

To provide a means for Education, Support, Public Awareness and Research.

## Donate Your Optimum Points to Lupus Ontario!

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

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

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

By donating your Points, you can help us both save and raise money!

Lupus Ontario thanks the many members who have donated their Optimum Points. Due to privacy laws, Shoppers Drug Mart cannot share the names of the donors with us, so we are unable to thank you personally. As of July 23, Lupus Ontario has accumulated 201,250 points. Thank you for your generosity!



# LUPUS LINK

- ONTARIO -

Volume 5, Issue 4

Fall 2007

## IN THIS ISSUE

### PRESIDENT'S MESSAGE

Get Ready to Walk for Lupus! 1

### RESEARCH REPORT

CellCept Trial Fails to Meet Objective 2

Malaria Drugs May Reduce Cancer Risk 2

Cyclophosphamide May Affect Male Fertility 2

Researchers Explore Role of Interferon-Alpha 2

U.S. Congress Awards Lupus Research Grants 3

### FEATURES

An Adoption Story Continued 4

Lupus Info Goal of Walk 7

Teen Talks About Lupus on Facebook 7

Tiziana Tolfo is Unstoppable! 8

### RESOURCES

EatRight Ontario, Disability Savings Plan, dxLupus and More 3

### NEWS & EVENTS

Italian Dinner 1

Upcoming Events 5

Dance for the Cure 6

'Flare' for Fashion 6

Walk A Block 10

### CONTACT INFORMATION

Board of Directors 11

Provincial Branches 11

Member Organizations 11

Publications Mail Agreement No. 40037439  
CHARITABLE # 88333 1472 RR 0001  
ISSN# 1194-8299

Return undeliverable Canadian addresses to:  
211-590 Alden Rd., Markham ON, L3R 8N2

Thank you for supporting  
Lupus Ontario

## OUR MISSION STATEMENT

To provide a means for  
Education, Support, Public  
Awareness and Research.

## GET READY TO WALK FOR LUPUS!



**WALK A BLOCK** in October will be the focus of our energies for the next few months. Please see Juanita's report in this issue on page 10 for details. The national date is October 21, but feel free to walk whenever you can. Join a walk in your area, have your own walk, or maybe organize a walk and be a team leader. We will help you. Please call Juanita at 905-415-1099 or 1-877-240-1099 or visit our website at [www.lupuscanada.org](http://www.lupuscanada.org) to register online.

### PRESIDENT'S WALK

As summer begins to wrap up, don't forget to be vigilant about sunscreen. While it is wonderful to have the kind of weather that makes you want to get out into the garden or just go for a walk, sunscreen should be part of your daily routine, even on cloudy days. Pace yourself in the heat and drink lots of water. These words of encouragement are really for everybody, not just those of us with lupus. Be well and manage your health positively.

In the Lupus Ontario office, Karen and Juanita are working overtime on Walk A Block and support group meetings. We have had our second support group meeting in the office in Markham and invite anyone interested in joining us on August 29 at 7 pm to call 905-415-1099 to confirm.

I have had lupus almost all my life. This is the vehicle I have been given for my journey. There is no cure YET! I live with hope that someday there will be a discovery that eliminates lupus for me, my sister Andrea in Vancouver, and everyone who deals with this life-altering disease. I am walking to make a difference and to raise public awareness that will hopefully bring earlier diagnosis, funding for research and education, and mostly fuel my hope for a cure. **I invite you to join me on Saturday, October 20th at 2 pm for my Lupus Ontario President's Walk from the historic Heintzman House in Thornhill.** If you can't be there, please be generous in your support and I will put your name on my T-shirt and walk for you, too.

Julia Kane

## ITALIAN DINNER 2007

Dancing with the Stars for Lupus



Ballroom dancing demonstration

Saturday November 3, 6:30 pm

Riviera Renaissance Parque — 2800 Hwy #7W, Concord

Tickets \$75 each — Call early to reserve! Lupus Ontario, 905-415-1099

Open Bar  
Antipasto Bar with Faggioli & Smoked Salmon  
Spaghetti Alla Chitarra Napolitana  
Ricotta & Spinach Stuffed Rotolo  
Grilled Chicken Breast Supreme  
Veal Scallopine  
Mixed Vegetables & Roasted Potatoes  
Spring Salad  
Chocolate Tartufo & Strawberries

## RESEARCH REPORT

### CELLCEPT TRIAL FAILS TO MEET PRIMARY OBJECTIVE

In June, Aspreva and Roche announced preliminary results for a clinical trial comparing CellCept (mycophenolate mofetil, MMF) to intravenous cyclophosphamide (IVC), the current standard of care for treatment of lupus nephritis. Response rates were similar for the two drugs, but the trial did not demonstrate that MMF was superior to IVC in inducing treatment response.

