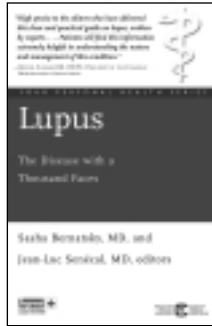


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READ ALL ABOUT IT!



Lupus Canada is celebrating the release of *Lupus: The Disease with a Thousand Faces*, an important new book for people living with the disease. Lupus Canada worked in partnership with Key Porter Books, senior editor Dr. Jean-Luc

Senécal and editor Dr. Sasha Bernatsky to fulfill the need for a widely available, up-to-date guide for those diagnosed with lupus, their caregivers, friends and families. The 160-page book is an updated and expanded version of Dr. Senécal's 1990 book of the same name, and it has been endorsed by the Canadian Medical Association.

"Lupus Canada is very proud of its role in making this book a reality," says Judi Farrell, Chief Operating Officer of Lupus Canada. "This book will become an important tool in understanding and managing lupus. It will educate readers about lupus, its symptoms and treatment. Proceeds from sales of the book help to raise funds to support lupus research and the development of further resources that could greatly enhance the quality of life of someone living with lupus."

Several prominent Canadian lupus researchers contributed to the book. "We were very pleased to have the enthusiastic support of members of the Canadian Network for Improved Outcomes in Systemic Lupus (CaNIOS), a group of researchers with a wide spectrum of expertise in lupus care and research," says Dr. Bernatsky, who is a rheumatologist and researcher at the McGill University Health Complex (Montreal General Hospital).



The new book was officially launched at a Lupus Canada board meeting on Feb. 5. From left: Len Funk, Past President, Lupus Canada (Winnipeg); Paula Sloss, Key Porter Books; Dr. Sasha Bernatsky (Montreal); Diane Ferland, CaNIOS (Toronto); Glenn Outhwaite, Vice-President, Lupus Canada (Kingston); Mark Purcell, Director, Lupus Canada (Oshawa); Mae Boa, President, Lupus Canada (Regina)

"Without their hard work and co-operation, this book would not have been possible. It was a great pleasure for Dr. Senécal and myself to serve as the editors for this book. I personally consider it a great privilege to have been involved."

Topics covered in the book include medications used to treat lupus, complementary therapies, concerns particular to women and children, the doctor-patient relationship and practical coping strategies. There is a list of resources and a glossary in the back.

For more information or to purchase a copy of the book, please contact Karen Furlotte at

Lupus Ontario at
1-877-240-1099 or
905-415-1099

or by e-mail at
lupusontario@bellnet.ca.

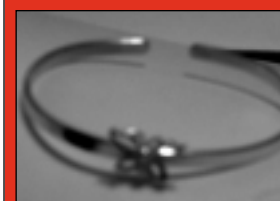
The price of the book is \$19.95 plus shipping, for a total of \$22.45.

Publications Mail Agreement No. 40037439
ISSN# 1194-8299

**Thank you for
supporting
Lupus Ontario**

OUR MISSION STATEMENT

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



Butterfly Bracelets

These beautiful sterling silver bracelets were made especially for sale at the Dance for the Cure. We only have a few left, but if you would like one they are \$35 each. Call Karen Furlotte at Lupus Ontario. (If there is enough interest, we could even order more!)

905-415-1099 or 1-877-240-1099

MESSAGE FROM THE PRESIDENT



Kevin Stannard

I hope everyone has survived the winter. I know it has taken its toll on me. I would like to take this opportunity to thank Juli and Shannon for mailing out the membership renewals. Lupus Ontario now has more than 1200 members and continues to grow.

Our Board of Directors is dedicated to the lupus cause. We

are all very busy with work and family schedules but we still manage to find time to volunteer our services to fight this disease. You, our members, can also help by volunteering. If your local group is planning a fundraiser or you have an idea, give us a call.

We are always looking for help on our various committees provincially. If that interests you, please give the office a call. Lupus Canada is also in need of volunteers. So, whatever level you would like to help out at, there is always an open door.

Lupus Canada's Annual General Meeting is in June in Ottawa. It would be great to have strong representation from our Ontario membership. For more information, please call our office.

In addition to funding clinics, Lupus Ontario supports several research projects. We have received three applications for the Geoff Carr Fellowship and are waiting for the peer review committee's recommendation. Research is vital in our battle against lupus, and we're proud to continue supporting these efforts.

Thanks to our dedicated volunteers for their hard work so far this year, and I hope we'll see more members at upcoming events and fundraisers. We need to WORK TOGETHER in whatever capacity we can, in order to CONQUER LUPUS.

Kevin Stannard, President

Vision Research Study

A vision research study is looking for people diagnosed with systemic lupus erythematosus (SLE) between the ages of 20 to 50 without significant nearsightedness.

