



# Lupus Canada Bulletin

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## 6th Annual National Lupus Patient Symposium

“Living Well with Lupus – Spectrum of Treatment Care”

Held on April 28, 2007 in Winnipeg, Manitoba

On a lovely day in Winnipeg, over 140 people gathered together to hear the latest information about lupus research and treatment. This national event, hosted by Lupus Canada and the Canadian Network for Improved Outcomes in SLE (CaNIOS) brings together patients from across Canada, their friends and family, and medical researchers on the frontlines seeking the causes of and cure for lupus.

This year’s event featured excellent speakers and topics of interest to all. Patient speaker Wendy Singer related her experiences of participating in research and how she was able to cope better during a lupus flare. Dr. Joan Wither spoke on family genetics in lupus. Dr. Matthew Liang focused on lupus medications in his presentation on the current and the future of controlling lupus. Dr. Doug Smith had a lively presentation on “eating well with lupus”. Dr. Carol Hitchon and Dr. Christine Peschken, both from Winnipeg, spoke about routine clinical care for people with lupus and the Lupus Day Program at the Arthritis Centre Day Hospital in Winnipeg respectively. A presentation from Dr. Arthur Bookman on Sjogren’s syndrome explained what it is and why it matters. Lastly, Dr. Paul Fortin gave an update on CaNIOS and research projects.

Feedback from the event indicated the Symposium was highly successful and well-received by all who attended. Reports from the Symposium evaluations showed:

- 86% of delegates indicated the speakers and sessions were extremely top-notch, informative and relevant to their life
- 69% of delegates noted their understanding of lupus increased by more than 50% from attending the Symposium
- 71% were very glad to have attended the Symposium

Some of those attending said:

*“Very knowledgeable speakers, fun networking, great silent auction”*

*“I’m going to make changes to my diet. I learned to take it easy and not overdo it”*

*“I learned a lot more about lupus. My wife has it but I never really understood a lot about it”*

Watch for the 7th Annual Lupus Patient Symposium coming in Spring 2008.

# Report from the President

Mae Boa, President Board of Directors

On behalf of the Board of Directors I am pleased to present an update on the activities of the organization. We held our annual leadership and general meetings in Winnipeg April 25 to 27 with representation from member organizations and divisions from across Canada. I want to thank Darlene Garner, President of the Lupus Society of Manitoba and her volunteers for hosting and organizing the events for us. Sincere appreciation is extended to André Vincent (Vice President) and Judi Farrell (Chief Operating Officer) for their impressive leadership over the two days. The participants found time to strengthen our national network, recognize volunteers and begin work on defining and discussing key programs, achievements, concerns and challenges. The result is a new Board of Directors committed to “working together to conquer lupus”. As noted by our Vice President “it was refreshing to see the enthusiasm and the renewed commitment to work together and develop a sustainable operating model”. As President, I am excited by our Pan-Canadian potential which is both impressive and powerful!

On the day following our business meetings, we once again co-hosted with CaNIOS our annual medical/patient Symposium. The bulletin includes highlights and other information on the Symposium. On behalf of the Board, I want to acknowledge our corporate sponsors for the event. We have enjoyed this partnership with CaNIOS for some six years now. I am very pleased to announce that through the generous contributions of our member organizations and divisions from across the country, we are able to contribute the final installment

of \$34,000 - a total of \$100,000 over three years – which has been matched by an anonymous donor. In total \$380,000 has been generated for CaNIOS in support of lupus related research work over the last six years. Thanks to all of our readers for donating to research to help us achieve this milestone!

Through the generosity of funding received by the Lupus Foundation of America we were able to send a delegate to the International Lupus Congress Leaders Forum in Shanghai, China in May. Carolina Pineda from our Quebec Division represented Lupus Canada and so look for articles from her in future editions of the Bulletin.

This is a banner year for lupus organizations – with our B.C. Society and the Lupus Foundation of Ontario celebrating 30 years and both the Lupus Society of Nova Scotia and Lupus Canada celebrating 20 years since formation!



Lupus Canada presented 30 year recognition plaques to Mike Hinman, President of BC Lupus Society and Pat Leece and Michelle Leece from the Lupus Foundation of Ontario.

# Lupus Canada Updates

Over the last 6 months, there have been many new developments at Lupus Canada. Here are a few of the highlights:

**Lupus Canada e-newsletter.** In this time of electronic information delivered quickly, Lupus Canada has created an e-newsletter that is sent every 2 months. Content of the newsletter focuses on timely updates and events, and links to relevant resources. People can subscribe to the newsletter by visiting the Lupus Canada website at [www.lupuscanada.org](http://www.lupuscanada.org) and registering. Past editions of the e-newsletter can also be found on the website under the “newsletter” section.

