



Lupus Link Notes

Volume 5, Issue 2

June 2007

Message from the President, Julia Kane

On Saturday April 14th Lupus Ontario held its' AGM (Annual General Meeting) at the Holiday Inn, Yorkdale, in Toronto. A great day was had with exceptional speakers. Visit our website for more information.

www.lupuontario.org We are holding our first regular support group meeting at our office in Markham on June 6th. If you would like to attend any future meetings please contact the office by phone or e-mail:

lupusontario@bellnet.ca. Have a sun safe summer.

LUPUS ONTARIO

590 ALDEN ROAD, SUITE 211
MARKHAM ON L3R 8N2

905-415-1099, 1-877-240-1099 FX 905-415-9874

The deadline for the Summer 2007 issue of Lupus Link is now July 15th. Please send submissions to the editor, Jaclyn Law at jaclynlaw@hotmail.com

***Note.** If you have not paid your 2007 membership dues, this will be your last newsletter. To renew call Karen @ Lupus Ontario 905-415-1099*

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PERSONAL JOURNEY by DEVI PERSAUD

This story begins in January 2006, I was twenty-seven years old and prided myself in trying to eat healthy, work out and lead a balanced lifestyle. I was living with my boyfriend and enjoyed socializing with my family and friends. Life was busy. My weekdays and most weekends were committed to overseeing a large staff in a customer-service department.

This is a snapshot of my life as I knew it.

Things slowly began to change in January 2006 when I first noticed that my hair started to fall out in clumps. I was becoming increasingly fatigued as the days passed and found myself needing more sleep than usual, becoming more stressed with constant migraines and feeling rather depressed at times. I found a few lumps in the back of my head and that's when the concern turned to panic. I went to the doctor to conduct some blood work and a full physical. All results appeared to be fine. There was no explanation for my ailments. Now April 18, 2006, I noticed my ankles became very swollen. I was very concerned and went to my doctor who suggested that maybe it was the way I was sitting at work for numerous hours that caused this swelling. He said he would send me to a specialist, which would take another 3 months! In the days to follow, my ankles became so swollen that I was not able to wear my own shoes. I called my doctor's office desperate and begged for them to get me a specialty appointment as soon as possible. They responded that there is nothing they can do. The days that followed found me having increased swollen arms and legs (I later learned as a result of having a kidney disorder), a high fever, and difficulty breathing. I then went to the Hospital emergency room. I was sent home, waiting again for an appointment with a specialist. I went to another hospital and again was told there was nothing they could do. They were about to send me home once again when a Doctor decided to first speak to the nephrologists that was on staff.

I explained what had been happening to me slowly for the last five months and how my condition was unexplained by the countless doctors and specialists that I had seen. She assured me that they would keep me in the hospital until they knew what a possible cause for my illness. I was admitted into the hospital where many tests were run and the doctor insisted on a kidney biopsy after all other tests showed only some symptoms of what they believed was Lupus. After seeing a Rheumatologist, we had now confirmed that I had Systemic Lupus Erythematosus (SLE) and that is when I decided to move back home with my family as it was closer to the hospital and I had the support of both my parents and my siblings. On the week-end of June 17, 2006 I came home from the hospital only to return by ambulance. There I spent three days in the intensive care unit, five days recovering which included learning to walk properly once again. The doctors explained that I had suffered an inflammation to the brain which resulted in a seizure.

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Lupus Ontario

FACT SHEET ORDER FORM

Made available through Lupus Canada & The Ontario Trillium Foundation

Please check all boxes that apply and mail, email or fax your request to Lupus Ontario.

