'm a different me from March of 2008. Today, I no longer play badminton regularly. Today, I still take my medication and occasionally drop in for acupuncture. Today, I'm the executive of four clubs at McMaster, dedicating myself to health awareness and fundraising for health organizations. Today, I have both the pleasure and privilege to write this, retelling a story that I once wanted to hide from all my friends. But if it's one thing that I've learnt through this journey, it's that life is not about keeping score or having that box with the most crayons. It's about finding your own unique set of colors, and using them as much as possible before they run out. And when they do, it takes a combination of perseverance, patience and courage to guide you through this journey full of uncertainties to find your next set of colors, which may just happen to be even more beautiful.

**Lupus Ontario has numerous upcoming events for the remainder of 2011 and even into 2012. If you or anyone you know would like to volunteer their time please contact the Lupus Ontario Office. For students that are in highschool we can help you achieve your 40 hours of volunteer time!**

**1-877-240-1099 | [events@lupusontario.org](mailto:events@lupusontario.org)**

# Durham Walk for Lupus 2011

## DURHAM WALK FOR LUPUS FUN FAIR & SILENT AUCTION



**WALK, RUN, SKIP, WHEEL OR RIDE FOR LUPUS**

5<sup>th</sup> Annual Walk For Lupus, Fun Fair & Silent Auction

**[www.durhamwalkforlupus.com](http://www.durhamwalkforlupus.com)**

Supporting



Lupus Ontario

**When:** Saturday September 10, 2011  
**Where:** Rotary Sunrise Lake Park, Whitby Lake  
**Time:** 9:30am-2:30pm

**To Register - Donate - Sponsor or For More Information**  
Please contact Shannon at 1.877.240.1099 or email  
[durhamwalkforlupus@rogers.com](mailto:durhamwalkforlupus@rogers.com)



*Honouring an Angel  
Ashleigh Prithipaul*



On Saturday May 14th the family of the late beautiful Ashleigh Prithipaul honoured her by hosting their 1<sup>st</sup> Annual Spring Dinner & Dance at Saint Luke's Anglican Church raising \$3500.00. The evening was filled with great food, music, raffle and lots of dancing.

Ashleigh sadly passed from lupus on April 3<sup>rd</sup>, 2010. Ashleigh's family will continue on to fight this battle as they all work together to one day conquer lupus.

A special thank you to Ann James, her wonderful family and their event committee. I would also like to thank Rona, Dennis, Lisa, Oswald, Ladena, William and Austin, Raj and all your extended family and friends.


Not only seeing the bond of strength that your family holds, but feeling it in our own hearts gives all of us around you added faith and courage. We thank you for this.



On behalf of myself, our Durham Support Group and Lupus Ontario, thank you...

Sincerely,  
Shannon Crawford  
Lupus ON Durham Branch

 BUTTERFLY RELEASE 



What a beautiful way to remember and honour our loved ones past  
and present... 

 Release your own butterfly for only \$10   
Together We Will Conquer Lupus...



 Please pre-order by August 1st to [durhamwalkforlupus@rogers.com](mailto:durhamwalkforlupus@rogers.com) 

# Events, Events & more Events!

## **Ambitious high school student Bronwyn Lefebvre plans fashion show to raise funds for Lupus Ontario and raises \$11,000**



**You're currently spearheading an ambitious fundraiser for Lupus Ontario. Why is this cause so important to you?**

I've been living with Lupus since the age of five and every year my school puts together a fashion show to raise funds for a desired charity, so I wanted to take this opportunity to raise money and awareness for Lupus Ontario.

In a way this event has allowed me to grow and realize that I am not the only one who is struggling with this disease. Once I started planning the event and placed my story in local papers and had my logo in Lupus Ontario's newsletter, I began receiving emails from various women who also suffer from Lupus. They gave me their support and congratulated me on my efforts with the organization.

I'm planning this show not only for myself, but for the millions of others who are also suffering.

At first my school was apprehensive about allowing me to pursue running the show, because in the past, runners have not raised money for the charities, but in the end they gave in. My teachers haven't been quite as supportive as I would like, and there have been phone calls home and to the guidance counselor because I've been working so hard with the fashion show; however, I catch up on weekends with the work I've missed. For peers, they have supported me 100 per cent and so has my family, which I am very grateful for.