**“Get In The Loop” Youth Newsletter.** Editor Charlene Johnson and her team of young writers and contributors are producing a quarterly youth newsletter. The articles focus on important issues for young people living with lupus such as telling friends about lupus, sun safety tips, staying active, healthy eating, and the health benefits of living with pets. The Youth newsletter is looking to reach more youth – readers, contributors, pen pals – so visit the “young [lupuscanada.org](http://lupuscanada.org)” section of the Lupus Canada website to view past editions and “get in the loop”.

**New article on Canada Pension Plan titled “Decisions, Decisions:** Over 60 years old and leaving work due to ill health? Should you apply for CPP-Disability or CPP-Retirement – Practical information to help make your decision. Researched and written by Pamela Bowes, Director of Support with input from Human Resources Development Canada staff, this article explores basic highlights of the two programs, some of the issues surrounding separate or simultaneous applications, and payment considerations. This article can be found on the Lupus Canada website under the Awareness/Support/Advocacy section.

**12 new lupus Fact Sheets** are now available (to view and print) on the Lupus Canada website. Topics in both French and English include: Lupus and Pregnancy, Osteoporosis and Lupus, Cardiovascular Disease and Lupus, Immunosuppressive drugs used in treating lupus, Other Conditions seen in Lupus and Diet, Nutrition and Lupus to name some of the topics.

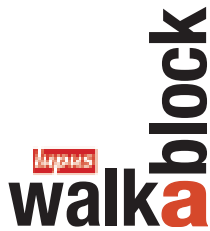
## Lupus Quebec Volunteer Wins Scholarship Award and Attends International Lupus Congress

As an official delegate of Lupus Canada, Carolina Pineda from Montreal Quebec attended the International Lupus Congress in Shanghai China from May 23 to 27, 2007. An active volunteer with Lupus Quebec, Carolina has participated as a team member with the annual “Spin-o-thon” fundraiser, provides support to people living with lupus, and participated in the planning of the Butterfly Gala held in honour of World Lupus Day on May 5, 2007 in Montreal. In Shanghai, Carolina will be meeting with other lupus organizations and looking at opportunities to increase awareness of lupus at the international level. We look forward to hearing an update from her participation at the Congress.

Carolina is working towards her Ph.D. in Anthropology from McGill University in Montreal where her area of research is in Women’s Experience of Chronic Illness in Canada. Recently Carolina was awarded a tuition scholarship from the National Education Association of Disabled Students (NEADS). This award is given to students who have demonstrated commitment to their studies and their communities, while living with a disability.

# WALK A BLOCK FOR LUPUS

What's new for 2007?



For Lupus Canada the year 2006 represented the 5th anniversary of Walk A Block for Lupus. It is because of the dedication of amazing volunteers to this event that 2006 became our most successful year for Walk A Block for Lupus. We are happy to report that 37 teams from communities across Canada participated in Walk A Block for Lupus and that these teams helped to raise over \$142,000.00. This amount is double the results of 2005! This is a remarkable achievement that we can all be proud of.

October (Lupus Awareness Month) is now only four months away and Lupus Canada has been working hard at planning for our 6th annual Walk A Block.

There are three big changes for Walk A Block for Lupus this year. This first exciting change is our new logo design which you can see pictured above. The logo has evolved into a more professional and dynamic representation of Walk A Block for Lupus and we hope it will be appealing to sponsors and participants alike! The second big change for 2007 is the move to a single walk date right across the country. Sunday October 21, 2007 is the date that has been chosen for Walk A Block for Lupus. Having a single walk date across the country will help bring more attention to lupus, the need for increased awareness as well as the need for increased funding for research that will help find a cure. Having a single walk date will also help with bringing sponsors on board who will support the efforts of the event and the event volunteers through financial contributions and in-kind donations. Our third exciting occurrence is the creation of an "e-newsletter". Please visit the Lupus Canada website ([www.lupuscanada.org](http://www.lupuscanada.org), Newsletter section) to view the latest edition of this newsletter. The e-newsletter will help you stay on top of all things "Walk A Block"! We are thrilled with these three new undertakings and are looking forward to great success with the 2007 Walk!

