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LUPUS CANADA OFFICIALLY LAUNCHES NEW LUPUS BOOK

by Len Funk, Past President Lupus Canada



(left to right) Len Funk, Past President; Paula Sloss, Key Porter Books; Dr. Sasha Bernatsky; Diane Ferland, CaNIOS National Coordinator; Mae Boa, President

On the evening of Feb 5, 2005 I was pleased to join the Lupus Canada Board of Directors and a few distinguished guests to celebrate the recent release of a newly published “Lupus the Disease with a Thousand Faces”. This new book is truly a labour of love by several Canadian doctors who contributed, but primarily, by Drs. Jean Luc Senécal and Sasha Bernatsky. Lupus Canada was very pleased to have Dr. Bernatsky attend the evening as the representative of

both authors. Lupus Canada presented plaques to Dr. Bernatsky recognizing the work, which the two doctors put into this project.

We were also pleased to have Paula Sloss attend the evening on behalf of Key Porter Books, the publishers of this book. Key Porter Books have arranged for both a Canadian version and an international copy, which will be marketed in a number of countries abroad. *Continued on page 2*

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

Lupus Canada Bulletin is published twice yearly by Lupus Canada and is circulated to individual members of associate organizations. For contact information, see page 12

Dr. Paul Fortin, Chair of CaNIOS was unable to attend but we were very pleased to have Ms. Diane Ferland, National Co-ordinator attend on behalf of the other contributors to the book who are affiliated with CaNIOS.

Mae Boa, President of Lupus Canada welcomed everyone and then called upon Len Funk to share some history of the efforts leading to the successful publication. We noted that it is a number of years ago when Key Porter

Books looking for a specific book about lupus to fill a need in their medical series of books approached Lupus Canada. At the time Dr. Senécal's professional commitments would not permit him re-writing the existing "Disease with a Thousand Faces" book. After discussions with Dr. Fortin and other doctors who were members of CaNIOS, it was fortunate that Dr. Senécal's commitments allowed for his return to the project as co-author.

Although I had the privilege as President, during most of the time of the project, to be closely involved; it was a great asset to have the national office and Judi Farrell, look after much of the detail.

We encourage everyone to contact the Lupus Canada national office to order a copy of the new book. An order form for the book is included in this newsletter. Please ensure the book gets plenty of circulation and is read by everyone you know.

Report From The President

Mae Boa, President Board of Directors

What I find most rewarding about being President of Lupus Canada is the opportunity to work with so many dedicated and committed volunteers and staff – at both the national and local level. This is reinforced for me each time I have the opportunity to participate in a committee meeting or attend meetings with the various member organizations from across the country. We continue to be a volunteer driven organization and I am very pleased to be a part of such a dynamic Pan-Canadian team!

The second annual World Lupus Day was May 10th. There were a variety of media-type activities undertaken by our member organizations to increase the awareness and the importance of this day. Members of Parliament and Members of the Provincial Legislature were contacted, Certificates of Recognition were issued in many provinces, proclamations and Member's Statements read in the Provincial Legislatures. It just seems to get better each year!

One of our strategic priorities is 'extending our reach' and I am pleased that as a result of our ground work in Quebec these past few years, we have a group of volunteers from Montreal who have come forward to establish a steering committee interested in providing lupus related services and support to people in Quebec. We were very pleased to have Miriam Gaudelli, chair of the steering committee attend our annual meetings in Ottawa. This group could well become our first Division. This is very exciting and will be a foundational piece of work for the Governance Committee.

Another good news story for Lupus Canada is the one year website development/design in-kind support we are receiving through Convergent Media Network. Under the leadership of Jan Mycholuk from Alberta, working with our operating committee chairs and Judi Farrell, our Chief Operating Officer, this project is moving along. This is a

tremendous opportunity for us and we want to ensure we obtain the maximum benefit from the Network expertise. This project will take up a great deal of our volunteer and staff time between now and the end of the year, defining needs and developing new materials. We look forward to introducing everyone to our new website look in early 2006.

