

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

Donate Your Optimum Points to Lupus Ontario!

Shoppers Drug Mart has introduced a new charity initiative that can greatly benefit the Ontario Lupus Association & Lupus Society of Hamilton (the future Lupus Ontario).

You can now donate some or all of your Shoppers Optimum Points to the OLA (we are currently registered under the OLA but will change this once we officially become 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 the OLA/LSH (Lupus Ontario).
- Call 1-800-SHOPPERS and talk to a customer service representative.

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

Join us at the 8th Annual Lupus Golf Classic

Sunday, September 19, 2004
Southbrook Golf & Country Club
Hamilton, Ontario



Tee off times start at 11 a.m.
For registration info and forms,
call (905) 527-2252
or go to www.lupushamilton.com

* Income tax receipts for amount allowed will be issued.

All proceeds to support research, education and community support of those living with lupus.

Green fees: \$110*

Visa and MasterCard accepted

Enjoy the Silent Auction gifts, prizes, putting and other contests - as well as the dinner, cart and golf!

The Ontario Lupus Association

590 Alden Road, Suite 204,
Markham, ON L3R 8N2



The Lupus Society of Hamilton



The Ontario Lupus Association

LUPUS LINK

- O N T A R I O -

Volume 1, Issue 2

Summer 2004

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Thank you for supporting the OLA

OUR MISSION STATEMENT

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

First World Lupus Day Declared

It's official! May 10, 2004, was declared the inaugural World Lupus Day at a press conference held at the 7th International Congress on Systemic Lupus Erythematosus and Related Conditions (and 5th International Patient Congress) in New York City, May 9 to 13.

As media representatives and congress attendees crowded into a conference room at the New York Hilton, various speakers reiterated the urgent need for more lupus research and increased education and awareness. Sandra C. Raymond, president of the Lupus Foundation of America (LFA), and Lupus UK director Brian Hanner, the co-chairs of this worldwide awareness event, recited the World Lupus Day proclamation (read it at www.worldlupusday.org). The proclamation has been signed by governors, mayors and ministers of health from around the globe.

Raymond and Hanner were joined by Mercedes Scelba-Shorte, a new LFA spokesperson and finalist on the hit show "America's Next Top Model." She revealed that she had lupus on the show. Scelba-Shorte talked about the impact the disease has had on her life and career. Actor/model Tomiko Fraser, whose younger sister Shneequa has lupus, delivered another heartfelt speech about her family's experience. Fraser has been an LFA spokesperson since 2000.

The May 10 announcement was the culmination of countless hours of volunteer work. World Lupus Day was a major international effort: the Steering Committee, which included



Actor/model and LFA national spokesperson Tomiko Fraser talks about the impact that lupus has had on her family. Fraser's sister, Shneequa, has a serious case of lupus.

Len Funk, then president of Lupus Canada, represented nine major lupus organizations from several continents. More than 100 lupus patient advocacy groups were also involved in gathering proclamation signatures and raising awareness.

- Jaclyn Law

Photo courtesy of the Lupus Foundation of America.

For more information about the New York conference, please turn to page 6

Dear Friends,



Karen Guest

I trust this finds everyone having a wonderful summer and enjoying whatever the weather might be.

There is light at the end of the tunnel. The OLA (Ontario Lupus Association) and the LSH (Lupus Society of Hamilton) are in the last stages of our merger. The OLA has applied for a name change to "Lupus Ontario," and we hope to have all of the official government documents by Sept. 1. The OLA and the LSH will come together under the new name officially at our

meetings in London on Saturday, Oct. 30, 2004. (Further details to follow by mail by the end of August.) This will be the final AGM for the OLA and the founding meeting for the new "Lupus Ontario." The process has certainly felt extremely long, but has been necessary for everyone involved to understand. Our charitable number will remain the same, with the LSH membership joining under that number. Our databases will be merged and all administrative duties such as the issuing of tax receipts, renewal of memberships, processing of donations and planning of special events will come out of the head office in Markham, Ont.

You have already seen the successful merger with our newsletter "Lupus Link - Ontario" and we are currently in the process of merging our websites. **Please note that www.lupusontario.org is under construction. Go to www.lupushamilton.com for Lupus Ontario info.** We hope this will be an easy transition for everyone!

