

9th International Lupus Congress, Vancouver, BC



Julia Kane, President, Lupus Ontario, and Dr. Zahi Touma with Poster presentation and Lupus Ontario Board Member Delegates, Heidi Nielsen and Anne Matheson with Julia and Dr. Touma. (Geoff Carr Fellow 2010) at Awards Reception

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www.lupusontario.org

Highlights from other areas of lupus research presented at the International Lupus Congress include:

(Excerpt from *Lupus Foundation of America, Update, June 2010*)

Clinical Trial Design: Due to the heterogeneity and complexity of lupus, clinical trial design has been one of the major challenges in the development of new therapies for lupus. Some lessons learned include: the length of the trial must be considered, as some drugs may require up to five years to demonstrate efficacy; the use of cytoxin created a standard of care that is hard to surpass; the speed of drug effectiveness needs to be compared; and the trial needs to distinguish whether it is targeting mild or severe disease. Further studies are also needed on clinical trial design.

Genetics: Lupus is a genetically complex disease, which means that multiple genes as well as non-genetic factors contribute to a person's risk for the disease. Recently, more than 20 genes have been identified that influence a person's risk for lupus. Further research will provide targets for the development of new therapies. Eventually, genes may also be able to help predict whether a person might develop lupus later in life.

Quality of Life: The impact of lupus on a person's quality of life and how a physician can help a patient manage their disease and maintain a quality of life has been poorly understood and under-researched. However, researchers are beginning to look at how depression, stress, and body image all affect health outcomes and a person's quality of life. The goal of this line of study is to develop a tool that will measure a person's quality of life, and to develop targeted interventions and strategies to assist patients in managing their lupus and improving their quality of life.

Continued on Page 8

Lupus Ontario strives for **EXCELLENCE!**



An Important Message to Our Supporters



Lupus Ontario places a high value on our relationship with you, our donors. Without your support we would not be able to achieve our mission to help those living with lupus live longer and better by raising funds that deliver vital support, education, awareness and research. We thank you for your commitment to us.

We believe that transparency and accountability are essential to our success. With this in mind, we have recently joined Imagine Canada's Ethical Code Program.

The Ethical Fundraising and Financial Accountability Code lays out a set of standards for charitable organizations to manage and report their financial affairs responsibly. By adhering to these standards, we are complying with generally accepted practices for soliciting and managing donor dollars. This is important because you, our supporters, are entitled to transparency and the greatest impact possible for your investment in us.

If you have any questions about our adherence to the Ethical Code, please feel free to contact 1-877-240-1099 or visit www.lupusontario.org to request/download our financial statements. You can also download the Ethical Code itself by going to www.imaginecanada.ca.

A role model in **her community**



Lupus advocate Paula Courtney with hundreds of the wine and beer bottles. she is collecting in Thunder Bay to help raise funds for lupus research.

Paula Courtney's passion to find a cure goes beyond finding a cure for herself. Paula was diagnosed with lupus at the age of 28 and given 10 years to live. While lupus isn't always fatal, she says, it's debilitating and painful.

Paula considers every day a blessing and feels that she is living on borrowed time. Thinking of what it would be like as a young child to have lupus makes her cringe. This is where she pulls her strength and determination from, and she is determined!

Her goal is to raise \$25,000 in support of the Lupus Ontario Fellowship for research at SickKids.

By Paula's calculations if every person in Thunder Bay donates 25 cents, they would raise the money. This set the Bottle Drive in motion.

A single wine bottle gets 20 cents back at The Beer Store and if you don't have bottles, a 25-cent donation is welcome.

"The point I'm trying to make is it's such a small donation and it's a win-win-win," Courtney said. "People think they've donated enough to other charities, but who doesn't have a quarter lying around the house?"

The Bottle Drive was held the weekend of July 17th and 18th. Paula accepted all beer, liquor and wine bottles as well as beer cans. She even went to the local restaurants in Thunder Bay and made arrangements to pick up their empty bottles for donation.