Our annual general meetings were held in Ottawa this year, June 1 to 3; followed by our annual national medical/patient symposium co-sponsored with CaNIOS. We very much value our partnership with CaNIOS to further our joint interests in the area of lupus related research. Over 100 people attended the one day symposium which hosted international speakers on *Learning to Live Well with Lupus*. We sponsored our first meeting of youth delegates from across Canada, with Jaelyn Law from Ontario leading and facilitating this outstanding group of youth leadership. Other significant accomplishments included approval of our Pan-Canadian Strategic Plan, the Pan-Canadian Communication Strategy and Implementation Plan, new volunteer management policies and guidelines, review of our first national board evaluation process, and the new slate of directors for the Board. We are very pleased to welcome four returning members and two new faces to our Board, Veronica Carroll from British Columbia and Nadalene Khan from Manitoba. The Presidents Council expressed thanks to Dale Williams for her leadership and welcomed Pat Leece as new chair. Various workshops were held with the members endorsing continued work on our divisional model and joint membership. Our volunteer recognition dinner was a fun-filled event expressing our appreciation to volunteers from across the country. Special recognition went to Shelagh Purcell and Ann Wyse from Ontario and Barbara Grimster from Prince Edward Island. Thanks to so many special guests and friends of Lupus Canada who joined us throughout the four days in Ottawa.



CANIOS UPDATE

By Diane Ferland

While there has been much “behind-the-scenes” activity at CaNIOS over the winter, a lot of it may be missed from the “public” at first glance. The CaNIOS pediatric membership is growing and we now boast our first community “lupologist”, Dr. Hector Arbigalla based in Lethbridge Alberta.

CaNIOS and Lupus Canada are taking the lead in the planning of a Consensus Conference called Lupus and Other Systemic Autoimmune Diseases (LOSAID). The dates are Dec 2-4, 2005 in Toronto. There will be a consumer/patient-day on Dec 2nd and then 2 days of meetings with physicians, researchers and consumers. The outcome will be the definition of a National Research Program for lupus and systemic autoimmune diseases.

This represents an expanding partnership between Lupus Canada and CaNIOS. Our relationship is growing and blooming!

CaNIOS Research:

1000 Canadian Faces of SLE: This new study is headed by Dr Christine Peschken (Winnipeg) and coinvestigators Dr Janet Pope (London), Dr Earl Silverman (pediatrics – Toronto), and Dr Glinda Cooper (National Institute of Health – Environment and Health) received funds from The Arthritis Society and the Institute of Musculoskeletal Health and Arthritis (TAS/IMHA) for her 1000 Canadian Faces of Lupus grant. She had presented the Manitoba portion of this study at the Saskatoon

meeting last June. (A report of her presentation is found in the Lupus Canada Fall 2004 bulletin). The participating CaNIOS centres (from Montreal to Vancouver) are in the process of gearing their clinics up for this study. We essentially are hoping for all persons living with lupus to agree to enroll. It would mean that once a year, there are some forms to complete on your opinion of your quality of health and life, the access to care that exists near you, medication use, and some other questions. In some centres we will also be asking if you would provide some extra research blood and urine to be stored for future analysis on antibodies specific for lupus. At present, the funds received are not enough to do the studies on the blood and urine on all participants.

The other 3 CaNIOS projects are still going strong!

GenES Study: More centres (in Sherbrooke, Montreal, Toronto and Calgary) are ready to present this study to their patients. The on-going centres of Toronto Western, London, Halifax, and Montreal General are going strong – with 47 patients and families enrolled and 91 families have completed the study as of April 12th. But, as always, we are still hoping to have more persons and their families participate.

The Health Improvement and Prevention Program or HIPP Study: Despite a slow start this project is coming along nicely. We are still only recruiting persons at the McGill University Health Centre (Montreal) and the University Health Network (Toronto). The HIPP intervention has been very well received by our first participants (65 participants are enrolled to date). Some have completed their first year and are being reassessed as we speak.

ThromboFIL Study: This study follows persons with SLE for 3 years monitoring if any thrombotic (like a

blood clot) events occur, especially in persons with 1 or more antiphospholipid antibodies. We are attempting to merge the yearly review this study requires with the ‘annual’ visit you may have at your lupus clinic. In this way, you and your doctor do not need to fill in the same forms twice.