The results relate to the induction phase of this study, designed to measure treatment response after 24 weeks of therapy. There were 185 patients in each of the drug groups. Treatment responses were similar: 56.2% in the MMF arm and 53% in the IVC arm were observed, and overall adverse effects were similar in the two groups. The companies are now assessing the drug's future potential. For details, visit [www.newswire.ca/en/releases/archive/June2007/27/c9492.html](http://www.newswire.ca/en/releases/archive/June2007/27/c9492.html).



Photo: Jacob Moulka

### MALARIA DRUGS MAY REDUCE CANCER RISK

Drugs used to treat malaria appear to reduce the risk of cancer in patients with systemic lupus, Spanish researchers reported in the June issue of *Annals of the Rheumatic Diseases*. It is possible that these drugs contribute to a protective effect against cancer.

Dr. G. Ruiz-Irastorza of the University of the Basque Country, Bizkaia, and colleagues studied 235 systemic lupus patients. Sixty-six percent (156 patients) had been treated with malaria drugs at some point. After an average follow-up time of 10 years, 1.3 percent (two patients) who received malaria drugs developed cancer, compared with 13 percent (11 patients) who had not received the drugs. The researchers estimated that people who received malaria drugs were 85 percent less likely to develop cancer than those who didn't.

Further research is needed, but Dr. Ruiz-Irastorza thinks that unless there is a reason a lupus patient cannot take malaria drugs, they should be added to treatment. For details, visit <http://uk.reuters.com/article/healthNews/idUKTON97641120070719>.

### CYCLOPHOSPHAMIDE MAY AFFECT FERTILITY IN MEN

In a study published in the July issue of *Arthritis & Rheumatism*, researchers at the University of Sao Paulo in Brazil have found that sperm damage linked to infertility is common in men with lupus and appears to be related to a commonly used treatment for the disease.

The research team compared sperm count, shape and function in 35 men with lupus to a group of healthy men. Men with lupus had lower average sperm counts and sperm motility, lower sperm volume and a lower percentage of normally formed sperm.

Analysis showed that men with lupus who had more treatments of intravenous cyclophosphamide were much more likely to have permanent sperm damage tied to infertility than men who had received the treatment less often.

While it isn't possible to predict which men with lupus will become infertile as a result of this treatment, the study suggests that about five years of treatment with the drug is associated with severe sperm damage. The researchers suggest that freezing and storing sperm should be discussed early in the treatment of men diagnosed with lupus. For more info, visit [www.cbc.ca/health/story/2007/06/29/lupus-sperm.html](http://www.cbc.ca/health/story/2007/06/29/lupus-sperm.html).

### RESEARCHERS EXPLORE ROLE OF INTERFERON-ALPHA

Using blood samples from two large repositories, rheumatologist Dr. Mary K. Crow and her colleagues at the Hospital for Special Surgery in New York compared 266 patients with systemic lupus with 405 of their healthy relatives. The team found that when a patient had high blood levels of a molecule called interferon-alpha, so did many of their healthy first-degree family members.

Normally, interferon-alpha helps defend the body from viruses. High levels of this molecule may confuse the immune system so that it attacks the self. Doctors have known for decades that lupus patients often have an abnormally high blood level of interferon-alpha, but don't know what role it plays in lupus. Because the blood samples in this study showed that some family members of patients with high levels of interferon-alpha also had higher levels than unrelated, healthy individuals, regardless of ethnic background, researchers think high

# lupus

## Lupus Ontario

### LUPUS ONTARIO BOARD OF DIRECTORS

Julia Kane, President (EC)  
Tina Sarta, Vice President/Treasurer (EC)  
Sharon Coslett, Board Secretary (EC)  
Vacant, Treasurer (EC)  
Laverne Nimigon, Director Fund Development  
Gloria Checkley, Director Volunteer Management  
Tiziana Tolfo, Director of Public Awareness  
Kevin Stannard, Director at Large  
Anne Matheson, Director of Communications

### PROVINCIAL BRANCHES

#### Toronto & GTA Region

Toronto West Branch and Support Group  
Toronto North Branch and Support Group  
Toronto North Support  
Scarborough Support Group  
Northumberland Support  
Oshawa Support Group

#### Eastern Ontario Region

Ottawa Branch  
Belleville Support Contact  
Lindsay Support Group  
Peterborough Support

#### Central Ontario Region

Barrie and Area Support Group

#### Northern Ontario Region

Sudbury Branch and Support Group  
Thunder Bay Branch and Support Group

#### Western Ontario Region

London  
Windsor Branch  
Kitchener/Waterloo

#### South Central Region

Hamilton Branch

#### Ontario Teen & Young Adult Support

Please contact office for information.



