

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

Donate Your Optimum Points to Lupus Ontario!

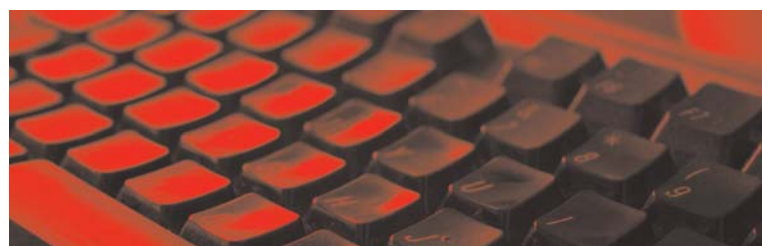
Shoppers Drug Mart offers a charity initiative that can greatly benefit Lupus Ontario.

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 e-mail will be sent to you as well as to Lupus Ontario.
- Call 1-800-SHOPPERS and talk to a customer service representative.

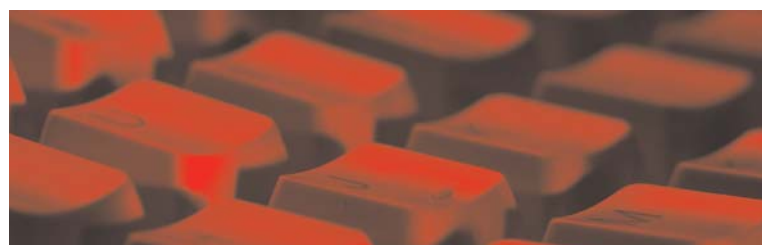
By donating your Points, you can help us both save and raise money!

Lupus Ontario thanks the many members who have donated their Optimum Points. Due to privacy laws, Shoppers Drug Mart cannot share the names of the donors with us, so we are unable to thank you personally. Thank you for your generosity!



WATCH

for Lupus Ontario's New, Updated Website, Coming Soon!
www.lupusontario.org



LUPUS LINK

- O N T A R I O -

Volume 5, Issue 5

Fall 2008

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Thank you for supporting
Lupus Ontario

OUR MISSION STATEMENT

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

LUPUS ONTARIO WELCOMES FRED CHORLEY AS EXECUTIVE DIRECTOR



President's Message

By Julia Kane



Julia Kane

As part of our strategic plan, we had decided to strengthen our organization by adding an Executive Director. Lupus Ontario is very fortunate to have found the ideal candidate. I would like to introduce and welcome Fred Chorley as the new Executive Director of Lupus Ontario. Fred comes to us with the expertise and experience to lead us forward and boost our momentum. He has past executive director experience and was highly recommended. Please join me in welcoming him to our lupus community.

It has been a busy summer as we continued to organize ourselves in the new office in Markham. The Bocce Tournament was a super day. The Irish Connection Golf Tournament in London on August 20th was a great success thanks to the dedicated efforts of Damian and Anne Byrne and their committee. Special thanks to all the volunteers and supporters who gave so generously. The silent and live auction items were spectacular.

We have a close-to-final fundraising total for the May Walk-a-Block for Ontario: \$86,000. This is outstanding considering the date change put us only seven months away from the previous walk, which raised \$265,000. That gives Ontario a one-year

total of \$350,000, so we have set our goal for May 2009 at \$400,000!!! With everyone's help, we can do it. See Juanita's report inside.

The Support Group Meeting in the office has been a success with Juanita's care and guidance. We always welcome new members. We are still hoping to start a downtown Toronto Support Group. For more information, please contact Juanita in the office. Of special note is the fact that the groundwork is being laid in London, Ontario, to start a new group with the assistance of Sabrina Pascoa. If you are in the area and would like to be involved, call us toll-free at 1-877-240-1099 and we will try to organize an initial meeting.

This newsletter may be too late to invite you to the Durham walk, but I have never seen a more dedicated volunteer than Shannon Crawford. She raises public awareness about lupus to a new level with every endeavour. Congratulations and thank you, from all of us living with lupus.

REMEMBER,
OCTOBER
IS LUPUS
AWARENESS
MONTH!

BE AN ADVOCATE.



UPCOMING EVENTS

OCTOBER

World Arthritis Day

Sunday, October 12
This year's theme is "Think Positive." For details, visit www.worldarthritisday.org.

