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**Thank you for supporting  
Lupus Ontario**

## OUR MISSION STATEMENT

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



Kevin Stannard

## MESSAGE FROM THE PRESIDENT



I hope everyone had a great holiday season, and best wishes for a healthy and prosperous new year!

Lupus Ontario has changed its year end to September 30, the same as Lupus Canada. This makes it easier for both groups. This means that we will have our annual meeting in spring, on Saturday, May 13 (see details in the Events section on page 3).

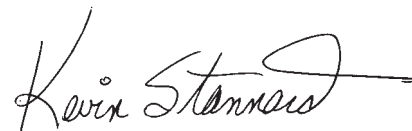
Volunteers are difficult to recruit, and I'm sorry to say that three of our board members have resigned. Shannon Crawford, Bill Rankin and Shannen Sorgi have all resigned from the provincial board, but still continue to help and support at the local level. I would like to thank all of them for their hard work and I'm glad to see they're still involved.

I also have good news: we have appointed Jody Breen, Anne Matheson and Diana Bozzo to the board. They bring new ideas and eagerness to the table with them. Thanks to Jody, Anne and Diana for coming forward and making a commitment. Welcome!

At the AGM, we will have elections, so if you would like to volunteer, please let Karen (our office coordinator) know. You can call her toll-free at 1-877-240-1099.

To wrap up, I have a bit of fundraising news. Through the London area Nevada sales, we have donated close to \$5,000 to Dr. Warren Neilson for a server for his lupus day program at St. Joseph's Health Care. This program is covered by OHIP and requires a referral from your physician. Read on for lots of research news, a touching personal story by Maria Fatsis, and info on purchasing the new Lupus Angel of Hope pin.

We must all work together to conquer lupus. Until next time, take care!




Kevin Stannard, President



### Still Available

The custom-made sterling silver Lupus Butterfly Bracelets have been so popular that we've ordered more! They're just \$35 each. Please call Karen Furlotte at 905-415-1099 to get yours.

## MORE LUPUS NEWS...

### OCTOBER'S AGM NEWS

At the Lupus Ontario AGM on October 29 in Toronto, after welcoming speeches from President Kevin Stannard and Lupus Canada COO Judi Farrell, Dr. Mandy Nikpour was awarded the Geoff Carr Fellowship and a sum of \$55,000 to continue her lupus research. It was also announced that last year, \$85,000 was sent to provincial clinics thanks to fundraising efforts. Treasurer Tina Sarta also delivered a positive financial report, noting that it was a record year for the Dance for the Cure, the Italian Dinner and Walk-A-Block. Julia Kane showed the touching personal videos that were played at the highly successful "Flare" for Fashion show as well as a recording of an interview that Julia and Diana Bozzo did on Rogers daytime television about lupus awareness.

### NEW LUPUS CANADA FACTSHEETS

Lupus Canada is excited to announce that the first of five factsheets in a new educational series - written and produced in Canada - are now available. Topics include living well with lupus (two parts), skin disease in lupus, lupus medications and kidney disease. These topics are among the most-requested by people seeking lupus information. The factsheets are also available online at [www.lupuscanada.org](http://www.lupuscanada.org). Thanks to Pamela Bowes, Director of Support, and Cheryl Magnusson, Chair of the Education Subcommittee, for coordinating the project.

### A GIFT FROM PETERBOROUGH

The Peterborough Arthritis Support Group donated \$1663.64 to Lupus Ontario in January 2006 from moneys they had raised. To Mrs. Florence Townsend and her group, we sent a big hug of gratitude because their generosity shows we are all working together to conquer lupus.

### OSHAWA SUPPORT GROUP AND FRIENDS WALK FOR LUPUS!

A Walk-A-Block fundraiser held at Oshawa Centre on October 16 raised an impressive \$5,182.40.

### WOMEN'S HEALTH MATTERS

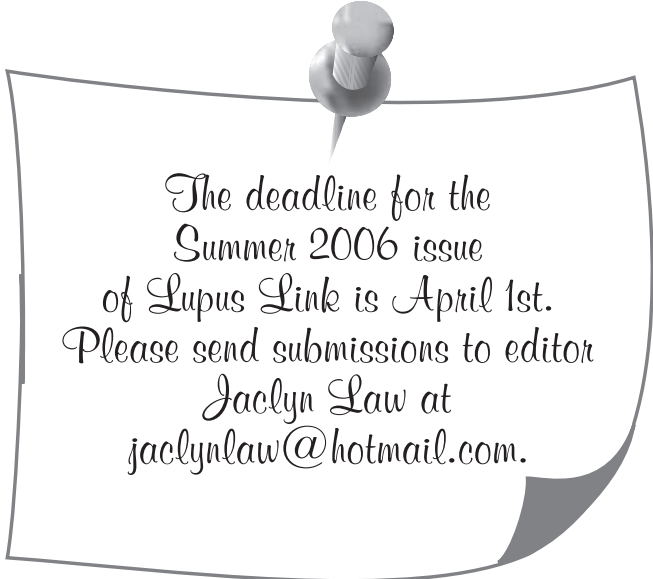
Lupus Ontario had a booth at the Women's Health Matters Forum & Expo at the Toronto Convention Centre on Jan. 20 and 21 for public awareness and education. Several great volunteers assisted Julia Kane at the two-day event, which celebrated its 10th anniversary this year.