590 Alden Road, Suite 211, Markham, ON L3R 8N2  
Tel: 905-415-1099  
Fax: 905-415-9874  
Toll Free: 1-877-240-1099  
E-mail: [lupusontario@bellnet.ca](mailto:lupusontario@bellnet.ca)  
Website: [www.lupusontario.org](http://www.lupusontario.org)

### LUPUS CANADA

590 Alden Road, Suite 211  
Markham ON L3R 8N2  
Toll Free (in Canada): 1-800-661-1468  
Phone: 905-513-0004  
Fax: 905-513-9516  
Email: [lupuscanada@bellnet.ca](mailto:lupuscanada@bellnet.ca)  
website: [www.lupuscanada.org](http://www.lupuscanada.org)

### MEMBER ORGANIZATIONS

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

**LE Society of Saskatchewan**  
Box 88, Royal University Hospital  
103 Hospital Dr.,  
Saskatoon, SK S7N 0W8  
Tel: 204-942-6825  
Toll Free: 1-877-566-6123  
Email: [less@sasklupus.com](mailto:less@sasklupus.com)

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

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

**Lupus Ontario**  
(see contact information above)

**Lupus New Brunswick**  
c/o Nancy Votour, 23 - 13 Ivan Ct.,  
Moncton, NB E1C 8T3  
Toll Free: 1-877-303-8080  
Tel/Fax: 506-384-6227  
Email: [lupins@fundy.net](mailto:lupins@fundy.net)

**Lupus Society of Nova Scotia**  
P.O. Box 38038,  
Dartmouth, NS B3B 1X2  
Tel: 902-425-0358  
Fax: 902-798-0772  
Toll Free in Nova Scotia:  
1-800-394-0125  
Email: [lupussocietyns@medscape.com](mailto:lupussocietyns@medscape.com)

**Lupus Newfoundland & Labrador**  
P.O. Box 8121, Station A, Kenmount Rd.,  
St. John's, NF A1B 3M9  
Tel: 709-368-8130  
Email: [lupusnfld@roadrunner.nf.net](mailto:lupusnfld@roadrunner.nf.net)

**Lupus P.E.I.**  
P.O. Box 23002  
Charlottetown, PE C1E 1Z6  
Tel: 902-892-3875  
Fax: 902-626-3585  
Email: [bargri@pei.sympatico.ca](mailto:bargri@pei.sympatico.ca)

The deadline for the  
Winter 2007 issue  
of *Lupus Link* is October 1.  
Please send submissions  
to editor Jaclyn Law at  
[jaclynlaw@hotmail.com](mailto:jaclynlaw@hotmail.com).

*Systemic Lupus Erythematosus (S.L.E.) is a disease in which the body's own immune system can cause damage to the skin, joints and internal organs. It affects thousands of Canadians, mostly women during child-bearing years. Although not yet preventable or curable, the disease can usually be controlled. Because the characteristics and severity of S.L.E. vary among patients, medical management must be individualized. It is important that persons diagnosed with, or suspected of having S.L.E., consult with their own physician to assure proper evaluation and treatment. Opinions expressed in articles appearing in the *Lupus Link* do not necessarily reflect those of Lupus Ontario.*

If you would like to contact Lupus Ontario's provincial branches or support groups, please call 904-415-1099 (or toll-free at 1-877-240-1099). Karen Furlotte, our office co-ordinator, will pass the request to the appropriate person. Thank you!

# lupus walk a block

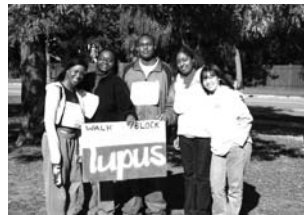
In October 2006, through the work of outstanding volunteers and dedicated walkers, **we raised over \$135,000** to help support the work of Lupus Canada and local lupus organizations across Canada.

This year, **Lupus Ontario** hopes to make the **Walk a Block for Lupus** an even more successful event, and we want you to join us.

For more information, please visit [www.lupusontario.org](http://www.lupusontario.org) or call Juanita Butler, Provincial Walk Coordinator for Lupus Ontario, at 1-877-240-1099 toll free or email at [lupusontario.info@bellnet.ca](mailto:lupusontario.info@bellnet.ca).