## HOW CAN YOU HELP?

There are many different ways that you can lend your support to the 2007 Walk A Block for Lupus event:

- Become an Event Coordinator! Start your own Walk

within your community! Lupus Canada has resources and tools to help you plan the event – from picking the location, getting media attention, finding local sponsors and suggestions for how to make your Walk an entertaining and successful event for everyone involved!

- Join a local Walk! You can contact Lupus Canada to learn more about Walks that are happening in your area and how you can join an existing team and collect pledges to support your participation.

- Support a Walker! Your financial contribution is very greatly appreciated and will help the Walker reach their fundraising goal.

- Sponsor a Walk! Perhaps you or your company has the interest and ability to make a larger contribution to Walk A Block. Your involvement could include a financial donation or a gift of merchandise and/or supplies for the Walk. Prizes and silent auction items are always appreciated and help raise money for Lupus Canada. As well, things such as bottled water and food help support the Walkers on the day of the event. Show your community that there is support for lupus.

- Volunteer for Walk A Block! You can help with the planning of a local Walk or help on the day of the event. Whatever skills and talents you have will help add to the success of Walk A Block for Lupus 2007!



## TIPS FOR A SUCCESSFUL WALK

Here are a few suggestions to help ensure the success of your Walk:

1. Set a fundraising goal for your event. Having a financial goal will help your team work together to achieve your target. It will also help maintain focus as the event approaches.
2. Decide on the type of event you would like to organize. Keep in mind any physical or logistical limitations that may exist. Would you like to have a smaller, friends and family Walk, or a larger community event? Remember the "5 W's" – Who, What, Where, When, Why and, of course, How?
3. Create your own Walk web page on the Lupus Canada web site. Having your own web page is an excellent way

# WALK A BLOCK FOR LUPUS

What's new for 2007?

for you, your team members and supporters to track the progress. Visit [http://www.lupuscanada.org/english/involvement/wab\\_2007.html](http://www.lupuscanada.org/english/involvement/wab_2007.html) to see how you can create your Team Walk web site.

4. E-mail or write letters to your friends and family about your event. It is important to let people know about your event and what they can do to support you. The people who are closest to you are a great starting point for support and donations. If you create a web page, be sure to include a link in your correspondence so everyone can visit your web site.

5. Ask everyone you know to support your event. People will not donate to your event if you don't ask! Think about approaching your co-workers, neighbours, or people you know through church or other cultural organizations. There are many ways people can support your event, whether as a participant, financial contributor, prize donor or volunteer. All of these roles are important and will help your event be a success!

6. Approach local businesses for support. Think about all of the places you frequent as a customer. Let them know about your event and ask for a donation or support. This is a great opportunity for your local businesses to get advertising, while also making a charitable donation. Let them know that donations to Lupus Canada are tax deductible. If a financial donation is not possible, perhaps they can contribute water, food or prizes for your event. Ask if you can post a flyer for your event at their location.

7. Approach a corporation to sponsor your event. This is

another great opportunity for businesses to get advertising. Many companies are looking for a different, perhaps less well-known charity they can be associated with. Starting a relationship with a corporation for this year's event could mean continued support for years to come.

8. Contact your local emergency personnel. Police, Ambulance and Fire personnel may like to take part in your event. For example, a booth can be set up to inform people about fire safety, or the importance of learning CPR. Having your local police officers or firefighters will help make the event more open to the community and will help generate public interest.

9. Set up a lupus information booth at your event. This is a great opportunity for you to generate more interest in your event. Many people do not know what lupus is, so having an information booth will help educate participants and community members.

10. Contact your local media about your event. Let your local media know that this is a national event taking place in communities right across Canada. If possible, add your personal story in your contact. The media appreciate human interest stories and this will help them understand why fundraising for Lupus is important to you and your team.

There are more resources available from Lupus Canada to help support you as you plan your Walk. Please contact the Lupus Canada Walk a Block Coordinator at 1-800-661-1468 to get an Event Coordinator Tool Kit.