Prior arrangements were made with The Beer Store to pick up whatever bottle and cans were collected by the end of the weekend. By Sunday Paula's garage was full.

Thunder Bay has proved that they are the City with a heart and Paula has shown that with determination and a positive spirit come great reward!

For more information contact Lupus Ontario

BENLYSTA Update

HGS, GSK announce full presentation of BLISS-76 Phase 3 BENLYSTA trial results for SLE at EULAR 2010

17, June 2010

Human Genome Sciences, Inc. (Nasdaq: HGS) and GlaxoSmithKline PLC (GSK) today announced the full presentation of results from BLISS-76, one of two pivotal Phase 3 trials of BENLYSTA® (belimumab) in seropositive patients with systemic lupus erythematosus (SLE). The results will be presented today in Rome at the 2010 Congress of the European League Against Rheumatism (EULAR).

"The evidence of durability of belimumab's clinical effect over the course of five years in a long-term Phase 2 continuation study, together with the favorable safety profile observed in the study, suggests that belimumab may have potential for chronic use in the treatment of patients with seropositive SLE"

"The BLISS-76 Phase 3 results presented at EULAR extend the findings of previous studies and reinforce our belief that belimumab, assuming regulatory approval, could deliver a significant therapeutic option for seropositive patients with systemic lupus," said David C. Stump, M.D., Executive Vice President, Research and Development, HGS. "In both of its pivotal Phase 3 trials in these patients, belimumab 10 mg/kg met its primary endpoint. The efficacy of treatment with belimumab plus standard of care compared with placebo plus standard of care was superior in both studies, with overall adverse event rates for belimumab comparable to placebo."

Carlo Russo, M.D., Senior Vice President, Biopharm Development, GSK, said, "Belimumab is the first medicine developed specifically for lupus that has reached this late stage of clinical development with positive results. The BLISS-76 results presented at EULAR, taken together with the results of BLISS-52, reinforce our belief that belimumab may play an important role for patients living with lupus"

Belimumab is an investigational drug and the first in a new class of drugs called BLYS-specific inhibitors. It is being developed by HGS and GSK under a co-development and commercialization agreement entered into in 2006. GSK submitted a Marketing Authorization Application to the European Medicines Agency (EMA) on June 4, 2010, seeking approval to market belimumab in Europe for treatment of autoantibody-positive patients with SLE. On June 10, 2010, HGS announced submission of a Biologics License Application (BLA) to the U.S. Food and Drug Administration seeking approval to market belimumab in the United States. No new drug for lupus has been approved by regulatory authorities in more than 50 years.

SOURCE: Human Genome Sciences, Inc. and GlaxoSmithKline PLC

The next generation of fundraisers

Logan Dickenson is an outstanding example of how valuable our youth truly are. Motivated by his Aunt's diagnosis, Logan has participated in Walk a Block for lupus for the last several years. By the end of Grade 3 Logan has raised over \$3,000 for the National Walk a Block campaign

Through bake sales, garage sales, and the support of those in his community Logan has shown that hard work and devotion go a long way towards one day finding a cure for lupus.

Logan represents the next generation of fundraisers, whose determination and enthusiasm will hopefully inspire all of us to make a difference in the lives of those living with lupus.

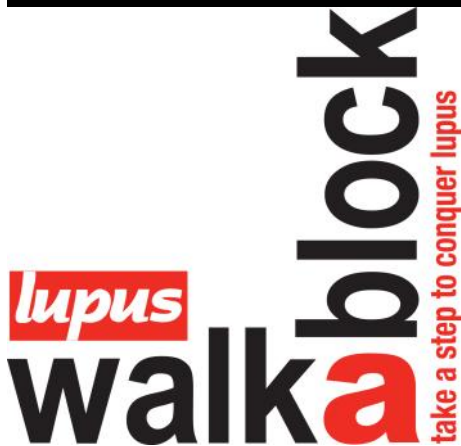
For more information on how you too can be involved please visit:

www.lupusontario.org



Logan Dickenson receives WAB certificate from Nicole Wright, Provincial Walk Coordinator.

