



President's Message



Hello from Marrakech, Morocco, where we are touring for a few days. Part of me must be a travel bug because I always love seeing new places, people and cultures. This year we have rented an apartment in Nice, France, for January and February. It is part of what I call our "bucket list," the things I would like to accomplish during my life. I have come to realize that "bucket lists" are important as long as they don't involve accumulating "things."

Linda Abel, a Lupus Ontario founding member who passed away a few months back, had a wander bug too and felt it was really important to have a taste of the world outside the comforts of familiarity even if you have lupus. To that end she has left a legacy, a bursary to assist someone with lupus to travel, and we hope it will help us send a young delegate to the next World Lupus Symposium, in 2013.

You should also consider what your priorities are for the coming year(s) and a possible "bucket list." It may include such things as finding an old friend, making an apology, telling someone how much he or she means to you, seeing a new place, or learning to play an instrument or speak in a new language. It could mean digging a well for a community in need or volunteering your time, writing a poem or even writing a book. Narrow it down to immediate and longer-term goals, but start fulfilling it. It will enrich who you are.

I have many people to thank for making my travels possible, especially Karen Furlotte, Juanita Butler, Nicole Wright, and Tom Koor. I was truly sorry to miss the wonderful Dance for the Cure and Dr. Janet Pope receiving the Lupus Ontario Hope Award; however, I can take 20 years of saying "We must go and live in Nice for a few months because visiting for a few days was never enough" off my "bucket list." No regrets.

Back in March!

Cheers, Julia

IN THIS ISSUE

- President's Message
- 2010 Geoff Carr Fellowship Review
- Lupus Day Program
- Keeping You in the Loop!
- Dance for the Cure—Viva Italia
- 25th Anniversary Italian Dinner, Dance and Silent Auction
- Walk for Lupus 2011 (formerly Walk a Block)
- Upcoming Events in Support of Lupus Ontario
- Let's Talk Support
- 1st Annual Butterfly Ball
- iGive.com
- HBC Rewards
- Shoppers Optimum Points
- Contact Information

2010 Geoff Carr Fellowship Review

Zahi Touma

Novel Disease Index Generates Hope for Improved Lupus Management

STREAM PhD Clinician Investigator Program

SUPERVISORS Dr. Murray B. Urowitz & Dr. Dafna D. Gladman

Despite being in the city for less than four years, Dr. Zahi Touma has helped uphold the University of Toronto's reputation of excellence in clinical research. For the first time in decades, Touma and colleagues have given hope to lupus sufferers regarding treatment development with their novel outcome measure of the disease's activity.

Following medical training at Kursk State Medical University in Russia, Touma completed three years of internal medicine training at the American University of Beirut in his home country of Lebanon. It was during a subsequent sub-specialty in rheumatology that he began to identify areas of lupus management in need of improvement. "Over the last two decades or so, we haven't had any drugs approved by the FDA for lupus treatment," notes Touma. "There are lots of trials going on, but [no drugs] have been approved yet. I looked at [the] studies and realized it may not actually be because of drug failure, but rather that we don't have appropriate measures to evaluate how disease activity is progressing."

Touma's research interests progressed when he was accepted as a rheumatologist by the Department of Internal Medicine in 2007. Six months later, he joined the Institute of Medical Science to embark upon his PhD project. "I didn't come to the IMS directly, but I knew [I wanted] to investigate clinical epidemiology, and specifically, clinical outcome measures," he explains. Under the guidance of his supervisors, Touma has been able to develop a reliable index – the SRI-50 – with the ability to capture partial improvement in lupus disease activity, an achievement that distinguishes it from pre-existing indices.

"Over the last two decades or so, we haven't had any new drugs approved by the FDA for lupus treatment."

To validate the index, the research team continues to collect data for their prospective study at the University of Toronto Lupus Clinic by applying the SRI-50 during clinic appointments. They are also investigating implementation strategies to assist physicians keen on incorporating the tool into their practices. Moreover, at least two drug trials have already adopted the SRI-50 as a secondary outcome measure, and several other drug companies have expressed interest in utilizing the index for future studies.

Touma attributes the rapidity of the SRI-50's initial success partly to the large patient cohort he is able to access through the U of T Lupus Clinic, one of the world's biggest centres for specialized lupus care. He is also quick to recognize those who have supported his research along the way. "My supervisors are great, and the lupus team is excellent. I also have to acknowledge the people who have been funding my stay here – [the Lupus Ontario Geoff Carr Fellowship and the University of Toronto Arthritis Centre of Excellence Fellowship]. I am extremely grateful."

Ultimately, Touma intends to delve deeper into the field and develop another novel index related to disease activity. His passion for improving the care received by his patients is the kind that drives innovative discovery with practical, clinical applications.