## Walk A Block for Lupus Provincial Contacts

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

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

In Manitoba contact:  
Lupus Society of Manitoba  
204-942-6825 or  
1-888-942-6825  
[lupus@mts.net](mailto:lupus@mts.net)

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

OR Pat Leece  
Lupus Foundation of Ontario  
905-894-4611 or  
1-800-368-8377  
[lupusont@vaxxine.com](mailto:lupusont@vaxxine.com)

In Quebec contact: Miriam Gaudelli  
514-710-0533 or  
1-866-666-1970  
[lupusquebec@yahoo.ca](mailto:lupusquebec@yahoo.ca)

In New Brunswick contact: Nancy Votour  
506-384-6227 or  
1-877-303-8080  
[lupins@rogers.com](mailto:lupins@rogers.com)

In Nova Scotia contact: Iris Scallen  
902-425-0358 or  
1-800-394-0125  
[lupussocietyyns@ns.sympatico.ca](mailto:lupussocietyyns@ns.sympatico.ca)

In Prince Edward Island contact: Barb Grimster  
902-892-3875  
[bargri@pei.sympatico.ca](mailto:bargri@pei.sympatico.ca)

In Newfoundland contact:  
Lupus Newfoundland and Labrador  
709-368-8130  
[lupusnfld@nl.rogers.com](mailto:lupusnfld@nl.rogers.com)

# WORLD LUPUS DAY

May 10, 2007

Thursday May 10, 2007 marked the 4th annual observance of World Lupus Day. This global undertaking began in May of 2004 when an international steering committee, representing Lupus organizations from 13 different nations, met in Eaton, United Kingdom for the first World Lupus Day. The reason for this international event

being created occurred because efforts to identify a cause and cure for lupus are being coordinated across nations. World Lupus Day provides both a day and a forum for various findings to be shared with the global lupus community. In addition, it was felt by the steering committee, having an international observance of World Lupus Day offers lupus patients the comfort of knowing their condition is recognized and being addressed on a global level.

Lupus Canada, in support of World Lupus Day, created the "Let's Talk About Lupus" campaign. The goal of "Let's Talk About Lupus" is to help promote lupus awareness while providing people with a way to feel like they can actually do something to help someone they know living with lupus. The campaign included 10 suggestions of how a person can help increase awareness of lupus.

In addition to this national campaign, many activities



and events took place right across Canada honouring World Lupus Day.

**Betty Bellamy** has been involved with the Lupus Erythematosus Society of Saskatchewan for a number of years. In 2004 she received an email from a contact at the Lupus Foundation of America telling her about plans for the first

observance of World Lupus Day. Betty, who has lived with lupus for 50 years, "was overcome to think that global awareness of lupus could happen," and knew she wanted to be involved in helping increase lupus awareness. Betty recalled being advised, by Dawn Elliot, that "You are not doing your members justice if you are not creating awareness among the legislature and politicians." Taking this advice to heart, Betty has worked hard to have politicians at all levels of government step up and recognize World Lupus Day. For the 4th year Betty successfully had World Lupus Day proclaimed within her municipality by the M.L.A. for Saskatoon/Silversprings, Mr. Ken Cheveldayoff. Also, Betty was successful in having World Lupus Day brought to the attention of members of the House of Commons by her local Member of Parliament, Lynne Yelich.

**Jennifer Oakes** is a volunteer with Lupus Canada. She lives in Caledon, Ontario and participated in an

# WORLD LUPUS DAY

May 10, 2007

awareness and fundraising campaign within her town for the second year. Jennifer was able to get her local newspaper to run a small story about World Lupus Day. In addition, Jennifer set up an information table at her local grocery store on May 10th. She sold awareness wristbands and angel pins, provided awareness and support information to her community and was even able to register some people for the Walk A Block for Lupus which she is coordinating for October 21st. Jennifer was successful in having her municipality proclaim World Lupus Day by Caledon Mayor Marolyn Morrison. Jennifer was able to raise \$369.76 for Lupus Canada from the generous members of her community.



On May 5, 2007 the **BC Lupus Society** organized a dinner, dance and silent auction in support of World Lupus Day at a Vancouver area restaurant. BC Lupus Society Director, Susan Milliken did a great job coordinating this event! More than 60 participants attended, with over \$3,500 being raised to help fund lupus research. Local area businesses along with members and volunteers of the BC Lupus Society were very generous in donating auction items, and more than 40 items were available for auction. Overall the evening was a huge success, not only because of the amount of money the BC Lupus Society raised, but also because so many people were given the opportunity to learn more about lupus and support those living with lupus. The BC Lupus Society is

looking forward to another successful World Lupus Day event next year!

Josephine Fromm is the President of the **Lupus Society of Nova Scotia**. Josephine organized student walks at two local schools to help increase lupus awareness, while at the same time raising funds for lupus. More than 500 students participated with children from West Highlands Elementary School in Amherst, Nova Scotia walking in the morning and kids from Cumberland North Academy in Brookdale, Nova Scotia walking in the afternoon. Together students from the two schools raised \$381.35 for lupus and enjoyed wonderful weather for the events!