Raising funds and awareness **TOGETHER!**



Thank You!

Over **2800 participants** in more than **30 communities** across Ontario raised more than **\$190,000**.

Your support and participation will continue to fund research and help those living with lupus in your community.

We could not do this without your generosity.

Top 5 Fundraising Participants

1. **\$20,548** Lisa O’Kane
2. **\$7,070** Tom Koor
3. **\$6,211** Katherine Aristone
4. **\$5,685** Vince Blosser/Nicole Hartshorne
5. **\$3,785** Emily Leung

Top 5 Fundraising Teams

1. **\$29,463** Lisa’s Loopy Lot
2. **\$14,407** Jennifer’s Journey
3. **\$8,547** President’s Walk
4. **\$6,874** Caledon Walk Team
5. **\$6,210** Memories of Georgia Verra

Fundraising Totals by Walk Location:

\$685 Ajax	\$735 Mississauga Private
\$820 Aurora	\$730 Mississauga Sts Peter & Paul
\$7,063 Barrie	\$45,469 Ottawa
\$6,874 Bolton	\$243 Petawawa
\$6,021 Bradford	\$1,406 Prescott
\$15,328 Brampton	\$3,054 Sault Ste Marie
\$751 Chesley	\$1,156 Scarborough
\$2,552 Clifford	\$2,976 Simcoe
\$2,190 Dryden	\$3,035 Sudbury
\$555 Elora	\$1,674 Sundridge
\$647 Georgetown	\$19,596 Thornhill
\$1,350 Guelph	\$3,301 Thunder Bay
\$15,854 Hamilton	\$1,990 Toronto CaNIOS
\$8,506 London CaNIOS	\$14,607 Toronto Leaside
\$2,895 London	\$9,356 Toronto Queens Park
\$3,695 Lupus Ontario Virtual Walk	\$302 Wallaceburg
\$2,430 Mississauga J.C. Saddington Park	\$4,014 Waterloo

Please note that the totals are not final figures.

1st Annual Ottawa Lupus Gala in Support of Walk a Block 2010



Organizing Committee Ottawa Lupus Gala 2010
Stephen O'Kane, Lisa O'Kane, Petrica Whiting, Jason Whiting,
Andrea Cochran and Charlie Cochran



"A night of fun and fabulous prizes, to raise money and shine a spotlight on Lupus, which has affected someone you know and love" was the promise of this year's gala. And it delivered.

The 1st Annual Ottawa Lupus gala was an overwhelming success. The gala was held on Saturday May 15th at the Chateau Laurier in Ottawa as part of the weekend's Lupus events. The 150 guests were treated to an evening of elegance, fabulous prizes, amazing food and lots of laughter.

Well known author and feature speaker Sara Gorman from Indiana, treated guests to blurbs from her book - Despite Lupus. Live and silent auction items raised close to \$15,000 with top prizes of a trip to Costa Rica and a suite at an Ottawa Senators game.

Lisa O'Kane

For pictures and information on the Ottawa Lupus Gala please visit

www.ottawalupusgala.org



Guest Speaker
Lupus author Sara Gorman



Ballroom at the Chateau Laurier



Faces of Lupus celeb!



Live and silent auction raised close to \$15,000



Table setting at the Chateau Laurier

Strength in numbers!



Barrie Heritage Park Walk



Barrie Family Walk



Bolton Walk



Bradford Lions Park Walk



Brampton Gage Park Walk



Chesley Walk



Clifford Walk



Elora Walk



Georgetown Walk



Guelph Walk



Hamilton Bayfront Park Walk



Kitchener/Waterloo Walk



Leaside (Toronto) Walk



London Springbank Park



Mississauga Private Walk



Prescott Walk



Queens Park Walk



Sault Ste Marie Walk



Scarborough Walk



Simcoe Walk



Sudbury Walk



Sundridge Walk



Thornhill Walk



Toronto CaNIOS Walk

Keep the momentum going!