We wish you all a wonderful summer. Don't forget the sunscreen!! ☺

COMING SOON

– UPDATED AND REVISED LUPUS CANADA WEBSITE.

TALK TO US!

Lupus Canada's new website will feature personal stories from individuals living with lupus to inspire others and to help create an understanding of lupus.

If you are willing to share your personal experience with lupus, such as a challenge you have overcome, or some friendly advice about living well with lupus or information about how Lupus Canada or a local lupus organization has been there for you – please write to us!

Send letters and photos to Steffanie Rundle, Assistant Chief Operating Officer

Lupus Canada
590 Alden Road, Suite 211
Markham, ON L3R 8N2
1 (800) 661-1468



Mrs. Florinda Teresa (Florie) Storr

The Florie Storr Lupus Fund

Lupus Canada has been presented with the very special gift of an endowment fund established in honour of the memory of Florinda Storr. The principal gift to create the fund has been generously donated by Mr. Hugh Storr in honour of his beloved wife, Florie. This investment to help those living with lupus will last into perpetuity, generating annual interest to support the important work of Lupus Canada and creating hope to find a cause and a cure.

The Florie Storr Lupus Fund will play a significant role in securing national lupus research and education efforts.

Donations to help build the fund can be made by contacting Lupus Canada or the Revelstoke Community Foundation

Lupus Canada
590 Alden Road, Suite 211
Markham, Ontario L3R 8N2
(800) 661-1468
Contact: Judi Farrell

Revelstoke Community Foundation
PO Box 2398
Revelstoke, B.C. V0E 2S0
(250) 837-5345
Contact: Geoffrey S. Battersby

*Lupus Canada would like to express heartfelt appreciation
and compassion to the Storr Family of British Columbia.
It is an honour to be a part of Florinda Storr's memory.*

INVEST IN A HEALTHY FUTURE FOR PEOPLE LIVING WITH LUPUS

Lupus Canada's national efforts to support people living with lupus are made possible through the commitment of volunteers and the generosity of donors. Each year, Lupus Canada carries out fundraising campaigns to ensure a strong national voice for the lupus community in Canada. Each and every gift received is valued and spent wisely.

You can help to ensure lupus research, education and awareness services into the future by making a planned gift. Consider leaving a legacy to conquer lupus by making a bequest to Lupus Canada in your Will, by naming Lupus Canada the beneficiary of a life insurance policy or an investment, or by donating shares. Each planned gift offers great tax benefits to you or your estate, and can be made without affecting your current lifestyle.

For more information about the many benefits of planned giving, please contact Judi Farrell at Lupus Canada's national office or speak to your financial advisor.

LUPUS "IN THE NEWS" DURING OCTOBER AWARENESS MONTH

Our special thanks go to Dr. Gifford-Jones for his support during October Awareness Month. Dr. Gifford-Jones writes a syndicated newspaper column in which he discussed lupus and its symptoms thus alerting thousands of readers to the disease with a thousand faces.

SHOW YOUR SUPPORT!



Light grey zippered hooded sweatshirt
(Currently available in size large only)

*Purchase a Lupus
Canada sweatshirt for
just \$35.00 (shipping
costs extra)*

Call Lupus Canada to place your order
and help to generate lupus awareness!

1-800-661-1468

AUTOMATIC REINSTATEMENT FOR CPP DISABILITY BENEFITS

An important change has just been announced for the Canada Pension Plan (CPP) disability benefit program.

People who are CPP disability benefit recipients and who return to work are now guaranteed that their benefits will be automatically reinstated if the attempt to return to work doesn't work out because their original disabling condition has returned. Previously, if a CPP disability beneficiary failed at a return to work, he or she would have to go through the entire application process again.

With automatic reinstatement, individuals just need to inform Social Development Canada of their inability to continue working within two years of the

date when their benefit stopped. They also need to provide a letter from a physician confirming the original disability has returned. Benefits will typically be reinstated within three weeks. There is no limit to the number of times, a person can request a reinstatement of benefits.

For more information, call Social Development Canada at 1-800-277-9914 or see the website www.sdc.gc.ca and then click on Persons with Disabilities and then CPP Disability Benefits.