As the event organizer and coordinator, I've been able to delegate tasks to my committee members, and taking on the ones that haven't been completed myself, hosting modeling auditions, designing the logo and information package, planning the show, contacting various stores and local businesses who are interested in either showcasing their styles or sponsoring the show, collecting donations, running errands, setting up music... It's definitely been a busy seven months but I wouldn't change anything and am excited to see how it will all turn out.

**How has having Lupus affected your everyday life?**

Lupus is a disease that causes the body to not understand the difference between good cells and bad cells, so it attacks itself. When the disease is active (known as a flare) it can attack and affect any organ in the body.

For me, it has affected my heart, blood and brain. I'm not allowed to live a normal life like many teenagers my age. I often feel as though I never had a childhood because I was constantly in and out of the hospital, and the disease has caused me to suffer short term memory, making studying for tests and exams much more challenging.

**Tell us a little bit about Voyage, St. Matthew High School's fifth annual fashion runway show.**

Voyage Fashion Show will be a night to remember with fashion from a variety of stores, designers and performance talent. Mix all that with good music and company and you get St. Matthew High School's traditional event that will blow everyone away!

Stores to look forward to are: MEXX, Bluenotes, Costa Blanca, Joe Fresh, Christine's Bridal, West 49, Stella & Dot Jewelry, Moore's TipTop and Marka's Boutique, plus various designers from our very own student body including 1086, Diamond Gold and Jenny, and Megan & Raeanne Designs. Musical talent will include Ottawa's very own Mike Kleff, Matthew McGeein, St. Matt's Glee Club and Cheer team and another acoustic performance by Alenka, Breanna and Carl.

**What are you hoping will come from this event?**

I'm hoping to raise over \$4,000 for Lupus Ontario and to make a fundraising name for my high school. This has been my dream to run the fashion show since grade 10, so I am hoping that all my work will pay off. The money raised will help those with Lupus live longer and better by delivering vital support, education, awareness and research.

**Has the Ottawa community been very supportive of your cause?**

I've learned you really need to be a salesperson in order to gain interest towards an event. Generally my close circle has been supportive but it's been hard trying to reach out to the community.

**At Local Tourist Ottawa, we like to celebrate the best of what the Nation's Capital has to offer. Can you tell us about your perfect day in Ottawa?**

I love downtown. I absolutely adore the environment it has to offer: shopping, yummy restaurants and everything I could ever ask for. Some of my all time favourite places to shop would be Aritzia, MAC, Club Monaco and Jacob. Throw all those stores together with some delicious mussels from Mangia and some gelato from Picolo Grande and you have my perfect day.

*Lupus Ontario would like to thank Bronwyn Lefebvre and all of those involved in the Voyage Fashion Show! Your hard work and dedication to helping those with lupus live longer and live better is truly appreciated!*

## Charity Barbecue

Julie and Mike Woelfle, owners of the Belwood Country Market, prepare a delicious burger for one of their many customers at the fourth annual Charity BBQ recently.



Julie & Mike Woelfle

There was also face painting and balloon animals for the kids at the mid-day event. The barbecue proceeds plus donations, totalling more than \$1000, was directed to Lupus Ontario for medical research. The Woelfles appreciate the contributions of their many suppliers, and the community who helped make the event a success. Lupus is a life altering and sometimes fatal autoimmune disease that can affect virtually any system in the body.

*News Express Correspondent / Wayne Robson  
News Express Fergus-Elora June 8, 2011*

## Our Lady of Peace Fashion Show

On May 26<sup>th</sup> Our Lady Of Peace Elementary School in Oakville, Ontario, held their 3<sup>rd</sup> Annual Fashion Show in support of Lupus Ontario.

During this event there was live music from students from grades 4-8. The musicians show cased there talent on guitar, drums and vocals.



Paige Cassidy & Erica Witt

The event also included complementary food and beverages served by OLP's very own student council with students modeling fashion from Triple Flip, The Bay, Sears, and Savvy Kids. The night was a huge success with an overwhelming turnout. In regards to the show, the students raised money for Lupus and raised an amazing \$1,730 for Lupus Ontario, the most raised in OLP's fashion show history! The reason why they chose lupus was because a young student named Jocelyn Fletcher was diagnosed with Lupus at a very young age. They decided it would be wonderful to have an evening in support of her. Jocelyn spoke at the fashion show and with her amazing story left audience in tears. Our Lady of Peace would like to thank Lupus Ontario's Nicole Wright for her attendance and also speaking. It was a great addition to the show!