For more information on how you can be involved in Walk a Block 2011

Contact Nicole Wright, Provincial Walk a Block Coordinator

at walkablock@lupusontario.org or 1-877-240-1099

Walk a Block 2010 - **Parliament Hill, Ottawa**



Ottawa Walkers stand at Parliament Hill for a group photograph



Lisa O'Kane giving the opening ceremonies speech

This year's event was incredibly successful, showcasing Lupus and joining together those affected by the illness and giving them the opportunity to share stories of strength and courage.

Led by bagpipes and armed with red pom poms, feather boas, horns and noise makers, our walkers made their way through Ottawa's downtown core turning heads and making noise for Lupus on May 15th. Close to 300 participants took part in the day's events which raised just over \$30,000 in pledges and donations.

The beautiful weather brought a great crowd who took part in the ceremonies which saw the Lupus Ontario flag raised at Ottawa City Hall where the Mayor proclaimed May 15th, Lupus Day in Ottawa. The group marched to Parliament Hill for photos and back to City Hall for a BBQ, children's games, clowns, music and a day of fun.

Lisa O'Kane

Lupus Ontario Sponsor

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Let's talk SUPPORT!



For many years some people felt going to a support group meant being put on the spot, or having all the attention placed on them as the new person. Things have changed and support groups have become more relaxed. It's a place where people with lupus can go to have the opportunity to listen, learn, be with others and share when they are ready.

Support groups are not only a place to talk, but also a resource tool. Sitting with a group of people who understand related conditions can make a world of difference in one's life.

Support groups are very important for people living with lupus. They provide emotional support for those facing similar circumstances or tough situations. In our lives some of us may suffer emotional difficulties and/or fears that we may find difficult to talk to others about. It can sometimes be hard to confide in those closest to us for fear of being judged, not being believed or understood, or we do not want to worry other people.

Some may feel that they simply do not have anyone to turn to for the support they need. Lupus support groups allow those living with this disease a chance to share information and openly discuss their problems without judgment, to process their feelings and to hear others talk about their concerns and also their successes. Participation helps those living with lupus deal more effectively with the ups and downs of the disease. The main focus of a support group is to help the person understand that they are not alone.

Lupus Ontario has 25 volunteer support centres around the province. To find the centre that best fits your interest, location and schedule or to find out more information on how to start a support group please contact Juanita Butler, SSW at 1-877-240-1099 or info@lupusontario.org.

THERE IS ALWAYS HOPE

A diagnosis of lupus should not define who you are, your limitations, or what you can accomplish. I have received great inspiration over the last several months from people, young and older, whose lupus journey seems to be all uphill. They still smile and encourage everyone around them, including me, to have hope and keep going with joy in my heart.

One step at a time, moving forward. In this issue you will see that Lupus Ontario has qualified for designation of the Imagine Canada Ethical Code Program. We continue to evolve with transparency and best practices in our organization as we build our programs while reducing costs.

These things give me hope for our future. We have benefited from the donation of time, energy and expertise of some wonderful volunteers who are forming new support groups in Toronto and London and also with new directions in governance and revised policies. The Lupus Walk a Block was successful as you will see and we are already working on ways to make it a more successful fundraiser in 2011.

There are new therapies on the way and there are some surprising results from other considerations.

- The clinical trials of several new drugs are proving effective for a larger % of people.
- Vitamin D is usually deficient in Lupus patients and supplements are recommended. (at least 2000 IU)
- Dr. Jan Dutz, Connective Tissue Disease Clinic, Vancouver, suggested at Lupus 2010 Café Scientifique, that the cream **Lac-Hydrin**, (Bristol Meyers Squibb Novartis) is an excellent cream for improving the texture and tone of skin affected by lupus. (I have been using it for over ten years.) It is available from Drug Stores and Costco, but may be behind the counter, so you need to ask for it.

