



# Lupus Canada Bulletin

Registered Charity Number: 119025872RR0001 (ISBN: 1183-8590) Fall 2007 Volume 14 No. 2

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“Never give up on your dreams”

— new Lupus Canada

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## “Never give up on your dreams”

Salimah Mussani — living well with lupus

Salimah is a young golfer from Burlington, Ontario, now 28 years old. What makes Salimah so unique is that she is pursuing a life-long dream to be a professional golfer, and to live well with her lupus. Sometimes the two goals work hand-in-hand, and at other times, it becomes hard to live with both at the same time. But she’s not one to give up on a dream.

Salimah grew up in Ontario, and was always involved in sports – sometimes playing up to six sports at a time. Initially she was eager to participate in team sports such as soccer and field hockey. But as a competitive person, she turned to golf at the age of 13, and enjoyed the change to focus just on her own skill development. And as the stories have recounted, she showed a natural ability to golf. In 1995 and 1996 she won back-to-back Ontario Junior Championships and in ’96 and ’98 won the Canadian Junior Championship.

After completing some high school in Ontario, Salimah moved to San Antonio, Texas to finish her high school, and giving her the opportunity to golf year round. She loved the prospect, compared to the typical four month golf season here in Canada. After high school, Salimah attended the University of Texas for two years, and then transferred to Stanford University in California to finish her degree in psychology and business.

When asked “why golfing?” Salimah eagerly answered that she loves the competition - she’s very competitive personally - and that every day is different. She cites that the golf courses are always new, she meets interesting people, and even the weather is constantly changing. It’s obvious that Salimah thrives on changes, and works hard to manage the challenges she experiences in a healthy way.

At the age of 20 in 2000, following 3 years of bouts of ill health, Salimah was diagnosed with lupus. Like so many other people with lupus, she had numerous health concerns that were treated in isolation. It was the luck in meeting a physician at Stanford University, coincidentally a rheumatologist, who put together all the pieces of the puzzle. She immediately started treatment, and for 2 years battled symptoms, medication side effects, rashes and the everyday challenges that come from having an episodic illness. But her love of golf continued to prevail, and despite the challenges, she golfed.

In 2002 Salimah turned professional, and joined the Duramed FUTURES tournament in early 2003. The Mission of the Duramed FUTURES Tour is to prepare the world’s best young women professional golfers for a career on the LPGA (Ladies Professional Golf Association) Tour. Five years later, Salimah is going strong, im-



Salimah with one of her golf mentors, Tiger Woods

proving her game, and making a name for herself. She's proud of her accomplishments, but also mentions that living with lupus has had a significant impact on her career and her personal life. These last 2 years have been her most successful professionally, but also very challenging.

In 2006 she won the Michelob ULTRA Duramed FUTURES Players Championship, and won her second consecutive CN Canadian Women's Tour title. This season, she placed fourth on the Lakefield Duramed FUTURES tournament, tied for third at the El Paso Golf Classic plus participated in 16 other tournaments through the FUTURES tour. Here in Canada, Salimah won the Canadian CPGA Women's Championship in August held at the Ladies' Golf Club of Toronto. Margaret Lover, a Lupus Canada volunteer and avid golfer at the club watched Salimah play on her final day and said "her swing is so smooth and easy, she makes it look effortless. It was a really hot day, but despite the heat she was so focused on the task. With her smile and focus, we look forward to watching her for a long time to come".

Along with the highs of winning, there have been the downs of coping with lupus. Salimah recounts how being a part of the golf tour can be very exhausting. Every week she is on the road, playing a tournament on the weekend and spending the week preparing for the event. It's a long time to be away from home. Salimah has to stay out of the sun, so she is learning to play earlier or later in the day. And she said "it's about the quality not the quantity" as a strategy to be prepared for every event.

When asked if being public about her lupus has affected her career, she's quick to answer "not at all". In 2005 she won the Duramed FUTURES Spirit Award for her courage in coping with lupus and pursuing her career in golfing. For Salimah, her golf skills and her lupus were given to her for a reason, and she strives to learn the reasons why. She appreciates the opportunities to raise awareness about lupus, gets lots of support from her fans, her family and the public, and loves when others approach her to tell of their struggles

to battle a health condition. She talked about a fan who emailed her, saying she was inspired by her story and message as she too had lupus. "Things come into our lives for a reason, sometimes on rocky roads, but these can always be viewed as opportunities" Salimah said.

Salimah wanted to join the Walk a Block event this year, but unfortunately her schedule did not allow her to be back in Canada. Salimah wants to be a part of the lupus movement in Canada, and has joined with Lupus Canada as our new "Ambassador". With her new role, Salimah would love to continue to share her story with other people with lupus, and is especially interested in working with other young people. If she can motivate or inspire others with her life journey, she is eager to join in.

When asked what messages motivate her personally, Salimah had many. Words like "courage" and "overcoming fear" are really big in her vocabulary, and her achievements show that she lives what she speaks. She said "grow and learn but don't regret. Negatives can't come from doing something from the heart. Jump off the cliff and let your wings help you fly".

Thanks Salimah, we wish you many successes for 2008, and we look forward to having you as our new Ambassador and working together to conquer lupus.