Interview by Nina Bahl

IMS Magazine – Winter 2011 Edition

Further reading regarding the SRI-50:

Touma Z, Gladman DD, Ibanez D and Urowitz MB. Development and Initial Validation of SLEDAI-2K (Systemic Lupus Erythematosus Disease Activity Index 2000) Responder Index (SRI-50). *J Rheumatol* July 12, 2010. (In press).

<http://www.ncbi.nlm.nih.gov/pubmed/21123323>

Touma Z, Gladman DD, Mackinnon A, and Urowitz MB. SLEDAI-2K Responder Index- 50 (SRI-50)

<http://www.sri-50.com>



Dr. Zahi Touma

Lupus Day Program

What is it about?

The Beryl and Richard Ivey Programs at St. Joseph's Hospital in London, Ontario, are for people who have rheumatic diseases. One of these programs is for those with Systemic Lupus Erythematosus.

As a participant in the program, you will learn more about lupus as well as ways to cope with and manage your symptoms. The goal of the program is to help you improve your quality of life.

Education and group sessions are provided for family members of participants. The goal of these sessions is to assist families to better understand the participant's condition and support them as they implement their new self-management techniques.

How much time is required?

You are expected to be available on a full-time basis, Monday to Friday, 9 a.m. to 4 p.m. for the two weeks of the program.

After this intensive phase, participants may continue to attend outpatient physiotherapy and occupational therapy, if this would be beneficial.

How do I get involved?

Step 1: A referral from your physician or therapist from the Rheumatology Centre to the program is required.

Step 2: Arrangements will then be made for you to come in for an intake assessment. This assessment will take approximately one hour. This will be an opportunity for you to learn about our programs and ask any questions you may have.

Step 3: After finishing the intake assessment, you must pre-register. If the next group is full, your name will be placed on a waiting list for the next available session.

Who will I see?

The Lupus Day Program is a comprehensive treatment program that combines treatment services provided by various health care professionals:

- Occupational therapists
- Physiotherapists
- Psychologists
- Social worker
- Rheumatologists
- Nurses
- Pharmacist
- Nutritionist

Where will I stay?

If you live outside London, inexpensive accommodations are available at several locations near the hospital.

Before entering the program, you will be provided with information regarding accommodations, costs and how to make reservations.

It is your responsibility to arrange accommodations prior to entering the program.

Who is eligible?

In order to attend the program, it is necessary to:

- 1) Have a confirmed diagnosis of Lupus
- 2) Your physician or therapist must complete and submit a referral form

Referrals from therapists outside the Rheumatology Centre must be made in conjunction with a family physician.

What will I do?

Each day in the program will involve a structured series of sessions or activities in which you will learn skills to manage your lupus.

Group sessions will involve the following areas:

- Lupus education
- Medical tests and symptom management
- Medications for Lupus
- Coping with chronic illness
- Dealing with fear and uncertainty
- Relaxation techniques
- Pain education and management
- Body image and self-esteem
- Joint protection and hand care
- Lupus and sexuality
- Relaxation training
- Relapse prevention
- Stress management/cognitive therapy
- Family education sessions
- Support services workshop
- Safe/effective water and land exercises
- Improving function
- Community resources available
- Energy conservation/fatigue management
- Proper body mechanics and ergonomics

Location:

The Lupus Day Program is located on the 3rd floor of St. Joseph's Hospital's Monsignor Roney Building, Room K365.

For more information:

St. Joseph's Health Care Centre

519-646-6340

www.sjhc.london.on.ca

Dr. Warren Nielson from the Lupus Day Program has created a CD called "Relaxation Instructions." The CD is available for purchase through Lupus Ontario at a cost of \$15.00.

1-877-240-1099

Keeping You in the Loop!

How to multiply the power of your **charitable donation**

While you're contemplating the gifts you're going to give to family and friends this year, don't forget about giving to those charities that are aligned with your values. And if you're going to give to charity, why not do it in a manner that really multiplies the dollars you are donating, to have an even greater impact?

Charitable Arbitrage

What I'm talking about here is charitable arbitrage. That is, creating a gift to charity that costs you much less than the dollars actually received by the charity. Now, make no mistake, simply the act of claiming a donation tax credit (or tax deduction in the case of corporations) provides a certain level of charitable arbitrage. Consider this: You make a donation of \$1,000 to a registered charity. You claim a donation tax credit for the \$1,000 gift and save, say, \$450 in taxes as a result (roughly the Canadian average for someone in the highest marginal tax bracket).

The end result? The charity receives \$1,000 in cash to use, while it cost you just \$550 (\$1,000 less the tax savings of \$450). By claiming the donation tax credit you're causing the federal and provincial governments to partner with you in making that gift.