*Article by Paige Cassidy and Erica Witt*

**This October**, Lupus Ontario and The SickKids Foundation will bring children living with Lupus together to lighten up their lives and help them deal with this life altering disease that affects their life on a daily basis. The purpose of the Butterfly Masquerade Ball is to show the children they are not alone in their healing process and to provide them with a positive support system. This event will also be open to children who have friends or relatives with lupus.



"We are honoured to have an event especially for children living with Lupus," said Juanita Butler, chairperson of the Butterfly Masquerade Ball. "The event will allow children living with Lupus to recover lost friendships and social cultural practices and traditions they were unable to learn during their time of treatment."

The Butterfly Masquerade Ball is intended to raise funds for research to find a cure for Lupus. The event is a Halloween costume party with food and beverages available including fun activities for the children as well as prizes to be won.

Lupus Ontario is the largest provincial voluntary organization dedicated to improving the lives of people living with lupus through advocacy, education, public awareness, support and research.

**Date:** Saturday October 8, 2011.

**Time:** 1 p.m. to 5 p.m.

**Location:** Thornhill Community Centre at 7755 Bayview Avenue, Thornhill, Ontario.

**Cost:** \$10.00 each

If you are unable to attend the event, please consider sponsoring a child for only \$10.00 who may not have the opportunity to attend this event. You can sponsor a child yourself or in honour/memory of a special person. Add the name to the butterfly and mail it along with your \$10.00 (per child) to Lupus Ontario. A wall will be dedicated at the Butterfly Masquerade Ball to post the sponsored butterflies. Help us help those with lupus live longer and live better.

**Please mail Ticket purchases and Sponsored Butterflies to:**

Lupus Ontario  
Juanita Butler  
2900 John St., Suite 301  
Markham, ON L3R 5G3

For more information please visit [www.lupusontario.org](http://www.lupusontario.org) or call 1-877-240-1099

You may also email Juanita Butler at [info@lupusontario.org](mailto:info@lupusontario.org)

Act as if what you do makes a difference. **It does.**

*William James*

## Giant Pillow Fight for Lupus

Feathers were flying in Almonte, Ontario on April 30, 2011 as UNPOSED Photography hosted a Giant Pillow Fight with proceeds to Lupus Ontario. All had fun, as 50 people of all ages chased their family and friends around the room.

Custom pillow cases were designed for the event and sold in advance for \$8 each at local stores. Fifty pillow cases were sold. Combined with the proceeds from a 50/50 draw a total of \$553 was raised.

Following the pillow fight, two family movies were shown: Despicable Me, and Tangled. The movies were occasionally interrupted by enthusiastic children still keen to squeeze in one last pillow fight.

Many thanks to Lisa O'Kane who made a presentation on behalf of Lupus Ontario at the event. Lisa is an absolute inspiration, balancing her struggles with Lupus with an extremely busy life and two small children. Many thanks also to the local businesses who helped out with the event: Tag Along Toys in

Kanata, Blackbird Gift Shop in Almonte, Arts Carleton Place, Heather Moxley Nutrition Counselling, Dennis Morrow Photography, and Ottawa Valley Cakes.

The event was hosted and sponsored by UNPOSED Photography of Carleton Place, Ontario. UNPOSED Photography was recently recognized by readers of Ottawa Metro as one of the top 5 photographers in the Ottawa region. The idea behind UNPOSED Photography is simple. Rather than traditional posing, people of all ages just play and have fun. And what could be more fun than a giant pillow fight!

A photograph from the event is below, as well as two examples of work by UNPOSED Photography including an image of Lisa O'Kane coping well as always!

For more information about UNPOSED Photography, please visit their website at [unposed.com](http://unposed.com) or on facebook at [www.facebook.com/UNPOSED](http://www.facebook.com/UNPOSED).

Image of pillow fight event courtesy of Peter Wright. Additional images courtesy of Robin Andrew, UNPOSED Photography.



## Living Well with Lupus

I'm writing this article in Chibougamau, QC awaiting my flight to Montreal where I then have a connecting flight to Toronto. There my wonderful husband will pick me up at the airport and we'll drive home to Brantford, ON. I just finished a week of teaching motivational and art therapy workshops in Waswanipi, QC at the Sabtuan Regional Vocational Training Centre.