Mail to:

Lupus Ontario
590 Alden Road Suite 211
Markham, Ontario L3R 8N2

Tel: 905-415-1099
Toll Free: 1-877-240-1099
Fax: 905-415-9874

Email to:

lupusontario.info@bellnet.ca
or
lupusontario@bellnet.ca

For additional information,
please visit the new
Lupus Canada website:
www.lupuscanada.org



- Learning To Live Well With Lupus Preventive Coping Strategies for Emotional Health
- Learning To Live Well With Lupus Preventative Coping Strategies for Physical Health
- Lupus Medications
- Men and Lupus
- Kidney Disease and Lupus
- Introduction to Skin Diseases
- Symptoms of Drug-Induced Lupus
- Non-Steroidal Anti-Inflammatory Drugs
- Sun Safety
- Anti-Malarial Drugs
- Corticosteroids
- Osteoporosis and Lupus
- L'Ostéoporose et le lupus
- Cardiovascular Disease and Lupus
- Les maladies cardiovasculaires et le lupus
- Pregnancy and Lupus
- Lupus et grossesse
- Nutrition, Diet and Lupus
- Nutrition, diète et lupus
- Infections, immunizations and Lupus
- Infections, vaccinations et lupus
- Immunosuppressive drugs used in treating Lupus
- Médicaments immunosuppresseurs utilisés dans le traitement du Lupus
- Other Conditions Seen in Lupus
- Autres maladies apparentées au Lupus
- Blood Disorders in Lupus and lab tests that detect them
- Troubles Sanguins Associés au Lupus et tests de laboratoire les détecter
- The Nervous System and Lupus
- Lupus et le système nerveux
- Balancing Act: Lupus, Activity and Rest
- Un bon équilibre: lupus, activité et repos
- Talking about lupus
- Parler du lupus
- Lupus research: What you can do & what the medical community is doing.
- Recherche sur le lupus

Name: _____

Address: _____ P/C _____

Phone: _____ E-Mail _____

Working together to conquer lupus

DENISE MEHTA IS RETIRING!



Ottawa Group presents Denise Mehta (left/centre) with Lupus Ontario Appreciation Awards

There was a presence, and a face which exuded more curiosity than the other some thirty-five faces, in the room. **It was Denise Mehta.** The event was the founding of the Ottawa Branch of The Ontario Lupus Association, under the auspices of The Arthritis Society. The place was Alex Wyse's workshop/studio. The time was June, 1981. This coincided with Denise being hired, as the Social Worker, by Dr. Robert McKendry, for the Rheumatology Unit at the Ottawa General Hospital. Rheumatology patients, especially many with lupus, have been appreciative of that hiring.

Some of the people at the meeting wondered if Denise would return to future sessions, which were, deemed by those present, to be informational and supportive in nature. She did. And for the next twenty-six years, Denise became a volunteer speaker and "teacher" in many kinds of information sessions both large and small in number, for lupus patients, their families and friends. The meetings for newly diagnosed lupus patients, the one-on-one teachings and small support groups (emotional support) have been unique.

She led the way in teaching about facilitating small groups. Within these years, there were many Information Sessions organized in Eastern Ontario communities: Pembroke, Renfrew, Almonte, Perth, Carp, Smith Falls and Cornwall being a few of them. With Denise's capacity as an organized, information packed, bilingual and interesting speaker, to say nothing of how she incorporated her sense of humour and understanding of the human condition into all these presentations, she was always a hit. Especially in one venue, Denise proved herself unbeatable. Half of a small restaurant was allocated to her group. Beside the audience, a rather noisy dinner party was going on. Denise carried on. Suddenly, the restaurant became very quiet. Everyone was listening to Denise. (Alex Wyse, who was always delegated to look after the husbands in the groups says that perhaps, she was talking about sex.)

Over the years, many lupus patients have sensed that Denise affected much that went on in her Social Work and Rheumatology Departments. Somehow, it is felt, she influenced Rheumatology Fellows, plus fellow Social Workers, medical students, pharmacists and nurses about the challenges chronically ill people live with, and about what help is needed. As well, Denise influenced this writer as a role model, not only for telephone

counselling, but for living. Now it is June, 2007. Denise has retired. She will be missed.