Are there other ways to create more cash for charities than it will cost you out-of-pocket? Sure.

Donating Flow-Throughs

Consider donating flow-through shares to charity. (Flow-throughs are a special class of share issued by junior mining companies that give investors an immediate tax deduction.) Suppose, for example, that you invest \$10,000 in flow-through shares. You'll generally be entitled to a tax deduction for \$10,000 in this case, with the deduction coming largely in the first year, and the small balance generally in year two. This will save you \$4,500 assuming a marginal tax rate of 45 per cent. Under our tax law, your adjusted cost base in the shares will be deemed nil in this case (so you will have a capital gain later when you sell).

Now, if you were to donate those flow-through shares to charity for the same \$10,000 value after receiving the full value of the tax deductions (generally after two years), you would trigger a capital gain, but our tax law will set the taxable capital gain at nil because you have donated the shares to charity.

You'll also be entitled to a donation tax credit for the \$10,000 value donated to charity in this example. This will save you \$4,500 in taxes at a marginal tax rate of 45 per cent thanks to the donation tax credit. Your total out-of-pocket cost? A mere \$1,000 (\$10,000 less \$4,500 from the deduction and another \$4,500 from the donation) but the charity receives \$10,000.

Donating Insurance

Here's another idea that can make sense. Consider the Joneses. This couple are both 65 years of age, in good health and in a comfortable financial position. The Joneses will purchase a term-to-100 life insurance policy jointly on their lives. The policy will pay out \$100,000 upon the death of the second one. Assume the policy will have premiums of \$1,425 annually, payable until they are both gone. After paying the first year's premium, they will donate that policy to their favourite charity (there is no tax credit for this gift because there is no cash surrender value in this case). Since the charity owns the policy now, the charity knows it will always be the beneficiary of the policy and will collect the \$100,000 death benefit when the second one dies.

Next, the Joneses are going to donate \$23,500 to the charity, which the charity will use to purchase a life annuity on the couple's lives. This annuity will pay out \$1,425 annually, exactly what is needed to pay for the life insurance policy the charity now owns. The couple will receive a donation tax credit for the \$23,500 gift, which will save them about \$10,575 at a marginal tax rate of 45 per cent. The out-of-pocket cost to the Joneses is \$14,350 in this example (\$23,500 less the tax savings of \$10,575 plus \$1,425 for the first year premium).

In the end, the charity receives a fully funded, irrevocable future gift of \$100,000 (albeit in the future) that cost the couple \$14,350. The Joneses are able to make a commitment to the charity today so that it can acknowledge the gift, they receive some tax savings today, avoid probate fees on the insurance proceeds, and set up a planned gift with a one-time transaction that avoids future payments and administration for the couple.

*Tim Cestnick
The Globe and Mail
December 8, 2010*

End of the penny?

Mint ponders coin's demise

The humble Canadian penny, our currency's most diminutive coin value-wise, may soon be extinct.

The Royal Canadian Mint, producers of more than 30 billion one-cent pieces since 1908, is pondering the fate of the copper. The reasons for its possible demonetization include dollars and sense. It costs taxpayers about a cent-and-a-half to produce and distribute a penny. You can't buy anything for a penny nowadays and in the past century, it has lost 95 per cent of its purchasing power, Bank of Canada deputy governor Pierre Duguay said.

Weighty, too, is how pennies tend to proliferate in change purses and pockets and are hoarded in jars, drawers and piggy banks. The Canadian Mint has begun the coin's long goodbye in earnest by consulting officials in Australia and New Zealand, where the penny was retired in 1990.

Still, there seems to be demand for the pretty penny, the 2010 version of which features Queen Elizabeth II in profile on the obverse and a pair of maple leaves on the reverse. The Mint punches out 816 million of them annually.

An informal survey of York Region businesses and consumers would suggest the penny's demise wouldn't exactly be mourned. "Ridiculous," said Richmond Hill resident Max Orzhekhov of the penny's production costs being more than its face value. "I wouldn't miss it." A shrug of the shoulders spoke volumes for Bruce Sheppard, a Beaverton resident who commutes to work in Newmarket. "All my change goes into a jar at home," he said. "It wouldn't make any difference to me one way or the other." Mr. Sheppard is convinced many merchants already round change to the closest nickel. "I don't see pennies as much anymore," he said. "Every morning I get my \$1.52 coffee from Tim Hortons and I get 50 cents change. It make sense to round it off to the nickel." Aurora fast food cashier Mackenzie McMullin would welcome a penniless society. "It would make life easier for me in terms of making change," she said with a laugh. "I deal with a lot of pennies all day long. It would be easier to round it off to the nearest nickel." Sotirat Ros, owner of United Convenience in Newmarket, gave the notion of eliminating the one-cent coin considerable thought. "It may not look important, but it's part of our currency," he said. "It would probably be a problem. If you start to round off to the nickel, and I owe you three cents, I'd lose two cents. I'm always dealing with pennies. They add up."