ACT/UCT Flea Market

Monday, October 13, 8 a.m. to 5 p.m.,
441 Gibb St., Oshawa (Canadian Tire lot)
Scoop up a bargain at this fundraiser!

Then and Now: 60 Years of Arthritis Research

Thursday, October 16, Toronto Marriott Downtown,
525 Bay St., 7-9 p.m.
This free educational forum is brought to you by
The Arthritis Society and the Canadian Arthritis
Network. To register for the October forum,
call 1-800-344-6926.

NOVEMBER

Thunder Bay Lupus Symposium

Saturday, November 1
For information, please call Paula Courtney at
807-626-9089.

Italian Dinner Dance 2008

Saturday, November 8, at the Riviera Parque in Concord
This event features a special dance performance
("Art of Argentine Tango"), an antipasto bar, open bar,
prize tables, raffle and silent auction. Tickets: \$85.
For details, call Lupus Ontario at 905-415-1099.

JANUARY 2009

Dance for the Cure

Saturday, January 24, The Terrace Banquet Centre,
Vaughan
Don't miss the glitz and glam of the 14th annual gala!
This year's spectacular theme is "Viva Las Vegas."
For more details, please see page 9 or visit
www.dancefortheure.ca.

MAY 2009

Walk a Block for Lupus

Get ready for our biggest fundraiser of the year! For
more information, turn to page 7.

Lupus Day Program

May 11-22, St. Joseph's Health Care, London, Ont.
This is a two-week, multidisciplinary group for people
with lupus. A preliminary assessment appointment and
physician referral are required. For details, contact
Vicky Bossenberry, 519-646-6000 ext. 66340
or vicky.bossenberry@sjhc.london.on.ca.

BRANCH NEWS

DURHAM REGION

On Saturday, July 12, The Durham Lupus Support Group
held a **Lupus Charity Garage Sale** in the parking lot at
St. Elizabeth School in Bowmanville from 8 a.m. to 1
p.m. I am very happy to announce that we raised \$1,578
toward our Walk for Lupus! A big thank you to all our
donors and a HUGE thank you to all my volunteers who
helped with our sale. This fundraiser would not have
been possible if it wasn't for all their dedication and
hard work. Please put your hands together for: *Andrea &
Brian Flury, Sylvia Szikszay, Melissa & Gary Munn,
Joanne & Laverne Nimigon, Nancy, Jen & Eugene Huska,
Judith Hickey, and Ken, Joan & Steven Crawford.*
We also hosted our **2nd Annual Walk for Lupus, Fun
Fair & Silent Auction** at Lakeview Park in Oshawa on
Sept. 13. We are thrilled to announce that we made
approximately \$20,000 for lupus. Our top individual
fundraiser was Jaclyn Smith, and our top fundraising
team was the Thornes&Peaches. *(continued on page 5)*



Lupus Ontario

2900 John Street, Suite 301
Markham, ON L3R 5G3
Tel: 905-415-1099
Fax: 905-415-9874
Toll Free: 1-877-240-1099
E-mail: info@lupusontario.org
Website: www.lupusontario.org

LUPUS ONTARIO BOARD OF DIRECTORS

Julia Kane, President (EC)
Tina Sarta, Vice-President (EC)
Emily Leung, Treasurer (EC)
Sharon Coslett, Board Secretary (EC)
James Christopher, Director of Fund Development
Gloria Checkley, Director of Volunteer Management
Tiziana Tolfo, Director of Public Awareness
Laverne Nimigon, Director of Member Services
Kevin Stannard, Director at Large
Anne Matheson, Director of Communications

PROVINCIAL BRANCHES

Toronto & GTA Region

Toronto West Branch and Support Group
Toronto North Branch and Support Group
Toronto North Support
Durham Region Support Group
Markham Support

Eastern Ontario Region

Ottawa Branch
Lindsay Support Group
Peterborough Support

Central Ontario Region

Barrie and Area Support Group
Collingwood Support Group

Northern Ontario Region

Sudbury Branch and Support Group
Thunder Bay Branch and Support Group
Dryden Information Group

Western Ontario Region

London
Windsor Branch
Bolton Branch
Brantford Branch
Kitchener/Waterloo Branch

South Central Region

Hamilton Branch

Ontario Teen & Young Adult Support

Please contact office for information.