**Register online today at [www.lupuscanada.org](http://www.lupuscanada.org)**

- Become a Team Leader
- Join a local Walk
- Support a Walker
- Be a sponsor for a Walk
- Volunteer with the planning



With your help, the awareness will grow.  
**To date, there are over 56 teams and over 100 individual walkers registered to WALK A BLOCK for Lupus in Ontario!**

**SAVE THE DATE!**  
**Sunday, October 21, 2007**

**Last Year's Total: \$140,000.00**  
**This Year's Goal: \$300,000.00**

**Together we can conquer lupus!**

## RESEARCH (CONTINUED)

interferon-alpha levels may play an important primary role, perhaps "lowering the threshold" so that, when triggered by some stimulus, the immune system produces autoantibodies and the person develops lupus. For more info, visit [www.hss.edu/newsroom\\_16674.asp](http://www.hss.edu/newsroom_16674.asp).

### U.S. CONGRESS AWARDS MORE LUPUS RESEARCH GRANTS

The U.S. Department of Defense (DoD) Congressionally-Directed Medical Research Program recently announced more than \$2 million US in grants for research on lupus and lupus biomarkers. U.S. Congress has now directed nearly \$5 million in new funding for lupus research through the DoD.

Dr. Steve Tomlinson, Professor of Microbiology and Immunology at the Medical University of South Carolina in Charleston, and Dr. Betty Diamond, Chief of the Autoimmune Disease Center for the Feinstein Institute for Medical Research at the North Shore Medical Center in Manhasset, New York, have each received grants of more than \$1 million.

Using a mouse model of lupus, Dr. Tomlinson will explore whether targeting a certain cascade of proteins, the complement system, with a treatment that targets areas where lupus is active can be safer and more effective by minimizing immune suppression in the rest of the body. Dr. Diamond will study estrogen's role in triggering lupus activity in some mouse models but not others. This could lead to better ways to test patients with lupus for hormonal disorders and new therapies based on hormonal regulation. For more details, please visit [www.medicalnewstoday.com/articles/72601.php](http://www.medicalnewstoday.com/articles/72601.php).

### Buy your 2008 Ottawa/Outaouais Entertainment Book!



**Use the coupons to save money all year on fine dining, fast food, attractions, entertainment and services.**

**Each book costs \$35. Part of the proceeds support Lupus Ontario.**

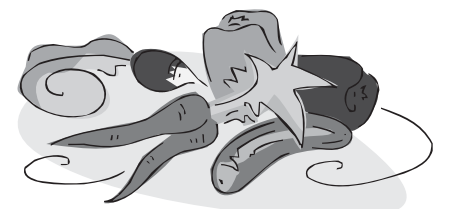
**For information, contact Betty Wong at 613-591-8899 or Joni Waiser at 613-744-0770.**



## RESOURCES

**WEBSITE:** The **Lupus Research Institute** in the U.S. has launched a patient-friendly website as part of a year-long initiative to educate people with lupus about clinical trials. "The community is seeing unprecedented interest from biotechnology and pharmaceutical companies that translates into dozens of companies interested in lupus and even more trials for lupus patients," the site explains. "As few as seven or eight years ago, there were just two to three trials in progress. Today there are 12 to 15." Visit [www.lupustrials.org](http://www.lupustrials.org).

**WEBSITE/HOTLINE:** Do you have a question about healthy eating? **Ask a Dietitian!** As part of the EatRight Ontario program, the provincial government has created a service for Ontarians to ask a dietitian questions about nutrition. Go to [www.ontario.ca/eatright](http://www.ontario.ca/eatright) or call 1-877-510-510-2.



**WEBSITE:** On March 19th, Finance Minister James Flaherty announced the creation of a **Registered Disability Savings Plan (RDSP)**, the first in the world. It is expected to have an impact on over 750,000 people with disabilities and their families who are, for the first time in history, facing issues related to people with significant disabilities outliving their parents. To learn more about RDSPs, the Disability Savings Grant and Disability Savings Bond, visit the PLAN website at [www.plan.ca/SocialPolicy\\_PolicyUpdates.php](http://www.plan.ca/SocialPolicy_PolicyUpdates.php).

**WEBSITE:** Thanks to Wendy Kool in Ottawa for letting us know about **DxLupus** ([www.dxlupus.org](http://www.dxlupus.org)), a patient-focused website about lupus. It offers lots of great resources, including videos, an overview of lupus research, and information for family members.

**WEBSITE:** Here's another of Wendy's terrific finds: a list of **pain management tips** from the Rothbart Pain Management Clinic in Toronto at [www.rothbart.com/tip/list.php](http://www.rothbart.com/tip/list.php). Here's an example you can try: "To accomplish a nice respite from pain, learn to visualize a place that is peaceful and comfortable, i.e. a pleasant vacation spot."

*Do you know of helpful lupus resources? Write to [jaclynlaw@hotmail.com](mailto:jaclynlaw@hotmail.com).*

FEATURE

# An Adoption Story Continued...

Shannon R. Crawford first wrote about her adoption experience in the Spring 2005 issue of Lupus Link. In this issue, she gives us an update on her family and shares her experiences of parenting with lupus.