Salimah participating at a LPGA golfing tournament this summer

photos courtesy of Salimah Mussani

# Message from the President

Mae Boa, President Board of Directors

October is a significant month for people living with the disease of lupus as it is our annual public awareness month. While increasing public awareness is a strategic priority for us – during October this takes on more specific activities such as promotion, materials distribution and of course our national fund raiser – Walk a Block for Lupus. Our member organizations and divisions and Lupus Canada have devoted countless volunteer and staff time and expertise to make this event bigger and better than last year! We had some fun and healthy ‘competitions’ underway to increase participation and awareness. Although the event has passed for this year, please consider contacting your local organization and join the team for next year to help find a cure for lupus. We are sure everyone will be out walking, running or riding to join us to increase resources and awareness of lupus in 2008.

It is with pride that I say Walk a Block has now completed its sixth year as our national fundraising program. If you check out the Lupus Canada website at [www.lupuscanada.org](http://www.lupuscanada.org), you will see that the program expanded to include this new electronic dimension. Individuals were able to contribute easily through our secure website.

Over the years, Lupus Canada and the Canadian Network for Improved Outcomes in Systemic Erythematosus (CaNIOS) have developed a unique and growing partnership in support of a broad research agenda related to lupus and lupus related research. In addition, CaNIOS researchers have been successful in obtaining various grants to support their ongoing research to find the cause and cure for lupus. I am pleased to report, that over the past seven years, thanks to funding support from our member organizations, divisions and with matching funds from an anonymous donor we have been able to generate over \$425,000 for CaNIOS in support of lupus related re-

search. On behalf of Lupus Canada, thanks to all of our readers for your donations to research to help us achieve this milestone!

As an up-date from the Board of Directors meeting held in September, we had a very successful strategic planning priority setting process. The Board continues to be fiscally responsible and approved a balanced budget for the new operating year with priorities that include:

- enhanced resources to support the expansion of Walk a Block
- continued development of training resources to support lupus group leaders
- up-dating lupus information sheets and developing new promotional materials for broader public awareness activities
- continued support for the direct mail fund raising program as a means of extending our reach across Canada
- focused corporate sponsorship activities in support of the annual joint medical/patient symposium with CaNIOS
- working together on initiatives to recruit and involve more youth members at the local and national level

While we have a small number of very dedicated staff at the local and national level, our organization continues to grow and thrive through the commitment and leadership of volunteers. If you have a particular interest or expertise you would like to share with us at the local or national level, please let us know. We are currently recruiting volunteers for projects and committees and I would invite your participation! The chair of the Volunteer Management Committee is Bev Ruffo, who may be reached electronically at [benefact@sympatico.ca](mailto:benefact@sympatico.ca).

We look forward to hearing from you soon!

# Lupus Canada and Waiting Room Information System celebrate another great opportunity to work together.

In the fall of 2005, Lupus Canada was approached by the Waiting Room Information System with a great opportunity and invitation to participate in their fall cross-Canada information campaign, with all services being fully donated.

The Waiting Room Information System has installed information racks in over 1600 sites (medical offices, family clinics, medical waiting rooms) in 480 communities across all 10 provinces. It is estimated that on an annual basis there are over 37 million patient visits to locations with an information system. While waiting to see their doctor, patients can review and select the various resources, and hopefully speak with their physician about lupus and lupus symptoms. With the Lupus Canada “Living Well with Lupus: An Introduction” brochure placed in 1,638 racks across Canada, we had a total of 21,066 brochures picked up over 3 months. On average, 57% of the brochures made available were picked up. As well, the WRIS indicates that for every brochure picked up, the brochure reaches another 2 individuals as it is passed among family and friends. In three months, we believe we reached over 40,000 people who learned more about lupus.

Building on this very successful campaign, Lupus Canada with a grant from The Ontario Trillium Foundation undertook a project to increase awareness of lupus in the province of Ontario. This time, our campaign is to last the full 12 months of 2007. As well, the Waiting Room Information System donated placement of the brochure in all locations across Canada for the first three months of 2007.

From January 1, 2007 to March 31, 2007, the brochure was placed in 1608 locations in 489 communities. Again, with this very successful campaign, we distributed over 11,000 brochures, and likely reached over 30,000 people across Canada, in both official languages.

The second campaign period, from April 1, 2007 to June 30, 2007 is equally impressive for the province of Ontario. There were 6,610 brochures taken during the period –

The brochure pick up rate was as follows:

## Brochure distribution

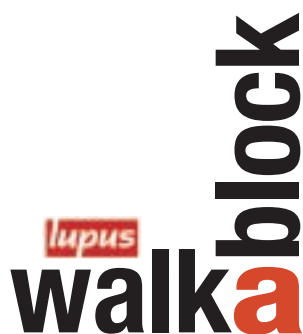
Location	Brochures Picked Up
British Columbia	1,356
Alberta	855
Saskatchewan	393
Manitoba	574
Ontario	4,987
Quebec	1,980 (584 in English, 1,396 in French)
New Brunswick	609 (326 in English, 283 in French)
Nova Scotia	378
PEI and Newfoundland	337
<b>Total</b>	<b>11,469</b>

this represents a 31% increase compared to the first quarter pick up rate for Ontario.

We are awaiting data for the third quarter of 2007, but we anticipate an equally successful outcome. And we still have another 3 months left in 2007 to reach even more people. As one of our key strategic priorities at Lupus Canada is to extend our reach and educate more people about lupus and lupus resources, the partnership with the Waiting Room Information System is proving to be most successful. However, as one example, maybe the best outcome was a call to Lupus Canada from a woman who said “I’m calling from Gander, Newfoundland and I picked up your brochure at my doctor’s office”. Knowing that we reached so many people is how we know the campaign was so successful.