LUPUS CANADA

590 Alden Road, Suite 211
Markham ON L3R 8N2
Toll Free (in Canada): 1-800-661-1468
Phone: 905-513-0004
Fax: 905-513-9516
Email: lupuscanada@bellnet.ca
website: www.lupuscanada.org

MEMBER ORGANIZATIONS

BC Lupus Society

200-1645 West 7th Avenue
Vancouver, BC V6J 1S4
Tel: 604-714-5564
Fax: 604-714-5555
Email: info@bclupus.org

LE Society of Saskatchewan

Box 88, Royal University Hospital
103 Hospital Dr.,
Saskatoon, SK S7N 0W8
Tel: 204-942-6825
Toll Free: 1-877-566-6123
Email: less@sasklupus.com

Lupus Society of Manitoba

105 - 386 Broadway Ave.,
Winnipeg, MB R3C 3R6
Tel: 204-942-6825
Fax: 204-942-4894
Email: lupus@mts.net

Lupus Foundation of Ontario

294 Ridge Rd. N., Box 687,
Ridgeway, ON L0S 1N0
Toll Free: 1-800-368-8377 in Ontario
Tel: 905-894-4611
Fax: 905-894-4616
Email: lupusont@vaxxine.com

Lupus Ontario

(see contact information above)

Lupus New Brunswick

c/o Nancy Votour, 23 - 13 Ivan Ct.,
Moncton, NB E1C 8T3
Toll Free: 1-877-303-8080
Tel/Fax: 506-384-6227
Email: lupins@fundy.net

Lupus Society of Nova Scotia

P.O. Box 38038,
Dartmouth, NS B3B 1X2
Tel: 902-425-0358
Fax: 902-798-0772
Toll Free in Nova Scotia:
1-800-394-0125
Email: lupussocietyns@medscape.com

Lupus Newfoundland & Labrador

P.O. Box 8121, Station A, Kenmount Rd.,
St. John's, NF A1B 3M9
Tel: 709-368-8130
Email: lupusnfld@roadrunner.nf.net

Lupus P.E.I.

P.O. Box 23002
Charlottetown, PE C1E 1Z6
Tel: 902-892-3875
Fax: 902-626-3585
Email: bargri@pei.sympatico.ca

The deadline for the
Spring 2009 issue of
Lupus Link is December 15.
Please send submissions
to editor Jaclyn Law at
jaclynlaw@hotmail.com.

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

If you would like to contact
Lupus Ontario's provincial
branches or support groups,
please call 904-415-1099
(or toll-free at 1-877-240-1099).
Juanita Butler, SSW and Provincial
Support Group Liaison, will pass
the request to the appropriate
person. Thank you!

DURHAM SUPPORT GROUPS

DURHAM LUPUS SUPPORT GROUP

The Durham Lupus Support Group meets monthly. The Group provides support and understanding with a wide range of speakers who present a variety of topics to help us learn to live better lives with lupus.

CHILD & YOUTH LUPUS SUPPORT GROUP

If you are a child under the age of 18 years and would like to join our Child & Youth Support Group, a part of the Durham Lupus Support Group, please call for details.



Lupus Ontario

1-877-240-1099

(905) 415-1099

www.durhamwalkforwalk.com

www.lupusontario.org

This support group will also be open to other children and youth in the Durham Region that are facing the challenges of living with a chronic illness.

IN MEMORIAM

Lupus is not just life-altering – it is life-taking. We at Lupus Ontario offer our condolences to the families and friends of the following cherished people, whom we lost in the past six months. It is not our habit to publish these names, but there were too many to ignore. Although we are grateful that Lupus Ontario has been the recipient of memorial donations, we would rather have a cure and continue working together to that end. I apologise if we have missed anyone's name.

Julia Kane, President, Lupus Ontario

Florence Carmichael *Mary Frances Perpick*

Mary Patricia Shea *Sandra Holly*

Roger Kilbreath *Georgia Verra*

Karen Sandu *Dana Courtland*

Cheryle Ritchie *Betty Atkinson*

Christine Best *Jamie Turner*

Judy Judd *Linda Tice*



ACT/UCT Flea Market

Monday, October 13
441 GIBB STREET
OSHAWA
in the
CANADIAN TIRE LOT

Pick up a great bargain!