CPP legislation was amended and approved by the provinces and territories to allow for automatic reinstatement to be added to the program.

RÉTABLISSEMENT AUTOMATIQUE DES PRESTATIONS D'INVALIDITÉ DU RPC

Un changement important vient tout juste d'être annoncé au programme de prestations d'invalidité du Régime de pensions du Canada (RPC).

Les bénéficiaires de prestations du programme de prestations d'invalidité du RCP qui retournent au travail ont maintenant la garantie que leurs prestations seront automatiquement rétablies si leur tentative de retour au travail n'est pas fructueuse en raison du retour de leur déficience. Anciennement, si un bénéficiaire de prestation d'invalidité du RPC échouait dans sa tentative de retourner au travail, il ou elle devait retraverser tout le processus de demande.

Avec le rétablissement automatique, les personnes n'ont qu'à informer Développement social Canada de leur incapacité à travailler, dans les deux ans qui

suivent la date où les prestations ont été interrompues. Elles doivent aussi fournir une lettre du médecin attestant le retour de la déficience initiale. Règle générale, les prestations seront rétablies dans un délai de trois semaines. Il n'y a pas de limite au nombre de fois qu'une personne peut demander le rétablissement des prestations.

Pour obtenir de plus amples renseignements, communiquez avec Développement social Canada au 1 800 277-9915 ou consultez le site Web suivant : www.dsc.gc.ca. Cliquez sur Personnes handicapées et ensuite sur Prestations d'invalidité au titre du RCP.

La loi sur le RPC a été modifiée et approuvée par les provinces et les territoires afin de permettre au rétablissement automatique d'être ajouté au programme.

*Thank you to the Multiple Sclerosis Society and the Episodic Disability Network
for contributing this information for the benefit of others.*

CANCER DRUG SHOWS PROMISE AGAINST LUPUS

Adapted and reprinted with permission from the University of Rochester Medical Center.

Rituximab, a drug used to treat lymphoma, appears to be very effective at treating lupus, with just one injection easing symptoms in several patients for a year or more. The results of the clinical trial were published in the August 2004 issue of *Arthritis and Rheumatism*.

Physicians at the University of Rochester Medical Center suspected that because lupus involves the same immune cells as lymphoma, a drug successful at treating lymphoma might also help lupus patients. So they tested rituximab, approved in 1997 to treat lymphoma, in lupus patients.

The results bear out the hypothesis. Eleven of the 17 patients had a significant drop in immune cells known as B cells, and the health of those patients improved significantly, an improvement that was evident for the 12 months that the study lasted. Several were able to reduce or go off their traditional lupus medications.

“In most patients, their lupus improved significantly,” says rheumatologist R. John Looney, M.D., who led the study. “Since lupus differs a great deal from person to person, the ways that patients improved varied. Some had less joint pain; some had fewer skin rashes. But everyone who had fewer B cells had significantly improved health. These patients were treated for a very brief period of time, and some of them are still doing just great, several years later.”

The benefit wasn't as marked for everyone, including patients who did not receive the full dose of the medicine in the “dose-escalation” study, as well as African-American patients. Scientists are investigating the differences. “Some patients don't

need much treatment, while others need all you can offer and more,” says rheumatologist Ignacio Sanz, M.D., an author of the paper and a lupus expert.

Scientists also noted the lack of significant side effects with rituximab. Some patients had a reaction to the infusion of the medicine, but in the

...this is the first really new and targeted therapy to come along in a long time.”

study, it occurred far less often than it does with cancer patients taking the drug. Current lupus treatments, in contrast, are laden with severe side effects. The anti-inflammatory drugs used to dampen the immune system leave patients vulnerable to infection, while steroids at high levels can cause everything from thinning bones to depression.

The difference in side effects is a result of the precision, or lack thereof, of the medicines. Current lupus treatments affect nearly all the cells of the body, including healthy and vital cells. Rituximab targets only B cells and is aimed at lowering their numbers. That's why the drug is available to lymphoma patients: Most have too many B cells, which make antibodies that flag down and kill microbes and other invaders in the body.