# Walk a Block for Lupus 2007

From Start to Finish A Huge Success



On a very snowy day in early March 2007, the Lupus Canada Fund Development Committee met face-to-face for the first time. On that snowy day, the Walk A Block 2007 plans were put into action. The Committee included Leisa Cadotte from Surrey, BC; Jennifer

Oakes from Caledon, Ontario; Margaret Lover, Var Shina and Nicole Zahradnik from Toronto; and Chaired by Mark Purcell from Oshawa, Ontario. Judi Farrell and Pamela Bowes from Lupus Canada joined the Committee meeting as well.

After a day of development, the Committee jumped into gear to start the early plans for October 2007. The Committee worked with a volunteer designer, Raymond Helkio, who designed the new Walk A Block logo for this year. Raymond had previously designed the "Living Well with Lupus" logo that is now on the Lupus Canada brochures and fact sheets, and it was great having Raymond help the Fund Development Committee. Certainly the new logo started Walk A Block 2007 off right!

**The 2007 Walk a Block was the most successful Walk to date — thanks to all the Event Coordinators, Team Leaders, Walkers, sponsors and donors.**

During the spring months, the group developed a short newsletter promoting the Walk that was sent to all previous team leaders and posted on the Lupus Canada website. Next, the Committee finalized the Event Coordinator Tool Kit – a huge resource package

that helped coordinators to plan and organize the best possible Walk. The Tool Kit included a "tips for a successful Walk" sheet, facts on lupus, how to approach local sponsors and write a media release and a timeline with deliverables to complete for Walk Day. With well over 80 Walks, from Vancouver to St. John's, the resources helped the Team Leaders to make their events as successful as possible.

In September, Jacquie Grech joined the Lupus Canada staff as the National Walk a Block Coordinator, and worked closely with the Event Coordinators from across Canada. Many potential walkers, team leaders and event coordinators benefited from Jacquie's helpful ideas and advice.

Here are just a couple of the highlights from Walks held across Canada:

- Leisa Cadotte and her committee spent the summer gearing up for her incredibly successful Walk a Block for Lupus event in Surrey BC. With over 20 corporate sponsors, the Surrey Walk at Bear Creek Park, offered something for everyone! Event activities included a silent auction, RCMP booth, and activities for children, great food and plenty of fun. New this year, Leisa secured sponsorship from the Running Room and held a 5km run alongside the Walk.

- Caledon East came alive on October 21 when the Caledon Trailblazers hit the beautiful trails of Caledon! While walking for a great cause, team members also soaked in the picturesque sights along the trails. Jennifer Oakes offered her walkers lunch, a raffle, silent auction and games for the children after the scenic walk.

- Walk a Block for Lupus was a great success all across Canada, ranging from small family walks to larger, all day community events. The walk organized by Nancy Votour in New Brunswick added a new twist to the walk with a kite-flying contest! Children/youth ages 4 to 19 entered kites designed

# WALK A BLOCK FOR LUPUS

What's new for 2007?

and produced by them in the contest that was held immediately after the walk. Clowns and a barbecue rounded out the successful 2 hour event providing fun for everyone!

- Winnipeg held its provincial Walk on October 21st at the Duck Pond in St. Vital Park. McDonald's Restaurants brought smiles to the faces of the many children that day, not just because of the pies and hot chocolate they donated, but when Ronald himself attended Walk A Block! There were several prizes won from the raffle as well as a fire pit keeping the October chill away.

- Crystal Melanson, organizer for the Midland – Penetanguishene Walk A Block, stirred up the small town communities of Midland and Penetanguishene, the morning of October 21st. Sponsorship included Central Taxi and KICX FM. KICX FM aired an advertisement for the event a few times a day for three weeks prior to the event. The local media including The Mirror and Free Press were also present to report on the first Walk A Block for Lupus event held in the community.

- Lupus Ontario coordinated a Walk at Queens Park in Toronto on October 20th. A hundred people attended this Walk right in the heart of downtown Toronto, the same site as the 2006 Walk. Participants had a great day

with a live band playing, lots of gifts, snacks, prizes and silent auction items.

The 2007 Walk a Block was the most successful Walk to date – thanks to all the Event Coordinators, Team Leaders, Walkers, sponsors and donors. Lupus Canada is continuing to finalize the amount of funds raised, but we have greatly surpassed 2006. The funds will help to support both local and national lupus programs, and support vital lupus research as we work toward finding the causes and cure for lupus.

And the next Walk a Block? Starting in 2008, the annual Walk a Block event will be moving to a new time of the year – the beginning of May to coincide with World Lupus Day on May 10th. We look forward to having you join this exceptional fund raising and awareness raising event – watch for more details to come.

Caledon Trailblazers Walk held on October 21st



## Walk A Block for Lupus Provincial Contacts

In British Columbia contact: Gayle Traquair  
BC Lupus Society  
604-714-5564 or  
1-866-585-8787  
info@bclupus.org

In Saskatchewan contact: Lloyd Driedger  
LE Society of Saskatchewan  
1-877-566-6123  
l.driedger@sasktel.net

In Manitoba contact:  
Lupus Society of Manitoba  
204-942-6825 or  
1-888-942-6825  
lupus@mts.net

In Ontario contact: Juanita Butler  
Lupus Ontario  
905-415-1099 or  
1-877-240-1099  
lupusontario.info@bellnet.