## AVAILABLE NOW...



*A Delicious  
Way to  
Show Your  
Support!*

After its first 1,000 copies sold out, the Lupus Erythematosus Society of Saskatchewan (L.E.S.S.) **Butterflies of Hope Cookbook** has entered its second printing! To get your own copy filled with tempting appetizers, beverages, main dishes, breads and desserts contributed by people with lupus, their friends and families, and L.E.S.S. volunteers, write to L.E.S.S. at Box 88, RUH, 103 Hospital Dr., Saskatoon, SK, S7N 0W8. Each copy costs \$10 plus shipping: add \$7 for orders of 1 to 3 books; add \$10 for 4 to 6 books. For orders of 7 books or more, please contact Irene by calling 306-931-1063, e-mailing [idriedger@sasktel.net](mailto:idriedger@sasktel.net), or writing to Box 151, Clavet, SK S0K 0Y0.

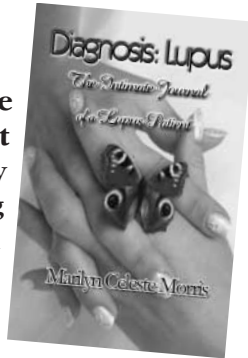


The deadline for the  
Summer 2006 issue  
of *Lupus Link* is April 1st.  
Please send submissions to editor  
Jaclyn Law at  
[jaclynlaw@hotmail.com](mailto:jaclynlaw@hotmail.com).

## RESOURCES

Sign up for the **Lupus Foundation of America's free e-newsletter, "Lupus Now Research Update."** Each edition will provide reviews of recently published papers from significant medical journals, translated into understandable language, as well as updates on clinical studies and other relevant news. The commentary will aim to put research findings into perspective, explain the limits to the conclusions that can be drawn, and examine the possibilities for future research directions. Visit [www.lupus.org/enevs](http://www.lupus.org/enevs).

**Diagnosis: Lupus – The Intimate Journal of a Lupus Patient** is an honest and touching new book by Marilyn Celeste Morris, a woman living with lupus, about her search for answers to baffling symptoms she experienced for years. For more information, visit [www.thewriterslife.net/marilyncelestemorris.html](http://www.thewriterslife.net/marilyncelestemorris.html).



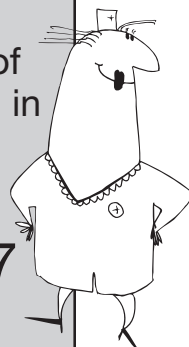
**ButYouDontLookSick.com** is a website that was started by Christine Miserandino, a young American woman with lupus who was tired of being told, "But you don't look sick!" It has personal essays and product reviews.

## CLINICAL TRIALS IN SYSTEMIC LUPUS ERYTHEMATOSUS

The University of Toronto Lupus Clinic, Toronto Western Hospital, is currently conducting studies evaluating the effectiveness of new investigational drugs for the treatment of systemic lupus erythematosus.

If you are a patient with a diagnosis of SLE and are interested in participating in a clinical trial or would like further information, please call

**416-603-5800 ext. 2077**



## EVENTS

### OTTAWA

#### *Lupus Educational Program*

Wednesday, March 15, 7 to 9 p.m.

Ottawa Hospital, Riverside Campus, Amphitheatre  
Session III: Lupus overview with focus on research  
Presentations by Dr. Doug Smith, D. Mehta MSW, C. Gosselin RN and S. Fong B.Sc. Pharm.  
RSVP: Nicole at 613-738-8400, ext 81840  
or e-mail [nflanagan@ottawahospital.on.ca](mailto:nflanagan@ottawahospital.on.ca)

### WASHINGTON

#### *National Autoimmune Diseases Conference*

March 29 and 30, Washington, D.C., U.S.A.

This AARDA event includes a public forum on autoimmunity and research news. The \$65 US registration fee includes continental breakfasts and dinner reception. For info, call 586-776-3900, e-mail [aarda@aarda.org](mailto:aarda@aarda.org) or visit [www.aarda.org](http://www.aarda.org).

### TORONTO

#### *Lupus Ontario Annual General Meeting*

Saturday, May 13

Bank of Montreal Institute for Learning,  
3550 Pharmacy Ave., Scarborough

More details coming soon.

### HALIFAX

#### *Living Well with Lupus: Lupus Canada's Learning and Sharing Symposium*

June 10, Halifax, New Brunswick

Please join us at the Delta Barrington Hotel to hear about living well with lupus and other important topics from expert speakers. The schedule of sessions and speakers is coming soon to [www.lupuscanada.org](http://www.lupuscanada.org). For more information or to receive a pamphlet, please call 905-513-0004 or 1-800-661-1468

# LUPUS ONTARIO HONOURS LONDONER JOHN RYAN



On November 5th, John Ryan was honoured with the highest award from Lupus Ontario, The Donna Chu Memorial Award, for outstanding commitment and service. John, who is 80, has been the driving force behind the Sport Celebrity Golf Classic held annually in the London area for the past 12 years. To date, it has raised over \$125,000 toward lupus research and education. Earlier this year, at the July 8th event, John was also presented with the Lupus Ontario Award, recognizing his outstanding volunteer commitment individually and in his association with ACT/ UCT.

# 20<sup>th</sup> ANNIVERSARY ITALIAN DINNER CELEBRATES

## *La Dolce Vita!*

The 20th Anniversary Italian Dinner was a wonderful evening of dinner, dancing and fundraising enjoyed by everyone and graciously hosted by the Colagiovanni family. This tradition puts the term FUN in FUNdraising. With Tony Iaccino as disc jockey and the hard work and dedication of this family and committee (liaised by Frances Gotkin), the dance has raised over \$200,000 to support Lupus Ontario. To commemorate this significant anniversary, Lupus Ontario presented etched glass Lupus Ontario Awards of recognition of the family's support and commitment to conquering lupus. Mark your calendar for 2006! The next dance date is November 4th!