Lupus is also a problem with B cells: They're found in the wrong proportion in the body's blood and tissue, and they're often misguided, making too many antibodies that mistakenly attack the body itself. The infighting clogs up the body with cellular debris, causing a variety of symptoms; then when the immune system detects the problem, it tries to ease up, leaving the patient open to infection.

“Lupus patients tend to have fewer B cells than normal, but their B cells are hyperactive and function in a very abnormal way,” says Sanz. “The immune system is hyperactive but disorganized; it's overreacting to some things but not enough to other things.”

Previous research had pointed to other immune cells, known as T cells, as the major culprit. But Looney and his team uncovered a more complicated process in which co-operation between B and T cells is at the core of the disease. The

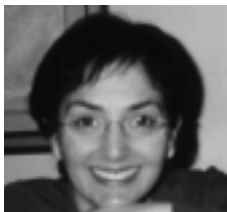
success with rituximab opens up a whole new vista – targeting B cells, reducing their numbers, and ridding the body of errant B cells – for treating the disease.

The Rochester team is now helping to design a much larger study of patients that may begin within the next year or so at multiple sites across the U.S., including Rochester.

“Our basic knowledge of lupus has been increasing exponentially during the past few years, but there have been few new treatments,” says Sanz, who heads the University's NIH-funded Autoimmunity Center of Excellence, where lupus is one of three diseases studied by two dozen researchers. “Prognosis has improved because of better support therapies like blood pressure control, anti-cholesterol drugs, dialysis and antibiotics, but this is the first really new and targeted therapy to come along in a long time.”

The medication for the study was supplied by Genentech, Biogen Idec, and Roche, which make and market Rituxan, the brand name for rituximab. The study was also funded in part by the National Institute of Arthritis and Musculoskeletal and Skin Diseases and the Lupus Foundation of America.

WHAT'S ON YOUR MIND?



Wendy Singer

The positive feedback I received on my last article, *My Yoga, My Self* (published in the Fall issue of the Lupus Canada

bulletin) has been truly gratifying. I am thrilled that some of you will benefit from my experience. Based on some of your comments, I'd like to remind you of two important points about practicing yoga:

1) The type of yoga you choose is very important. There are many styles of yoga, some of which are far too strenuous. I practice the gentle form of Svaroopa. With the use of props to facilitate getting into and holding poses, Svaroopa teaches that support equals release. There is no need to push unnecessarily. The same benefits can be realized with no strain on the body. It's best to start gently and at a suitable level.

2) Yoga can be used to identify changes in how you feel, which is an invaluable tool when managing an illness like lupus. It can also help identify feelings of wellbeing and peacefulness, which is why Svaroopa is referred to as 'bliss' yoga. The benefits of yoga are physical, psychological and spiritual. It's a wonderful coping skill and self-healing tool.

Now I have more great news to share with you! Last year I joined a two-year study at the Montreal General Hospital Lupus Clinic (part of the McGill University Health Centre) called Health Improvement and Prevention Program. HIPP focuses on prevention through knowledge by offering courses on topics such as coping, education and exercise. Initiated by Dr. Paul Fortin in Toronto and Dr. Deborah De Costa in Montreal, it is available through

the Toronto and MUHC lupus clinics. Dr. Ann Clarke and Dr. Chris Pineau, site investigators of the Montreal initiative, state that: "the objectives of this study are to determine whether HIPP will improve health status in patients with lupus and will lead to a reduction in heart disease and bone loss". I believe that prevention is the key to good health, so I was excited to learn more.

All HIPP patients complete a questionnaire that assesses how you deal with your lupus. My results showed that I could benefit from some education on coping, which qualified me to participate in the Mindfulness - Based Stress Reduction workshop leg of the study. Competently led by Ms. Maria Dritsa in Montreal and Dr. Susan Abbey in Toronto, the course combines yoga, meditation, and discussion about coping tools. As it is offered in a group setting, I discovered that other patients' issues are similar to mine. It was so comforting to learn that my problems are not unique!

Our first exercise was a guided meditation called the body scan. I hadn't enjoyed meditation in the past, but was open to trying again. To my surprise, I felt positive effects. I suppose that in the past I hadn't been as open to learning and healing as I am now. With the use of guided meditation CDs provided by the program, I began practicing the body scan and sitting meditation at home. The beauty of meditation is that it allows and trains you to focus on something other than your feelings or worries. It quiets the mind and clears out any thoughts (good or bad), which magically gives your body a break - some time to rest and heal.