OR Pat Leece  
Lupus Foundation of Ontario  
905-894-4611 or  
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In Quebec contact: Miriam Gaudelli  
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In New Brunswick contact: Nancy Votour  
506-384-6227 or  
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In Prince Edward Island contact: Barb Grimster  
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bargri@pei.sympatico.ca

In Newfoundland contact:  
Lupus Newfoundland and Labrador  
709-368-8130  
lupusnfld@nl.rogers.com

# Lupus International Congress

Shanghai China — Carolina Pineda

**T**he opportunity for me to attend the 8th International Lupus Congress in Shanghai, China this past May was both exciting and unexpected. With funding provided through the Lupus Foundation of America (LFA), Lupus Canada was invited to select an individual to attend the congress and represent the organization in a forum dedicated to discussing World Lupus Day initiatives around the globe. To my honour and delight, I was the lucky individual nominated to participate and a few short weeks later, I found myself on the other side of the world alongside a dynamic group of individuals dedicated to improving the lives of people living with lupus in their communities and abroad.

The “Lupus Leaders Forum” was attended by me and other delegates from distinguished countries including Argentina (Teresa Cattoni), Spain (Blanca Rubio Hernández and Isabel Díaz Quintero), Belgium (Nele Caeyer), Mauritius (Babs Venkatasamy), Norway (Fatima Lavoll), the United Kingdom (Michael Fenn), Malaysia (Esha Gupta), Germany (Rudolf Hocks), and Indonesia (Anne Gracia and Ayu Bisono). Sandra Raymond, Leslie Hanrahan, Duane Peters, and Mary Worstell of the LFA were also in attendance as the organizers and facilitators of this momentous event. Our discussions throughout the day focused on the following areas:

- 1) The many activities undertaken by the international community of lupus organizations
- 2) The external factors affecting the ability of these organizations and local governments to serve people living with lupus
- 3) The partnerships that are necessary in order to strengthen lupus patient advocacy and service, as well as gain endorsement for the World Lupus Day proclamation
- 4) The opportunities and challenges faced by each organization in publicizing and implementing WLD objectives in their home countries

- 5) Identifying priorities for World Lupus Day program development in 2008 and beyond.

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*“Among the objectives of this federation would be to raise global awareness of lupus as a serious chronic illness...”*

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In the final part of the Forum, we discussed the creation of an International Lupus Federation (ILF) that would unite lupus patient groups worldwide in a common mission to provide hope, help and support to people affected by lupus. Among the objectives of this federation would be to raise global awareness of lupus as a serious chronic illness, influence government and private sector physician and public health programs to increase support for patients, their families, and caregivers, build individual lupus organization capacity to optimally serve lupus patients in each country, and establish partnership for the Federation with appropriate world health organizations. All of the delegates expressed interest and enthusiasm for a structure like the ILF and, thanks to the generosity of the LFA, we will reunite in Washington D.C next year

# Lupus International Congress

Shanghai China

to discuss the next steps in fostering international collaboration between lupus patient groups.

Among other highlights from my trip to Shanghai were: the “Patient Program” organized in tandem with the main congress, the “World Walks for Lupus” event, and the luxurious Gala Dinner. The “Patient Program” featured presentations by Chinese and American doctors and specialists addressing lupus, its diagnosis, and treatment, as well as information on the prevention of important health conditions like kidney and heart and blood vessel disease. With English, Cantonese, and Mandarin translators at hand, speakers entertained important questions from the audience following each presentation. As part of this program, all participants were provided with the opportunity to participate in lupus-friendly physical therapy sessions lead by Yoga and Tai Chi instructors.

The “World Walks for Lupus” event was held bright and early on the morning of May 25th. Hundreds of patients, their doctors, caretakers, friends, and families’ walked a stretch of one and a half kilometers. By walking together, we were able to show that living well with lupus means that patients can enjoy and participate in activities that lead to an overall better quality of life. Wearing matching hats, t-shirts and waving pictures of patients and signs with the WLD proclamation, we walked/ran/wheeled along a path next to the Bund River in what was for me one of the most exciting and inspiring events of the congress.

The same evening, the LFA treated all delegates of the Lupus Leaders Forum to an extraordinary evening of dining and entertainment at the congress’ Gala Dinner. Live performances throughout the evening included Chinese acrobats, classical musicians, an electrical violin player, a traditional face-changing artist, and a very talented duo of nine-year old dancers. To close the evening, the international dele-

gates were invited onto the main stage to sing “Because for what I am.” This beautiful song was written by Tika Bisono and Anne Gracia of Yayasan Lupus Indonesia and is dedicated to people living with lupus. Our performance had the entire audience on their feet as they swayed along and showed their support to lupus patients around the world.

My overall experience as a participant of the 8th International Lupus Congress and the Lupus Leaders Forum was spectacular and I sincerely thank Lupus Canada for selecting me to attend as a representative of the organization. This once-in-a-lifetime opportunity taught me so much about what it means to be an advocate for people who live with lupus in an increasingly global and connected world. Learning that similar challenges and goals are shared by people in such diverse contexts has convinced me that it is necessary to collaborate internationally if we seek to achieve great things for the local lupus community. Given the energy and dynamism that was exhibited by delegates of the Lupus Leaders Forum, I truly believe that any initiatives that are carried out in conjunction with other lupus patient groups will be both powerful and greatly successful.