ITALIAN DINNER DANCE 2008

Saturday, November 8th
Riviera Parque

2800 Hwy #7 West, Concord

ANTIPASTO BAR 6 PM

Open Bar

Prize Tables, Raffle

Silent Auction



Special dance performance –
Art of Argentine Tango
by Elizabeth Sadowska,
artistic director of
Rhythm & Motion Dance Studio,
and guest partner.

Tickets \$85 each
Call early to reserve



Lupus Ontario

905-415-1099

BRANCH NEWS

We had an amazing silent auction, fun fair, donation bake, raffle, Princess Canopy with visits from Cinderella, Spiderman and other characters, lots of activities for kids and a fundraising table. The Manuel family sold pears and beautiful necklaces for lupus, and we had a DJ play great music and keep the crowd moving.

The Durham Lupus Support Group would like to say a big thank you to our Butterfly sponsor, ACT/UCT, Charlie and Carol Voelker for their continued support, and our Angel sponsors, Nowpac and The Carpenters' Union Local 397. Thank you to the sponsors and donors of our silent auction, as well as Sylvia Szikszay, Silent Auction Chair. To my volunteers, a humungous THANK YOU to all of you. I would also like to send a special thank you to my family for their hard work and dedication.

The Durham Lupus Support Group has also launched a **Child & Youth Group**. We will meet one Sunday a month from 1 to 3 p.m. and will open our group up to other children and youth in Durham Region facing the challenges of living with a chronic illness and disability. I welcome Brenda & Kathryn Stewart and Jody & Jaclyn Smith. This group will thrive because of your dedication, support and willingness to take on this journey. Again, I thank our volunteers. Without you, Durham Region would not have a voice.

Shannon Crauford

Durham Lupus Support Group Facilitator
www.durhamwalkforlupus.com

OTTAWA

Lupus Ontario: "Volunteers for a Quarter of a Century" was the epithet for **Douglas Smith**, F.R.C.P(C), and **Denise Mehta**, M.S.W., at the Ministry of Citizenship and Immigration Volunteer Service Awards Event, held in Ottawa on June 5th.

Dr. Smith has worked consistently as Medical Advisor for the Ottawa Branch. Denise Mehta, as well as developing and facilitating Small Group Emotional Support Groups, has presented on much-appreciated topics, especially "Lupus in the Newly Diagnosed," "Coping with Lupus" and "Lupus and the Family."

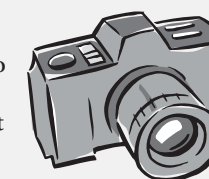
Also in attendance were Service Award recipients **Gloria Checkley** (15 years' service), **Joni Waiser** (5 years), and **Betty Wong** (15 years). They are dedicated volunteers who have worked with the Ottawa Steering Committee in various roles. Gloria also represents Ottawa as the Provincial Board Member. Congratulations to all!

MISSISSAUGA

To read about Mississauga's 2008 Walk a Block for Lupus and see pictures from the event, visit http://infocus.mississauga.com/?view=photos&event_id=1815.

SEND YOUR NEWS!

Do you have branch news to share? Email jaclynlaw@hotmail.com. If you're planning to take photos for the newsletter with a digital camera, please set your camera to the highest possible resolution and email the images at full size. Thank you!



RESEARCH REPORT

GENE MUTATION IMPLICATED IN LUPUS COULD BACTERIA BE TO BLAME?

Scientists at the Oklahoma Medical Research Foundation (OMRF) have discovered a gene mutation that may cause the immune system to stay active after fighting an infection, which leads to damage in the body. Researchers say that this may be caused by a variation of the gene TNFAIP3, thought to be a "brake mechanism" for the immune system.

The study, led by Patrick Gaffney, M.D., and Kathy Moser, Ph.D., of the OMRF, was published in the August issue of the journal *Nature Genetics*. "TNFAIP3 can be thought of as a critical brake mechanism for the immune system. When the gene doesn't function properly, the immune system redlines," Dr. Gaffney stated.