Merci Denise! Bon chance!

Submitted by Anne Wyse

P.S. Denise has recently been involved in the production of the "Lupus Canada Fact Sheets"



Continued from page 1. PERSONAL JOURNEY

I began to do a lot of research. I wanted to fully understand what Lupus SLE really was and what I could do to fight it and try to regain my normal existence once more. I was in a depressed state of mind as well as body. I did not know what the next day held for me or if I had the energy to even face it. I closed myself off from extended family and friends and did not want to be confronted with their questions or have them gaze upon me only to take pity. The medication also made me appear physically different and due to the fact that I had gained a lot of weight, I no longer recognized the girl in the mirror staring back at me. I was now better informed about the disease and when I thought medical science could not provide me with the explanation I sought for; I turned to the only other source that I believed would; God. I returned to services with my family. I had never considered myself a religious individual but am grateful for the spiritual guidance that I gained from having been in the presence of a higher being.

August 2006, I had formed a new lifestyle, one which excluded working, partying and partaking in any stressful events. I was now being forced to reevaluate my life and really try to understand what makes me feel good and indulge myself in it. I would look at photo albums and home videos to take myself to that happy place in time again. I slowly started exercising to gain strength and endurance. My next doctor's appointment came and I couldn't wait to show them my progress! What they saw in me prior was a person who was consumed by the disease. Before them now stood a fighter, someone who was determined to get better. My test results all showed that I was improving and my doctors were very impressed.

Today I am stronger mentally now than I have ever been even before I was first diagnosed with Lupus SLE. I now accept that I have to work at being healthy in both body and mind. I exercise on a regular basis, attend church, try to eat right and of course do the things in life that make me happy. I read once that laughter and happiness can cure anything, so I try to do a lot of that. One year later, I am clinically now in remission and I having no plans of changing that!

This summer I want to organize a walk to raise money for Lupus research not only to challenge myself but because I am thankful that I am physically able to do so! Last summer I was in and out of the hospital and I am very grateful for my development both physically and mentally. I would like to give back to the community and provide an opportunity to raise awareness about Lupus SLE and help others afflicted with this disease. I am determined to be an example, rather than a statistic.

Lastly and most importantly I have been blessed with amazing people around me. God, my family, boyfriend and friends have been there every step of the way and have been my backbone through it all and without them it would not have been possible!

Edited with the help of Taschea Moola

UPCOMING EVENTS

ACT/UCT 2007 Flea Markets

Located at 441 Gibb Street
Oshawa, ON on the Canadian Tire parking lot.
Time: 9 a.m. to 5 p.m.
Canada Day (July 1, 07)
Labour Day (Sept. 3, 07)
Thanksgiving Day (Oct 8, 07)

WALK A BLOCK FOR LUPUS

Join us and help make the Walk-A-Block an even more successful event.

How you can help:

Be a Team Leader

Join a local Walk, Support a Walker,
Be a sponsor for a Walk or Volunteer with the planning.

Working together to conquer lupus!

lupus
walk a block

Please contact; Juanita Butler, SSW
Provincial Walk Coordinator
905-415-1099

Toll Free: 1-877-240-1099

lupusontario.info@bellnet.ca

Or register online at www.lupuscanada.org

ITALIAN DINNER 2007

Saturday November 3, 6:30 pm
Riviera Renaissance Parque
2800 Hwy #7W, Concord

Ballroom Dancing with the Stars for Lupus

Open Bar

Antipasto Bar with Faggioli & Smoked Salmon
Spaghetti Alla Chittara Napolitana

Ricotta & Spinach Stuffed Rotolo
Grilled Chicken Breast Supreme
Veal Scallopine
Mixed Vegetables & Roasted Potatoes
Spring Salad
Chocolate Tartufo & Strawberries

Prize Tables, Raffle

Ballroom Dance Show

Tickets \$75.00 each
Call early to reserve
Lupus Ontario 905-415-1099



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