It has been three and a half years since our lives changed forever. This is when my husband, Steven, and I were blessed with our beautiful Sarah Elizabeth.

When we adopted our daughter, I had many concerns. Sarah wasn't even a week old and I was already thinking about all the "what ifs": What if she wants to find her birth family? What if she ever says "You're not my real mom"? What if she feels different because she's adopted? What if my lupus makes parenting too difficult?

These initial thoughts were taking away from the enjoyment of just bringing home a precious new baby and finally getting to be the mother I had always dreamed of being. It is amazing how time has changed my initial fears. Life is about being parents and being a family.

Steven and I decided near the beginning how Sarah's adoption story would go. Quite simply, we will love her, encourage her, support her, praise her, teach her, and will always be there for her. If and when she decides that she would like to find her birth family, we will love her, support her, encourage her and will always be there for her. So far, Sarah is well-adjusted and happy. She is strong-willed and stubborn and knows what she likes and does not like. We would not change a thing. This is part of who she is.

We've been through many experiences together: the ups and downs of getting rid of the beloved "Soothie & Bubba" (Sarah's soother and bottle), the joys of potty training and the teaching of manners. Dealing with the occasional meltdowns in the middle of



Steve, Shannon and Sarah

Loblaws. The "I wants" and "But why, Mommy?" These are things all children go through, not only adopted children.

I read Sarah stories about adoption, such as *How I Was Adopted*, *An Adoption Story* and *A Mother for Coco*, just to name a few. Sarah knows the word "adopted," but doesn't really grasp it. We do not push the subject, either. When she is older, we will answer with age-appropriate answers that are honest.

When I was reading her the story *How I Was Adopted* a while ago, Sarah stopped and looked at the picture of the birth mother and the baby in her tummy. She shocked me when she said, "Mamma, I didn't grow in your tummy." I thought about her statement quickly. Then I said, "No, Peanut, you grew in another lady's tummy for Mommy." I debated with myself about whether I should elaborate, but chose to wait to see if another question would pop up. It didn't.

As Sarah gets older, we know the harder questions will come. We'll deal with them when it happens.

In my first article about our adoption experience for

especially worried. She finally made time to see the doctor, who immediately suspected lupus and sent her to a rheumatologist. The rheumatologist confirmed the diagnosis and admitted her to hospital, where she stayed for three weeks.

"It all happened so quickly," says Tiziana. "I barely understood what lupus was. It seemed inconceivable that one month earlier I felt entirely normal. I cried constantly."

The sun shone brighter in 1990 when Tiziana married Louis Tolfo, the love of her life and her anchor when the disease incapacitates her. She continued to be treated with prednisone, a common and effective therapy for treating lupus patients, but one that can cause weight gain, hair loss, mood swings, diabetes, bone loss and osteoporosis. Following her wedding in 1990, Tiziana underwent a fibular graft, surgery she describes as "hell." This surgery preceded two hip replacement surgeries in her mid-20s, and two revision surgeries several years later.

Tiziana's greatest challenge came in 1998 when she discovered she was pregnant.

"Pregnancy is supposed to be filled with excitement and joy, but all I could feel was a tremendous fear," she says.

Pregnancy for women who have lupus is challenging. Unlike other arthritis and autoimmune diseases such as rheumatoid arthritis, in which the disease often goes dormant during pregnancy, women with lupus are still susceptible to flare-ups, increasing the risk of complications to the mother and child. After a very difficult pregnancy, Tiziana and Louis welcomed their son, Justin. As Tiziana struggled to bring her body back to good health, she worried about her baby who, born just shy of 30 weeks, had his own set of challenges to face. Following six weeks in the hospital, Justin was sent home and is now a healthy, happy eight-year-old.

Tiziana describes her journey as a wild roller-coaster ride. "I'm on an involuntary path, but I continue to find strength through the support of the wonderful people I have around me."

So - what advice would Tiziana give to newly diagnosed patients?

"I would tell them to hang in there, to stay strong. I would tell them that there is light at the end of the tunnel. Take it one day at a time, and do everything you can do today - don't put it off until tomorrow." ●



## DID YOU KNOW?

- Lupus affects more than 50,000 Canadians.
- Women are affected by lupus up to 10 times more often than men.
- Lupus is a systemic illness, affecting not only the joints and tissues but also the blood vessels, lungs, heart, kidneys and brain.
- In the past four decades, lupus mortality has diminished from more than 50% at five years to current levels of less than 20% at 20 years.