Meditation is portable. Did you know it can be done while eating or walking, at home or in public (but never while driving!)? It requires concentration. Some days this comes

easily, other times my mind is so active that it takes the entire CD to clear my head. After my eight-week workshop ended, it was a challenge to dedicate time to meditation, but once I started to feel the benefits, it easily became a part of my life.

To complement the yoga and meditation, a dash of cognitive behavior therapy is thrown in. A valuable lesson I learned was this: my thoughts are just that - thoughts. Meditation techniques teach you to deal with issues as they arise, acknowledge them, and let them go. Imagine that - we actually have control of our thoughts! I have a busy mind that regularly features my own creative drama, both comedy and tragedy. This takes up an enormous amount of precious energy. With some work, I can pause the show, as if I have a remote control for my emotions. This creates room in my head for pleasantries rather than worry, for quiet rather than clutter. I'm not suggesting that I've become devoid of thought, but I am thinking in a more realistic and concrete way. Let's face it, lupus doesn't go away, nor does the fear of what tomorrow may bring. Today I feel great - yesterday I couldn't move my hands. But constant worry can only make things worse. So why not give ourselves a break and change the channel from time to time?

I had the opportunity to see this in action recently when my doctor notified me of some abnormal test results. This called for more testing. I think that a few months ago I would have been somewhat hysterical over the possibilities of what might lie ahead. Instead I caught my thoughts, acknowledged I was concerned, and let them go. I was very lucky this time. My test results started to improve. It was only after I received the good news that I let out a sigh of relief. I was probably not going into a flare - at least not right now. It was

an accomplishment to not have wasted two months panicking and worrying myself sick, but instead, taking things day by day.

Another valuable tidbit is the emotional garbage can theory. This is where we dump all the stuff we just can't or don't want to cope with. When the can overflows with emotions, it becomes a danger zone and needs to be emptied. Taking garbage out is daunting, as the feelings you once discarded will naturally surface. It is better to deal with thoughts as they arise rather than all at once out of necessity. Scraping the bottom of the wastebasket is like cleaning out your messy closet. You want to keep it fresh and clean for as long as possible. Yoga and meditation can teach us to acknowledge thoughts or issues before they are thrown aside. I think my lupus feeds on the negative, so the more I can deal with before it becomes a part of me, the better.

The meditation, yoga, and cognitive behavior therapy teachings are a wonderful trio. They draw attention to some basic facts. Lupus patients have limited resources. We need to find ways to balance our scale and do things that make us happy. In October, I started a new job after being off work for 3 years. This was a difficult adjustment. The workshop helped me to understand that at the time, I had taken on more than my resources could handle, which made me emotionally unstable. Rather than blaming my struggle on my inadequacies, I learnt that I simply didn't have the physical resources to handle everything on my plate. I've since adjusted and am finding ways to achieve balance, even if it does require forcing myself to say the N word once in a while. Eliminating the heavy burden of blame again frees up brain space, which can be filled with happy, easy thoughts, like dreams of hot fudge sundaes, my nieces, the bright blue sky and crisp white snow, what bath bead to put in my bath – you know, the important things in life.

The HIPP study is a gift to lupus patients. I have participated in a four-session education course given by my dedicated physicians, which focused on knowledge of lupus, coping, cardiovascular health and osteoporosis. My bone density and cholesterol are being monitored, I have the option of consulting with a dietician, and I'm starting an exercise program called CHIP (Cardiovascular Health Improvement Program), which focuses on heart health and physical fitness. In addition, all patients who participate in HIPP will receive a lupus health passport containing general and personal information about lupus, risk factors and medication.

HIPP is demanding in terms of commitment, energy and time. There were some mornings when I would have preferred to stay in bed than go to my courses, but the payoff is invaluable. I'm glad I pushed myself.

Learning how to cope with and manage lupus is a life-long winding, bumpy road. With the right help, guidance and tools, I think we can all find ways to improve our quality of life. We can pave the road, keep it straighter, and even ensure the scenery along the way is more beautiful. I don't think we can do this alone. Thank you to all the professionals who had this insight and brought the HIPP program to life.