The Australian government's Prices Surveillance Authority issued guidelines for managing the withdrawal of the one-cent coins from market and to soothe any consumer worries.

For cash purchases, the price is rounded to the nearest five or 10 cents. Purchases with debit and credit cards continue to be made to the exact cent.

The decision to remove the coins had a negligible impact on prices, the Australian Treasury noted.

The Bank of Canada has also surveyed the potential inflationary ramifications of putting the penny out to pasture.

The findings show any impact on inflation would be insignificant and more likely non-existent, Mr. Duguay told a Senate committee in May.

"On some transactions, the merchant loses and the consumer wins; on some, the merchant wins and the consumer loses," he said. "However, on balance, it evens out."

*By Chris Traber
yorkregion.com
July 22, 2010*

Penny by penny...they make a big difference!

Lupus Ontario would like you to donate your pennies and help those with lupus live longer and better lives.

Do you groan at the thought of rolling them from your change jar? Do you hesitate to pick them up off the ground?

Why not donate your pennies to Lupus Ontario?

The benefits of donating your pennies:

- Receipts will be issued of \$20.00 or more
- We will roll the pennies for you

Why not get creative and ask your friends and family to join in on your penny drive. You could even get your community involved. The sky's the limit!

For more information please contact Lupus Ontario
1-877-240-1099 | 905-415-1099
info@lupusontario.org



Dance for the Cure - Viva Italia

Dance for the Cure was held on January 29, 2011, at the Terrace Banquet Centre in Concord, with 700 guests in attendance. This year marks the 16th anniversary of the event with more than \$1 million raised since its inception.

The Italia-inspired evening took us on a journey of cuisine, fashion, design and culture. Guests were treated to a fantastic dining experience, live music, dancing and an exceptional live and silent auction.

Tiziana Tolfo created Dance for the Cure over 16 years ago, and what started as a small gathering of friends and family has grown to become the single largest fundraiser for lupus research in Canada. Tiziana states that "I was diagnosed with lupus over 20 years ago. I could not continue to do this without the support of my family, my friends and my community; the majority of which coincidentally happen to be of Italian heritage. **VIVA ITALIA** is my 'thank you' to all of them."

Barb DiGiulio of radio station THE FAN 590/680 News hosted the evening, which included Lupus Celebrity Ambassador Patrick McKenna, who presented Dr. Janet Pope with the Hope Award. Dr. Pope received this award for her work and dedication to those living with lupus. She has a busy schedule as Professor of Medicine in the Division of Rheumatology at the University of Western Ontario; Division Head in Rheumatology at St. Joseph's Health Centre in London; a member of the Canadian Early Arthritis Cohort; Vice-President of CaNIOS (Canadian Network for Improved Outcomes in SLE); a member of the executive of the Canadian Rheumatology Research Consortium; and also contributes to several advisory boards. She has published over 100 peer-reviewed articles. Dr. Pope always has time for her patients and volunteers her time to respond to questions submitted by lupus patients on Lupus Ontario's website under "Ask the Expert." She gives hope to those living with lupus.

The evening was a resounding success, raising **\$110,000** for lupus. The funds go to support **Lupus Ontario**, the **AARC Foundation**, and the **Paediatric Lupus Clinic at the Hospital for Sick Children** in Toronto.



Dr. Janet Pope
Hope Award recipient

*"What you do for yourself stays
with yourself but
what you do for others goes on
forever."*

-Vivian Risi



Table setting

This event was possible because of the generosity of many local businesses that support the cause. In particular, we want to recognize our sponsors.....**Presenting Sponsor:** Vivian Risi, Royal LePage, Your Community Realty; **Gold Sponsors:** Beaver Valley Stone, Rose Wood Flooring, and Unilock Ltd.; **Silver Sponsors:** Bestway Stone, DeCaria Engineering, Queensway Audi, Rivalda Oaks Kitchens, SF DeMelis Construction; **Print Sponsors:** Sunrise Printing & Clone Graphics, Adverttek Printing; **Airline Sponsor:** Air Canada; **Media Sponsor:** Dolce Magazine

25th Anniversary Italian Dinner

The 25th Annual Italian Dinner Dance was held on Saturday, November 6th at the Riviera Parque in Vaughan. Guests were served an amazing dinner and entertained by special dance performances by Club Viva Dance.

The Donna Chu Award was presented to the Colagiovanni family on the occasion of their 25th anniversary of the Italian Dinner, Dance and Silent Auction.