Researchers are investigating a new diagnostic tool called the multifocal electroretinogram to study function from the retina, which is the sensory lining inside your eye (rather like the film in a camera) in patients with lupus. We will compare the results between patients taking the drug called Plaquenil® and patients not taking the drug.

The study will take place at the Hospital for Sick Children. Different aspects of your vision will be assessed followed by the multifocal electroretinogram. You will also receive an eye examination by Dr. Michael Easterbrook, an ophthalmologist. The total length of the study is approximately 2.5 hours.

Reasonable out-of-pocket expenses to cover meals and travel will be provided. For more information, please contact Rita Nobile at

416-813-7790

or by e-mail at

rita.nobile@sickkids.ca

We're on the Web!

Visit www.lupusontario.org

to find back issues of

Lupus Link, make a

donation, or read about lupus.

A TRIBUTE TO DAWN ELLIOT

By Honey Agar



Dawn Marie Elliot passed away peacefully at home on January 15th, 2005, as a result of complications arising from a 25-year battle with lupus.

Dawn and I first met about 15 years ago when she came to George Brown College to hear a lecture on lupus. After the meeting, Dawn approached me and asked how she could become a member of the Ontario Lupus Association, and how she could help. That

was the beginning of a wonderful friendship.

Dawn was a dedicated and tireless advocate for people with lupus. Her knowledge and expertise far outweighed mine and she seemed to have connections in every area. She never hesitated to put someone in touch with the OLA, as we were known then, or find individuals who would help promote our cause. Dawn's heart and soul belonged to the community. She loved the young particularly and devoted her life to helping, counseling, defending and advocating on their behalf.

Dawn was actively involved in the founding of Lupus Canada, helping and working, whatever it took – no task was considered too difficult. Dawn provided leadership, inspiration, organization and strength, and held several board positions including Vice-President.

Dawn hated the spotlight, but those of us who worked with her knew she was the real power behind the scene. She was the one applying for grants, suggesting and/or interviewing candidates for positions, developing communications and overseeing governance issues. She was truly our leader and innovator.

Dawn devoted her life to helping others and her work was recognized by many organizations. She received the YWCA Woman of Distinction Award, the Commemorative Medal for the Queen's Golden Jubilee, and the Donna Chu Award.

Her husband of 25 years, Stu, and her family were always an important part of her life and we are thankful that they shared so much of her with us. We have lost a friend, a mentor and a wonderful humanitarian, but Dawn has left us with a great legacy as her courage and enthusiasm will help to carry us forward as we work to conquer lupus.

Lupus Canada is establishing a memorial fund in Dawn's name. Please call 1-800-661-1468 or 905-513-0004 if you would like to make a donation.

RESEARCH

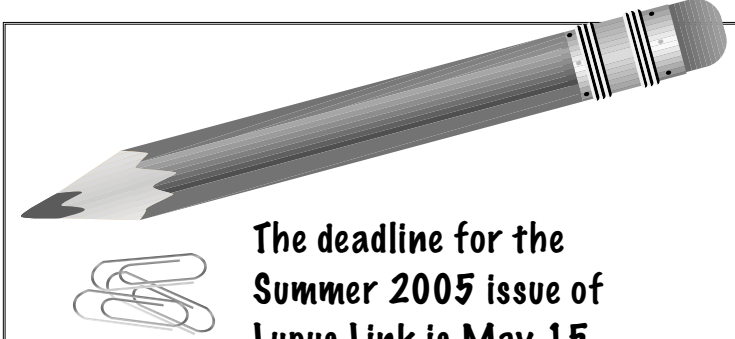
Gene associated with lupus identified

Researchers at the University of Minnesota have identified, for the first time, a gene variation associated with systemic lupus erythematosus (SLE). The gene variation, known as PTPN22, is found in approximately 16 percent (or one in six) healthy Caucasians in the U.S. However, nearly one in four (or 23 percent) lupus patients carry this variant, which has also now been associated with risk for type 1 diabetes and rheumatoid arthritis. The study was published in the *American Journal of Human Genetics* in September 2004.

"This appears to be a very important gene for lupus," said Timothy W. Behrens, M.D., professor of medicine, Medical School, and principal investigator, "and this is the first time we have identified a variant that predisposes to many different autoimmune diseases. We hope that this discovery will lead to the identification of other genes associated with lupus and other immune disorders." Behrens believes that dozens of genes may be responsible for lupus and that discovering the combination of these genes will be important to developing better diagnosis and treatment of the disease.

Organs commonly affected in SLE include the skin, kidneys, joints and lungs. The severity of disease and the response to therapy vary widely between patients, said Dr. Behrens, and this makes the diagnosis and management of lupus very challenging. "If we know which genes predispose a person to lupus, we may be able to diagnose and treat the disease earlier," he said. "In addition to discovering which combination of genes lead to lupus and other immune diseases, we also hope this information will help us identify new drugs and therapies."

Adapted with permission from the University of Chicago Press Journals.