If you would like to know more about Svaroopaa yoga, visit <http://www.masteryoga.org>. For information about HIPP, contact Anne Cymet, Nurse Coordinator for Toronto at (416)603-5800, ext. 2895, or Carolyn Neville, Nurse Coordinator for Montreal at (514)934-1934, ext. 44718. Please note that as this study is new, there are no results as of yet. This is simply an account of my personal experience.

Wendy Singer is a former member of the Board of Directors of Lupus Canada and an active supporter of programs and services for people living with lupus.

NEW EXERCISE DVD'S AVAILABLE



Tai Chi for Arthritis DVD

(Multi-language edition), Wellspring Media 2002; approx 80 minutes; 424.95 US; 62-page illustrated paperback handbook, \$10.00 US. By Paul Lam, MD.

Tai Chi is believed to be one of the most effective ways to improve health and fitness and promote relaxation. This program, part of Dr. Lam's 'Tai Chi Self-Teaching Beginner Series' is designed especially for people with arthritis and other conditions that affect the joints. Available online at www.taichiproductions.com or write to US East Action Video, PO box 3102, Rancho Cordova, CA 95741-3102.

The Right Moves for Lupus: A Gentle Fitness Program DVD

If lupus has you on the sidelines instead of in the middle of action, this new low-impact exercise program may be perfect for you. Through the guidance of a licensed ACE (American Council on Exercise) instructor who has lupus herself, "The Right Moves for Lupus" can help you get moving in the comfort of your own home. available from the LFA, Piedmont Chapter, online at www.lupuslinks.org or by calling (704) 375-8787.

NEWS FROM LE SOCIETY OF SASKATCHEWAN

Sylvia Higgins Memorial Essay Award Winners

The winning entries of the Sylvia Higgins Memorial Essay Awards 2004, were announced at the LE Society of Saskatchewan Annual General Meeting on November 13, 2004.

Lynne Brochu, "A Glance At Lupus: Helping Clients to Help Themselves" received the award for the Medical Category, and Susan Grant, "Tour of the Center of Activation of Lupus", the award for the General Category.

Lynne is a physiotherapy student enrolled in the School of Physical Therapy, College Of Medicine at the University of Saskatchewan, and Susan is a Sergeant with the Saskatoon City Police, in Charge of Resource Officers in the Saskatoon School System.

Invitations were extended to all essay entrants to attend the LESS 25th Anniversary AGM. In addition to the

winners and their families, Cheryl Holtz, Estevan, and Jenna Leith, Saskatoon, and their families attended, adding a bright youthful presence to the anniversary celebrations.

The winning essays were read at the meeting and presentations were made by Dr. Earle Decoteau, LESS President, and Betty Bellamy, Sylvia Higgins Chairperson.

LE Society of Saskatchewan was honoured to have in attendance Mae Boa, Lupus Canada President, who brought greetings from Lupus Canada and presented LESS with a commemorative 25th anniversary plaque, accepted by Dr. Decoteau.

Betty Bellamy welcomed special guests Lynne and Dianne Higgins, daughters of the late Sylvia Higgins, and read congratulatory messages from Lynne Yelich, MP Blackstrap, and Ken Cheveldayoff, MLA Saskatoon Silver Springs.

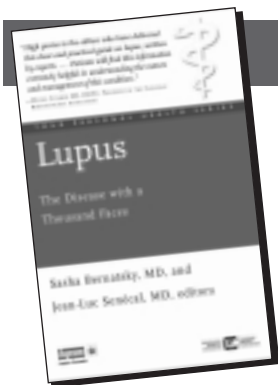
Guests were able to view a photographic display of LESS activities 1979 to 2004, and a special anniversary cake and refreshments were enjoyed by all.

Personal Stories Make Public Awareness Impact

Coronary Artery Rehabilitation Group (CARG) December 2004 newsletter "Heart a Facts" carried Betty Bellamy's story, "My Journey". The article can be found on line at the CARG website www.carg.ca. Go the Newsletter link to the December 2004 issue, pages 5 to 9.