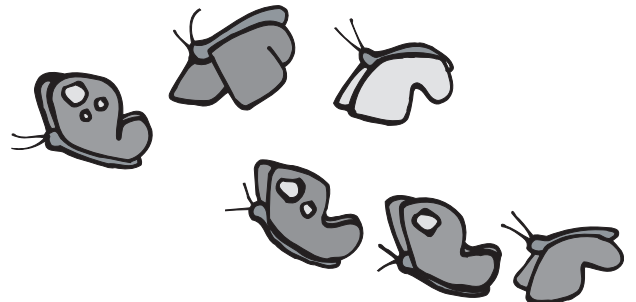
Julia Kane presents Lupus Ontario Awards to Christine & Tony Iaccino (top left), Connie & Chris Barbieri (top right), and Maria and Tony Colagiovanni.



# MISSISSAUGA'S WALK



On October 23, Yvette & Toni Tetrault, chairs/coordinators of the Mississauga Branch of Lupus Ontario, led their "Wellness" group along with family and friends throughout Square One Shopping Centre to raise over \$1,000.



# Fashion Statement



On October 26th, Lupus Ontario presented “Flare” for Fashion 2005, hosted by Jacintha Wesselingh of CTV and Julia Kane of Lupus Ontario. This exciting

event featured five faces of lupus along with fabulous Ford Models.

Held at the wonderful Paramount Conference and Venue Centre, the fashion show was preceded by a mouthwatering reception featuring champagne, chocolate and hors d’oeuvres. The silent auction, raffle and door prizes were a great success thanks to the many donors and supporters. By the end of the evening, the amazing amount of \$50,000 had been raised in support of Lupus Ontario.

We’re already planning the next show! It will be held Thursday, October 19th, and we hope you can join us!



(Top) From left to right: Cathy labani, Tamara Conlan, Tiziana Tolfo, Julia Kane and Diana Bozzo (Committee Chair), whose personal videos, played at the show, had a great impact on the audience.

(Left) From left: Co-hosts Jacintha Wesselingh of CTV and Julia Kane

# DANCE FOR THE CURE RAISES A RECORD \$61,000

By Tina Sarta

The 11th Annual “Dance for the Cure” was held at La Gondola Banquet Hall, in Concord, Ontario, on Saturday, February 4th, 2006. This event was sold out for the third year in a row. Over 400 guests were treated to live music, a fabulous meal, and an exciting silent auction. Over \$61,000 was raised for lupus research (\$10,000 more than the previous year). This year’s presenting sponsor was Hampton Securities and participating sponsors were Risi Stone Systems, Beaver Valley Stone, Unilock, Scotiabank, and Royal Lepage, Your Community Realty. In addition to the sponsorships, over 150 local companies donated money or items for the auction and raffle.

This event was started when Tiziana Tolfo was diagnosed with lupus. It started as a small get-together of family and friends, and has grown to a major fundraiser. This year’s event also paid tribute to Bruno Coppola, a member of our community who lost his battle with lupus on November 22, 2004, at age 38.

Due to the popularity of the dance, next year the event will be moved to the Terrace Banquet Hall, a much larger venue. Mark your calendar and plan to join us on January 27, 2007, for an evening of fun and laughter!

## THANK YOU

Lupus Ontario would again like to acknowledge the major sponsors of the event, and the retailers and designers:

*Premier Event Sponsor:* Queenscorp Group. *Presenting Sponsors:* Berkeley Developments and Lido Wall Systems. *Principal Sponsors:* D’Orazio Infrastructure, Baker Schneider and Ruggeiro LLP, and Scotiabank. *Supporting Sponsor:* Chubb Security. *Participating Sponsors:* AGM Productions and Jim DeAngelis. All eight Ford Models were also generously sponsored. Clothing and accessories were provided by Mijanéaux, rk, Femme de Carriere, CINCYN, Melanie Lyne, Franco Mirabelli, Ines DiSanto and Harry Rosen. A special thank you to CTV for all the weeks of TV announcements that far exceeded our hopes for public awareness.



(From left) Tiziana Tolfo, Dr. Murray Urowitz (Director, The University of Toronto Lupus Clinic, Toronto Western Hospital), and Louis Tolfo at the Dance for the Cure.

# Connecting!!!



By Jody Breen

While manning the lupus display table after a recent Walk a Block event at my local mall, I listened to and shared stories with numerous people, but one man in particular stood out.

He had been standing at the table for a couple of minutes, reading the information on the display board, before I approached him. I asked, “Do you know someone with lupus?” He shook his head and said “No” while checking out my cane and my movements. He continued with, “Is this lupus?”

I told him that this was “my lupus” and about how each person’s lupus experience is different. I told him about the complexity of the disease. I talked for about five minutes, and he shook his head the whole time. Then I asked him about himself. I found out he was a private home builder and I know, from being around the business, that you have to be damn good to build for 45 years and keep busy just from word of mouth.

He is now 82 years old and lives on 500 acres up in Bobcaygeon that he bought in 1959. He putters away at his cottage by adding addition after addition. We talked for about an hour and a half about building codes and the poor quality of homes being built these days. We showed off photos of our spouses. Like me, he had a lot of interests and I could relate to his morals – I felt like I was talking to myself 49 years from now, which gave me some sense of hope of reaching that age.

The man was waiting this whole time for his wife, who was shopping. My wife, Jennifer, arrived from home, where she had been working hard on her new school course. She joined our conversation.