The deadline for the Summer 2005 issue of Lupus Link is May 15. Please send submissions to jaclynlaw@hotmail.com.

Epstein-Barr Virus and Systemic Lupus: The Puzzle Starts to Take Shape

Epstein-Barr Virus (EBV) is one of the most common viruses – most people have developed antibodies to it by adulthood. It is the virus that causes mononucleosis (the “kissing disease”) in teens and adults, and it has long been suspected of playing a role in the onset of systemic lupus.

Dr. Uk Yeol Moon (Catholic University of Korea, Seoul) and colleagues have shown that lupus patients have elevated loads of EBV in their blood, suggesting that EBV is abnormally regulated in lupus. The patients also had increased numbers of EBV-infected B cells, which may contribute to enhanced autoantibody production in this disease, the researchers say in their paper, published online May 11, 2004, in *Arthritis Research & Therapy*.

“There is enough information to support the theory that EBV is one of the triggers of SLE,” says Dr. Yehuda Schoenfeld (Sheba Medical Center, Tel-Hashomer, Israel), an expert in the field. But he stresses, “This is not the same as saying EBV causes SLE. It joins genetic preponderances and other risk factors in contributing to the illness.” If, in the future, people at risk of developing SLE after EBV infection can be identified, then perhaps they can be vaccinated against EBV, he suggests.

In their paper, Moon and colleagues explain that EBV is suspected of playing a role in predisposing to SLE for several reasons. First, EBV promotes proliferation of B cells after infection, “and thus it poses a prolonged antigenic challenge,” which may trigger SLE in genetically prone individuals, they note. Second, EBV-infected B cells can become a continuous source of autoantibodies. Third, sequence homologies exist between SLE autoantigens and some EBV proteins. “If EBV is indeed involved in the pathogenesis of SLE, then there must be some association between EBV infection and SLE,” they hypothesize.

To investigate this, they determined EBV types in 66 SLE patients and 63 normal control individuals by direct polymerase chain reaction (PCR) analysis of mouthwash samples. They also compared EBV load in blood between 24 SLE patients and 29 healthy controls using seminquantitative PCR assay.

Of note, there was no significant difference in EBV-type distribution in SLE patients and normal controls, the researchers say. “Thus a specific type of EBV in SLE patients does not appear to be responsible for the abnormal T-cell reaction to EBV.” However, the SLE patients did have EBV loads in peripheral blood mononuclear cells (PBMCs) that were more than 15-fold those in normal control individuals. The reason for this is not clear.

Moon’s team did not test whether T-cell function was impaired in the SLE patients “as has previously been reported.” Instead they compared EBV loads between SLE

patients with and without strong immunosuppression but found no difference between the two groups in terms of EBV load, “suggesting no direct effect of immune function on EBV load.”

“The increased EBV burden may cause SLE by stimulating autoantibody production because of the sequence homology between autoantigens and EBV proteins,” they suggest.

“The increased EBV loads in SLE appear to be consistent with the finding that SLE patients often have what appears to be a primary or reactivated EBV serologic response,” they conclude.

Adapted and reprinted with permission from JointandBone.org.

Study details:

Moon UY, Park SJ, Oh ST, et al. Patients with systemic lupus erythematosus have abnormally elevated Epstein-Barr virus load in their blood. *Arthritis Res Ther* 2004; 6:R295-R302.

RESOURCES

New books from autoimmunity experts



Women and Autoimmune Disease: The Mysterious Ways Your Body Betrays Itself by Robert G. Lahita, M.D., with Ina Yalof (Regan Books, 2004, \$39.95) is a fascinating and candid look at several autoimmune disorders by one of the world’s leading lupus experts. Lahita writes about lupus, fibromyalgia, rheumatoid arthritis, Sjogren’s syndrome and numerous other disorders.



The Autoimmune Connection: Essential Information for Women on Diagnosis, Treatment, and Getting On With Your Life by Rita Baron-Faust and Jill P. Buyon, M.D. (McGraw-Hill, 2004, \$24.95) thoroughly explores the links between autoimmune diseases and offers information on diagnosis, treatments, and risks for women with one or more autoimmune diseases.

Despite causes of lupus proving complex, critical “checkpoint” suggesting new therapy is revealed

Mouse studies yield cause and potential cure, with human studies in progress

Scientists at The Rockefeller University have determined that the autoimmune disease lupus results from a combination of genetics that likely varies from person to person, and that a common “gatekeeper” gene called FCRgIIB is critical to the prevention of this devastating disease.

What’s more, the same scientists have determined that reversing the defect of that gatekeeper gene can restore health in animal models of lupus by preventing the unfortunate accumulation of auto-antibodies that lead to the vexing symptoms – fatigue, fever, joint pain, anemia, and in some cases, kidney failure, seizures and neurological damage, blood clotting and respiratory inflammation – associated with the disease.