Hub City Square and Round Dance Association newsletter "Square News" also carried the story in their November 2004 issue. Thank you to Betty Bellamy for publicly sharing her story to generate awareness in two very different populations.

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“WALK-A-BLOCK” FOR LUPUS

British Columbia Girls Choir and BC Lupus Society walk in mutual support.

On Saturday, October 30, during Lupus Awareness Month, the British Columbia Girls Choir united with the B.C. Lupus Society in a “Walk for Lupus” at Westminster Quay Market. The purpose of this event was to raise awareness of this disease and to raise funds for both organizations.

Recently one of the choir’s long-time singers, Elaine Rojano, was diagnosed with the disease. B.C. Girls Choir Board of Directors and Staff feel the partnership between the two organizations is fitting. BC Girls Choir is an all girls’ organization and Lupus usually affects young women of childbearing age.

The walk ended with a song and a word from the President of the BC Lupus Society.



WALK A BLOCK – FROM NEWFOUNDLAND AND LABRADOR

A group of individuals met at the Pearlgate Track and Field, in Mount Pearl on October 31, 2004. They didn’t gather for a Halloween party.... they all lived on different streets... had different careers and different responsibilities....what brought them together? They all wanted to Walk a Block for Lupus. They are individuals who volunteered their time to promote public awareness and to help improve the lives of those living with lupus. Their

collective efforts resulted in a contribution of \$1,454.00 to the 2nd National Walk-a-Block for Lupus. Proceeds received from participants after the group walk increased this contribution! The spirit of other lupus organizations was also present as t-shirts from Lupus Ontario and WLD hats and buttons were distributed as prizes to lucky participants. Thanks to all who participated, contributed and collected pledges.



ONTARIO - SENIOR ACHIEVEMENT AWARD FOR VOLUNTEERISM.

Congratulations to Cookie Heyermans, Lupus Foundation of Ontario, who received the Senior Achievement Award for Volunteerism. Cookie was one of 20 individuals selected in Ontario. The Provincial Award was presented to Cookie by Lieutenant Governor, His Honour James K. Bartelman on Dec 16th.

Tribute to Dawn Elliot



*Dawn Elliot
1955 – 2005*

*There is a road we call remembrance
Where thoughts and wishes meet.
We take that road in thought today
For the one we could not keep.*

*She walks with us down quiet paths
And speaks in the wind and the rain
For the magic power of memory
Brings her back to us again.
(Author unknown)*

Dawn Elliot passed away on January 15, 2005 as a result of complications arising from a 25 year battle with lupus. Dawn was respected, loved and came into the lives of many. The true extent of the people she touched was evidenced by the caring messages that Lupus Canada relayed to Dawn's family. Messages came from all across Canada, sent by friends, colleagues, and many volunteers with whom she worked to advance the lupus movement in Canada.

In addition to being a founding member of Lupus Canada, Dawn was also deeply involved over the years as a volunteer with the Canadian Women's Foundation, Cliffcrest Community Services, West Hill Community Services, and Emily Stowe Shelter. Dawn was the proud recipient of the Queen's Golden Jubilee Award following nomination by the Health Charities Council of Canada and a YWCA Women of Distinction Award in recognition of her extensive service to the community.

Dawn was an inspiration to all. Her smile, vitality, understanding of people and her eyes won you over as soon as you met her. Her family at home was central to her life yet she reached out to people in such a way that her family grew to include many, many friends and colleagues.

Dawn Elliot was a determined ambassador for lupus in her quest to improve the quality of life for those that live with a chronic illness each day. As a mentor to others, she supported and provided encouragement to achieve goals that might have been thought unattainable. Dawn's achievements were many. Her challenges were well described in one of the messages: "Her accomplishments were huge and belied the constraints imposed by an unremitting lupus that made every achievement a monumental task."

Another friend commented, "I will remember most vividly the professionalism, enthusiasm and joie du vivre which Dawn consistently displayed. She will be missed by all whose lives she touched."

Lupus Canada has established the Dawn Elliot Memorial Fund to continue Dawn's commitment. Please contact Lupus Canada for further information or to make a contribution.

LUPUS CANADA 2005 – 2006

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