Honey Agar and Frances Gotkin were each presented with original paintings from Julia Kane for 25 years of service to Lupus Ontario.

This year's Italian Dinner raised over **\$15,000** for Lupus Ontario and topped last year's success.

A special thank you to the Colagiovanni family (Tony, Maria, Christine, Tony, Connie and Chris), Barbara and Frank Nacinovitch, Honey and Roy Agar, Frances and Jerry Gotkin, and all the volunteers and supporters who made it such a memorable evening.



Colagiovanni family (Connie, Tony, Maria and Christine)



Frances, Barbara, Honey, Club Viva Dancers, Julia, Connie and Maria



Julia and Frances



Julia and CaNIOS representative

DONATE NOW feature at 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

Walk for Lupus 2011



What is Walk for Lupus?

Walk for Lupus, formerly known as Walk a Block, is Lupus Canada's single most important annual fundraising and public awareness event. Walk for Lupus began just eight years ago with a small walk in Ontario and has now grown into an event that involves thousands of participants across Canada. Each year we have seen funds more than double, therefore enabling us to improve the lives of those living with lupus.

Lupus Canada will be celebrating its 10th Annual Walk for Lupus event in 2011. The event occurs in communities across the country and serves as a chance for patients, families and friends to come together to raise money and awareness while walking in support of lupus. To raise money, team members collect pledges for their walk either online or offline. There are many ways in which a person can support the Walk for Lupus.

- Join a walk and collect pledges
- Support a walker
- Sponsor a walker
- Volunteer at an event
- Become a coordinator and plan your own walk
- Sponsor the Walk for Lupus at either the provincial or national level

In Ontario there are over 35 walks held across the province in the month of May. Our largest walks occur in Ottawa, Thornhill, Hamilton, Brampton, Toronto, London, Bradford, Barrie and Bolton. In 2010 Lupus Ontario generated 65% of the total gross revenue towards the National Walk for Lupus campaign.

May 10, 2011, will mark World Lupus Day. Walks and other events will take place worldwide to generate awareness of lupus and to raise funds to help support services for people living with lupus.

Celebrities Join Campaign for Lupus Awareness

Debra McGrath currently stars on CBC's *Little Mosque on the Prairie* and was a founding member of the comedy troupe *Women Fully Clothed*.

Colin Mochrie is most recognized for his work on *Whose Line is it Anyway?* and is currently touring with comedic partner Brad Sherwood on the *Evening with Colin & Brad* tour.

Patrick McKenna is best known for playing Harold Green on the television series *The Red Green Show* and Marty Stephens on *Traders*.

All are alumni of The Second City and have been involved in multiple facets of the entertainment industry both in Canada and the US.



"Having lupus directly affecting my family makes it easy to be involved with Lupus Canada—but I stay because of all the fabulous work they do."

Patrick McKenna

"We are involved with lupus because we really believe that with money and focus, this terrible and complicated disease could become a thing of the past."

Debra McGrath & Colin Mochrie

Getting Started

Register online - create your own webpage

- Go to www.walkforlupus.ca
- If you are a returning user, enter your username and password
- If you are a new Walk Fundraiser, click on “register”

By registering you can create your own webpage. Having your own webpage is an excellent way for you and your supporters to track your fundraising progress. Your pages can include a personal note, story or photo and allows you to post updates. Your supporters can donate directly online and they will receive an electronic tax receipt immediately. You can also use this as a way to thank your donors and communicate your fundraising successes.

Register through the Lupus Ontario office

Your team can also be registered through the Lupus Ontario office. Pledge forms and pledge envelopes will be mailed to you upon registration.

Please contact:

Nicole Wright

Fundraising & Events Coordinator

1-877-240-1099 | 905-415-1099

events@lupusontario.org



Corporate Partnership - Why we need your help!

Lupus continues to be under-recognized and under-funded. Your Corporate Partnership is not only a good business investment but an investment in our mission to improve the lives of those living with lupus. By sponsoring either at the provincial or national level, your company can:

- Enhance your company's image and visibility
- Differentiate the company from competitors
- Help develop closer relationships with current and prospective customers
- Showcase products and services
- Unload obsolete inventory
- Compete more effectively against bigger firms that have much larger advertising budgets
- Continue to promote community relations that can help a company achieve visibility as a good community citizen
- Provide businesses access to various audiences, including employees, business decision makers, and government regulators as well as consumers
- Provide a great opportunity for employee involvement, through team building or volunteer involvement

Even if your company cannot make a financial contribution, there are many other ways that you can help keep our expenses low so that more money raised can go to support our mission. This could include: food and food products (coffee, hot dogs, buns, fruit, paper plates, and napkins), media (radio and TV PSAs, and newspaper ads), event supplies (barbecues, tables and chairs), or in-kind services (first aid, photographer or entertainment).