The research team observed that the immune system has difficulty winding down in lupus patients who have the gene variant, while normal versions of TNFAIP3 produce a protein (called A20) in healthy individuals that regulates and shuts off the immune response. They suspect that the variant does not produce enough of the protein, or it makes one that is less effective. In healthy individuals, normal versions of the TNFAIP3 gene produce a protein (called A20) that regulates and shuts off the immune response. In lupus patients with the variant, the immune system has trouble turning itself off, Gaffney said.

TNFAIP3 joins a list of lupus-associated genes that researchers have discovered. Lupus is a multi-genic disease, meaning there's no single gene that causes lupus, but the TNFAIP3 variant may work with other mutant genes to cause lupus in some people. The team will continue to study the TNFAIP3 variant for links to other gene variations.

Dr. Moser explained, "Every single lupus-associated gene we discover is just as important as the others. Each gene can set off new opportunities and new projects for us. You never know which gene is going to give you the best chance to develop new therapeutics or better diagnostics."

For more information, visit www.omrf.org/omrf/news_releases/Releases/2008/20080801.asp.

A physician at the Cincinnati Children's Hospital has discovered a bacterial trigger of autoimmune liver disease that has implications for lupus. With funding from the Lupus Research Institute, Dr. Jochen Mattner helped confirm a suspicion that certain bacterial or viral infections can cause strong immune responses that trigger autoimmune illnesses.

In May's issue of *Cell Host & Microbe*, Dr. Mattner reported that the gut bacterium *Novosphingobium* triggers autoimmune liver disease in mice. The bacterium, with its unique cell wall antigens, activates specialized immune system white blood cells that provide help for autoreactive B cells. The findings imply that antibiotic treatments in humans might prevent or halt the autoimmune process in people who are genetically susceptible.

To read the article abstract, visit www.ncbi.nlm.nih.gov/pubmed/18474357.

OVARIAN FUNCTION AND FERTILITY PRESERVED IN WOMEN WITH LUPUS

Ovarian function can be preserved and disease activity controlled in women with severe systemic lupus erythematosus when treated with a 6-month course of cyclophosphamide followed by the immunosuppressant mycophenolate mofetil, according to a study presented in June at EULAR 2008, the Annual Congress of the European League Against Rheumatism, in Paris, France. The study was led by Professor Athanasios G. Tzioufas at the National and Kapodistrian University of Athens.

For study details, visit www.eurekalert.org/pub_releases/2008-06/elar-ofa061208.php.

RESOURCES

BOOKS

Lupus: A Patient's Guide to Diagnosis, Treatment, and Lifestyle by Ana I. Quintero del Rio, M.D.

Written by a senior research scientist at the Oklahoma Medical Research Foundation, this book alleviates fears and corrects misconceptions about lupus. It includes information about symptoms, treatment options, lifestyle choices, environmental influences and more. 200 pages. \$19.95, available at www.amazon.ca. Also available by the same author: *The Lupus Life Journal: Your Personal Journey of Hope*, which offers inspiration and space to record your experiences. 208 pages. \$17.95, also at www.amazon.ca (release date: Oct.1).



WEBSITE

Quit Smoking

www.hc-sc.gc.ca/hl-vs/tobac-tabac/quit-cesser/index-eng.php
Need advice on kicking the habit? Health Canada's website provides tips on preparing to quit (and preparing to help someone else quit), and you can download a free guide to becoming a non-smoker.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

www.niams.nih.gov
This respected research institute has overhauled its website to become more user-friendly. Choose the "Health Information" tab to find NIAMS' information about living with lupus, Sjögren's syndrome and fibromyalgia.

MedicAlert

www.medicalert.ca 1-800-668-1507
If you wear MedicAlert jewelry, remember to update your information regularly. You can also visit to learn about its "No Child Without" program, which offers free MedicAlert protection to elementary school-aged kids (ages 4 to 14) with pre-existing medical conditions or allergies. MedicAlert also has a sale on select items for existing members until October 11.

BOCCE BALL TOURNAMENT RAISES \$10,000 by Tina Sarta

The 17th Annual Nick Barbieri Charity Bocce Ball Tournament was held on August 15 at the Ambercroft Labourers 506 Training Centre in Richmond Hill. This annual event is organized by the L.I.U.N.A. Local 506 and the Toronto Construction Association, General Contractors' Section. Each year, one charity is designated to receive the proceeds from the event, and this year, Lupus Ontario was chosen. A cheque for \$10,000 was presented to Julia Kane.