The findings are reported in the January 28 edition of *Science* and in January’s *Nature Immunology*.

“Our *Science* publication makes an important new point in responding to lupus as an autoimmune disease,” says Jeffrey Ravetch, M.D., Ph.D., professor and head of the Leonard Wagner Laboratory of Molecular Genetics and Immunology. “Although the disease itself is a reflection of a cumulative set of factors that work in concert to reach a threshold and then trigger symptoms that are self-enhanced and self-sustaining, we have shown that it may be enough to simply correct a critical ‘gatekeeper’ function and thereby reverse the disease.”

Ravetch, a leader in basic immunology known for his elucidation of an important family of antibody binding molecules called the Fc receptors, and his colleagues have learned that a specific Fc receptor functions to prevent the accumulation of the auto-antibodies that are responsible for the disease progression in lupus. They have also discovered that the Fc receptor is defective in lupus-prone strains of mice. Restoring its strength is sufficient to avert disease in those susceptible animals.

“Once we determined that this receptor inhibits the culprit immune system cells from becoming activated and limits the production of auto-antibodies, we wondered whether restoring it as the body’s last bastion of defense would be enough to prevent autoimmunity,” says Ravetch.

In the *Science* publication, the researchers found that in mice genetically predisposed to lupus-like autoimmunity and with a reduced Fc receptor capacity, they could artificially coax the Fc receptors back into working order. Their modest increases in Fc receptor activity – the equivalent of effective gene therapy in humans – was enough to push the mice back to health.

“The difference between immune and autoimmune for each individual is quite small,” he added. “We were able to re-establish the Fc receptor’s activity by increasing its expression by only about 40 percent, and in only about half the B cells.”

Betty Diamond, M.D., a physician-researcher at Columbia University’s College of Physicians and Surgeons, is collaborating with Ravetch to take the first steps in determining whether the same progression to lupus, including Fc receptor

failure, occurs in humans. “Jeff has laid the groundwork well for understanding this pathway to disease,” says Diamond. “We have hopes of confirming this pathway in humans with lupus.”

What may be even more interesting in the Rockefeller team’s findings is that the experiment restored the health of mice with lupus-like symptoms by increasing Fc receptor inhibition of auto-antibody formation. Auto-antibodies that were produced before the therapy persisted in the body, but with no further evidence of disease. These findings suggest that if the human disease is synonymous with the mouse model, a gene therapy approach to restoring Fc receptor activity in lupus patients could cure the disease’s aggravating and disabling symptoms.

“The immune system is a balance between too much and too little,” says Ravetch. “We’re seeing the inhibitory Fc receptor on dendritic cells, another immune system cell type, may play a similar role in other illnesses. We may reach a convergence of understanding on immune system-related diseases, where small adjustments to certain strongholds, like the Fc receptor, may be enough to restore health in multiple diseases.”

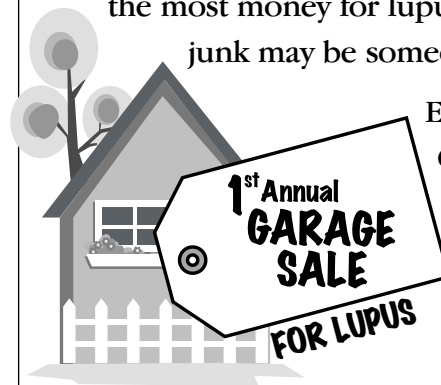
Reprinted with permission from The Rockefeller University.

1st ANNUAL GARAGE SALE FOR LUPUS

Join us for our 1st Annual Garage Sale for Lupus, the weekend of **June 4 & 5, 2005!** Hopefully all the Ontario branches and groups of our members, family and friends will take up the challenge and consider holding a Garage Sale for Lupus along with us. We are having one in Thornhill/Richmond Hill on June 4 & 5, but any weekend in June would be great. Advertise in your local papers (it may be free for charities) and let’s see which group can raise the most money for lupus! Remember, your junk may be someone else’s treasure!

Every penny counts!
Good wishes &
good health to all.

*Julia Kane &
Tina Sarta*



AN ADOPTION STORY

By Shannon Crawford

It was a beautiful fall day. The sun was shining gently through the window. I could hear the sounds of the birds singing their pretty morning wakeup song. The smell of the coffee perking was making its way through the whole house.