For more information on how you can help, please contact:

Nicole Wright

Fundraising & Events Coordinator

1-877-240-1099 | 905-415-1099

events@lupusontario.org

Let's talk **SUPPORT!**

F eeling

L ousy

A nd

R eally

E xhausted



When lupus symptoms appear, it's called a "flare." These symptoms may come and go. You may have joint pains and a fever one week and no symptoms at all the next. You may find that your symptoms flare after you've been out in the sun or after a hard day at work.

Even if you take medications for lupus, you may find that there are times when the symptoms become worse. Learning to recognize that a flare is coming can help you take steps to cope with it. Just before a flare, many people with lupus may experience some of these symptoms:

- Feel very tired
- Skin rash
- Stomach discomfort
- Headaches
- Dizziness
- Persistent weakness
- Ache all over
- Painful, stiff or swollen joints
- Slight to high fever
- Persistent loss of appetite
- Involuntary weight loss
- Increasing hair loss
- Nose bleeds
- Chest pain that increases with breathing
- Shortness of breath
- Persistent unusual headache
- Nausea or vomiting
- Puffy eyelids
- Blood in the urine
- Abnormal blood clotting problems
- Raynaud's phenomenon (fingers turning white and/or blue in the cold)
- Seizures
- Mouth or nose ulcers
- Fluid retention

Steps to prevent flares, such as knowing your limits, not over-exercising, and getting enough rest and quiet, can also be very helpful.

Tips for dealing with a lupus flare

- Recognize a flare is coming.
- Set realistic goals and prioritize.
- Talk with your doctor.
- Limit time you spend in the sun.
- Get enough rest and quiet.
- Moderately exercise when possible.
- Maintain a healthy diet.
- Develop coping skills to help limit stress.
- Develop a support system by surrounding yourself with people you trust and feel comfortable with (family, friends, etc.).
- Join a support group – visit www.lupusontario.org for more information.

Managing lupus flares

The notion of an ache or pain flaring up – think of the stiff elbow your grandmother gets when there's a storm approaching – is a small annoyance. For lupus patients, a flare can be much more serious and is a reminder that the disease is still with them, no matter how long it has remained quiet.

(Continued)

What causes a flare?

Lupus patients often suffer unpredictable bouts of the disease – a flare – followed by periods of remission. What causes a flare is almost as unpredictable as when the flare will occur, but there are some common catalysts, including sunlight – especially for those lupus patients who are photosensitive – and an illness that does not go away. Stress can also trigger flares in lupus patients.

For those who have not been diagnosed, this continued recurrence of symptoms might be the first clue that lupus is the cause. For patients already diagnosed with lupus, flares may occur less.

How can a flare be prevented?

Treatment plans for lupus help control the onset of symptoms and flares. Those plans may include:

- Physical and emotional rest
- Exercise – light to moderate workouts e.g., yoga, aquafit
- Good nutrition
- Avoidance of direct sunlight and other sources of ultraviolet light
- Speaking with your doctor/rheumatologist
- Joining a support group and talking about how you feel can make a vast difference
- Calling Lupus Ontario for telephone support at 1-877-240-1099

Flares are to be treated seriously; however, they are signs that lupus is active. That is why it is imperative for lupus patients to take care of themselves, as well as understand and follow their treatment plan.

http://arthritis.about.com/od/lupus/ss/doihaveulupus_3.htm

For more information about lupus, please visit our website at www.lupusontario.org.

Juanita Butler, SSW
1-877-240-1099 | 905-415-1099
jbutler@lupusontario.org

Living with Lupus

“There are moments when everything goes well; don't be frightened, it won't last”. – Jules Renard

I think I would have been a kindred spirit with the sardonic Renard, for it is with the same wry humour that I have successfully managed to preserve my sanity. Over the past thirteen years there have been fleeting windows of wellness wherein I have been free of pain, full of life and energy, and ready to conquer the world. Yet remission has been ephemeral, lasting just long enough for me to refuel and fortify myself for the next round of the battle. And when I am well, I am constantly watching over my shoulder, knowing that at any time, without warning it sneaks up on me like a thief, and steals another small piece of my soul. When it is time to wage battle again I'm left wondering for how long, and whether good health will visit me anymore. Welcome to my life with lupus.

This *Disease with a Thousand Faces*, knows as many manifestations as it has victims, and seldom will you hear the same story from more than one. While my own tale is unique in its specifics, the substance of it is much the same as those with whom I travel this path.