Please remember that this is your organization and we value your input and support. With the development of this new organization comes changes to our operating structure. You, our members, will need to elect a new Board of Directors, provide input and vote on our new set of by-laws, and give us input toward the direction you want to see our new organization take. We will be mailing out to each of you a package that will include the recommended "Slate" of officers and directors for the new board, a copy of our old by-laws with the new, recommended amendments, Founding/AGM registration form and meeting details and voting procedures for our meetings on Oct. 30.

I am truly excited to see the positive change that are not only happening in our own provincial organization, but also in our national organization, Lupus Canada. Coming together to serve the entire lupus family of Ontario and Canada is a benefit to us all. We truly are seeing improved quality of life for lupus patients and we need to continue to touch the lives of those who are fearful of living with a chronic illness. That is why we must not give up our fight and why we must come together as ONE to support, educate and fund research so that one day, the causes and cure for lupus will be found.

ONE Vision, ONE Image, ONE Message and ultimately ONE CURE!!!

Thank you for your continued support and all the best to each one of you. This is your organization and we, the Board of Directors, are here to support you and to develop the services you need to cope daily with lupus. Please don't hesitate to contact us at any time.

Take care,

Karen Guest,
President, The Ontario Lupus Association



WE NEED YOUR HELP TO RAISE FUNDS

We need your fundraising ideas and assistance. Consider hosting/organizing a fundraising event in your home, your community or participating in one that is already planned. We would love to share with you the current events that are happening throughout the province that could be very easy for you to organize in your community.

For Example; Dart Tournament, Yuk Yuk's comedy club "A Night of Laughs", Local establishment Golf Tournaments, Dinner & Dance, Walk-a-Block, "Be-a-Host" dinner party with your guests making a donation to your charity instead of bringing a hostess gift, afternoon tea party etc.

These are just a few ideas that you can do with our assistance. Every dollar raised allows us to continue to provide services and support to the Lupus communities of Ontario. Please give us a call and let's share our ideas and we can continue to

WORK TOGETHER - TO CONQUER LUPUS

ONTARIO LUPUS ASSOCIATION BOARD OF DIRECTORS

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

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Member Organizations

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Box 88, Royal University Hospital
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Email: bargri@pei.sympatico.ca

PLEASE SUBMIT YOUR IDEAS AND ARTICLES FOR OUR NEXT NEWSLETTER BY SEPTEMBER 30, 2004 TO:

Jaelyn Law

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W: http://www.lupusontario.org

PROVINCIAL BRANCHES, SUPPORT GROUPS AND CONTACTS

Area/Support Type	Contact Person	Contact Information
Toronto & GTA Region		
Toronto West Branch and Support Group Leader	Jacque Tetrault	905 501-7795; wellness_group@hotmail.com
North Toronto Branch and Support Group Leader	Cathy Ferren-Palmer	416 499-1053
North Toronto 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	Anne Wyse	The Arthritis Society 613 723-1083
Belleville Support Contact	Monica Plumpton	613 961-1152; monark@lks.net
Kingston Branch	Irene Smith	613 530-2129
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; rbibeau@cogeco.ca
Northern Ontario Region		
Sault Ste. Marie Branch	Patricia Korbut	705 949-2836; Arthritis & Lupus Info 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	Paula Courtney	877-240-1099
Western Ontario Region		
London & Area Branch	Karen Guest	519 641-3788; olalondon@sympatico.ca
Windsor Branch	Kevin Stannard	519 974-7869; Kevin.stannard@sympatico.ca
Provincial Teen & Young Adult Support Contact		
Ontario Teen & Young Adult Support Contact	Jaelyn Law	jaelynlaw@hotmail.com
Ontario Teen & Young Adult Support Contact	Jodie Nimigon	905 623-1209; 613 236-4655; jrosenimigon@hotmail.com

Dear Members,



Summer greetings to all! I hope this letter finds you well and enjoying the summer weather.

This is my first opportunity to communicate with you since I became President of the LSH in April and I look forward to embarking on this new journey with all of you.

Unfortunately, I have not had a chance to meet all of our members, so let me tell you a little about myself. I have a Master of Science degree in Community Health and Epidemiology and I work as a Health Promotion Specialist. My work includes developing health communication campaigns, healthy public policies and research. In my spare time I enjoy working out and dragon boating, and I'm learning to play baseball.