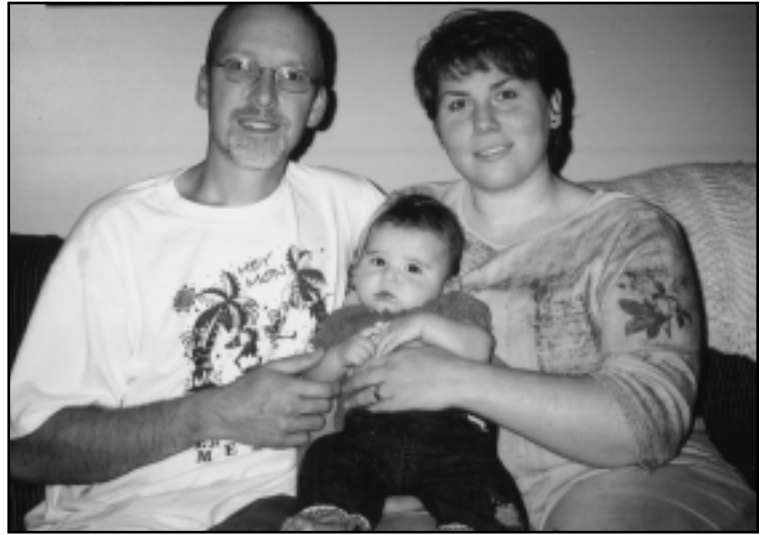
No one else was up yet, just me with my thoughts. I should have been thinking, what a perfect day for a wedding – my wedding! Instead I was thinking, how am I going to get through this day, plus put on my game face and pretend that I feel great, am in no pain and have no fear of having a seizure today? One thing I didn't want to hear today was "Are you OK?" or "Take it easy!" This was my wedding day, and nothing was going to ruin it. (At the time I was married I didn't have a confirmed diagnosis of lupus. I had already been off work for a pre-existing medical condition that had been hanging over my head.)

Fortunately, everything went well. Steven and I had our wedding and our reception. It was the most beautiful day ever. I'm happy I didn't allow lupus or epilepsy to rain on our parade. I'm sure the percocet helped – but either way it was a perfect memory I'll have forever.

Steven and I very much wanted to have a baby. Shortly after our wedding, we had an appointment at the Motherisk clinic at Sick Children's Hospital in Toronto. The purpose of this appointment was to pre-plan a pregnancy, to discuss medications that I was taking at the time, and the potential risks to myself and a baby. Steven and I had a lot to think about, and a confirmed lupus diagnosis wasn't even thrown into my mix yet. All that was on my mind was having a baby.

How I had dreamed of it. The feeling of a life growing inside me, that pregnant glow, the stretch marks across my belly that would serve as an everlasting memory of carrying a child, the leg cramps, backache, and giving birth. I wanted to sit quietly with my hands on my belly as the baby took a roll inside me. I lay awake in bed many nights, fantasizing about what our baby would look like, what colour eyes he or she would have. We had baby names picked out, baby furniture stored, baby clothes and baby toys. We were ready; we just needed a baby! I spent so much money on home pregnancy tests it was crazy. Then, to our delight, it happened – I was pregnant. We found out on New Year's Eve, 2000. Steven and I kept very quiet about it, which was hard because we have a very close family. We were just about to tell our families the wonderful news when it happened – I lost the baby. We were crushed. Shortly after this I had another miscarriage.

I now had a hole in my heart that I thought would never heal. A short time later, after years of joint and muscle



And baby makes three: Steven, Shannon and adorable Sarah Elizabeth

pain, mouth and nose ulcers, pleurisy, hair loss, swelling, and Raynaud's syndrome, I was finally diagnosed with lupus after a flare, which was probably caused by the emotional stress of the miscarriages. I was depressed, and no longer knew what my purpose in life was.

But, time passed and I slowly got back on my feet. My focus was back on having a baby – it was all I could think about night and day. Steven and I tried for almost a year with no luck. My doctor referred us to a fertility clinic in Toronto. After many diagnostic tests, we were told we had a fertility issue.

We considered several options. Artificial insemination and in vitro fertilization can be costly, and are not guaranteed procedures. After learning about the procedures, risks, and the financial cost, we decided to think about things for a month. Steven and I started to wonder if we were receiving a sign from a higher power. Having a baby wasn't supposed to be this hard. I started thinking that maybe this was my body's way of warning me not to try again, what with the miscarriages and fertility issues, plus the added risk of my lupus flaring with a pregnancy.

We started thinking about adoption. It was an easier decision for Steven at the beginning. He didn't want to risk my health. I, on the other hand, went through a mourning process. I mourned the reality that I would never have a baby, and experience everything that goes along with that. But then I thought about what was more important: being pregnant or being a mother. I knew then that adoption was our answer.

First, we looked into international adoption agencies. Then we decided to give our local Children's Aid Society a try. I called the CAS, and it quickly sent us an application package. This first step was approved a week

later. We were asked to enroll in mandatory adoption classes, which have a waiting list of several months. In January 2004, one week after Steven and I completed the classes, a social worker contacted us to arrange a home study.

Steven and I were nervous about the home study. Having someone come into our home, and having to open up to a complete stranger about all aspects of our life, was intimidating. My biggest fear, of course, was that after everything we had been through – the classes, the medical exams, the criminal background checks, personal autobiographies, financial questions, and home visits – we would be rejected. I was afraid that my having lupus would prove too big an obstacle. I truly couldn't relax until the moment our social worker called and I heard those glorious words: "You've been approved."