# WORLD LUPUS DAY

May 10, 2007

**Lynn Dickinson** works in downtown Toronto and has a friend who lives with Lupus. Lynn was very involved in the Walk a Block for Lupus in 2006, raising more than \$2,000 and wanted to help continue promoting lupus awareness on World Lupus Day. Lynn decided to organize a bake sale at her work place. She had several co-workers help with the baking and once all the goodies had been sold \$257.90 had been raised. Lynn then donated this money to Lupus Canada.

Pamela Bowes, Director of Support for Lupus Canada is (shown on this page) accepting a cheque in the amount of \$1200.00 from staff at **Father F.X. O'Reilly School** in Tottenham, Ontario. The staff held various fundraising events over the school year and generously donated the funds to Lupus Canada in honour of a

teaching colleague living with lupus and in honour of World Lupus Day.

These are just a few of the amazing stories of people across Canada trying to make a difference for those living with lupus. The number of events that took place this year has increased over 2006 and there are plans to strengthen the campaign for 2008.

Lupus Canada is stronger because of you – **Thank You.**



## Advance Order Form

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

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

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

### Please send me:

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

### Add Shipping and Handling:

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

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

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

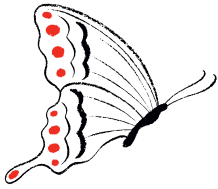
Cardholder \_\_\_\_\_ Number \_\_\_\_\_ Expiry date \_\_\_\_\_

### Ship to:

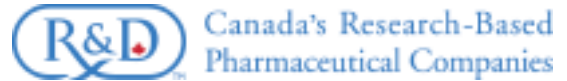
Name: \_\_\_\_\_

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

Telephone Number: \_\_\_\_\_ Email: \_\_\_\_\_



## Thanks to our sponsors who supported the 2007 Symposium:





**Thanks to the Speakers at the “Living Well with Lupus – Spectrum of Treatment Care” Symposium:**



- Wendy Singer, Patient Speaker, Montreal Quebec
- Dr. Joan Wither, Toronto Western Hospital, Toronto, Ontario
- Dr. Matthew Liang, Brigham and Women's Hospital, Boston, Massachusetts
- Dr. Doug Smith, Arthritis Centre, Ottawa Hospital, Ottawa, Ontario
- Dr. Carol Hitchon, University of Manitoba, Winnipeg, Manitoba
- Dr. Christine Peschken, Arthritis Centre, Winnipeg, Manitoba
- Dr. Arthur Bookman, Toronto Western Hospital, Toronto, Ontario
- Dr. Paul Fortin, Toronto Western Hospital, Toronto, Ontario

## Lupus Volunteers Recognized across Canada

At the annual leadership meetings held in Winnipeg in April, Lupus Canada and all of the members organizations across Canada recognized and cele-

brated the outstanding contributions of our volunteers. Volunteers are the heart and soul of the lupus movement across Canada, and give their gift of time working together on our shared vision of “Life without lupus”.

Lupus Canada is stronger because of you – Thank You.

### **BC Lupus Society**

Eileen Fraser  
Rhonda Harborne  
Rena Hummel  
Cathy Imrie  
Sandra Tong

### **Lupus Erythematosus Society of**

#### **Saskatchewan**

Vi Van Allen  
Betty Bellamy  
Bob Bellamy  
Bev Boensch  
Tanya Cockburn  
Betty Cole  
Irene Driedger  
Lloyd Driedger  
Vié Haugerud  
Michelle Heichert  
Graeme Humphries  
Darlia Katelnikoff  
Merle Klein  
Lynda Lightfoot  
Dr. Janet Markland  
Judy Nagus  
Pat Nichols  
Betty Ovans  
Judie Oxtoby  
Debbie Posehn  
Derril Rogerson  
Dr. Alan Rosenberg  
Julianne Weber  
Marianne Weber  
Gloria Wildeman

### **Lupus Society of Manitoba**

Lesley Bray  
Tracy Broughton  
Verona Clark  
Betty Cusitar  
Bill Cusitar  
Debbie Dohan  
Rob Dohan  
Len Funk  
Clint Garner  
Darlene Garner  
Hailey Garner  
Hayden Garner  
Lazer Grant  
Lori Harasym  
Elaine Hutton  
Kirk Kennedy  
Shari Kennedy  
Nadalene Khan  
Sandy Leppky

Dr. Christine Peschken  
Donna Skrynyk  
Sharon Treemer  
Patrick Walker

The Arthritis Society  
Contour Photocopy

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Sharon Coslett  
Frances Gotkin  
Julia Kane  
Laverne Nimigon  
Tina Sarta  
Kevin Stannard  
Yvette Tetrault