I was fortunate to attend the Lupus Canada AGM in Saskatoon in June. It was an incredible experience and I

was able to meet the amazing people working together to conquer Lupus in Canada.

Our office has moved and is now being shared between two home offices. Our phone number and e-mail address will stay the same. You can reach us at 905-527-2252 or at info@lupushamilton.com.

We are hosting a golf tournament on September 19, 2004 to raise funds for lupus research and education and support of people living with lupus. The tournament will be held at the Southbrook Golf and Country Club and starts at 11 a.m. (registration begins at 10 a.m.). More information about our tournament is on our website: www.lupushamilton.com. Please contact us if you're interested in participating!

Best wishes for a safe and happy summer!

Shannen Sorgi
President, Lupus Society of Hamilton

**CALL FOR NOMINATIONS
WE NEED YOU!**

The Ontario Lupus Association and the Lupus Society of Hamilton nominating committee is looking for members in good standing to submit nominations for the Board of Directors of the new Lupus Ontario.

All positions on the new board require nominations. The recommendation from the Executive Committees of both the OLA and LSH is to reduce the size of our existing board to a minimum of 3, maximum of 10.

The slate for the new Board will be as follows: President, Vice President, Treasurer, Secretary, Director of Fund Development, Director of Education/Public Awareness, Director of Volunteer Management, Director of Member Services and 2 Directors-at-Large.

(Job descriptions for board positions will be available upon request.)

WE NEED YOU! Come join our team!

Be a part of the exciting changes ahead within your organization and the lupus community of Ontario. Please contact the OLA or LSH for further details and nomination forms.

**THE ONTARIO LUPUS ASSOCIATION
ANNUAL GENERAL MEETING 2004**

We cordially invite you to join us For the final AGM and Luncheon of the Ontario Lupus Association and the founding meeting of the new Lupus Ontario to be held on Saturday, October 30, 2004 at the Four Points Sheraton Hotel & Suites in London, Ontario.

Come be a part of our NEW BEGINNING and the future plans for the lupus movement in Ontario!

We want you to be a part of the exciting changes ahead for the lupus community of Ontario. The Lupus Society of Hamilton and the Ontario Lupus Association are excited about becoming ONE.

We must continue to Work Together – To Conquer Lupus.

A registration package will be forwarded to you by the end of August.

If you have any questions, input or concerns, please contact us at 1-877-240-1099 or by e-mail at lupusontario@bellnet.ca.

LUPUS CANADA AND GOVERNANCE - WHAT IS THIS ALL ABOUT?

By Mae Boa, President, Lupus Canada

The strategic mandate for governance activities over the past two years has been to define roles and responsibilities of the lupus movement in Canada, and to propose a sustainable governance model and organizational structure to support the decision-making model.

The Governance Committee was chaired by the first vice-president and included representation from across the country. This work has been very much grass roots oriented and included workshops at both the regional and national level. Throughout the process, strategic and timely communications to all the member organizations was a priority for the Board of Directors of Lupus Canada.

Outcomes include the Key Roles of the Board of Directors and Chief Operating Officer of Lupus Canada, agreement on our Pan-Canadian Policy areas such as vision, mission, strategic directions and the performance assurance activities to monitor our progress. There is also a better understanding and agreement on the Key Functions of the Lupus Canada National Board/Office and Member Organization Boards and the responsibilities assigned to each in making decisions that affect the family of lupus organizations. By-law changes were required to implement these changes and these have also been approved.

During the annual meeting in June in Saskatoon, the first Board of Directors was approved under the new model. The Board size was reduced from 23 to 13 and the Board was moved to regional representation from member organization delegate representation. The chairs of the Board policy committees were approved: Ross Pattee (B.C.), Governance Committee and André Vincent (Québec), Performance Assurance Committee. All other standing committees of the Board are now operating committees with reporting through to the Chief Operating Officer (Judi Farrell). This will make for timelier decision-making on operational issues without having to wait for Board meetings, which are held three times a year.

The inaugural Presidents Council meeting was held in Saskatoon with Dale Williams (Newfoundland/Labrador) elected as chair and Barbara Grimster (P.E.I.) elected as vice-chair of the Council. Members of this new operational committee consist of all Presidents of our member organizations. In

addition to operating responsibilities, the Council will also provide advice to the Board of Directors and has voting rights at our annual general and special general meetings.