When Doug’s wife finally showed up, I realized the photo he had shown me wasn’t a picture of his wife when she was younger – it was a photo of his young wife. But that’s not the purpose of this story. When she showed up and saw Doug smiling and laughing as we exchanged stories, Laura Leigh looked at Doug smiling, then looked at me, and said “You’ve really sparked something in him! He never smiles or talks to anyone.”

This caught me by surprise because of how long Doug and I had been talking. After Doug’s wife said this, I turned to him and he said to me – my wife is a witness – “I’m pretty much deaf, but I do well when I can look at some people’s eyes.”

*Jody Breen is Lupus Ontario’s Director of Member Services and the Support Group Leader for Oshawa/Durham.*

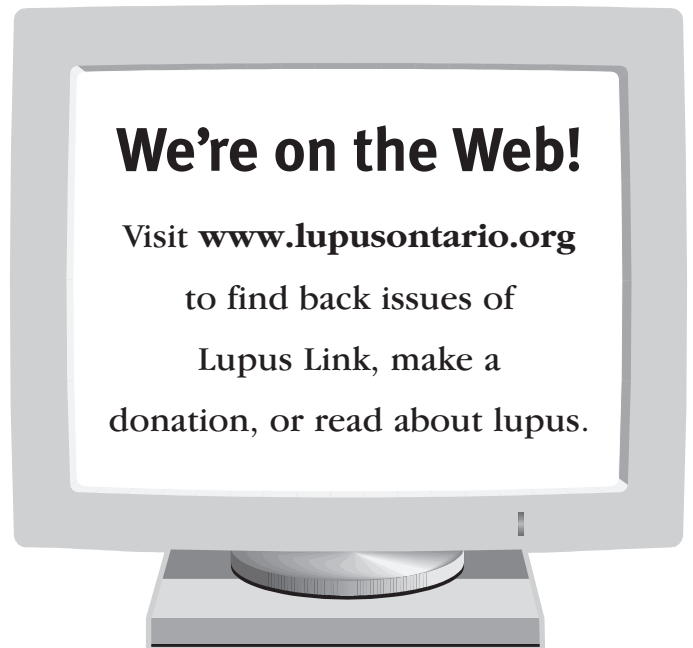
## We’re on the Web!

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

to find back issues of

Lupus Link, make a

donation, or read about lupus.



# Lupus Angel of Hope



This poem is included on a small display card with each angel pin:

Wear this "Thoughtful" little angel to help make the world aware,

That those with Lupus face a struggle that is often hard to bear.

Hear the wish for understanding that this Lupus angel brings,

Carrying hope for the future with each flutter of its wings.

We are pleased to announce the launch of the Lupus Angel of Hope!

It is part of a product line called

*"Thoughtful Angels"*

that is distributed across Canada through stores such as Carlton Cards. Each pin costs \$7.95, and \$1 from each pin will be donated to lupus. Lupus Ontario also sells the pins for \$10.

Tell your friends about the Lupus Angel of Hope!

Pin enlarged to show detail.

## ARTHRITIS DAY PROGRAMS AT ST. JOSEPH'S LONDON

St. Joseph's Health Care London offers new day programs for people with lupus and scleroderma.

A multidisciplinary team offers treatment, education and self-management techniques. Each program runs for two weeks, from 9 a.m. to 4 p.m. Monday to Friday. Inexpensive accommodation near the hospital can be arranged.

Education and group sessions are also available for family members to help them to better understand their loved one's condition and support them as they implement new self-management techniques.

Admission to any Rheumatology Day Program is through a referral from your family physician or a specialist. If you already have a therapist at the Arthritis Institute, they can also make the referral.

For more information, call (519) 646-6340 or visit [www.sjhc.london.on.ca/sjh/programs/fms/fms.htm](http://www.sjhc.london.on.ca/sjh/programs/fms/fms.htm)

## STEM CELLS AND LUPUS

Scientists have used a form of stem cell therapy to improve survival rates for the most severely ill lupus patients. The results were published in the Journal of the American Medical Association in February.

Fifty patients received transplants of blood stem cells that came from their own bone marrow. Half the patients were symptom-free and were in remission at five years, and 84 percent overall had survived five years. There was no untreated control group. The study will likely lead to a larger study with more than 100 patients that will begin in a few months. The procedure was inspired by a therapy used to treat cancer. For more details, visit <http://jama.ama-assn.org/cgi/content/short/295/5/527>

## CELLCEPT TRIAL RESULTS PUBLISHED

The results of Dr. Ellen M. Ginzler's investigator initiated trial (IIT) comparing orally administered CellCept (mycophenolate mofetil) to intravenous (IV) cyclophosphamide as induction therapy for active lupus nephritis were published in the New England Journal of Medicine on Nov. 24, 2005. The conclusion was that, in this 24-week trial involving 140 patients, CellCept was more effective than IV cyclophosphamide in inducing remission of lupus nephritis and had a more favourable safety profile.

CellCept is an immunosuppressant or "anti-rejection" drug used in combination with other immunosuppressive drugs for the prevention of rejection in patients receiving kidney, liver and heart transplants. Research is ongoing both in organ transplantation and related areas, such as autoimmune disease. CellCept is not approved for the treatment of either lupus erythematosus or lupus nephritis.

Based on Dr. Ginzler's IIT and acceptance of Aspreva's study protocol by regulatory authorities, the company moved forward with its global phase III Aspreva Lupus Management Study (ALMS). The first patient in this study was treated in July 2005, and completion of the induction phase of the trial is expected in late 2006. Aspreva intends to include the data from Dr. Ginzler's IIT to supplement the results of the company's trial in its applications for approval with regulatory authorities.