It's my greatest challenges living with Lupus that inspires my passion for the work that I do. When I look back on my life's journey, I was diagnosed with Lupus (SLE) at the age of 40. Frustrated with the unpredictability of this disease of a thousand faces, I got depressed. Unable to work due to lupus I was grateful for the financial support I received from CPP Disability. This new chapter in my life with Lupus gave me appreciation and gratitude for the things that we can so often take for granted when we are well.

Now at the age of 52 and blessed to be in remission for 5 years, my life with Lupus has been a journey of challenges, celebrations and lessons learned. After a career in advertising and teaching, three years ago I opened my business "Motivation Through Inspiration". I am honoured to now have over 40 clients across Ontario and Quebec sharing a positive message. I consider myself living well with Lupus and although my career is busy I maintain balance with healthy living. Where you are now is based on everything that has happened in the past but where you are headed hasn't happened yet so focus on the positive and the best is yet to come. Often we can get caught in a cycle of negative thinking and live our days filled with worry. Attitude is everything in living well with Lupus. Listen to your body for the inner messages it is giving you. Remember to be good to yourself, take time to rest, eat healthy and respect maintaining balanced living to reduce stress. Choosing to be happy not because of your circumstances, but in spite of your circumstances, nothing can steal your joy. That is the secret to living well with Lupus. Lupus will not define my life; it's a new beginning and a choice to live well with the "wolf" in my life.

Article by: Diane Forbes

April 15, 2011



## Synergy for Life—Dance Into Spring raises \$3000 for Lupus Ontario

On April 2nd, Synergy For Life held a dinner and dance in support of Lupus Ontario. Synergy For Life is a newly developed not for profit organization which fundraises in support of under recognized and under-funded debilitating diseases. With one of its founding members and CEO directly affected by the disease, the event was well attended and very personal. The event was held at the Grand Baccus Banquet Hall and Conference Centre in Scarborough, Ontario. With over one hundred people in attendance, the event was a success. The night was mastered by Rochelle Dickenson, the CEO of Motivated Moms. Toronto Professionals Inc provided an excellent silent auction. Kevin Herod provided a comedied performance in support of the cause. Several generous donations were made by sponsors such as Sirius Satellite Radio Canada, Ste. Anne's Spa, the Wine Rack and Blockbuster to name but a few.

All proceeds will go directly to Lupus Ontario to fund and support research towards a cure. With over \$3000 in contributions and donations Synergy For Life is a proud sponsor.



Abigail Grimes & Michelle Agard  
from Dance into Spring



Grand Baccus Banquet Hall

## Upcoming Events in Support of Lupus Ontario

September 10, 2011	Durham Walk for Lupus
September 10, 2011	Bolton BBQ at Prudential Real Estate
September 17, 2011	Koski Kup Ball Hockey Tournament at Withrow Park in Toronto
Month of October	Lupus Awareness Month
October 8, 2011	Butterfly Masquerade Ball at the Thornhill Community Centre
October 16, 2011	Scotiabank Toronto Waterfront Marathon (see pg 14)
October 20, 2011	Bowl for Lupus in Ottawa at Walkley Bowling Centre
November 12, 2011	Italian Dinner at the Riviera Parque (see pg 11)
January 28, 2012	Dance for the Cure at the Terrace Banquet Hall
May 2012	Walk for Lupus in Communities throughout Ontario
May 10, 2012	World Lupus Day

If you are interested in hosting a third party event in support of Lupus Ontario please contact Nicole Wright [events@lupusontario.org](mailto:events@lupusontario.org) | 1-877-240-1099 for more information.



### *Thank You!*

Over **2000 participants** in more than **25 communities** across Ontario raised more than **\$155,000**.

Your support and participation will continue to fund research and help those living with lupus in your community.

We could not do this without your generosity.

*Please look for the Walk for Lupus Newsletter coming out in August 2011 for final results, highlights, pictures and information about*

# RAISIN' IT UP FOR MA DUKES AND FOR LUPUS AWARENESS

By Urbanology Staff of June 5, 2011

[www.urbanologymag.com/2011/06/raisin-it-up-for-ma-dukes-and.html](http://www.urbanologymag.com/2011/06/raisin-it-up-for-ma-dukes-and.html)

"How do you raise it up for your Ma Dukes?" was the question posed to guests arriving to Walnut Studios for Raise It Up For Your Ma Dukes, an art-benefit kickoff organized by ear2muchcollective to generate buzz for Lupus Awareness Month and Mother's Day.