\*Sources: Toronto Western Hospital Lupus Clinic, Arthritis Community Research & Evaluation Unit

**The Lupus Clinic** at the Toronto Western Hospital was established in 1970 as a patient-care referral centre designed to promote expert care for patients with lupus, to train future rheumatologists and to facilitate research into this disease. Today Drs. Murray Urowitz, Dafna Gladman and Paul Fortin oversee the care of more than 1,280 patients who are registered in the Lupus Clinic. One of the largest centres for specialized lupus care and research in the world, patients in the clinic are evaluated according to guidelines established by lupus experts, including a detailed history, physical examination and blood and urine tests.

Article reprinted  
courtesy of the  
Brazilian Carnival Ball

# Unstoppable

Powerhouse Tiziana Tolfo refuses to let lupus slow her down.

PHOTOGRAPHY BY EDWARD POND

TIZIANA TOLFO IS A vivacious 39-year-old with an infectious laugh and bigger-than-life personality.

She also has a severe form of lupus, a group of autoimmune diseases that cause inflammation in the skin, muscles and joints. The heart, lungs, kidneys, blood vessels and the nervous system can also be compromised.

Tiziana was diagnosed at the age of 20, and over the past 19 years she has endured more tests, specialist visits and hospital stays than most people twice her age. But she's Tiziana, so she's not just optimistic, she's making lemonade from the big bag of lemons life has tossed her way.

"This isn't the way I pictured my life,"

explains Tiziana. "But you know what? Life is good right now – I want to do as much as I can when I am feeling well."

Life has not always been so good. Tiziana was a healthy child and adolescent, so when she experienced a sudden rash, extreme fatigue, fever and swollen joints for two weeks during her final exams in college, she was surprised but not



Tiziana Tolfo with husband, Louis, and son, Justin

WWW.EDWARDPOND.COM

## ADOPTION (CONTINUED)

*Lupus Link*, I wrote about my concerns about being a mom with lupus. Lupus has posed a few challenges, more so when Sarah was a baby. I found it difficult in the beginning, having to get up a few times throughout the night for diaper changes and feeding. Even though some nights were harder than others, I did it because it had to be done. I have to admit I miss those special moments in the night. This was our time. Just giving Sarah her bottle and rocking her back to sleep was a joy. I miss that new baby smell.

When Sarah was an infant, we had many pajama days, just getting through the day together. As she grew older we both adjusted to each day. On good days, we would go for long walks, do some shopping and visit family and friends.

On bad days when my lupus was more active, we'd stay home and take it easy. One thing that truly saved me on my bad days was Sarah's toy room. I had a baby gate across the door. I'd put a big comforter down on the floor with a ton of her baby toys. I'd lie down on the toy room floor and play with her and rest my eyes. I always had that mother's ear open. She'd play around and on me, a happy little camper. And I didn't feel guilty about being so tired, because she was playing and having fun.

Now that Sarah is older, she notices when Mommy is having an off day. I think she likes these days, to be honest with you, because we open the fold-out couch and watch her Disney movies. I'll get her a drink and snacks and we just take it easy. What I find so sweet is when I'm having a bad day, she'll say things like, "Mommy your lupus acting up." She doesn't understand what lupus is exactly, but she knows it makes me very tired and causes me pain sometimes. She is my little mother hen on these days. It melts my heart.

Sarah even loves attending my lupus support group meetings. She likes to serve everyone treats and makes sure everyone is OK. She loves our lupus carnivals, especially because she gets to spend time with Uncle Laverne.

Being parents has gone beyond any expectations we had. It is the best blessing anyone could have. How a child can fill your life with so much love, joy and happiness is sometimes surreal. We know that whatever challenges come up, we will handle them. We love our life with our beautiful little lady and soak up every minute with her!

*Shannon Crawford is the leader of the Oshawa Lupus Support Group.*

## UPCOMING EVENTS

### Walk A Block for Lupus & Fun Fair Saturday, September 15 Lakeview Park, Oshawa

Registration: 9 a.m. – 10 a.m.  
Walk: 10 a.m. – 11 a.m.  
Lunch: 11 a.m. – 12 p.m.  
Silent Auction: 9 a.m. – 12:30 p.m.  
Fun Fair: 11 a.m. – 4 p.m.

Enjoy Fun Fair games, an airbrush tattoo artist, face painting, cookie decorating, a balloon artist, Jumping Castle, band and much, much more! Please contact Shannon Crawford for more info at 905-697-2941 or shan\_crawford@hotmail.com.



Shannon Crawford's Van

### ACT/UCT 2007 Flea Markets

441 Gibb St. in the Canadian Tire parking lot, Oshawa  
Labour Day (Sept.3), Thanksgiving Day (Oct. 8)

### Lupus Ontario President's Walk Saturday, October 20, Thornhill

Join Lupus Ontario president Julia Kane at the historic Heintzman House at 2 p.m. to walk and raise funds for lupus!