What a great sunny day! Both bocce ball enthusiasts and those trying it for the first time had fun. Everyone was also treated to non-stop eating all day long, starting with a delicious breakfast and followed by a day-long barbecue. There were so many raffle items that the draw went on for over one hour.

More importantly, this was a great opportunity to create awareness for lupus in the community. Julia Kane spoke passionately about the work of Lupus Ontario and the struggles faced by lupus patients everywhere.

A big "Thank you!" to the organizers for their dedication and hard work and for choosing Lupus Ontario as this year's charity.



LAS VEGAS
January 24, 2009
The Terrace Banquet Centre

Please join us for our 14th Annual Gala
A magical evening of food, dancing
Auctions and entertainment.
All proceeds to Lupus Ontario,
AARC Foundation &
SickKids Foundation
For more info, please call 905 415 1099

Dance **FOR THE CURE**
www.danceforthecure.ca

NEWS



A Sweet Success!

Last October, Mary Jane Okkerse held a lupus walk in Sparta, Ontario. Her friends participated and brought their children, including Elina Lattanzio, 8, of St. Thomas, Ontario. In May, Elina decided she wanted to raise more money for lupus, so with the help of her sister Klara, 5, and cousin Mikaela, 4, she baked cookies and cupcakes. Elina then set up a table, made signs and sold the treats at her grandparents' yard sale for five hours, raising a grand total of \$100 – half of that before 9 a.m.! Elina's mom, Krista, reports, "People were very generous – many shared stories of loved ones with lupus."



Elina Lattanzio, 8, sold baked goods to raise funds for lupus. Her mom says, "Many people were surprised she wasn't saving up for something for herself. We were very proud!"

A WINNING GAME

What a great event! The First Annual Silver Lakes golf tournament to support Lupus Ontario was held on Sunday, September 7th. The event, organized by 17-year-old Sonny Pawlowicz, was a tremendous success, raising over \$7,000 in its first year. There was also a great silent auction, and everyone had a fabulous dinner thanks to the wonderful staff at Silver Lakes. Thanks, Sonny, for helping to support Lupus Ontario!



OTTAWA CLINIC RECEIVES FUNDING

A bit of good news that didn't make it into our last newsletters: Every year, the Ottawa branch of Lupus Ontario receives donations through the hard work of many volunteers who take part in the Door to Door campaign. Lupus Ontario adds to these monies, which are then allocated to lupus research at the Ottawa Clinic. On February 10, at a meeting of the Ottawa branch, Anne Wyse (founder of the branch) presented Dr. Doug Smith with a \$15,000 cheque.

WELCOME TO OUR NEW LUPUS FELLOWS!

Announcing the 2008-2009 Geoff Carr Fellowship was awarded to Dr. Zahi Touma, who will be working with Drs. Gladman and Urowitz at the Toronto Western Lupus Clinic.

This year, Lupus Ontario is pleased to announce that we have a new fellow at the Hospital for Sick Children, Dr. Sathis Kumar, whose partial one-year Lupus Ontario Fellowship was matched with funds from the Hospital for Sick Children Foundation. Dr. Kumar will be working under the guidance of Dr. Earl Silverman.

We will have a report from both these Fellows in the New Year about their work in the lupus clinics.

MOUTH GUARD — GOOD ORAL HEALTH IS CRUCIAL FOR THOSE WITH LUPUS by Jaclyn Law

Patricia Morton was diagnosed with lupus 17 years ago. Three years later, she learned she had Sjögren's syndrome, a condition in which the immune system attacks moisture-producing glands. Since then, she has coped with an oral health problem common to people with lupus: dry mouth.

"Dry mouth is very uncomfortable," Morton, 52, says from her home in Kansas City, MO. "At times, the dryness makes it hard for me to speak." Among other things, it can also make chewing and swallowing difficult.

Dry mouth is just one of three serious oral health conditions for the estimated 10 to 20 percent of adults with lupus who have Sjögren's syndrome. Because the saliva in our mouths helps neutralize acid made by certain bacteria, when saliva is reduced, the risk of tooth decay dramatically increases. Also, decay-causing bacteria grow at a much higher rate in a dry mouth. For Morton, the combination of lupus and Sjögren's syndrome has resulted in serious dental problems, including losing 10 teeth.