The event was inspired by a visit in February, by Maureen "Ma Dukes" Yancey, mother to the late great producer J Dilla, who passed away in 2006 to his illness. Artwork all over the studio displayed memories of Yancey's brief visit in Toronto in an effort to highlight Mother's Day and shed light on the disease.



Admirers of J Dilla packed Walnut Studios and the crowd was receptive of the streeter done on how people raise it for Ma Dukes. With live music, open bar and stunning art, it was a feel good environment to raise awareness.

"We all need to be aware of a disease like lupus, that silently is killing off so many people," says Najat Mahammed, member of the ear2muchcollective.

Nana Gyamfi-Kumanini Jr. a.k.a. DJ Nana, was also spotted in the crowd. Nana, who has been doing Dilla related events and parties for the last two years donated all the proceeds to lupus research. Member of the collective himself, he shared how he got around to meeting J Dilla's mother.

"I'm very suspicious of charities. I did all my digging to find out how I could get in contact with her. We created a bond, instantly," says Nana.

Over the course of phone calls and e-mails he came to find out that she had never been to Toronto before.

"Me being a Dilla fan and knowing she never been here... Off the strength of that, I said I have to fly you out," Nana explained.



Nana and his team had her down for about a week where she did interviews and meet-and-greets. It is from that, that they decided to put together a short film that will be released in the near future. A small teaser of an upcoming documentary of Ma Duke's experience in Toronto was shown at the fundraiser.

Part of the proceeds of the art sold at the event will be donated to Lupus Ontario. And the ear2muchcollective hopes to host a similar event geared towards mothers annually in May.

Words By. Ranjit Dhatt + Photos By. Fitzroy Facey

## DONATE NOW feature at [www.lupusontario.org](http://www.lupusontario.org)

Lupus Ontario has implemented a new "Donate Now" feature on our website. It's quick, easy and safe!

- Click on the "Donate Now" button
- Select the "Donation Type"
- Select "Gift in Honour" or "Gift in Memory" (if applicable). Cards will be mailed to the recipient by Lupus Ontario
- Fill out the donor information
- Fill out the payment information (secured)
- All donations over \$20.00 will be issued a tax receipt

# Ready for a **Challenge?**



## Support **Lupus Ontario**

**Make your Waterfront Marathon, Half Marathon or 5k more meaningful** by going the distance for Lupus Ontario. Run or walk in honour of a loved one or to simply give something back to your community. No matter which distance you participate in, your fundraising makes a difference!

## Sign-up online to raise funds as part of the Scotiabank Group Charity Challenge! Follow these 3 easy steps and sign up today!

1. Choose **Lupus Ontario** as your official charity at <http://www.torontowaterfrontmarathon.com/en/charity.htm> Some charities offer incentives that may require special discount codes to be entered upon registration. Before registering for your event, please follow the instructions provided by the contact person at your selected charity.
2. **Register online\*** for the marathon, half-marathon or 5k run / walk. This is the easiest way to enter and you will receive an instant confirmation by email. Be sure to select that you are a **Charity Challenge Runner** and enter the discount code (if applicable) provided by your charity captain. You will receive an email confirming your race registration from EventsOnline.
3. **Get Ready to Start Fundraising.** Once you have successfully registered you will receive a confirmation screen requesting you to **CLICK SUBMIT** to allow EventsOnLine to transfer your information over to Artez. Upon Clicking **SUBMIT**, you will be directed to the online fundraising program. You can then edit your personal fundraising page and start collecting pledges for **Lupus Ontario**. The exciting new system allows online fundraising for all our charity partners, plus new interactive features to help you with your fundraising! You will receive an email from your Charity confirming your fundraising registration, which will include your username and log in information. Keep this email for easy access back to your fundraising site — where you can edit your fundraising goal, upload photos and videos, update your message, and send emails to family and friends to ask for their support. This Artez Interactive online fundraising service is entirely **free** to you and the charity, thanks to Scotiabank's sponsorship. This way, every penny you raise goes to your chosen charity. Send invitations to your friends, family and co-workers to support you in YOUR run—for YOUR cause!