Clinicians estimate that one-third to half of lupus patients have lupus nephritis. There has been no new approved treatment for SLE or lupus nephritis in over 30 years. Current treatments involve the off-label use of cancer drugs and other immunosuppressant drugs.

## LUPUS AND OBSTETRIC PROBLEMS

Women with systemic lupus erythematosus (SLE) or rheumatoid arthritis (RA) have sharply increased risks of obstetric complications compared with other women, according to study findings presented in November at the American College of Rheumatology (ACR) Annual Scientific Meeting.

The research shows that women with SLE have twice the risk of developing hypertensive disorders as do women with RA, and both have significantly higher rates than the general obstetric population.

Eliza F. Chakravarty, MD, assistant professor of medicine, Division of Immunology and Rheumatology, Stanford University School of Medicine, Stanford, California, presented the findings.

The investigators evaluated rates of pregnancies in women with either SLE or RA and compared maternal and fetal outcomes to those of women in the general obstetric population. The researchers concluded that women with SLE or RA should have careful prenatal monitoring.

*[Presentation title: Obstetric Hospitalizations in the United States for Women With SLE and RA. Abstract 991]*

## GENES COULD PREDICT LUPUS SEVERITY

Gene signatures, or patterns, may help predict the severity and frequency of lupus activity, a new study suggests. "A key finding is that the combination of gene signatures is a much better indicator of disease activity than any one signature alone. Further study and validation of these signatures may lead to new, targeted therapies for lupus," University of Minnesota researcher Emily C. Baechler said in a prepared statement.

The findings were to be presented at the ACR meeting in November. The study included 81 lupus patients and 41 healthy people in a control group. Researchers collected blood samples and used gene expression microarrays to identify blood markers of lupus activity and correlate those markers with severe disease activity scores. They were able to identify 10 genes that, together, were the best indicators about current and future lupus activity. Baechler said that these signatures could be a useful clinical tool to help doctors identify patients at risk for severe disease and tailor their treatment plans accordingly.

## STRESS HORMONE AND LUPUS ANTIBODIES

A breakthrough in lupus research was reported in the Jan. 17, 2006, Proceedings of the National Academy of Sciences (PNAS) in a report entitled "Immunity and behavior: Antibodies alter emotion."

Some people with systemic lupus experience subtle but insidious changes in behaviour, such as unusual feelings of fear (or lack of fear) and loss of interest or curiosity. And an estimated 8 in 10 at some point experience progressive cognitive impairment (headache, confusion, fatigue, memory loss, difficulty expressing thoughts and, occasionally, seizures or strokes).

# RESEARCH ROUND-UP

Aside from inflammation in the brain, the causes of these behavioural and cognition issues have been elusive. Funded by the Lupus Research Institute, Dr. Betty Diamond, Chief of the Division of Rheumatology and Professor of Medicine at Columbia University College of Physicians and Surgeons and colleagues made three discoveries.

Using mice, they concluded that lupus antibodies can destroy nerve cells in the brain. Specifically, anti-DNA antibodies damage neurons in an area called the hippocampus, which houses memories and the ability to navigate, among other things. They can also damage the amygdale, which governs emotional responses.

They also found that infection can help these antibodies penetrate the brain, which is normally protected the blood-brain barrier. They also identified the Alzheimer's drug memantine as a potential drug model for inhibiting lupus brain damage.

The researchers identify the stress hormone, epinephrine, as the agent responsible for letting the antibodies reach the amygdale. They cause damage by binding to neurons and activating a receptor on the surface of the cell. Overstimulation of the receptor can lead to cell death. Epinephrine, also known as adrenaline, is produced by the adrenal glands in reaction to stress. Increased levels of the hormone can raise blood flow to the brain and cause leaks in the normally well-sealed barriers.

The researchers identified two potential therapies. Memantine blocks glutamate, and may prevent cell death in parts of the brain. They also propose investigating a small molecule (a peptide) that may be able to protect brain cells from the antibodies.

## POTENTIAL BIOMARKER FOR LUPUS ATHEROSCLEROSIS

Research reported at the ACR meeting indicates that a certain form of the normally "good" high density lipoprotein (HDL) cholesterol linked to cardiovascular health plays a counterproductive role in people with systemic lupus and rheumatoid arthritis, promoting atherosclerosis (hardening of the arteries) and heart disease in many of these individuals.

The menacing HDL form is pro-inflammatory HDL (piHDL), according to research by Bevra H. Hahn, MD, Maureen McMahon, MD, and colleagues at the David Geffen School of Medicine at UCLA, and it can be measured and treated. According to Dr. Hahn, women with lupus are about 7 to 10 times more likely than women without the disease to suffer a heart attack or stroke. Dr. Hahn said that traditional risk factors for atherosclerosis, including high blood pressure, increased cholesterol levels, diabetes mellitus, older age and postmenopausal status, are ineffective for predicting atherosclerosis in lupus patients.

Dr. Hahn said that uncovering a potentially important role for pro-inflammatory HDL, which is easily measured, may provide a sign, or biomarker, to determine which patients are at increased risk. She added that a test (a fluorescence assay) could be developed in as little as two years to identify people at risk and start them on preventive treatments, such as cholesterol-lowering statins.

## ANTI-SEIZURE DRUG COULD BE EFFECTIVE FOR LUPUS

A common anti-seizure drug may be effective against certain conditions associated with lupus, according to animal research at Wake Forest University School of Medicine. The drug, valproic acid (for example, Depakene), prevents skin disease and reduces the severity of kidney disease in a mouse model of lupus, said Nilamadhav Mishra, M.D., a rheumatologist at Wake Forest University Baptist Medical Center, at the ACR meeting.