### Italian Dinner 2007 Saturday, November 3, Concord

For details, please turn to page 1.

### Dance for the Cure Saturday, January 26, Vaughan

For details, please turn to page 6.

## OUTSIDE ONTARIO

### Second Annual Youth Symposium October 27-28 Radisson Hotel, Saskatoon

The Lupus Erythematosus Society of Saskatchewan invites youth to Saskatoon! Speakers include Dr. Alan Rosenberg, a Saskatoon pediatric rheumatologist who will explore issues of importance to young people with lupus. Network with your peers and more!

There is no charge to attend, but please register. Participants are responsible for their own expenses. For info, contact Irene Driedger at idriedger@sasktel.net or (306) 931-1063.

### Living Well with Lupus Patient Symposium May 31, 2008 Delta Hotel, Montreal

Sessions and speakers to be announced – watch the Lupus Canada website at www.lupuscanada.org for more details!

# Dance FOR THE CURE

2008 SPONSORSHIP PROGRAM

Saturday January 26th, 2008  
 The Terrace Banquet Centre  
 1680 Creditstone Road  
 Vaughan, Ontario

Cocktail Reception: 6:30pm  
 Dinner: 7:00pm  
 Master of Ceremonies:  
 John Derringer, Q107

# Winter Wonderland

Enjoy a sumptuous dinner, dance to live music, bid in our silent and live auctions, and enter a raffle draw!

Last year, 800 guests enjoyed a memorable evening while raising \$130,000 for lupus research. We are planning a bigger and better event this year with a goal of \$150,000. Come experience the magic of a Winter Wonderland and help conquer lupus.

The beneficiaries of this year's event are Lupus Ontario and the Lupus clinics at Toronto Western Hospital and Toronto Sick Kids Hospital.

For sponsorship opportunities, to donate silent auction items or order tickets, please call Karen at Lupus Ontario, 905-415-1099 or 1-877-240-1099.



## 'FLARE' for FASHION

Be a part of a prestigious fashion charity event, 'Flare' for Fashion, benefiting thousands who suffer from lupus, a debilitating and life-threatening disease.

Join actress Rachel Blanchard, Entertainment Tonight Canada host Cheryl Hickey, and singer-songwriter and Canadian Idol judge Sass Jordan to help raise awareness of lupus. Come and enjoy an evening of fun, fashion and 'Flare,' all in support of finding a cure for lupus.

Thursday, October 18, 2007, 7 pm  
 Mississauga Convention Centre  
 75 Derry Road West

Silver Seating Tickets are \$100 each, which includes Premium Hors D'oeuvres, Sit-Down Dinner, Fabulous Fashion Show and Entertainment!

For more event details and tickets, please call 905-278-6286 or visit [www.flareforfashion.ca](http://www.flareforfashion.ca).

## Does Your Employer Have a "Matching Gifts" Program?

When an eligible employee makes a donation to an approved charity, some companies will match each dollar. If you are planning on making a contribution, check with your company to see if they participate in such a program – you could double your donation!

The following are participating companies that we are aware of:  
 FIJI Water, POM Wonderful, Paramount Farms, Teleflora, AgriSense and Suterra.

## LUPUS INFO GOAL OF WALK

By Jillian Follert

(This article appeared on [newsdurhamregion.com](http://newsdurhamregion.com) on July 13, 2007.)

DURHAM -- A few years ago, Jaclyn Smith had never even heard of lupus.

Today, the 16-year-old is a fountain of information, teaching her friends about the disease, filling in her teachers and gearing up for a second year of fundraising through Walk a Block for Lupus.

"I want everyone to know that a lot of people get this disease and it's really tough," she says. "But maybe, raising money will help find a cure."

It's been two and half years since Jaclyn was diagnosed with lupus.

After years of being sick on and off, the Blackstock teen landed at the Hospital for Sick Children where doctors first thought she had a blood disorder.

"They diagnosed me with lupus three weeks before my 15th birthday," she says. "I didn't know what it was. My family and friends and everyone were really surprised."

Lupus is a chronic disease that causes the immune system to attack healthy cells, leading to inflammation, tissue damage and organ failure. It can affect any part of the body and symptoms vary widely which is why it is known as "the disease with a thousand faces."

Lupus Canada estimates at least 50,000 Canadians live with the disease, which is most prevalent in women ages 14-45.

In Jaclyn's case, lupus attacked her brain first.

"I had a headache for 26 days straight," she recalls. "On a scale of one to 10, it was a nine or a 10 most of the time. I had to hide out in my room, I couldn't listen to people talking." The disease has also affected her kidneys.

### Teens Help Tackle Lupus

Fortunately, Jaclyn is now being weaned off the steroids that kept her symptoms at bay and crossing her fingers that she will go into remission.