### Incentives

- The first 10 participants to register for the 5km, 21 km, or the 42 km will be registered for free!
- BUT if you raise \$750 by race day, we will refund your registration fee! (ask us for details)
- Lupus Ontario running t-shirts will be provided to those who raise a minimum of \$150 by September 9th, 2011.

Register to Walk, Run or Wheelchair the 5km, Half Marathon or Full Marathon and support Lupus Ontario. Sign up with the ARTEZ online fundraising system and create your own fundraising page or download a pledge sheet. Set a personal goal and collect pledges from your family, friends, neighbours and co-workers. Persuade others to join the team. Start fundraising today!

For more information, please call Nicole Wright at 905-415-1099 or e-mail at [events@lupusontario.org](mailto:events@lupusontario.org).

Do you have a personal story about lupus that you would like to share? Please submit your story for consideration for the next Lupus Link.

The deadline for submission is August 31, 2011.

Send to: 2900 John St. Suite 301  
Markham, ON L3R 5G3  
[nwright@lupusontario.org](mailto:nwright@lupusontario.org)

# iGive.com Help Lupus Ontario When You Search OR Shop!

A penny a search and a portion of each purchase will be donated to **Lupus Ontario** for free. How often do you search or shop online?

Whether it is searching online for the perfect Holiday gift or for your personal wish list make **iGive.com** your search engine for products at over 700+ stores. All you need to do is sign up at [www.iGive.com](http://www.iGive.com) and start your search engines! A penny a search and a portion of each purchase will be donated to **Lupus Ontario**. Searching OR shopping means a donation. It's just that free and easy. As an **iGive** shopper, you have access to exclusive coupon codes, free shipping deals, and sale alerts.

Here are just a few of the stores participating in the donation program:

- Aeropostale
- Cheap Tickets
- Kodak Gallery
- Nike
- Sears
- Travelocity.com
- Apple Store
- eBay
- Lancome
- Nine West
- Sheraton
- Toys R Us
- Bath & Body Works
- Expedia.ca
- MattellShop.com
- Old Navy
- Sirius/XM Radio
- Weight Watchers
- Best Buy
- FTD.com
- Microsoft Store
- Payless Shoes
- Sony Style
- Vitamin Shoppe
- Chapters/Indigo
- Home Depot
- Naturalizer
- Scholastic Store
- Starbucks

Make a point of giving.

Donate your Hbc Rewards points to your favourite cause.



Make a point of giving.

Use your Hbc Rewards points to help Lupus Ontario

What if I told you that you could help us make a difference—by shopping?

Well, you can when you join the **Hbc Rewards Community Program**

It's an easy and exciting way to shop your favourite Hbc items and make a contribution to Lupus Ontario.

All you have to do is enrol as an Hbc Rewards member by visiting [www.hbc.com/rewards](http://www.hbc.com/rewards). Once you're a member, you can link your Hbc Rewards account to Lupus Ontario and automatically start contributing your Hbc Rewards points. So that every time you shop at the Hbc family of stores, you can truly make a difference to our cause.

So how do you link your Hbc Rewards account? That's simple. All you have to do is:

1. Visit [www.hbc.com/community](http://www.hbc.com/community)
2. Go to **Donate to a Community Group**
3. Search for our group by entering our Public ID # 2680757
4. Select the percentage of points you would like to donate (minimum of 10%)

If you have any questions or want to learn more about the Hbc Rewards Community Program, visit [www.hbc.com/community](http://www.hbc.com/community). We really think this is a great way to help our great cause and look forward to seeing the results.

**PS. If you join the Hbc Rewards Community Program today, Hbc will give Lupus Ontario 2,000 much needed bonus points up to a maximum of 100,000.**

## Donate your Shoppers Optimum Points

Shoppers Drug Mart offers a charity initiative that can greatly benefit Lupus Ontario.

You can now donate some or all of your Shoppers Optimum Points to Lupus Ontario and help us redeem them for merchandise at Shoppers Drug Mart such as office supplies and fundraising items for auctions, door prizes and raffles. Here's how you can help:

- Visit [www.shoppersdrugmart.ca](http://www.shoppersdrugmart.ca) and click 'Donate Your Points to Charity Today.' A confirmation email will be sent to you as well as to Lupus Ontario.
- Call **1-800-SHOPPERS** and talk to a customer service representative.