JULIA KANE, PRESIDENT, LUPUS ONTARIO

Highlights Continued from Page 1

Adult Stem Cell Transplantation: Adult stem cell transplantation has shown promise in research as a potential treatment for lupus, particularly for those with severe disease and major organ involvement. Data from a pilot study indicates that certain patients have achieved a sustained remission without any drugs for up to five years.

Lupus-Related Cardiovascular Disease: Individuals with lupus have significantly higher rates of cardiovascular disease. Ongoing studies are examining the role of Type 1 interferon in causing cardiovascular disease in individuals with lupus. Type 1 interferon is a protein that binds to certain cell receptors. Excerpt from LFA Update

25th Silver Anniversary

Italian Dinner Dance and Silent Auction

SATURDAY NOVEMBER 6, 2010

Riviera Renaissance Parque
2800 Highway #7 West
Concord, Ontario



*Antipasto Bar 6:00-7:00pm
Dinner to Follow*



Special Performance by
CLUB VIVA DANCE

PROCEEDS TO LUPUS ONTARIO
(Tax Receipt \$25.00 per ticket)
\$85.00 per Person

For Tickets and Information
Please call Juanita at 905-415-1099
or Maria at 416-638-6108

WALK FOR LUPUS, FUN FAIR & SILENT AUCTION

DURHAM LUPUS SUPPORT GROUP

LUPUS ONTARIO DURHAM BRANCH

2nd SATURDAY OF EVERY SEPTEMBER

SATURDAY SEPTEMBER 11th, 2010

EVENT TIME: 10AM-2PM

EVENT LOCATION: ROTARY SUNRISE PARK, WHITBY
LAKE SIDE

EVENT ADDRESS: 269 WATER STREET, WHITBY

CONTACT: SHANNON CRAWFORD

TELEPHONE: 905-697-2941

EMAIL: durhamwalkforlupus@rogers.com



**“Some people give time, some money, some their skills and connections, some literally give their life’s blood.
But everyone has something to give.”**

Barbara Bush



Volunteers are in high demand and are valued and respected. There are many ways that you can help. We currently have a need for volunteer committee members in several walk locations for Walk a Block 2011 and for facilitators for the Lupus Support Groups in select areas.

Enquiries about volunteering on the Board of Directors or event committees are always welcome and we can often use help in the office at Lupus Ontario. Please contact Lupus Ontario to offer your time and talent. Together we will make a difference in the lives of those living with lupus. Please work with us to help find a cure.

Jump start 2011....

Become a Lupus Ontario Member Today

There are many benefits to membership with Lupus Ontario

- You will receive a complimentary booklet titled “Living Well with Lupus; Facts”
- You will receive four newsletters a year with up to date information from current research as well as upcoming lupus activities
- You will be part of a vibrant organization that is making a difference in the lives of people living with lupus

New/Renewal Membership Fee: \$25.00

(Membership Year January 1—December 31)

If you wish to pay by credit card, please call 1-877-240-1099 or simply download our

Membership Brochure

from the website and mail it to the Lupus Ontario office.

Donate your Shoppers Optimum Points

Shoppers Drug Mart offers a charity initiative that can greatly benefit Lupus Ontario.

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

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

Every little bit helps!

Lupus Ontario recognizes that our fundraising efforts are built on the strong dedicated support of our many donors and volunteers who keep lupus at the forefront of their minds. We are passionately committed to helping those with lupus live longer and better by raising funds that deliver vital support, education, awareness and research.

Lupus Ontario is asking you to continue to help and.....FUNDRAISE TODAY!!!!

Just a few ideas:

- Bake Sale/Garage Sale
- Dinner Party
- Bike Run
- Penny Drive
- Lemonade Stand
- Wedding Bombonieres
- Golf/Ball Tournament
- Anniversary/Birthday Party
- Donation Coin Boxes in your community

Remember no event is too small. It can be a fun, easy and quick way to generate FUNDS in a single day. The sky’s the limit. Please promote Lupus Ontario as the #1 recipient charity throughout your community.