And because the drug has been on the market since 1983, Mishra said that clinical trials to use valproic acid for lupus could begin as early as next year. Mishra's team tested valproic acid in a type of mouse that develops lupus that is similar to the lupus that occurs in people. None of the mice in the treatment group developed skin disease whereas all mice in the placebo group developed it. The results were similar for kidney and diseases of the spleen.

The company also discussed with the FDA its options for pursuing an indication of prevention of loss of bone mineral density (BMD) in women with lupus. Genelabs has pursued a BMD indication since receiving an approvable letter for its Prestara New Drug Application (NDA) in 2002. The FDA stated that additional positive prospective phase III clinical trial data would be necessary before the FDA would consider reviewing an NDA for BMD in lupus.

In a press release, Genelabs stated that, based on the recent FDA interaction, the company believes that pursuit of an indication for treating the signs and symptoms of lupus is a more viable route than an indication for prevention of BMD loss in lupus. It is designing a new clinical trial and plans to work with the FDA in the development of the protocol and formally meet with the agency again regarding the trial design. Because the company currently does not have sufficient funds to conduct another clinical study of Prestara on its own, if an additional clinical trial is conducted it would likely be in conjunction with a new or existing collaborator, or, alternatively, Genelabs may have to delay or discontinue future development of Prestara.

*(continued on page 10)*

## RIQUENT CLINICAL TRIAL SET TO BEGIN

On Jan. 11, La Jolla Pharmaceutical Company announced that it will start a multi-dose clinical study in lupus patients of its drug candidate, Riquent, which will evaluate on an ongoing basis the ability of higher doses of Riquent to further reduce anti-double-stranded DNA (dsDNA) antibodies over the next year.

Antibodies to dsDNA are associated with the progression of lupus kidney disease that often results in treatment with drugs that have life-threatening side effects and increased hospitalization. This study is part of La Jolla's overall clinical program, which includes an ongoing Phase 3 clinical trial to evaluate the use of Riquent in preventative and acute settings. The multi-dose study will use the same doses that are being evaluated in the ongoing Phase 3 trial, which is being conducted under a Special Protocol Assessment with the FDA, and is designed to demonstrate the clinical benefit of Riquent to delay time to renal flare. A renal flare is a significant increase in inflammation in the kidney that destroys kidney tissue, reduces or stops kidney filtration, and may result in the progression to end stage renal disease.

## NEW AWARDS GRANTED BY LUPUS RESEARCH INSTITUTE

In October, following a scientific review of the largest number of grant applications ever received – nearly double that of previous years – the non-profit Lupus Research Institute awarded \$4.5 million U.S. in new grants to 15 scientists investigating novel research approaches to lupus. Recipients will receive 3-year, \$300,000 U.S. grants to pursue innovative and creative work that has the potential to make significant impact on lupus research. For a list of investigators and studies, visit <http://www.nih.gov/news/pr/dec2005/niams-22.htm>

## ANTI-MALARIALS AND TNF-ALPHA

Anti-malarial drugs are most effective in people with lupus who are genetically predisposed to high levels of tumour necrosis factor alpha and low levels of the cytokine IL-10.

A study published in the journal Arthritis Research & Therapy reveals that anti-malarial drugs, widely used to treat systemic lupus, bring serum levels of tumour necrosis factor alpha (TNF-alpha) back to normal in SLE patients. The research shows that these drugs are more effective in patients who have two specific genetic variations (polymorphisms) on the TNF-alpha and IL-10 genes that predispose them to abnormally high levels of TNF-alpha and low levels of the cytokine IL-10. This finding may help identify which patients are most likely to benefit from anti-malarial therapy.

Patricia Lopez from the University of Oviedo in Spain and colleagues from the Hospital Universitario Central de Asturias in Oviedo matched 192 SLE patients with 343 healthy individuals to act as controls. The researchers

genotyped both patients and controls for two specific polymorphisms on the TNF-alpha and IL-10 genes. Lopez et al. then measured TNF-alpha serum levels in 171 of the SLE patients and 215 of the controls. The patients were asked about any treatment received before the study.

The results show that average TNF-alpha serum levels were higher in the population of SLE patients than in the group of controls. However, patients who had been taking anti-malarial drugs for at least three months before the study had serum levels of TNF-alpha similar to those of controls. Patients who had not been taking the drugs before the study had much higher levels of TNF-alpha.

The study found that, in patients with both polymorphisms, TNF-alpha levels were four times lower if the patient had been taking anti-malarial drugs. For patients who do not have the polymorphisms, the difference in TNF-alpha levels was much less significant between patients who were on anti-malarial therapy and patients who were not. Patients with both polymorphisms had a four times higher probability to respond well to anti-malarial therapy (and not need any other therapy) than other patients.

For more details, refer to Arthritis Research & Therapy 2006, 8:R42 (13 February 2006).

*Do not alter or stop your treatment plan without consulting your physician.*



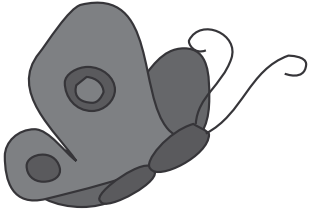
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# A LIFE WITH LUPUS

## *A Story of Hope and Courage*

*By Mary Fatsis*

**M**y name is Mary, I am 26 years old and this is my journey.

I was diagnosed with lupus when I was 21. I had been symptomatic for a while...joint pains, butterfly rash, and fingers turning blue in the cold.

When I looked up my symptoms on the Internet, the first thing that showed up was AIDS. Then, one day on the subway, I saw a huge sign that read, "Lupus – The Disease with a Thousand Faces."