During the home study, I had submitted a personal profile for our social worker to present to birth moms. It contained a letter to the birth mother, pictures and non-identifying information about me and Steven.

Unbeknownst to us, during our home study, our social worker presented our profile to a birth mom whom she thought might be a good match. Like many adoptive parents, we hoped to adopt a newborn, so we figured that it would be two to five years before we might be blessed with a baby. We were in for a huge surprise.

Our home study was finished February 14, 2004. Five days later, our social worker called and said, "I need to come over." We thought she just wanted to take care of more paperwork. When she arrived, she sat down and didn't waste any time. "You've been chosen to adopt a baby – and the birth mom is due Friday!" Needless to say, Steven and I nearly had heart failure. We were incredibly excited. It was so surreal. Things were happening so fast...

Our social worker made sure that we had plenty of extended support. I believe in my heart that if Steven and I didn't have such close, supportive family members and friends who know our situation and who are there for us when we need them, that our application would not have gone through so smoothly.

Our precious daughter, Sarah Elizabeth, was overdue, born on March 14. I wrote this in my diary after seeing our little girl for the first time at the hospital:

Our Sarah,

How beautiful you are. You are 18 hours old. You look so peaceful. The head nurse said to me, "Would you like to hold your baby for the first time?" and then handed you to me. You opened your eyes and looked up towards me. I had just met you and I already loved you. I just stared at you; my heart became whole at that very moment.

My tears started to flow – I couldn't stop them. This moment was so overwhelming. I am so happy we have been blessed with you and you with us. I will never forget this moment. The moment I finally became a Mommy and Steven became a Daddy.

While adoption may not be the right option for everyone, it kept our hopes and dreams of having a family alive. I think being a mother is the best job I will ever have.

If you'd like more information about our story or adoption, please e-mail me at shan_crawford@hotmail.com or lupusontario@bellnet.org with the subject heading "Lupus Adoption Story." Please note that the adoption process happened very quickly for Steven and me, which may not be typical.

RESOURCES

- For information about drugs, chemicals and disease during pregnancy and lactation, visit the Motherisk website at www.motherisk.org or call 416-813-6780.
- To contact the Ontario Association of Children's Aid Societies, visit www.oacas.org or call 416-366-8115.

COPING

Smart Moves

When your body tells you something, don't ignore it. Sometimes, it knows better than you do.

By Jaclyn Law

I recently took a women's self-defense course. After two full days of punching, kicking, blocking and yelling, we reached the grand finale: board breaking. The target: a 10x10-inch piece of wood set up on a little stand.

One of the instructors went first. One punch, one broken board, gasps of awe around the room. Then she invited each of the students to try.

At first, I watched as other girls and women smashed boards to wild, supportive applause. I didn't have any lupus pains in my hands, wrists or arms that day, so I figured it would be okay for me to try it, too. My knee was sore and the instructors knew I had arthritis, but a sore knee wouldn't stop me.

I knelt behind the board. The instructor told me to make a very tight fist, to place it over the centre of the board, and to think about hitting the pillow beneath the wood. I took a deep breath, focused on the centre spot, and brought my fist down.

Thunk. My first bounced off the board, not even cracking it. Second try. *Thunk.* Again, my fist bounced off. I was stunned and embarrassed. Why, when an eight-year-old had put her fist through a board minutes before me, was I having so much trouble? (continued on page 8)

Smart Moves (continued)

"You know," another instructor said quietly, coming up behind me, "sometimes when we have arthritis, our brains won't let us do something that could hurt us."

I was still embarrassed, but I knew she was right. I wanted to break that board, but when I brought my fist down, deep down, I didn't feel like I really meant it. Some little voice had warned me, "Don't do it." And that's why I bounced off.

Before the wood-smashing had started, the instructors had offered two other options: breaking the board with a foot or with a rolled-up magazine. I tried the magazine, even though I was skeptical that it would do the job. Success! (I gotta say, breaking stuff is fun!) I still have the broken board.

Later, as I walked home, I realized that what the instructor said made a lot of sense. Our brains want to protect us. That's why, when we trip and fall, our hands fly out in front of us, breaking the fall and stopping our head from colliding with the pavement. We react without thinking. Our brain – our survival instinct – takes over, keeping us out of danger.

I also realized that my brain sends me these subtle messages constantly, and a lot of them apply to my health. I haven't always been a good listener. For most of the ten years that I've lived with lupus, whenever I heard that little voice pipe up, "Maybe you shouldn't..." I didn't even let it finish. I'd go ahead and say yes to another freelance writing project, or invite people over for dinner, or offer to help my mom with her Christmas shopping. To me, these are enjoyable activities, but they also ate up energy that I probably couldn't spare. And, I think, at times I paid the price with achy joints, sore muscles and intense fevers.