With proper oral care, your doctor and dentist can help ease symptoms of dry mouth by prescribing medications that stimulate saliva, such as Evoxac® (cevimeline) and Salagen® (pilocarpine). Your dentist or doctor may also suggest using an oral rinse, such as chlorhexidine, saltwater mouthwashes, or gums and candies containing xylitol. (Sugary candies, which can cause tooth decay, should be avoided.)

The second primary oral health concern for those with lupus is mouth ulcers, which may be painful. "There seems to be a greater incidence in the young and in patients with active disease," says Ernie B. Luce, D.D.S., a clinical assistant professor in the Department of General Dentistry at the University of Texas Health Science Center at San Antonio. "Forty-six percent of children with lupus have mouth ulcers, while 18 percent of adults and children with lupus have ulcers at any given time."

While ulcers can heal on their own, several drugs are used to treat them, including hydroxychloroquine, azathioprine, dapsone, and thalidomide. Using antiseptic mouthwashes and drinking plenty of fluids may also help. Experts suggest avoiding spicy, acidic, or hot foods that can aggravate ulcers.

To prevent a third common oral problem—gum disease—people with lupus must practice good oral hygiene and seek dental care. Luce acknowledges that this can be tricky when one's health is already challenged. "For many of our lupus patients, dental care is often not at the top of the priority list."

The consequence is that small dental problems can quickly become big ones. Luce recommends choosing a dentist who will provide early and aggressive preventive care. "Maintaining healthy teeth in the presence of lupus is far easier, and almost certainly less expensive, than restoring teeth to health in the presence of lupus."

Morton, who wears partial dentures and sees her dentist every three months for a checkup and cleaning, couldn't agree more. "Immediately start an aggressive dental plan," she says. "Be very insistent in educating yourself and asking your dentist and doctor questions. The health of my remaining teeth is always foremost on my mind."

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A MOUTHFUL OF ADVICE

Everyone should pay attention to their teeth and gums, but people with lupus have special concerns that require extra vigilance. Good oral care is critical and should be part of your wellness strategy. Here is some advice to chew on:

- See your dentist to determine if you have any existing dental problems and discuss how often you should have checkups.
- Practice good oral hygiene. Ask your dentist or hygienist to review your brushing and flossing techniques.
- Watch for signs of periodontal disease: gums that are swollen, bleeding, red and/or sensitive; painful, sensitive teeth.
- If you have dry mouth, talk to your doctor about treatment.
- Before you have major dental work, talk to your doctor. He or she may advise you to postpone the procedure if your lupus is active, because steroids and immunosuppressives you may be taking can delay healing and make it harder to fight infection.
- Tell your dentist all the medications you are taking, whether your lupus is active, and whether you have concerns about blood clotting. Your dentist may ask you to adjust your medication dosage (for example, extra prednisone) for a few days before and after the procedure to help your body cope with the stress.
- If you think you have an infection, seek treatment immediately. Infections can be especially dangerous for people with lupus whose immune systems are compromised.

Sharing My Lupus Story

by Diane Forbes

On the eve of my 50th birthday, I reflect on how my lupus journey started on my 40th birthday. That morning, I woke up with swelling and redness on my face. Upset, I went to the walk-in clinic, and they couldn't explain what caused this and suggested that perhaps I was allergic to something. I came home very frustrated to a large group of friends and family singing "Surprise! Happy birthday!"

The next year was filled with unexplained chronic fatigue, arthritis, alopecia, kidney infections, Raynaud's phenomenon, Sjögren's syndrome and a red butterfly-shaped rash on my face. After numerous doctors' appointments and blood tests, I was referred to the McMaster Lupus Clinic, where I was diagnosed with systemic lupus erythematosus. I was given medication to help control the symptoms, since there is no cure. I read as much as I could about this new chapter in my life, and I was scared about the uncertainty of my future.