The annual meeting delegates also approved motions that will see Lupus Canada work with member organizations interested in operating as a Division of Lupus Canada. It is anticipated that Divisions will have the same rights and privileges as member organizations in the structure. Many of our member organizations want to pursue discussions around joint membership; that is, if you are a member of a provincial organization, you are also a member of Lupus Canada. Of course, revenue sharing of membership fees still needs to take place. Some member organizations are considering relinquishing their legal status with Lupus Canada assuming more administrative work on their behalf.

These are exciting times for our lupus family of organizations and there is much work to do collaboratively on the whole Division concept, particularly in defining basic membership services and in the development of a Pan-Canadian funding formula. Sharing of membership lists, joint fund raising and revenue sharing are certainly issues of concern to all of us across the country. This work will continue as part of the Governance Committee activities.

Priorities for this year also include development of our Communications Strategy, including audit of current policies and practices that is being funded through our Health Canada grant; update of our Strategic Plan and beginning discussions on the Pan-Canadian Research Strategy.

As the new President of Lupus Canada, I believe we have an excellent team of staff and volunteers in place to advance our strategic priorities! Recognizing that we are still in transition, our new Board will focus on policy work with our operational activities managed by our Chief Operating Office, Judi Farrell. Other good news from Saskatoon is that the Board approved hiring another professional staff with primary responsibilities for fund development. We see this as an investment which has the potential to ensure our future financial stability and organizational growth!

BREAKING NEWS

HUMAN GENOME SCIENCES COMPLETES PATIENT ENROLLMENT IN A PHASE 2 CLINICAL TRIAL OF LYMPHOSTAT-B FOR THE TREATMENT OF SYSTEMIC LUPUS ERYTHEMATOSUS

On July 29, Human Genome Sciences, Inc. announced that it has completed the enrollment, randomization and initiation of dosing of patients in a Phase 2 clinical trial of LymphoStat-B, human monoclonal antibody that recognizes and inhibits B-lymphocyte stimulator (BLyS), for the treatment of systemic lupus erythematosus. BLyS is a naturally occurring protein (discovered by Human Genome Sciences) that is required for the development of B-lymphocyte cells into mature plasma B cells, which produce antibodies, the body's first line of defense against infection. In lupus, rheumatoid arthritis, and certain other autoimmune diseases, elevated levels of BLyS are believed to contribute to the production of autoantibodies – antibodies that attack the body's healthy tissues.

The double-blind, placebo-controlled, multi-center Phase 2 clinical trial is designed to evaluate the safety, optimal dosing, and efficacy of LymphoStat-B. A total of 449 patients with active systemic lupus have been enrolled in the trial and randomized to receive one of three different doses of either LymphoStat-B or placebo over a 52-week

treatment period, in addition to standard-of-care therapy. Efficacy will be measured according to scores on the SELENA SLEDAI (Systemic Lupus Erythematosus Disease Activity Index) and BILAG (British Isles Lupus Activity Group) SLE disease activity scales. Time to first lupus disease flare also will be measured.

LymphoStat-B has received a Fast Track Product designation from the U.S. Food and Drug Administration (FDA) for its potential use in treating lupus. Results from a Phase 1 clinical trial presented at the American College of Rheumatology annual meeting in October 2003 demonstrate that LymphoStat-B is well tolerated and biologically active in patients with systemic lupus erythematosus. The results show no clinically significant differences from placebo in adverse events or laboratory abnormalities. No drug-related serious adverse events were reported. As expected based on preclinical research, the Phase 1 results show that LymphoStat-B significantly reduces the levels of circulating B (CD 20) cells, the precursor cells to those that produce the body's normal and abnormal antibodies. Results of the Phase 2 trial are expected in fall 2005.

For more information on LymphoStat-B, visit www.hgsi.com/products/LSB.html. For more information about the FDA's Fast Track Drug Development Programs, visit www.fda.gov.

CELEBRATE OUR 19TH ANNUAL ITALIAN DINNER AND DANCE, SATURDAY, NOVEMBER 6, 2004 IN WOODBRIDGE, ONTARIO!