Everyone should pay attention to that voice, but for people living with lupus and other chronic conditions, it's essential. So, the next time you're trying to decide if you should take on that extra project at work, go to that three-day music festival with your friends, or stay up all night cramming for a midterm, stop and tune in to that little voice. It's smarter than you think.

Fundraising Report

We would like to say a big thank you to all the wonderful, generous friends who donated towards lupus research when renewing their membership. To date, we have raised more than \$5,000 with approximately half the renewals received. It is wonderful to kick off 2005 knowing that the support for working together to conquer lupus has not been totally overshadowed by tragic events around the world.

There have been other shining examples of fundraising support that we would like to share with you.

Lidia DiRezze-Malfara of Richmond Hill held a "Pampered Chef" party with family and friends that raised \$773.56 for Lupus Ontario! Not only was it a wonderful fundraiser, but a super time was had by all.

A very generous couple chose Lupus Ontario as their designated charity in lieu of gifts for their wedding. The donation request and return envelopes were included in their wedding invitations. Such inspiration resulted in donations of \$12,000. On behalf of the Board of Directors, a token Canadian Mint coin embossed with a butterfly was presented to the couple to acknowledge their unselfish spirit in support of Lupus Ontario.

This inspired my family to designate Lupus Ontario as the recipient of donations instead of our usual Christmas gifts to the adults of the family. A total of \$825 was received from all, including parents. Everyone agreed that it was a wonderful way to make the season more meaningful.

Another young couple, married on Feb. 5, gave a donation to Lupus Ontario instead of buying memento favours for their guests. We printed cards of thanks acknowledging the donation and placed them on the guest tables.

Frontier Wolsley, a large distributor in Mississauga, designated Lupus Ontario as its charity for the year at the suggestion of one of their employees. They sent in donations from its employees and proceeds from a company golf tournament.

The Dance for the Cure, which took place on Jan. 29 in Concord, was a spectacular event with over 400 attendees thanks to the hard work and dedication of its volunteer committee. We will have an update and pictures for you in the next issue.

How lucky we are to have so many thoughtful generous people working together to conquer lupus!

MOTHER'S DAY CARDS

Sunday, May 8th is Mother's Day. If you'd like to make a donation on behalf of your mother, grandmother, or another special woman in your life, Lupus Ontario will send her a special Mother's Day card to acknowledge your generous contribution. This is a wonderful idea for the woman who has everything! Just send or call in your donation by May 1 along with the name and address of the card recipient. A receipt will be mailed as designated.

Lupus Awareness begins with you and we will assist in any way we are able with fundraising ideas and projects. Volunteers are needed for a Fund Development Committee. If you have ideas or just energy and a desire to make a difference, contact Julia Kane at Lupus Ontario.

by Julia Kane, Director of Fund Development

DID YOU KNOW...



that you may be eligible for the Disability Tax Credit? For more information, visit the Canada Revenue Agency website at www.cra-arc.gc.ca/disability/ or call 1-800-959-8281.



Lupus Ontario

Please join us for this national symposium on lupus!

Hosted in collaboration with CaNIOS (Canadian Network for Improved Outcomes in SLE)

Learning to Live Well with Lupus

Saturday, June 4th, 2005 - Ottawa, Ontario

Lupus Canada continues its tradition of connecting people living with lupus with lupus researchers at its annual symposium - a valuable forum for health information, peer interaction and updates on lupus research.

This year's symposium will be held at The Crowne Plaza Ottawa Hotel, centrally located downtown in Ottawa near the Parliament buildings, museums, shopping and attractions.

Keynote Address: Dr. Mary Ann Dooley, Saturday, June 4, 2005 - 9:00 a.m.

Saturday Sessions:

10:00 a.m. - 10:30 a.m.	Pregnancy and Neonatal Lupus and Postpartum
11:00 a.m. - 12:00 p.m.	A Patient's Perspective
11:15 a.m. - 12:15 p.m.	Kids, Tweens & Teens: Transition to Adolescent
12:15 p.m. - 1:30 p.m.	Lunch
1:30 p.m. - 2:30 p.m.	Psychological Impact of Lupus: Strategies for Better Coping
3:00 p.m. - 4:30 p.m.	Concurrent Sessions The Puzzle of Life with Lupus: Making the Pieces Fit Start of Life Kids, Tweens & Teens Adulthood

An application has been made to the Maintenance of Certification program of the Royal College of Physicians and Surgeons of Canada for a total of 5.5 credits for this symposium.