Please contact Lupus Ontario at 1-877-240-1099 or email us at info@lupusontario.org to notify us of an event in support of a great cause.

Lupus Ontario's Board of Directors

Julia Kane, President
Tom Koor, Vice President
Emily Leung, Treasurer
Gloria Checkley, Board Secretary
Tina Sarta, Director of Fund Development

Ruth Tarvudd, Director of Volunteer Management
Heidi Nielsen, Director of Public Awareness
Laverne Nimigon, Director of Member Services
Heather Knoll, Director at Large
Anne Matheson, Director of Communications

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Provincial Branches

Toronto & GTA Region

Toronto West Branch & Support Group
Toronto North Branch & Support Group
Toronto North Support Group
Toronto South Support Group
Toronto Beaches Support Group
Durham Region Support Group
Markham Support Group

Eastern Ontario Region

Ottawa Branch
Lindsay Support Group

Central Ontario Region

Barrie and Area Support Group
Collingwood Support Group

Northern Ontario Region

Sault Ste Marie Support Group
Sudbury Branch & Support Group
Thunder Bay Branch & Support Group
Dryden Information Group

Western Ontario Region

London Support Group
Windsor Support
Bolton Support Group
Brantford Support
Kitchener/Waterloo Support Group
Guelph Support Group
Ridgetown Support/Chatham

South Central Region

Hamilton Branch & Support Group

Ontario Teen & Young Adult Support

Please contact Lupus Ontario for information



Lupus Canada

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Member Organizations

BC Lupus Society

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Email: info@bclupus.org

LE Society of Saskatchewan

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103 Hospital Dr.,
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Toll Free: 1-877-566-6123
Email: less@sasklupus.com

Lupus Society of Manitoba

105-386 Broadway Ave.,
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Fax: 204-942-4894
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Lupus Foundation of Ontario

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Fax: 905-894-4616
Email: lupusont@vaxxine.com

Lupus Ontario

(see contact information at left)

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c/o Nancy Votour, 23-13 Ivan Ct.,
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Email: lupins@rogers.com

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Fax: 902-798-0772
Email: lupussocietyns@ns.sympatico.ca

ACT/UCT 2010

Flea Markets

In Support of Lupus Ontario

Where:

441 Gibb Street, Oshawa,

In the Canadian Tire parking lot

Time:

8:30 a.m. to 4:30 p.m.

Monday, September 6th

Monday, October 11th

Lupus Ontario event listings for Summer 2010 to January 2011

- Month of July 2010** Bottle Drive in Thunder Bay
August 7, 2010 Niagara Fallsview Casino Bus Trip
September 11, 2010 Durham Walk for Lupus, Fun Fair & Silent Auction
September 12, 2010 Chippin In For Lupus Golf Tournament in Brockville

October is Lupus Awareness Month!

- November 6, 2010** 25th Anniversary Italian Dinner at the Riviera Parque in Vaughan
January 29, 2011 Dance for the Cure at the Terrace Banquet Centre in Vaughan
Weekend of April 1, 2011 Lupus Ontario AGM, Symposium
Weekend of May 14 & 15 2011 Walk a Block Weekend

New Support Group in Downtown Toronto

Initial meeting :September 13th, Toronto Western Hospital Lupus Clinic, 7PM

Guest Speaker : Dr. Murray Urowitz, A LUPUS UPDATE

RSVP to Rowena Rodriguez, e-mail rodriguez.rowena@gmail.com

or call Juanita Butler at Lupus Ontario, 905-415-1099



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Our Mission:

Lupus Ontario is a team of caring and enthusiastic volunteers and staff who are passionately committed to helping those with lupus live longer and better by raising funds that deliver vital support, education, awareness and research.

RETURN UNDELIVERABLE CANADIAN ADDRESSES TO:

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