I have experienced a life threatening blood disorder, joint pain so extreme that I couldn't walk and at times prayed for death, and countless relatively minor symptoms so varied that I began to feel like I was losing my mind and turning into a raving hypochondriac. I have been so pumped up on prednisone that I would pray for sleep, which would elude me for days until I collapsed from sheer exhaustion. Over thirteen years of fatigue has been my constant companion, to the point that I cannot remember what life was like without it.

Every time I am unwell I wonder how I will possibly get through, yet no matter how dire my circumstances seem, I always manage to convince myself that it could always be worse and I press on, hanging on for dear life until my next remission.

Living with lupus has taught me a lot about gratitude. Every day that I wake up with relatively little pain, I am thankful. For every day that I can walk I am thankful. People have marveled at the pace my life maintains and I am thankful that I don't combat the illness by resigning myself to a subsistence of giving up by lying around saying “I can't”.

I am grateful for Lupus Ontario and its supporters. As recently as 35 years ago a diagnosis of Lupus was a virtual death sentence. And while I manage lupus, I have hope that someday advances in research will allow those who follow me to conquer it. My hopes and dreams WILL someday become reality thanks to you.

Tina Sibbald
December 2010

Tina Sibbald is a Realtor currently living in Bradford, Ontario. Married with 3 kids aged 20, 17 and 14, her Lupus diagnosis came in 1997 and its life altering implications have launched a lifelong journey of self discovery which has led her to embrace as best she can whatever surprises each day brings.

Upcoming Events in Support of Lupus Ontario

February 23, 2011

April 2, 2011

April 2nd & 3rd, 2011

Throughout May 2011

May 21, 2011

June 11, 2011

June 16-19, 2011

June 20 & 21, 2011

September 10, 2011

September 17, 2011

Voyage Fashion Show at St. Matthew High School in Orleans

Synergy for Life presents: Dance into Spring at the Grand Baccus Banquet Hall in Scarborough

Lupus Ontario AGM and Workshops (see details on page 13)

Walk for Lupus in communities throughout Ontario

Belwood Country Market Charity BBQ

Butterfly Ball at the Thornhill Community Centre

Bollywood Awards in Partnership with Swag Bag Inc.

Lupus Canada AGM

Durham Walk for Lupus

Koski Kup Ball Hockey Tournament at Withrow Park in Toronto

SYNERGY FOR LIFE PRESENTS DANCE INTO SPRING



Saturday, April 2, 2011 at 6:00 p.m.

A Semi-Formal Event in Support of Lupus Ontario

Join Us for an Evening of Dinner, Dancing and Live Entertainment

Silent Auction and Wonderful Prizes to be won!

Tickets: \$65.00

\$20.00 tax receipt per ticket purchased

Tickets are available for purchase at www.synergyforlife.ca or through Lupus Ontario at 1-877-240-1099.

Thank you and please help us make this event a night to remember!

Grand Baccus Banquet and
Conference Centre

2155 McNicoll Avenue
Toronto, ON M1V 5P1



Lupus Ontario

Charitable registration #88333 1472



ANNUAL GENERAL MEETING

LUPUS ONTARIO – 2011

Saturday April 2nd, 2011
Lupus Ontario Annual General Meeting
Holiday Inn, Yorkdale

Sunday April 3rd, 2011
Lupus Ontario Presents: SLE Update—Toronto Lupus Clinic at 40
MaRS Centre

Saturday April 2nd, 2011
Holiday Inn, Yorkdale
3450 Dufferin Street, Toronto
Cost \$20.00 (including lunch)



9:30 a.m. to 10:00 a.m.	Registration and Coffee
10:00 a.m. to 12:00 p.m.	Annual General Meeting
12:00 p.m. to 1:00 p.m.	Lunch
1:00 p.m. to 6:00 p.m.	Support Group Leader Workshop

Sunday April 3rd, 2011
MaRS Centre Auditorium
101 College Street, Toronto
Cost \$10.00



12:30 p.m. to 1:00 p.m.	Registration
1:00 p.m. to 3:00 p.m.	Lupus Ontario Presents SLE Update—Toronto Lupus Clinic at 40 Presenting current Lupus Research from around the world

For more information, contact the Lupus Ontario office. You can mail, fax or call in your registration. To attend both Saturday and Sunday the total is **\$30.00**. Please notify us of any dietary restrictions if you are attending the Saturday session.

905-415-1099, Toll-free: 1-877-240-1099, Fax: 905-415-9874

Send to: Lupus Ontario, 2900 John Street, Suite 301, Markham, ON L3R 5G3

Confirmation form for attendees

Name: _____
Address: _____
City: _____ Postal Code: _____
Phone: _____ e-mail (required): _____
Cheque Visa Mastercard
Card #: _____ Expiry date: _____

“Children are one third of our population and all of our future.”