Hors d'oeuvres, four-course Italian meal, ice cream & desserts, open bar, coffee/espresso/tea, DJ, door prizes, raffle. Tickets: \$75.00 Adult / \$40.00 Child

In 1983, Maria Colagiovanni's daughter, Connie, was diagnosed with lupus. After contacting the Ontario Lupus Association, the Colagiovanni family saw the need to create lupus awareness, assist those living with lupus and raise funds toward finding the causes and a cure. The OLA suggested a dinner event and The Italian Dinner and Dance was born!

Now in its 19th year, the event attracts more than 250 family members, friends and supporters – it's the social event of the year!

If you enjoy a wonderful atmosphere, fabulous food and being around great people, then plan to attend this event!

For ticket information, please contact the OLA or Maria Colagiovanni at (416) 638-6108.

Your Input, Please!

What would you like to see in the next issue of Lupus Link? This is your newsletter - tell us what you think! E-mail your ideas and comments to our new editor, Jaclyn Law, at jaclynlaw@hotmail.com or write to the Ontario Lupus Association.

CaNIOS: A BIT OF HISTORY, A BIT OF BUSINESS AND A LOT OF RESEARCH

A bit of history

The Canadian Network for Improved Outcome in Systemic Lupus Erythematosus, or CaNIOS, was created in 1995 with the specific goal of running the Study of Methotrexate in Lupus Erythematosus or "SMILE" study funded by The Arthritis Society. Dr. Paul R. Fortin and other physicians interested in research in SLE from across Canada gave birth to CaNIOS and insured its growth through two other peer-review research projects, the Lupus Erythematosus and Psychotherapy (LEAP) trial and the study on lupus and malignancy.

In 2001 at the Barcelona International Lupus Congress, Len Funk, then president of Lupus Canada, initiated the first joint Lupus Canada and CaNIOS "executive" meeting. This informal meeting was the springboard for our now joint Annual General Meeting (AGM). This has resulted in a strong collaboration between our two organizations.

A bit of business

In the autumn of 2001, Lupus Canada helped CaNIOS organize its first formal Investigator AGM. During that meeting, CaNIOS formalized its organization and struck a mission statement and goals.

Mission Statement

CaNIOS is a group of Canadian investigators coming together to improve the outcome of lupus patients across our country through collaborative research.

Goals

1. To facilitate the care of Canadian lupus patients.
2. To improve the outcomes in Canadian lupus patients.
3. To describe the lupus patient population in Canada.
4. To facilitate research in lupus and autoimmune diseases.
5. To provide a large patient base to address clinically important issues through research.
6. To take advantage of the unique features in the Canadian lupus population.
7. To look at sub-groups of the Canadian lupus population: pediatric lupus patients, minorities and men.
8. To contribute to the global and international effort on lupus research through the uniqueness of the Canadian lupus population.
9. To provide mentorship to young investigators and trainees who are interested in developing a career in lupus research.

A lot of research - in Ontario

The national co-ordinating centre for CaNIOS is at the University Health Network in Toronto. Within Ontario there are three fully active centres and two associated centres. Drs. Doug Smith (Ottawa), Janet Pope (London), Paul Fortin, Murray Urowitz and Dafna Gladman (Toronto) all manage active SLE clinics that also collaborate through CaNIOS. All three clinics have benefited from the varied support provided by the OLA. The financial support has aided in the creation of lupus-specific clinic days (or half-days) in these centres, allowing for the exploration of many facets of living with SLE with patients and their families. These clinics also allow the merging of research into a regular medical visit – interested study participants do not to make additional trips to the clinic in order to help with research. This saves time and avoids loss of work hours for patients, and also decreases the repetition of physical exams, bloodwork and even completion of questionnaires.

A lot of research - at Saskatoon and across Canada

The third AGM (and the second one held at the same time as the Lupus Canada AGM) took place June 17 and 18, 2004 in Saskatoon. As with any AGM, CaNIOS reviewed some business/administrative issues. The most exciting portion was the introduction of the computer program for the start of the CaNIOS National Database. The dream is that this database will capture all relevant information gathered at each lupus clinic on those people with lupus willing to have this information used for research. CaNIOS hopes to be able to provide a description of the Canadian lupus population in the near future. The second day of the AGM was devoted to CaNIOS' scientific meeting. What is so amazing about this day are the ideas, advice and constructive criticisms that fly around the room as the doctors help each other refine research ideas and generate new research questions. CaNIOS was lucky to have Dr. Graciela Alarcón attend for an afternoon and provide advice for Dr. Christine Peschken's (Winnipeg) grant, "The 1000 Canadian Faces of Lupus."