*Carolina Pineda lives in Montreal, Quebec. She is presently working towards her Ph.D. in Anthropology from McGill University where her area of research is in Women’s Experience of Chronic Illness in Canada. Carolina recently received a tuition scholarship from the National Education Association of Disabled Students.*



## Living Well with Lupus: Pathways to Good Health Bien vivre avec le lupus: Une Voie vers la Bonne Santé

7th Annual National  
Lupus Patient Symposium  
Saturday, May 31st, 2008  
Montreal, Quebec

Lupus Canada, in partnership with the Canadian Network for Improved Outcomes in Systemic Lupus (CaNIOS) is proud to host this national educational event – the only national lupus patient symposium held in Canada.

Building on the successes of previous symposiums, next year's event features excellent speakers, great networking opportunities, and a silent auction with lots of unique gift items. The speakers represent top-notch physicians and researchers from across Canada on key lupus topics. Smaller con-current sessions will allow participants the opportunity to explore topics of interest in more detail, and engage in discussions with the session facilitator. The complete agenda includes the following sessions and activities:

### What did people say about Symposium 2007?

*86 % of delegates indicated the 2007 speakers and sessions were extremely top-notch, informative and relevant to their life*

*69% of delegates indicated their understanding of lupus increased by more than 50% from attending the Symposium*

*71% indicated they were very glad to have attended the Symposium*

### AGENDA

#### Patient Perspective “Lupus is not just about wolves”

Carolina Pineda

#### Plenary Session – Kidney Disease in Lupus

Dr. Joanne Bargman

Con-Current Sessions:

#### Youth to Adulthood – The Transition Years

Dr. Lori Tucker + Dr. Gaëlle Chedeville  
Pediatrics, Division of Rheumatology, Montreal  
Children's Hospital

#### Update on Lupus Research in Canada

Dr. Paul Fortin

#### La maladie cardiaque et le lupus

Dr. Christian Pineau

Lunch, Networking, Silent Auction, Display Tables

Con-Current Sessions:

#### Mise-a-Jour sur la recherche sur le lupus au Canada

Dr. Paul Fortin

#### Managing Arthritis and Employment: How are People Coping

Dr. Monique Gignac

#### A Recipe For Success... Healthy Eating to Help You

Pam Piotrowski

Plenary Sessions:

#### Lupus and the Nervous System

Dr. John Hanly

#### Keeping Well Around the Clock

Dr. Deborah Da Costa

The registration fee to attend this all day Symposium, including your lunch, is \$45.00. People living with lupus, their family and friends, and health professionals are encouraged to attend.

To register or learn more about the event, contact Lupus Canada at 1-800-661-1468

Join us in Montreal on May 31st. We look forward to seeing you there.

# Light Bulb Issue Heating Up For People With Lupus

In the last several months, the issue of the phasing out and elimination of incandescent lighting in favour of compact fluorescent lighting has come up in Canada, and some people from the lupus community are quite worried about the developments. Incandescent lights are the traditional light bulbs that we use at home, the invention of Thomas Edison over 125 years ago. Fluorescent bulbs are generally thought of as the long thin bulbs that we see in offices, malls and most public places. Compact Fluorescent Lighting, or CFL, are the somewhat smaller bulbs that are used in typical lamps and light fixtures found in our homes.

Here are some facts to best describe the present situation:

- Fluorescent lighting is more energy efficient than incandescent bulbs. When comparing the two types of bulbs with equivalent brightness, the fluorescent bulb uses a greater proportion of its energy for power, and less is converted into heat. Therefore, the fluorescent bulb uses less energy to operate, runs cooler and doesn't warm up the surrounding area. As well, the fluorescent bulb lasts about 10 to 20 times longer than the incandescent bulb.

- With regards to disposal of the bulbs, an incandescent bulb can generally be thrown away in household garbage, whereas a fluorescent bulb must usually be disposed of in other ways. This is due to the mercury that is contained in fluorescent bulbs, even when the bulb has burned out. If you happen to break a fluorescent bulb, there are several clean up precautions that are suggested in order to reduce mercury exposure, while a broken incandescent bulb can be disposed of much easier.

- Fluorescent bulbs at this point cost more than incandescent bulbs. However the price of these bulbs, especially if their utilization increases, is expected to drop.

- Fluorescent bulbs emit UVA and UVB rays. They also "flicker" at a high frequency, sometimes about 60 to 100 times per minute. When a fluorescent bulb is turned on, it has a big burst of light (compared to the incandescent bulb) that can be hard on the eyes.

## **Why are the Provincial and Federal Governments "hot" on this issue?**

Earlier this year, the Ontario government announced they will ban the sale of inefficient incandescent light bulbs by 2012, in favour of low wattage fluorescent bulbs. This government anticipates that replacing the 87 million incandescent bulbs used each year in the province would save six million megawatt hours every year – enough energy to power 600,000 homes. As well, the fluorescent bulbs will reduce greenhouse emissions, an even greater benefit for the Ontario environment.