She is starting to get back to normal teen things – like playing baseball – but is keenly aware that lupus might always be a part of her life.

"It's hard, especially if you're my age. I lost some friends because people didn't understand," Jaclyn says.

But she has also found new support through the Oshawa Lupus Support Group, a group of people from across Durham who meet monthly to hear speakers, discuss issues and offer advice.

Group leader Shannon Crawford says there is a huge need for public awareness when it comes to lupus and plans to make that a focus of this year's fundraising event.

In past years, the annual walk was a small event for family and friends, held at the Oshawa Centre.

This year, it is moving to Lakeview Park and will include a fun fair and silent auction to attract a broader range of people.

"We've never really been visible to the public and we need to be," she says. "I've talked to people who had no idea there was a local lupus support group. This disease is more common than people think and we want people to know we're here."

Last year, Walk a Block for Lupus events across Canada raised over \$135,000. This year, the goal is \$300,000.

The local walk takes place Saturday, Sept. 15, at Lakeview Park in Oshawa. Registration starts at 9 a.m. followed by the walk at 10 a.m. and fun fair from 11 a.m. to 4 p.m.

To register, sponsor a participant or make a donation, visit [www.lupuscanada.org](http://www.lupuscanada.org).

For more information on the local walk or support group, contact Shannon Crawford at 905-697-2941.



## TEEN EDUCATES ABOUT LUPUS ON FACEBOOK

Children of parents with lupus find peer support

By Tamara Shephard ([tshephard@insidetoronto.com](mailto:tshephard@insidetoronto.com))

On the eve of her wedding, a young, vibrant Karen Gnidec suffered a stroke.

Determined, she pressed on, and walked down the aisle on her father's arm with a cane and a brace, one arm in a sling.

Diagnosed at age 19 with central nervous system lupus, doctors gave her seven years to live. But pressing on and overcoming adversity has become a way of life for Gnidec.

Now 50, and a single mom to three daughters, she has withstood 52 hospital admissions, the removal of one kidney, half her pancreas and four cornea transplants.

The potentially life-threatening autoimmune disease attacks healthy tissues throughout the body and causes inflammation, pain, and possible damage to multiple vital organs.

For years, Gnidec suffered in silence, "in big denial," she said. That changed in February when lupus stole the vision in her right eye, as well as her 30-year career as a physiotherapist, despite IV "burst" treatments of prednisone and cyclophosphamide.

That's when her youngest daughter, Danielle, 15, asked her to explain her illness.

"I always wanted to know about it, but when she'd talk about it, I never wanted to hear it. It frightened me. Now, I accept it. Learning more about it helped me not be afraid because I understand it."

Within days, Danielle had created a "lupus awareness" group on Facebook to offer peer support to other children whose parents have lupus.

Inspired by other Facebook groups pledging humanitarian donations to Africa if 1,000 people join it, Danielle did the same, pledging to donate to the Lupus Foundation of Canada to aid research.

She surpassed her goal. As of yesterday, the group - differentiated from other "lupus awareness" Facebook groups by its red butterfly insignia - boasted 1,019 members. Group members can donate Shoppers Drug Mart "Optimum" points, as well as Canadian Tire money.

"I'll either explain things, or give them some support," Danielle said of her Facebook group. "I've had a couple of e-mails that made me cry; they're just so sweet. I'm really surprised at how many kids' parents have lupus and they didn't know anything about it."

Already, the teen's Facebook group is sharing scientific breakthroughs, dates of upcoming lupus walks, and encouragement to keep spreading the word about the condition, known as "the disease of a thousand faces."

In its most severe form, lupus can cause disfiguring rashes and scarring, multiple miscarriages, kidney, heart and lung failure, impaired neurological function, strokes, heart attacks, even death.

Lupus affects approximately 50,000 Canadians. Eighty per cent of new lupus cases are diagnosed among women in their prime of life, between ages 15 and 44.

Last Thursday on World Lupus Day, Danielle led another lupus awareness campaign, this one at her school, Richview Collegiate, where she sold "Conquer Lupus" bracelets, sweatshirts and Mother's Day pins.

Gnidec said Danielle, and her two older daughters, Vanessa, 20 and Alynn, 18, are her greatest support.

"It makes me feel so proud," Gnidec's said of Danielle's campaign to raise lupus awareness. "Lupus is hard on the person who has it, but also hard on everyone around it."

Danielle reads to her avid book-lover mom, opens her mail and makes sure she's home when her mom bathes or cooks. Gnidec's older daughters drive her to appointments and run errands.

"I think kids who have parents with a disability either kick into that very responsible mode, or they run away," Gnidec said, noting her daughters do the former. "These are life lessons. I just think they're learning their life lessons early."