Look for more exciting news from CaNIOS in future issues of Lupus Link!

- Diane Ferland

LUPUS CANADA AGM AND SYMPOSIUM IN SASKATOON A SUCCESS

By Mark Purcell

I had the pleasure of attending the Lupus Canada Annual General Meeting and Medical Symposium in Saskatoon from June 16 to 19. The highlight of the conference was the symposium on the Saturday. The first symposium was held three years ago in Niagara Falls. It was such a success that it was decided to hold one each year as the last day of the annual conference. This year, we enjoyed four inspiring and educational medical presentations and an excellent lunchtime speaker, Arlene Jorgenson, an occupational health nurse specialist based in Saskatoon. Her talk kept everyone in stitches. She talked about believing in yourself and pushing your boundaries, but most of all, never forgetting to keep your ability to laugh - not just at yourself and your limitations, but at the world itself, and also to see the humour in everything you do. Here are descriptions of the medical presentations:

ETHNICITY AND LUPUS

This year the theme of the conference was "The Kaleidoscope of Lupus" and the keynote speaker was Dr. Graciela S. Alarcón from the University of Alabama at Birmingham. Dr. Alarcón spoke on the research she has done on the multi-ethnic component of lupus. She has been working on the LUMINA (an acronym for Lupus in Minority populations: Nature vs. nurture) study since 1994 and has followed 550 patients. Her study focused on Hispanic, African-American and Caucasian patients from Alabama, Texas and Puerto Rico. She found that there is a longer delay in diagnosis and treatment for people with lupus in socio-economically disadvantaged areas. These results are not surprising given that few HMOs in the U.S. are willing to pay for the large number of tests that is often required to make a lupus diagnosis. Dr. Alarcón noted the number of lupus cases in these populations is rising.

LUPUS IN CANADA

The second speaker, Dr. Christine Peschken from the Rheumatic Disease Unit at the Health Sciences Centre in Winnipeg, talked about lupus from a Canadian perspective. There are a lot of similarities around the world in terms of symptoms, diagnosis and treatment, but Canada has a unique lupus profile because it has a large number of immigrants, which provides a rich pool for study. Dr. Peschken's studies in Winnipeg have come to a lot of the same conclusions as Dr. Alarcón's in the U.S. The diagnosis rate of lupus is growing

within the immigrant and First Nations populations. It was interesting to note that the number of diagnoses is increasing at a similar rate in both countries as understanding of lupus grows.

LUPUS IN TEENS AND KIDS

The third speaker was Dr. Ross Petty from the Division of Rheumatology at B.C. Children's Hospital in Vancouver. He explained that medications and their side effects as well as lupus itself affect the physical and psychological well-being of youth differently than they do adults. Children and teens don't like to be singled out, so having lupus can be very difficult for them socially. Dr. Petty's clinic works with young lupus patients to help them cope with the many changes caused by lupus, and assists them in making the transition from paediatric to adult medicine.

ENVIRONMENTAL INFLUENCES

The afternoon session was a talk about environmental influences on the development and course of lupus. The speaker, Dr. Glinda Cooper, is from the epidemiology branch of the National Institute of Environmental Health Sciences in Durham, North Carolina. She told us that the environment plays a large part in how lupus progresses and how it is triggered. It may also offer clues as to how we can control lupus. Environmental influences such as the substances we come into contact with naturally, such as dust and chemicals carried on the wind, as well as those we eat and drink and apply to ourselves can affect us in ways we do not realize. Dr. Cooper encouraged us to eat and drink things that will affect us positively and avoid things that affect us negatively, such as smoking. There are a lot of things we cannot control in the environment, but we need to learn what affects us and how we can make things better.

TEAMWORK

The rest of the afternoon was spent in breakout sessions and panel discussions on how we can help Lupus Canada and CaNIOS promote lupus research. There were a lot of good discussions about fund development initiatives, public awareness and advocacy. Everyone had a great time. The Lupus Erythematosus Society of Saskatchewan should be commended for the great job they did of finding excellent speakers for the conference. They've raised the bar for what we need to do for next year in Ottawa!