**Lupus Canada  
Quebec Division**  
Miriam Gaudelli

**Lupus New Brunswick**  
Catherine Marsh

### **Lupus Society of Nova Scotia**

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June Broyden  
Shannon Brundage  
Lynda Cavanagh  
Brent Cusack  
Jo Fromm  
Laurence Fromm  
Brian Gunn  
Matthew Lepper  
Melanie Lepper  
Margie MacInnis  
Linda MacRae  
Pam and Frank Malone  
Merrie Mills  
Sharon Moody  
Eileen Power  
Iris Scallon  
Tina and Arend Smit  
Megan Trenholm  
Nancy Trenholm  
Dawn and Franck Zwicker

### **Lupus Canada**

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Diana Bozzo  
Diana Bruneau  
Leisa Cadotte  
Kay Cox  
Doug Farrell

Dr. Paul Fortin  
Al & Karen Guest  
Raymond Helkio  
Andrea Horcsak  
Charlene Johnson  
Shari Kennedy  
Jaclyn Law  
Margaret Lover  
Janice Moffat  
Jennifer Oakes  
Lorrie Powless  
Shelagh Purcell  
Bob Robinson  
Bev Ruffo  
Var Shina  
St. Joseph Printing  
Nicole Zahradnik

### **Lupus Canada Board Members Completing Terms**

Veronica Carroll  
Len Funk  
Cathy Jackson  
Nadalene Khan  
Cheryl Magnusson  
Andrea Ou-Hingwan  
Glenn Outhwaite  
Ross Pattee  
Mark Purcell  
Nancy Votour  
Mark Purcell

Thank you to our Member Organizations who acknowledged the importance of volunteer recognition and submitted the names of these individuals

**At Lupus Organizations across Canada, we know that the act of volunteering helps us grow into the people we would like to become. Volunteers play a fundamental role in making a difference to the lupus community. Thank you to all these wonderful volunteers.**

# Ross Pattee

Special Volunteer Recognition – April 2007



Our Special recognition this year honoured Ross Pattee for his outstanding volunteer commitment and dedication. Ross has been involved with the lupus movement for many years. Ross first became involved with

Lupus Canada in 1992 when he became the provincial delegate to the Lupus Canada Board of Directors. Prior to this, Ross was the President of the BC Lupus Society. After serving on the Board for several years, Ross stepped down, but continued to be actively involved with the BCLS. In 1999, Ross accepted the position of Chair of the Lupus Canada Research Committee, and again came onto the Board of Directors. In 2002 Ross accepted the new and challenging opportunity to become the first Chair of the Governance Committee as Lupus Canada and the member organizations moved toward a new organizational structure. At the

April 2007 AGM in Winnipeg, Ross stepped down from the Board, but his dedication, support and wise leadership skills have immensely helped the organization. At the annual volunteer recognition dinner, Len Funk, a fellow Board member and Past President of Lupus Canada shared these words with guests:

“In 2001 both Ross and I were fortunate enough to attend the International Lupus Congress in Barcelona. It was at this setting that the two of us were able to sit down over lunch with the Canadian Doctors, and have a very enlightening discussion about the needs, plan and aspirations of those who treat many of our patients and deliver the majority of Canadian research in lupus. Following that meeting and upon returning to Canada, Ross was able to help lead the Research Committee forward as Lupus Canada became involved, on behalf of the Member Organizations, in funding a portion of the National Coordinator position which helped put CaNIOS on the map. Ross has decided it is time to take a breather, and recharge his own batteries. Ross, your generosity and great sense of humour will always be remembered. Ross, you have made tremendous contributions to our past and our future”.

## Lupus Physician and researcher wins award from McGill University Health Centre

On May 17, 2007, Dr. Christian Pineau from the McGill University Health Centre Department of Medicine received an award for Innovation in Clinical Care or Quality. This award recognizes an individual or team associated with the MUHC Department of Medicine that has implemented a clinical program or innovation that has had a positive impact on patients.

In a letter of nomination from colleagues Dr. Sasha Bernatsky and Dr. Ann Clarke, they said “Dr. Pineau has actively pursued strategies aimed at preventing cardiac disease in the systemic lupus patients that are served by the Montreal General Hospital Lupus Clinic. This has included focusing more detail on potentially reversible risk factors

for cardiac disease, such as hypertension, cholesterol, antiphospholipid antibodies, and homocysteine. To the practice of annual assessments of SLE patients for general health issues, Dr. Pineau advocated for and successfully introduced yearly systematic evaluation of some of these particular cardiac risk factors (e.g. homocysteine). Thus it is clear that, at home and abroad, Dr. Pineau is making a difference for patients with systemic lupus.”