Ontario is not alone in this initiative. Other provinces, including Nova Scotia and British Columbia, are considering similar initiatives, and others are likely to follow. The Government of Canada announced in April that they will set national performance standards for efficient lighting that could result in the limited use of incandescent lighting to be replaced by fluorescent lighting. Canada will also be following in the footsteps of countries further along on this issue, such as Australia, the United States and the United Kingdom in adopting this new lighting standard.

From the point of view of both the environment and energy consumption, the idea seems to be worthy. But for those with specific health concerns who are impacted by light sensitivity and fear the possibility of increased lupus flares, this is a very fearful step to take.

## **What are the health issues?**

Fluorescent bulbs are brighter, flicker and emit UVA and UVB rays. This poses problems for people with health concerns such as:

- Many people with lupus have photosensitivity – generally sensitivity to the sun (which emits UVA and UVB rays) but fluorescent bulbs can be just as hard to tolerate. People may experience burning eyes, blurred vision, dry or scratchy eyes, skin sensitivity or rashes or other symptoms including increased lupus symptoms. The increased exposure to UV rays could cause lupus flares.

# Light Bulb Issue Heating Up For People With Lupus

- Many people with lupus have sensitivity to brightness in general, and fluorescent bulbs can frequently be too bright on the eyes. People with this sensitivity generally prefer low watt incandescent bulbs

- The fluorescent lights flicker and can cause excessive eye fatigue and headaches with long exposures – people with lupus report these anecdotal experiences.

- People with other health conditions may also have difficulties with fluorescent lighting. There are again some anecdotal reports that people with autism, attention-deficit disorder and Tourette Syndrome have troubles with the brightness, flickering and UVA/UVB rays emitted from this form of lighting. As well, people with cancer who are going through (or who have completed) radiation treatments have indicated that fluorescent lighting is hard to tolerate. We are not alone in the health struggles we experience from this form of lighting.

## What do we know scientifically?

Unfortunately there isn't lots of hard scientific proof that exists to illustrate that people with lupus are at risk from the lighting, or that photosensitivity symptoms are experienced or intensified with exposure. There is some thought that the UVA/UVB rays might be cancer-causing, but again hard evidence is lacking. Dr. Richard D. Sontheimer, an expert lupus physician wrote in the Summer 2007 edition of the Lupus Now magazine that "The issue of lupus photosensitivity is a complex one and one of the least scientifically studied clinical aspects of cutaneous and systemic lupus... if a person with lupus is exposed to unshielded fluorescent lighting at close distances for prolonged periods of time, then the cumulative exposure to UVB and UVA could be a problem" \* Physicians might note increased symptoms due to UVA and UVB exposure in patients who experience photosensitivity. But ask people with lupus who have photosensitivity, and most will say that fluorescent bulbs are just way too hard on the eyes, even with brief exposure. Come to the Lupus Canada office and find most of the fluorescent bulbs turned off and replaced with small lamps.

Without research and evidence to prove the health impact of the lighting, experts and physicians are unable to definitively say that fluorescent lighting has a negative effect. However, it is and will be a valid concern for people with lupus if and when incandescent lighting is restricted or banned.

## What's likely on the horizon?

In the next couple of months, and probably the next couple of years, further action will undoubtedly happen on this issue. Efforts to help our environment stay healthy need to be explored and addressed. Some likely actions will include:

- Further debate as to whether this ban is even an effective environmental move. Some people in the environmental field believe there are other ways to reduce energy use and greenhouse emissions that should be addressed first. Others worry about the impact on the environment with more bulbs needing safe disposal, and increased exposure to mercury in the household.



# Light Bulb Issue Heating Up For People With Lupus

•Increased effort to gain public and political support for this issue, and hopefully create opportunities for people to come forward and address the negative health issues experienced from fluorescent lighting. In the United Kingdom, a group called SPECTRUM has formed to make their views known to elected officials and the general public. This group represents several health charities- including Lupus UK – working on behalf of people with light sensitivity to raise the concerns of moving solely to fluorescent lighting. Lupus UK has noted that approximately 60% of their members indicate they have light sensitivity. As well, Lupus UK is reaching out to various government ministries and departments to alert them to the problem, even stating that banning incandescent light bulbs (effective in the UK by 2010) is in breach of the Disability Discrimination Act. Lupus UK and other organizations are posed to continue with their advocacy efforts.

•More research into photosensitivity, UVA and UVB exposure and the impact of fluorescent bulbs on the health of those who are adversely affected. Let's hope for that action, as all people with lupus will benefit from this kind of research.

•Better products developed. Already the GE Consumer and Industrial Lighting division in the USA has announced they are developing incandescent bulbs that will be just as effective as compact fluorescent bulbs but will be more energy efficient and produce less greenhouse gas emissions than existing incandescent bulbs. This kind of product invention might give people the opportunity to choose between fluorescent or incandescent lighting.

## What you can do

Presently, people can purchase a specific acrylic diffuser that covers fluorescent tube lights and diffuser covers for other light styles. They may not be the easiest to find, but they are available. Dr. Sontheimer from the Lupus Now magazine stated that with shielding, the fluorescent light source posed no significant risk for people with systemic lupus.

The other action we can take is to stay informed and current on the topic. As the governments and environmental groups move forward with the idea, it will be important for people with lupus and other health concerns that experience

photosensitivity to weigh in on the topic. Like all advocacy initiatives, we need to raise awareness to the negative impact that removal of incandescent lighting can have. Many may not even be aware of how these bulbs hurt people's health. We need to ensure our voice is heard. And we need to join forces with others who experience the same concerns as there is more impact when we have strength in numbers.