LUPUS EXPERTS MEET IN THE BIG APPLE

The 5th International Patient Congress on SLE and Related Conditions was held May 9 to 13 in New York City. Chaired by well-known rheumatologist Dr. Robert Lahita, the event attracted physicians, researchers, scientists and lupus patients from around the globe - 1,500 in all registered for the congress, the highest number in its history. (The patient congress was held in conjunction with the 7th International Lupus Congress for professionals.) A press conference was held on May 10 to declare the first-ever World Lupus Day (see our cover story for more details).

Lupus patients and their companions attended presentations by respected lupus experts such as Dr. Joan T. Merrill, Dr. Robert Phillips and Dr. Jill P. Buyon on a wide variety of subjects. We've reported on two of the presentations, "Cancer and SLE" and "Heart Disease and Lupus," in this issue of Lupus Link, and we'll be bringing you more reports from New York in future issues.

At a gala dinner on May 12, Dr. Lahita announced that the next lupus congress will be held in Shanghai, China in 2007, followed by Vancouver in 2009 (start saving for airfare!). So far, the congress has been held every three years. After the 2007 conference, it will be held every two years to keep pace with the large volume of exciting new developments in lupus research.

CANCER AND SLE

Presenters: Sasba K. Bernatsky, MD, MSc, Montreal General Hospital Research Institute, Clinical Epidemiology; Ann E. Clarke, MD, Montreal General Hospital, Immunology/Epidemiology; and Rosalind Ramsey-Goldman, MD, PhD, Northwestern University School of Medicine, Arthritis Ward

Why Study Cancer and Lupus?

A higher risk of cancer has been documented in association with other autoimmune diseases. For example, patients with Sjogrens syndrome are 30 to 40 times more likely to develop lymphoma than the general population, and scleroderma sufferers are 4 to 16 times more likely to develop lung cancer due to scar tissue in the lungs. Drs. Ramsey-Goldman, Bernatsky and Clarke explained that the research into cancer and lupus between 1992 and 2001 was inconclusive - half of the studies showed a greater risk, but not as much as with other autoimmune diseases. They also noted some of these studies' limitations: too few participants, too-short follow-up periods, and incomplete data on cancer occurrence.

Current Research and What It Means

The doctors reported on the major, multicentre, international study (involving 10,000 patients in 23 countries, followed for an average of eight years). The

study began approximately in 2000, but the data collection has been ongoing at various sites since 1958. Researchers on this project included members of the Systemic Lupus International Collaborating Clinics (SLICC) and the Canadian Network for Improved Outcomes in SLE (CaNIOS). The study continues to look at the risk factors for cancer in lupus patients. The research team has already published several articles on this study, with more papers currently under review.

The doctors found that there was a slight increase in risk for hematological cancers - four times greater than the general population, but still less than one percent. They found no higher risk of gynecological cancers. The risk of lung and liver cancers and non-Hodgkin's lymphoma was found to be slightly higher, but still "extremely small." The doctors are currently studying whether or not long-term use of immunosuppressive drugs increases cancer risk in lupus patients.

Implications for Treatment

If further research shows that a higher risk of cancer is not associated with immunosuppressive therapies, this could lead to less resistance from patients towards these drugs, greater use of steroid-sparing medications, and improved disease control.

Taking Action

To decrease cancer risk, the doctors recommended adopting a healthy lifestyle by eating lots of whole grains, vegetables, fruit, beans and other high-fibre foods, maintaining a healthy weight, avoiding excessive alcohol and high-fat foods. They also noted that women taking immunosuppressive drugs should have annual Pap smears as part of their overall wellness strategy.

HEART DISEASE AND LUPUS

Presenters: Dr. Susan Manzi, University of Pittsburgh Medical Center; Graduate School of Public Health, Adult Rheumatology, Internal Medicine; Anne MacKinnon, Toronto Western Hospital, Project Co-ordinator; and Dr. Murray B. Urowitz, MD, FRCPC, Toronto Western Hospital, Director, Centre for Prognosis Studies in the Rheumatic Diseases

Heart disease is a serious complication affecting many people living with lupus. The presenters noted that lupus can target the heart lining (pericardium), the heart muscle, valves and coronary arteries. Atherosclerosis, or hardening of the arteries, is also a major problem. The theory is that when the walls of blood vessels are injured (for example, by lupus, smoking, infections or too-high homocysteine levels), LDL cholesterol (the so-called "bad" cholesterol) is oxidized and trapped inside the vessel walls. Inflammatory cells enter the vessel wall, where macrophages (which are part of the immune system and normally gobble up foreign bodies) ingest

the oxidized LDL to form foam cells. Foam cells, T cells and smooth muscle cells from the artery wall give rise to visible fatty streaks. As more foam cells develop, the fatty streaks become atheromatous plaques and eventually fibrous plaques. If a plaque ruptures, it could lead to obstruction of the arterial lumen and clotting on the rupture may occur to further occlude the lumen, leading to a myocardial infarction.