Dr. Pineau was also a presenter at the 5th Annual “Learning to Live Well with Lupus” Patient Symposium in June 2006 with his topic “Osteoporosis and Heart Disease”

Congratulations to Dr. Pineau on this award.

# Research

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

## Maintaining CaNIOS' Strength, Sustainability and Success through SARD Research Alliance

"We can rejoice from the many successes we have experienced again this year", said Paul R. Fortin, the current Chair of CaNIOS. "Yet our measure of success will be if CaNIOS can renew itself." This was the message of renewal and rejuvenation that highlighted this year's 6th CaNIOS Principal Investigator's meeting in April in Winnipeg. Among several issues discussed by lupus researchers and their research assistants and coordinators during the meeting, the realization of the Systemic Autoimmune Rheumatic Disease (SARD) Research Alliance (SRA) was foremost in the future directions of the network. SRA represents a vision that is aimed toward the collaborative partnerships of several systemic rheumatic disease organizations. The basis whether this young yet unfunded alliance becomes successful is also dependent on whether CaNIOS remains strong, sustainable, and successful; and whether its sister founding member, the Canadian Scleroderma Research Group (CSRG) continues its unprecedented funding growth.

Two observers during the Winnipeg meeting on behalf of Lupus Canada, Debbie Dohan and Shari Kennedy, were fortunate to observe this year's interactive discussion and brainstorming among members on key issues such as infrastructure and research funding supports. Both witnessed the important milestones reported for two CaNIOS-led studies: the Genetic and Environmental Factors in SLE (GenES) and 1,000 Canadian Faces of Lupus. Both projects which are funded by the Canadian Institutes of Health Research (CIHR) are up for renewal this year, as did in a challenging way, the Health Improvement & Prevention Program (HIPP) last year. Notably, the Health Improvement and Prevention Program (HIPP) funding continues for 4 more years, and despite a 6-month funding interruption for which Lupus

Canada and its provincial organizations pooled resources to keep the study afloat, HIPP continues recruitment in Toronto and Montreal, with the addition of London as a new site this summer. The renewed HIPP funding will allow CaNIOS to complete this randomized clinical trial and to obtain a definitive answer as to whether the HIPP intervention can improve the quality of life of those with lupus while decreasing their risk of serious complications such as cardiovascular disease or osteoporosis. Wendy Singer, a HIPP graduate, presented to the audience of the Lupus Canada Patient Symposium in Winnipeg a powerful testimonial. She described the empowerment she obtained during her HIPP participation. The knowledge she learned, the emotional and physical strength she gained, and the pro-active attitude empowered upon her by the study, helped her recover in a bout of lupus flare a year earlier.

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*"Yet our measure of success will be if CaNIOS can renew itself."*

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Significantly, a spin off of the HIPP study, the Lupus Health Passport, has been generating interest from lupus patient associations south of the border such as the Lupus Foundation of America and Rheumination, and from pharmaceutical companies who are interested in

# Research

continued

using the passport for baseline studies in their lupus clinical trials. Validation of an American version is thus forthcoming, and a French-Canadian version is currently being produced for use in French-speaking regions of Canada. CaNIOS owns the copyright to the passport and we hope that, as part of CaNIOS intellectual property, the passport will become synonymous to our brand. Simultaneously, discussions on how to transform the paper version into an electronic format have been ongoing for months, albeit sluggish due to lack of funding and sponsor. Three formats are being considered: a web-based portal supported and based on an institution's informatics platform, a web-based format designed to be hosted by a secure site outside of a hospital's informatics system, and an electronic format where patients can download the supporting program from a remote site to their personal computer, fill out the e-passport and/or carry their e-passport on a memory flash drive for update with a nurse practitioner. Whatever format it will be, the e-passport represents a tool aimed at empowering lupus patients with knowledge of their own condition and making them pro-active in up-to-date record keeping of their own personal health information.