Select Panel for the Promotion of Child Health 1981

SickKids: World-Class Care for Children with Lupus

SickKids is the largest paediatric centre for autoimmune diseases in Canada, with globally recognized expertise in both clinical care and basic research. Among its areas of expertise is paediatric lupus with international leadership provided by Dr. Earl Silverman, a major contributor to the advancement of patient care and understanding of this disease.

Established in 1986, SickKids lupus clinic was the first in a paediatric or adult hospital to create a combined clinic bringing together rheumatologists and nephrologists. It also pioneered the introduction of psychiatrists, social workers and clinicians from adolescent medicine in the care of patients, helping them manage the multitude of concerns related to lupus, such as the side effects of medications used in treatment, impact on one's family, siblings, and personal social life and schooling. This interdisciplinary model has improved patient care and has given children a better sense that they are not alone in combating the disease.

SickKids now has two clinics – Paediatric Systemic SLE Clinic and Neonatal Lupus Erythematosus (NLE) Clinic – treating children from as young as two years old to 18 years in the SLE Clinic and providing care beginning in the pregnancy of mothers of children with NLE and continuing until age 18. As a leading centre for training paediatric Rheumatology and Nephrology subspecialists and specialists in paediatric lupus, the clinic is a mandatory rotation for paediatric residents.

The Clinics currently see over 175 patients and has a database of over 425 patients, making the combined clinics the largest paediatric lupus clinic in the world. The Neonatal Lupus Clinic follows children born to mothers with lupus to monitor these babies for any potential effects of their mother's illness on their well-being and in particular for any heart problems which may be seen in these infants and has now followed more than 250 mother/child pairs.

The size of the patient population in the database enables SickKids to do extensive research and generate new knowledge into the nature of the disease. Clinician-scientists working within the clinic are already among the world leaders in publishing significant lupus findings in the form of articles and research publications. Their research interests include genetics and neonatal lupus, atherosclerosis (the hardening of the arteries) and other lupus-related diseases such as heart disease and cancer. Dr. Silverman has been invited to write the sections on paediatric lupus for major textbooks in paediatrics and rheumatology as well as multiple review articles.

In addition to its knowledge of lupus, SickKids is a leader in basic research for a range of different autoimmune diseases. This combined critical mass of expertise in clinical care, research and basic science will drive globally-relevant discoveries in the field of autoimmune diseases such as lupus.

Lupus Ontario is hosting a children's event – Butterfly Ball – on June 11, 2011. The Butterfly Ball will be raising funds for research to help children living with lupus. Please help us help those living with lupus and join us in supporting the Butterfly Ball by calling Juanita Butler at 1-877-240-1099 or emailing her at info@lupusontario.org

Butterfly Ball June 11, 2011
1:00 pm to 5:00 pm

Thornhill Community Centre
7755 Bayview Avenue,
Thornhill, Ontario
L3T 4P1

A Ball for Children with lupus
.....for friends of Children with lupus and their friends
.....for Children who have friends or family with lupus
.....for all Children who want to have **FUN!**

Come join us for:
.....GAMES.....
.....SILENT AUCTION.....
.....FACE PAINTING.....
.....PRIZES.....
.....DANCING.....
.....ENTERTAINMENT.....
.....AND SO MUCH MORE.....

For only \$25.00
(per person)
Children under 3 years of age are free.
Help us help Children living with lupus!
All proceeds will be going to Lupus Ontario
All Monetary donations will be receipted.
For more information or for tickets
please call Juanita Butler at
1-877-240-1099 or email jbutler@lupusontario.org

IN SUPPORT OF
SickKids
FOUNDATION

lupus 
Lupus Ontario

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 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. 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
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. 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 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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Lupus Ontario

2900 John Street, Suite 301
Markham, ON L3R 5G3
Tel: 905-415-1099
Toll Free: 1-877-240-1099
Fax: 905-415-9874
Email: info@lupusontario.org
Website: 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

Lupus Canada

3555-14th Avenue, Unit 3
Markham, ON L3R 0H5
Toll Free (In Canada): 1-800-661-1468
Tel: 905-513-0004
Fax: 905-513-9516
Email: info@lupuscanada.org
Website: 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

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

Lupus Society of Manitoba

105-386 Broadway Ave.,
Winnipeg, MB R3C 3R6
Tel: 204-942-6825
Fax: 204-942-4894
Email: 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

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

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

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

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
Fax: 902-798-0772
Email: lupusocietyns@ns.sympatico.ca

Lupus Ontario

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2900 John St. Suite 301

Markham, ON L3R 5G3

Tel: (905) 415-1099 Fax: (905) 415-9874

Toll Free: 1-877-240-1099

Website: lupusontario.org

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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