\* All Shoppers Optimum Points are transferred to Lupus Ontario as anonymous donations.

All donations received through these programs are anonymous to Lupus Ontario. Therefore, we would like to take this opportunity to thank you for your ongoing support.

# Lupus Ontario's Board of Directors

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Website: [www.lupusontario.org](http://www.lupusontario.org)

## Provincial Support Centres

### Toronto & GTA Region

Toronto West Branch & Support Group  
Toronto North Branch & Support Group  
Toronto North Support Group  
Toronto South Support Group  
Toronto Beaches Support Group  
Durham Region Support Group  
Markham Support Group

### Eastern Ontario Region

Ottawa Branch  
Lindsay Support Group

### Central Ontario Region

Barrie and Area Support Group  
Collingwood Support Group

### Northern Ontario Region

Sault Ste Marie Support Group  
Sudbury Branch & Support Group  
Thunder Bay Branch & Support Group  
Dryden Information Group

### Western Ontario Region

London Support Group  
Windsor Support  
Bolton Support Group  
Kitchener/Waterloo Support Group  
Guelph Support Group  
Ridgetown Support/Chatham

### South Central Region

Hamilton Branch & Support Group

### Ontario Teen & Young Adult Support

Please contact Lupus Ontario for information

**For more information on your  
Local Support Centre please contact:**

Juanita Butler, Provincial Support Group Liaison, SSW  
905-415-1099 or 1-877-240-1099  
[jbutler@lupusontario.org](mailto:jbutler@lupusontario.org)

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Fax: 905-513-9516  
Email: [info@lupuscanada.org](mailto:info@lupuscanada.org)  
Website: [www.lupuscanada.org](http://www.lupuscanada.org)

## Member Organizations

### BC Lupus Society

200-1645 West 7th Avenue  
Vancouver, BC V6J 1S4  
Tel: 604-714-5564  
Fax: 604-714-5555  
Email: [info@bclupus.org](mailto:info@bclupus.org)

### Lupus SK Society Inc.

Box 88, Royal University Hospital  
103 Hospital Dr.,  
Saskatoon, SK S7N 0W8  
Toll Free: 1-877-566-6123  
Email: [lupus@lupusssk.com](mailto:lupus@lupusssk.com)

### Lupus Society of Manitoba

105-386 Broadway Ave.,  
Winnipeg, MB R3C 3R6  
Tel: 204-942-6825  
Fax: 204-942-4894  
Email: [lupus@mts.net](mailto:lupus@mts.net)

### Lupus Foundation of Ontario

294 Ridge Rd. N., Box 687,  
Ridgeway, ON L0S 1N0  
Tel: 905-894-4611  
Toll Free: 1-800-368-8377  
Fax: 905-894-4616  
Email: [lupusont@vaxxine.com](mailto:lupusont@vaxxine.com)

### Lupus Ontario

(see contact information at left)

### Lupus New Brunswick

c/o Nancy Votour  
55 Grant St. Apt 17  
Moncton, NB E1A 3R3  
Tel/Fax: 506-384-6277  
Toll Free: 1-877-303-8080  
Email: [lupins@rogers.com](mailto:lupins@rogers.com)

### Lupus Newfoundland & Labrador

P.O. Box 8121, Station A, Kenmount Rd.,  
St. John's, NF A1B 3M9  
Tel: 709-368-8130  
Email: [lupusnfld@nl.rogers.com](mailto:lupusnfld@nl.rogers.com)

### Lupus P.E.I. & Lupus Quebec

Toll Free (In Canada) 1-800-661-1468  
Tel: 905-513-0004  
Fax: 905-513-9516  
Email: [info@lupuscanada.org](mailto:info@lupuscanada.org)

### Lupus Society of Nova Scotia

P.O. Box 38038,  
Dartmouth, NS B3B 1X2  
Tel: 902-425-0358  
Toll Free in Nova Scotia: 1-800-394-0125  
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Lupus Ontario

## Volume 9, Issue 5 Spring/Summer 2011

Published by Lupus Ontario

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Charitable # 883331472 RR0001

ISSN# 1194-8299

### Our Mission:

Lupus Ontario is a team of caring and enthusiastic volunteers and staff who are passionately committed to helping those with lupus live longer and better by raising funds that deliver vital support, education, awareness and research