Three important discoveries highlight CaNIOS research this year. First, the GenES study focusing on the analysis of autoantibodies from serum samples of parents and siblings of lupus patients, found an increased frequency of anti-nuclear antibodies (ANA) in lupus patients and their family members than expected when compared to population controls. Furthermore, GenES found that family members, as in lupus patients, have a significant decrease in the proportion of natural killer (NKT) cells (a type of white blood cell) which correlates with the presence of a positive ANA. This finding has now been submitted for peer review in a reputable scientific journal. Second, a budding rheumatologist working with the Lupus Nephritis New Emerging Team (LuNNET), Dr Carol Landolt, reported in the recent Canadian Rheumatology Association (CRA) Meeting in Lake Louise, Al-

berta that increase in sustained T cell (a type of antibody-producing white blood cell) activation promote disease activity in lupus. And lastly, data emerging from the 1000 Faces of Lupus Study which were also presented during the CRA meeting showed that aboriginal Canadian lupus patients appear to accumulate the most damage compared to Caucasian Canadian, Asian Canadian, and African Canadian patients. It is postulated that this may be due to socio-demographic and behavioral factors rather than to greater lupus activity or severity. The study suggests that aggressive risk management reduction and education may be of benefit in reducing damage accumulation. All these research findings from CaNIOS studies underscore the importance of the collaboration between researchers and patients in making headway toward a better understanding of their disease. All research achievements mentioned came along with the struggle to maintain CaNIOS infrastructure. More stable infrastructure funds are needed to cover core CaNIOS National Office personnel such as the positions of the National Scientific and Development Coordinator, Administrative Coordinator, CaNIOS Database Manager/Administrator and CaNIOS Laboratory Technician. A solution to this perennial problem was articulated at the Winnipeg meeting by the CaNIOS Chair through his vision of the SRA. It will mean that CaNIOS needs to partner, initiate the creation, and growth of other systemic autoimmune rheumatic disease groups such as Scleroderma, Vasculitis, Sjögren's Disease, and Poly/Dermato-myositis. "By sharing the same infrastructure we can simultaneously advance research in these systemic rheumatic diseases," concluded Dr Fortin. A united, yet independent existence of these disease groups through a SRA virtual centre should not remain a dream for so long. As long as there are movers with great visions like the CaNIOS Chair.



Dr. Paul R. Fortin



Shari Kennedy

## Principal Investigator's Day — A Patient Perspective

As a person living with lupus for the past 20 years, I have been on the receiving end of many conventional treatments and have also been a drug study participant. In this quest for wellness, I have continually sought relief, hoping for a cure to be found. As a patient walking through the doctor's office, I only have one thing in mind. Selfish as it may sound, I am seeking that magical cure for my ailment. I question, why does it take so long to find new drugs and why can't we be closer to finding a cure or cause of lupus? In my doctor's office, I do not question what efforts are being made to understand this baffling disease.

I was recently invited to attend the CaNIOS meeting as a patient representative during the Lupus Canada AGM held in Winnipeg this April, 2007. Canadian Network for Improved Outcomes in SLE (CaNIOS) mission is to improve outcomes for lupus patients through collaborative research. My involvement in the meeting was acknowledged and accepted by the team of researchers. I was tentative to what I was able to contribute to the meeting or the brainstorming sessions. I do feel honoured to witness what is happening behind the scenes in lupus research.

As an observer, I witnessed the committee's dedicated efforts to work tirelessly behind the scenes to make the lives of lupus patients better. I observed efforts to collaborate and form alliances with other research bodies to better coordinate research efforts. I learned of the efforts

to move to new potential studies as well as the ongoing work to optimize current studies, such as the 1000 Faces of Lupus Study. I also learned of the time, money and efforts that the research teams need when completing a study. This is all done while continuing to practice in Rheumatology and respond to patients health concerns. With the strength of this team of doctors and health care professionals, the committee is looking ahead at what needs to be done. With this determination, comes the startling obstacle of supporting, financially, new clinical trials, current research and new emerging studies.

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In the end, I have walked away with a better appreciation of what is happening in lupus research. I have realized that people are taking huge efforts to improve the lives of lupus patients. This understanding has helped in reassuring me that there is a future for positive developments occurring, that will impact the understanding of lupus.

I would like to thank the CaNIOS team for having a patient representative attend this meeting and I have appreciated the knowledge that I have gained from this experience.

Shari has been a lupus volunteer for the past ten years. She began volunteering as a Support Group leader which later led to a term as President of Lupus Manitoba. Shari has participated in various Lupus Canada Volunteer activities. Currently she is involved in the Volunteer Management Committee with Lupus Canada. She was diagnosed with lupus when she was in her early 20's just after graduating from nursing school. She works as a part-time nurse in an outpatient clinic and lives in Winnipeg with her husband and daughter.

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

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