Clotting Risk in Lupus Patients

Up to 50 percent of lupus patients have antiphospholipid antibody syndrome (APLS), which is associated with higher risk of blood clots, strokes, pulmonary emboli, miscarriage and deep vein thrombosis. It's suspected that the presence of these antibodies may facilitate the uptake of oxidized LDL into

cells in the blood vessel, leading to the creation of foam cells. Patients at risk of blood clots should ask their doctors about preventive therapy such as daily aspirin.

Taking Action

The doctors suggested positive lifestyle changes - specifically, to pay attention to modifiable risk factors (those we have control over) such as smoking, obesity and lack of physical activity. Patients with hypertension (high blood pressure), hyperlipidemia (excessive cholesterol) and diabetes should be monitored closely by their physicians. Steroids should be used judiciously - although they effectively control inflammation, they can also give rise to a number of cardiac risk factors such as obesity, hypertension, hyperlipidemia and diabetes.

- Jaclyn Law

NEW STUDY SUGGESTS PEOPLE WITH LUPUS MAY BENEFIT FROM CHOLESTEROL-LOWERING DIET

A study published in the April 19, 2004 edition of the Journal of Experimental Medicine provides new information about the relationship between autoimmune disease and an excess of cholesterol in the blood. Dr. Kenneth Walsh and his colleagues at Boston University's School of Medicine suggests there is a link between autoimmune diseases, such as lupus, and atherosclerosis, a cardiovascular condition caused by the buildup of fatty deposits in the arteries. The results may provide additional evidence that people with lupus can benefit a diet that lowers cholesterol.

RESEARCH IN MICE

The researchers created a new strain of mice prone to develop atherosclerosis and autoimmune disease by cross breeding mice that are prone to develop each condition. According to the researchers, these cross-bred mice had bigger fatty deposits in their blood vessels than their parent mice, providing further evidence that autoimmune diseases make heart disease worse.

Interestingly, however, Dr. Walsh and his colleagues have found that the reverse also may be true: that atherosclerosis can make autoimmune diseases, such as lupus, worse. The new cross-bred mice had more severe symptoms than their parent mice. According to the researchers, the symptoms were made even worse by feeding the mice a high-fat diet, suggesting that the buildup of fatty deposits contributes to autoimmunity.

THE CHOLESTEROL CONNECTION

Previous studies have suggested that people with lupus can improve their quality of life through a cholesterol-lowering diet. This new study provides additional insight into the reasons that this type of diet may be beneficial to people with lupus and other autoimmune diseases.

Dr. Walsh and colleagues also discovered that the cross-bred mice had high levels of cell debris in their blood. Previously published research has suggested there is an important link between development of autoimmune diseases, such as lupus, and defects in how the human body clears up dead or dying cells within the bloodstream that are constantly being replaced, a process known as apoptosis. It is believed that the body's inability to properly remove cell debris may help to trigger autoimmune disease.

THE FUTURE OF TREATMENT

Systemic lupus erythematosus is associated with accelerated heart disease and strokes, said Dr. Joan Merrill, consulting medical director for the Lupus Foundation of America. The paper by Dr. Walsh and his colleagues may provide a useful method for investigating the connections between how the body regulates cholesterol, the interplay between cholesterol regulation, dead cell clearance and the immune system, and risks for autoimmunity and heart disease. Dr. Merrill added, when the balance between these elements breaks down, this may increase the risk for lupus and/or heart disease. By continuing to dissect these connections on the molecular level we can be optimistic that important new diagnostic tests and treatments might be found.

The study was funded by a MERIT award from the National Institute of Aging, one of the 26 federally-funded institutes and centers that comprise the National Institutes of Health, an agency of the U.S. Department of Health and Human Services.

Adapted from an article that appeared on the website of the Lupus Foundation of America.