If you have any thoughts about this topic, please let Lupus Canada know. Send us an e-mail at [lupuscanada@bellnet.ca](mailto:lupuscanada@bellnet.ca)

## Other Informative Resources:

Lupus UK – [www.lupusuk.com](http://www.lupusuk.com)

Lupus International  
(also following this topic closely)  
[www.lupusinternational.com](http://www.lupusinternational.com)

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

Spectrum – an alliance addressing light sensitivity  
in the United Kingdom  
[www.spectrumalliance.org.uk](http://www.spectrumalliance.org.uk)

Government of Canada EcoAction website  
[www.ecoaction.gc.ca](http://www.ecoaction.gc.ca)

*\*Quote from Dr. Sontheimer from page 11 of article Ask the Experts, Summer 2007, Lupus Now magazine published through Lupus Foundation of America. To read more, contact Lupus Foundation of America or visit [www.lupus.org](http://www.lupus.org)*

# Research

Jaime O. Claudio, Ph.D, National Scientific and Development Coordinator, CaNIOS

## CaNIOS Leading Lupus Research In Canada

As the leader in lupus research in Canada, CaNIOS is paving the way for better understanding of the disease. In the research updates below, CaNIOS describes the recent progress of the 5 Canadian Institutes of Health Research (CIHR) funded studies that are being conducted by Canadian investigators throughout the country.

### 1000 Faces of Lupus

Funding for the 1000 Faces of Lupus study has just ended, but exciting months are ahead of us for the analysis of data gathered in the past 5 years. Last spring, a glimpse of the data collected through the study was presented by Dr. Christine Peschken, the principal investigator of the study, to CaNIOS members who gathered in Winnipeg for their annual meeting. Dr. Peschken reported the success of enrolment to the 1000 Faces of Lupus study and highlighted important early findings:

- 1) There are differences in lupus characteristics between Canadian ethnic populations (Asian, African American, Aboriginal, Caucasian) in terms of age at onset, clinical manifestations and autoantibodies.
- 2) Asian and African Canadians have the highest frequency of severe lupus manifestations.
- 3) Aboriginal people have less severe manifestations than previously described, and are similar to Caucasians.
- 4) Aboriginals had the highest damage scores and Asians the lowest, in spite of the above differences in frequency of severe lupus manifestations
- 5) Aboriginal people were much more likely to be living below the poverty line, had the lowest levels of educational attainment, were more likely to be smokers, and

more likely to have self-reported past or current problems with alcohol.

6) Low income was an independent predictor of damage accumulation, suggesting that socioeconomic factors may be playing an important role in the worse outcomes in Aboriginal Canadians.

These findings will be presented in details at the American College of Rheumatology Annual Meeting in Boston in November 2007.

### GenES (Genetic & Environmental Factors in SLE)

The GenES Study recruitment has ended and exciting results from data analysis are now being uncovered. At least 2 peer-reviewed publications are expected to be released this year. The findings from these reports will include:

*“The GenES Study recruitment has ended and exciting results from data analysis are now being uncovered.”*

- 1) In the first-degree relatives of lupus patients, there appears to be a reduced proportion of a type of blood cells known as natural killer T cells. These cells are believed

# Research

continued

to keep the immune system in check. A lower number of these cells may therefore be predisposing factors for lupus and other autoimmune diseases and could be a target for future treatments.

2) Working together with scientists in the UK, GenES investigators found that a gene on the long arm of human chromosome 1 is associated with lupus and may act by affecting the activation of T cells, leading to increased chronic activation of T cells in lupus patients and their parents.

3) Several other manuscripts are in preparation. These reports will include analysis on environmental data collected from study participants, descriptions on the screening of different candidate genes that may cause lupus, and results of laboratory data describing the expression of different autoantibodies on lupus patients, their siblings and their parents.

## **HIPP (Health Improvement & Prevention Program)**

Recruitment has been steady in both Toronto and Montreal centres for the HIPP Study. To date, 213 patients have been enrolled into the study. In the winter months, London, Ontario, will start recruitment into HIPP as soon as their research ethics board approves the study protocol. Meanwhile, interim data analysis by looking at the preliminary benefits of HIPP has demonstrated the feasibility of estimating the cardiovascular risk in lupus patients. It further suggests that a HIPP intervention may decrease cardiovascular risk.

## **LuNNET (Lupus Nephritis New Emerging Team)**

One major finding from LuNNET will be presented in November at the American College of Rheumatology Annual Meeting in Boston. Briefly, lupus patients were studied for expression of several genes in their blood cells using molecular biology techniques. The results indicated that the level of expression of these genes can be correlated with disease activity and an altered cellular profile. This can be used in the future as markers

to develop diagnostic tools that could predict disease activity.

## **ThromboFIL (The Role of Thrombophilic Factors in Persons with SLE)**

The recruitment phase for the ThromboFIL study has ended and all the data collected from study participants had been entered into the ThromboFIL database. Data analysis is underway to evaluate the risk of thrombosis in lupus patients at the time of diagnosis and yearly afterwards.