When I read the list of symptoms I realized they were similar to mine. I went back to the Internet, this time to the Lupus Canada website ([www.lupuscanada.org](http://www.lupuscanada.org)). The more I read, the more I was convinced that this was what I had.

I booked an appointment with my family doctor. "I have lupus," I told him. He laughed and said, "Since when are you a doctor?" He sent me for bloodwork and then booked an appointment for me to see a rheumatologist.

Her examination and the bloodwork confirmed my diagnosis...Systemic Lupus Erythematosus.

Before my diagnosis, I was a very active 21-year-old. I worked at a bank, lived at home with my parents and loved going out with my friends. My dreams were to settle down, have children, own a home and have my parents see my children grow up to have a good and happy life.

The diagnosis scared me and I wasn't sure what it meant. I slipped into a low, sad period. For the next two years I wanted to deny that this was happening. I kept working, using the medication to push through the pain. The symptoms grew more intense and I was referred to Dr. Dafna Gladman at Toronto Western Hospital.

I started going to appointments with her two or three times a month. Like many other people with lupus, I was prescribed prednisone. At that time, I was in an unsupportive relationship and I wasn't taking care of

myself. I missed my doctors' appointments and took more medication than prescribed.

I was becoming more depressed and I ended up gaining over 100 pounds and couldn't even get out of bed. I was too embarrassed to ask my family for help, which I will live to regret.

Finally, in September of '04, I went to the emergency room at Scarborough General Hospital. It was a nightmare. They were very busy and I waited endlessly.

Finally, one of the doctors told me there was nothing they could do for me that night.

My mom fought for me to stay in the hospital to get the help I needed until the next morning, when Dr. J. Stein arrived. He called me by my name and admitted me to the hospital right away. I called my mom and told her I had been admitted and that meeting Dr. Stein was like meeting an angel.

After a few days of testing, it was decided that I needed a hip replacement, and that I also had fractures in my back. I attribute both to my overuse of prednisone.

I had the hip replacement in October '04 with Dr. E. English. He is an excellent orthopedic surgeon and the surgery went very well.

In November '04 I was admitted to Bridgepoint Hospital for rehab. Depression had set in again. I didn't want to get out of bed, wasn't eating properly and didn't do my physiotherapy exercises. I just wanted everything to go away. It was like I was awaking from a bad dream.

My first symptoms of peripheral neuropathy began there at Bridgepoint. My dad intervened by calling Scarborough General Hospital. Dr. Stein had me transferred back there and had a neurologist do some tests. After seeing a second neurologist, I was diagnosed with a severe form of peripheral neuropathy.

*(continued on page 12)*

*"Weeping  
may endure  
a night  
but joy  
comes in  
the morning."*

*(A Life with Lupus continued)*

“Am I going to die?” I asked.

“You are not going to die, but you are going to live a miserable life,” the neurologist told me.

I felt so lost, so scared and confused. When I returned to Scarborough Hospital, Dr. Stein sat down beside me as I was crying. He moved his legs as if he were riding a bicycle and said “Mary, you will walk again, vitamins and exercise...vitamins and exercise.” I will never forget that!

Every day Dr. Stein came in to talk to me. Every day I asked the same questions. He would sit, listen patiently and answer my questions.

During this period of time, my beautiful social worker, Sandeeta, was always there for me. She always tried to encourage me but, at that time, I just didn't care. I want her to know that it may have seemed like I wasn't listening, but I was.

Sandeeta did everything in her power to get me back to rehab. But because of my depression and unwillingness to fight “tooth and nail” for my life, several rehab centres in Toronto refused to provide a bed for me. In the end, I went to Seven Oaks...a seniors' home!

I spent six months of my life there. I celebrated my 26th birthday there. That was something I will never forget.

I don't regret going to Seven Oaks because I met wonderful friends who gave me hope and courage. One day I woke up and realized that the only person who can make a difference for me...is me!

Very excited, I picked up the phone and contacted Bridgepoint and within a week there was an opening. So, here I am today. It's been a long journey and I'm tired, but for the first time I look forward to a happy and healthy future.

Bridgepoint's staff has supplied essential help on this journey. I've received endless love and support. This time, the rehab component has been so different because I am the seeker.

There is a huge change in me emotionally...I'm so determined. I'm going to the gym and also pool therapy. I'm very happy to be here, although still scared about what lies ahead. I have upcoming surgeries – a foot tendon release and a breast reduction and tummy tuck. I'm scared but very hopeful and excited while I wait for them.

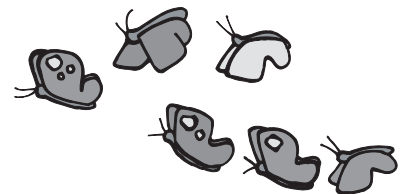
We are only given one life to live and I'm not sure I will ever understand why I've been given this journey, but if it was to make a difference in someone else's life... it was worth it!

*“One day I  
woke up and  
realized  
that the only  
person who can  
make a  
difference for me...  
is me!”*

My parents have been my angels of strength and determination. They left Greece when they were very young and struggled to raise me and my brother. I've made many mistakes but they have always been there for me. They are my life!

I would like to thank other people who have been a great help to me: Karen Furlotte from Lupus Ontario and Judi Farrell and Pamela Bowes from Lupus Canada for giving me the life-changing opportunity to share my story. Thank you so much for taking the time to talk to me, and also for my beautiful, sterling silver butterfly bracelet and, of course, the beautiful Lupus Angel of Hope pin.