Confirmation Form

- I would like to attend the symposium in Ottawa on June 4, 2005. Here is my registration fee of \$30.00 (lunch is included).
- I cannot attend the symposium but would like to make a donation of \$ _____ in support of this event.
- My cheque is enclosed. Charge to my: Visa MasterCard American Express

Card Number: _____ Expiry: _____

Signature: _____

Name: _____

Street Address: _____

City: _____ Province: _____ Postal Code: _____

Telephone Number: _____ E-mail Address: _____

Mail To: Lupus Canada National Office, 590 Alden Road, Suite 211, Markham, Ontario L3R 8N2

Credit Card Payments Can Be Faxed To: 905-513-9516





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 Toll Free: 1-877-240-1099
 E-mail: lupusontario@bellnet.ca
 Website: www.lupusontario.org

Lupus Ontario

PROVINCIAL BRANCHES, SUPPORT GROUPS AND CONTACTS (rev. Feb4/05)

Area/Support Type	Contact Person	Contact Information
Toronto & GTA Region		
Toronto West Branch and Support Group Leader	Yvette	905-501-7795 wellness_group@hotmail.com
Toronto North Branch and Support Group	Cathy Ferren-Palmer	416-499-1053 lupusgroupinfo@aol.com
Toronto North Support Contact	Wilma Duffin	416-496-3962
Scarborough Support Group Leader	Sonia Chisholm	416-293-8419
Northumberland Support Contact	Shelagh Purcell	905-373-0490
Oshawa Support Group Leader	Jody Breen	905-571-4771 jodybreen@hotmail.com
Eastern Ontario Region		
Ottawa Branch	David Boal	The Arthritis Society 613-723-1083 David.boal@sympatico.ca
Belleville Support Contact	Monica Plumpton	613-961-1152 monark@lks.net
Central Ontario Region		
Simcoe Support Group Leader	Marlene Burgess	705-722-3440 mnt52@rogers.com
Simcoe Support Group Leader	Jan Gillis	705-720-2812
Lindsay Support Group Leader	Stewart Stainton	705-324-4246
Peterborough Support Contact	Josee Bibeau	705-748-3119 jbibeau@cogeco.ca
Northern Ontario Region		
Sault Ste. Marie Branch	Patricia Korbut	705-949-2836 Arthritis & Lupus Information Centre 705-253-2173
Sudbury Branch	Paulette Cordeau	877-240-1099
Sudbury Support Contact	Elaine Gareau	705-983-4343
Sudbury Support Contact	Brenda Seguin	705-692-3650
Thunder Bay Branch and Support Group Leader	Ruth Tarvudd	807-983-2349 lupus@tarvudd.com
Western Ontario Region		
London Contact	Peggy Serratore	519-659-4359 serratore1@sympatico.ca
Windsor Branch	Kevin Stannard	519-974-7869 Kevin.stannard@sympatico.ca
Ridgetown Support/Chatham Area	Cathy-Ferren Palmer	519-401-4866 lupusgroupinfo@aol.com
Kitchener/Waterloo	Rosemary Kropf	519-888-6301
Hamilton Branch	Lorrie Powless	905-527-2252
Ontario Teen & Young Adult Support		
Ontario	Jaelyn Law	jaelynlaw@hotmail.com
Ontario	Jodie Nimigon	905-623-1209 • 613-236-4655 jrosenimigon@hotmail.com

LUPUS ONTARIO BOARD OF DIRECTORS

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Mark Purcell	Director at Large	636 - 50 Richmond St. E. Oshawa, ON L1G 7C7	Tel: 905-438-0847 Home: 416-490-6364 x233 (w) Fax: 416-490-6911 Email: purcellm@msn.com

Member Organizations

BC Lupus Society

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Tel: 604-714-5564
Fax: 604-714-5555
Email: bclupus@telus.net

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

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

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

Lupus Society of Manitoba

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

Lupus Foundation of Ontario

294 Ridge Rd. N., Box 687,
Ridgeway, ON L0S 1N0
Toll Free: 1-800-368-8377 in Ontario
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Lupus P.E.I.

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Lupus Canada

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Fax: 905-513-9516
Email: lupuscanada@bellnet.ca
website: www.lupuscanada.org

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.

WARNING!

If you haven't renewed your Lupus Ontario membership for 2005, this will be your last newsletter. We need your support! Please contact the office as soon as possible.

Donate Your Optimum Points to Lupus Ontario!

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

- Visit www.shoppersdrugmart.ca and click "Donate Your Points to Charity Today." A confirmation e-mail will be sent to you as well as to Lupus Ontario.
- Call 1-800-SHOPPERS and talk to a customer service representative.

You're invited to...

Toronto East A.C.T./U.C.T. Club 2005 Flea Markets

Location: 441 Gibb St., Oshawa,
on the Canadian Tire parking lot
Time: 9 a.m. to 5 p.m.

Dates: Victoria Day (May 23),
Canada Day (July 1),
Labour Day (Sept. 5) and
Thanksgiving Monday (Oct. 10)
Proceeds will be donated to Lupus
Ontario and other charities!

Are you between the ages of 18 and 25 and do you have lupus? Lupus Canada is looking for young leaders to attend our national symposium in June (for more info, see page 9).

Visit www.lupuscanada.org for details on how you can apply!

Lupus Ontario

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