## **To learn more about lupus research in Canada and CaNIOS, visit**

[www.lupuscanada.org](http://www.lupuscanada.org)

and go to the Research Updates section. The latest CaNIOS Research Participants Newsletter (Fall 2007 edition) is posted here.

[www.canios.ca](http://www.canios.ca).

The CaNIOS website has lots of information about clinical trails and lupus research projects.

Prepared by: Jaime O. Claudio, Ph.D. CaNIOS National Scientific & Development Coordinator..



**Dr. Jaime Claudio**

Dr. Jaime O. Claudio obtained his Ph.D. in Experimental Medicine at McGill University through a combined Canada International Development Agency and National Cancer Institute of Canada scholarships. A Career Development Fellowship from the Canadian Blood Services sponsored his postdoctoral training at Toronto General Hospital's Oncology Research Laboratories. In 2005, he joined The Canadian Network for Improved Outcomes in SLE (CaNIOS) as National Scientific and Development Coordinator where he continues to work with the national

group of investigators working together to improve the outcome of lupus patients across Canada through collaborative research. The CaNIOS Coordinating Centre is located at Toronto Western Hospital.

## Lupus Canada seeking new volunteers

“Work together, grow together — volunteer”

We are eagerly seeking volunteers who would like to join and help the lupus movement.

We especially need volunteers to:

- Join the Public Awareness and Communications Committee
- Be a part of the Fund Development Committee
- Assist Lupus Quebec as they prepare to host a number of activities at the 7th Annual National Lupus Patient Symposium in May 2008
- Join the Lupus New Brunswick team to assist with their education and awareness activities

Contact Lupus Canada or your local lupus organization to learn more about how you can get involved.

## New Government Benefits Information on the Lupus Canada website:

Canada Pension Plan  
Disability Benefits or Retirement Benefits  
*Practical Information to help make your decision*

Canada Pension Plan Disability  
and Returning to Work  
*What happens to my CPP benefits  
if I gradually return to work*

To read these articles,  
visit the Government Benefits page under the  
Awareness/Support/Advocacy section. Go to

[www.lupuscanada.org](http://www.lupuscanada.org)

# Lupus Boutique Order Form

1) **MAIL TO:** Lupus Canada, 590 Alden Road, Suite 211 Markham, Ontario L3R 8N2

**IF PAYING BY CREDIT CARD, to place your order:**

2) **Call (905) 513-0004 or 1 (800) 661-1468** or 3) Fax the completed form below to Lupus Canada at: **(905) 513-9516**

### Please send me:

- \_\_\_\_\_ copies of Lupus, The Disease with a Thousand Faces @ \$19.95 = \_\_\_\_\_
- \_\_\_\_\_ Lupus "Angel of Hope" @ \$7.95 = \_\_\_\_\_
- \_\_\_\_\_ Package(s) of 5 Conquer Lupus Wristbands @ \$15.00 (Minimum Order) = \_\_\_\_\_
- \_\_\_\_\_ Package(s) of 10 Conquer Lupus Wristbands @ \$20 each = \_\_\_\_\_

### Add Shipping and Handling:

- Orders up to \$20.00, add \$3.00 for shipping and handling \_\_\_\_\_
- Orders from \$20.00 to \$50.00, add \$5.00 for shipping and handling \_\_\_\_\_
- \_\_\_\_\_ Lupus Hooded Sweatshirts @ \$35.00 (Shipping & Handling Included in cost of sweatshirt) \_\_\_\_\_

**Total** \_\_\_\_\_;

Visa  Mastercard  American Express  Cheque # \_\_\_\_\_

Cardholder \_\_\_\_\_ Number \_\_\_\_\_ Expiry date \_\_\_\_\_

### Ship to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ Prov \_\_\_\_\_ P/C \_\_\_\_\_

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info@bclupus.org

Lupus Erythematosus  
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103 Hospital Dr.  
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www.sasklupus.com  
less@sasklupus.com

Lupus Society of Manitoba Inc.  
105 – 386 Broadway  
Winnipeg MB R3C 3R6  
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Fax: 204 – 942 – 4894  
lupus@mts.net

Lupus Foundation of Ontario  
www.vaxxine.com/lupus  
Box 687 294 Ridge Rd N  
Ridgeway ON L0S 1N0  
ON only 800 – 368 – 8377  
Phone: 905 – 894 – 4611  
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lupusont@vaxxine.com

Lupus Ontario  
www.lupusontario.org  
211 – 590 Alden Rd  
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lupins@rogers.com

Lupus PEI  
www.lupuscanada.org/pei  
Phone: 902 – 892 – 3875  
bargri@pei.sympatico.ca

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www.lupuscanada.org/novascotia  
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Dartmouth NS B3B 1X2  
NS only 800 – 394 – 0125  
Phone: 902 – 425 – 0358  
Fax: 902 – 798 – 0772  
lupines@ns.sympatico.ca

Lupus Newfoundland  
& Labrador  
http://www.envision.ca/webs/  
lupusnfldlab/  
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**Systematic Lupus Erythematosus** is an autoimmune disease that affects thousands of Canadians, mostly women in their child-bearing years. Symptoms vary greatly from patient to patient and treatment is highly individualized. Patients are urged to contact their physician or health professional with any questions or concerns they might have. Opinions expressed on these pages do not reflect those of Lupus Canada.

Lupus Canada Bulletin is published twice yearly by Lupus Canada and is circulated to individual members of associate organizations.

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