I would like to thank my mom and dad for giving me the most precious gift, life. To Niko, I love you....You are my favourite brother. To Jody and Jennifer Breen, you are my angels also. I don't know what I'd do without you two. To my girls at Bridgepoint – Ashley, Kim, Mae, Judy and Wendy – thank you for your love and support. To my best friends, Amanda and Melanie, thank you for always being there. To Dr. J. Stein and Dr. E. English.... Thank you for ALWAYS lighting a ray of hope for me. My dearest Evelyn, I didn't forget you...You are my shining star.



## FINDING OUR VOICE

by Anne Matheson

Over the past three years, I have had the opportunity, through my job at Hamilton Health Sciences, to advocate for the patient's voice in education and healthcare. I am enthused about the growing trend towards an interdisciplinary approach to learning and care, and the growing acceptance that patients and carers are the "experts" in how they feel and what it is like to live with or care for someone with a particular illness or condition. It's well understood that when people can influence decisions that directly influence their lives, their self-esteem and self-confidence increase, and this is beneficial to their health and well-being.

Progressive healthcare institutions and universities are beginning to involve patients in the design of programs and services that they will use. This collaboration not only empowers patients, it also provides an opportunity for our physicians and health care team of tomorrow to learn the necessary skills to interact with patients in health care management.

I thought you would be interested in hearing about a conference I attended November in Vancouver. The following is adapted from a summary written by Wayne Weston, who was on the conference task force.

### **Where's the Patient's Voice in Health Professional Education?**

This question captured the imagination of 240 participants at the first international conference on this topic in Vancouver from November 3-5, 2005. There were delegates from patient groups around the world, including marginalized populations, lobby groups and patients-as-teachers programs. In addition there were health professional educators, researchers and students from schools of medicine, nursing, occupational therapy, social work, psychology, law and other related

professions. Participants ignored traditional boundaries and focused on learning from each other no matter what their background or credentials.

A variety of approaches are already being used in some settings. For example:

- Patients sit on advisory groups helping to define the curricula of professional schools.
- Lay persons serve as simulated or standardized patients helping students learn communication and other clinical skills more effectively.
- Patients contribute their experiential knowledge as teachers. For example, they help students learn how to perform a more accurate and gentle physical examination.
- Patients participate in research projects as equal partners, not just as subjects – they are involved in determining research questions and the culturally-sensitive approaches to gathering information.
- By sharing their personal stories of illness and disability, patients help students develop and maintain attitudes of respect and compassion.
- By working in partnership with those who provide community services, patients help to improve programs so that services will be more accessible and appropriate to all those in need.

One goal of the conference was to share ideas and successful strategies so that these approaches and others would become more widespread and effective. The conference concluded by affirming several principles and suggesting a number of important recommendations, including these:

- Health professional educators must collaborate to break down the interprofessional barriers that limit understanding and effective teamwork.

*(continued on page 14)*

# EDUCATION

- Health professional schools must teach graduates to be advocates for both patients and community – to be able to recognize and analyze the predicaments facing their patients and communities and work with them to identify the appropriate resources for preventing, solving or at least mitigating the impact of these issues.
- Health professional educators should consider how to include patients and families as active participants in educational activities across the spectrum of health professional education, from entry level to continuing professional development.
- The language of the professions often betrays a paternalistic bias. Health professionals need to be sensitive to the power of language.
- The models of care used by many health professions are sometimes outmoded and ineffective – they focus on what professionals are comfortable with rather than on what consumers need. In collaboration with patients, educational programs must develop more comprehensive models of care that address the full range of dilemmas facing them, including the social, economic and psychological dimensions.

The participants returned to their own diverse settings around the world with a renewed sense of hope and determination that they will all work together as partners to make all health professional schools more responsive to the needs of those they serve.

*The conference was organized by the Division of Health Care Communication, the College of Health Disciplines, and Interprofessional Continuing Education of the University of British Columbia. Funding was provided by The Primary Health Care Transition Fund, Health Canada, the Social Sciences and Humanities Research Council of Canada and the British Columbia Medical Services Foundation (administered by the Vancouver Foundation).*

*Anne Matheson is Lupus Ontario's webmaster and she recently joined the Board of Directors.*



## TELL US YOUR STORY!

Lupus Canada is developing a brand new website, and we are seeking contributions for a **Personal Profiles** section. We would like to receive inspiring stories with themes of empowerment and living well with lupus from a variety of perspectives. Each profile would be about half a page to one page in length, and would probably include your picture. Potential topics include: coping with a diagnosis, staying healthy, working and lupus, family and lupus, participating in Lupus Canada events such as the Symposium and Walk A Block), pregnancy and lupus, creating awareness about lupus, youth and lupus, humour and living with lupus, giving as a volunteer, advocacy and lupus, and World Lupus Day events. In fact, the sky is the limit. If you would like to contribute your profile, please contact Pamela at [Pamela.Bowes@bellnet.ca](mailto:Pamela.Bowes@bellnet.ca).

## It's Time to Renew Your Membership!

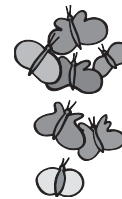
Please remember to renew your membership for 2006. You can do it by mail, phone, cheque or credit card. \$25 is all it takes to support Lupus Ontario. A special thanks to everyone who has already renewed and the many generous members who have also donated toward our education and research funding. Together, we are working to conquer lupus.





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### LE Society of Saskatchewan

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 Email: less@sasklupus.com

### Lupus Society of Manitoba

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 Email: lupus@mts.net

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 Email: lupusont@vaxxine.com

### Lupus New Brunswick

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 Toll Free: 1-877-303-8080  
 Tel/Fax: 506-384-6227  
 Email: lupins@fundy.net

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*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.*

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