How could this possibly happen to an energetic supermom who had already dealt with years of infertility and a near-death experience from childbirth complications? I had an exciting career as a self-employed graphic designer, working from a home office to be with my children. I know that they say that God only gives you what you can handle, but when I started having the cognitive and fine motor skill impairments from my high level of antiphospholipid antibodies, I got depressed. I was totally overwhelmed that some days I would feel fine and then, without reason, the next day I couldn't get out of bed. It was like someone pulled the plug on my energy and I had turned into a spectator of life, not able to participate in the things I enjoyed. Even with a fantastic husband and supportive family, I felt as if I had been robbed of my life as I knew it.

In addition to the alopecia, I had to deal with the extreme weight gain from all the medication I was on, and I felt uncomfortable in public when I had to explain what was wrong with me. Lupus is a disease of a thousand faces, and people don't realize that it is a "self allergy" in which the body attacks its own cells. Cognitive behavioural therapy helped me improve my attitude, and I started journalling and celebrating my good days.

With my symptoms under control and blessed to be in remission, I asked my doctor if I could get a job, since freelancing was unpredictable and my husband had been downsized. Monitored closely, I worked part-time at a call centre. I chose this job to improve my cognitive abilities and fine motor skills on the computer. It also proved to me that I could work a regular short shift to get my stamina back. After six months, I was ready for more challenges, and I accepted a contract job at an art gallery. It was a perfect fit, since I was an artist with advertising experience, and it was a tremendous opportunity for personal growth. The better I did, the better I felt, and I was gradually able to get off all my medication. My bloodwork is now normal. The lupus had disappeared as mysteriously as it had come!

Since March 2007, I've enjoyed being an account executive with the local radio station. My career has expanded beyond my wildest dreams to include teaching workshops on Self Esteem & Goal Setting. It brings me great pride to be able to help my clients increase their business with creative radio advertising, and also share my positive attitude, energy and enthusiasm as a motivational speaker. I realize that my life has been a journey, and I wouldn't be who or where I am if I hadn't had these life experiences. Attitude is everything, and I don't have a perfect life, but I certainly count my blessings and make the best of what I have. I selectively share my story to not draw attention and pity on where I was, but instead celebrate where I am – as I turn 50, I know the best is yet to come!

Diane Forbes lives in Brantford with her husband and two teenage sons. She is a successful motivational speaker. She may be contacted by emailing forbesgd@exculink.com.



lupus



**WALK A BLOCK FOR LUPUS
MAY 9-10, 2009**

**lupus
walkablock**



"Block off" May 9-10 for Walk a Block for Lupus 2009!

We are well on our way with new ideas, great team players and lots of enthusiasm. We started our sponsorship campaign early this year and have implemented new approaches and excellent opportunities for all participants.

Lupus Ontario has also created great new initiatives to increase the number of participants in 2009. One of these is the Red Shoelace Campaign, to be held in conjunction with the 2009 *Walk a Block for Lupus*. Purchasing a set of red shoelaces from Lupus Ontario and wearing them on the day of the walk is a further demonstration of your support for our cause. We believe the Red Shoelace Campaign will also increase awareness for *Walk a Block for Lupus 2009*.

This year's fundraising goal is \$400,000, and in order to reach it, we will need additional walk areas. Our target for 2009 is 250 walk sites, totalling 5,000 walkers across the province, and we know that if we all work together, we can reach this ambitious goal.

Here is a chart that can help you break down pledge donations. With this chart, it should be easy for you to help us reach our *Walk a Block for Lupus 2009* goal.

Suggested Donation Plan	Amount Raised
Ask 4 family members for \$25	\$100
Ask 5 friends for \$15	\$75
Ask 6 co-workers for \$20	\$120
Ask 5 neighbours for \$10	\$50
Ask 4 businesses for \$25	\$100
Approach 11 people you don't know for \$5	\$55
Total Raised	\$500

In May 2008, *Walk a Block for Lupus* raised \$86,000 in Ontario. We all worked extremely hard and dedicated much time to this important annual event. We already have 37 Team Leaders on board for the 2009 *Walk a Block for Lupus*, and are working hard every day to meet our 2009 goal.

If you are interested in joining a team, volunteering your time to help out on May 9-10, or would like to have your own walk, please call the Lupus Ontario office at 1-877-240-1099 or locally at 905-415-1099 and ask for Juanita. There are many areas where your help is welcome and needed.

"Let's keep working together to conquer lupus!"