

# CANADIAN SCLERODERMA NEWS



SCLERODERMA SOCIETY OF CANADA

MAY 2009

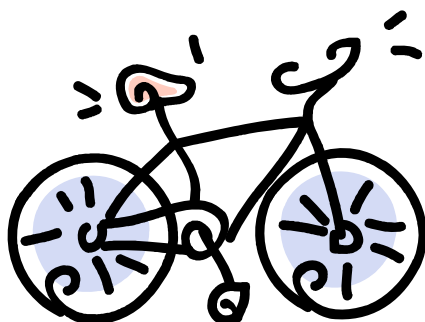
## ACROSS CANADA FOR SCLERODERMA

Two adventuresome young people from Quebec are cycling across Canada for scleroderma. Valérie Hébert and Stéphane Marchand will ride their bikes across the country in two stages. They left Montreal on May 30 to begin the first stage, which will take them to St. John's, Newfoundland, then they will begin the second stage in July, cycling from Vancouver to Montreal.

Their objective is to raise funds for scleroderma research and to pay tribute to Valérie's father who suffers from the disease. You can learn more about them and their adventure by visiting their website, <http://valerieetstephane.com/homeenglishversion/index.php>.

Although their venture began with a provincial orientation, having a focus on their home province of Quebec, it has become one with a national orientation as well. The Scleroderma Society of Canada and its provincial Member organizations are supporting this venture by way of spreading the news, by encouragement and through financial support. With a national emphasis we hope to make it a successful joint effort in support of Valérie and Stéphane's initiative.

All funds raised go to support scleroderma research and the work done by Sclérodémie Québec. Donations may be made through the 'donations' link on the home page of this website, or they may also be made online through a donations service on Valérie and Stéphane's website. Donations may also be made by cheque, payable to 'Sclérodémie Québec' and sent to Valérie and Stéphane, 890 Hyacinthe Hudon, Boucherville, QC J4B 6Y7.



June is  
Scleroderma  
Awareness  
Month

# 10th Annual Scleroderma Knowledge Exchange Conference Scleroderma Society of Canada

The Scleroderma Association of Manitoba is very honoured to host the 10th conference and General Meeting of The Scleroderma Society of Canada. It will be held on October 2 & 3 at the Delta Hotel, Winnipeg. We invite you to attend this wonderful opportunity to hear current information and to meet others with similar interests.

On Friday, October 2nd, you may choose to take an afternoon walking tour called Pestilence, Shamans & Doctors. Or a tour of Winnipeg or you may choose to lounge at the pool. (More information on page 5) We hope that everyone will join us for a buffet dinner in the evening and enjoy talking to the CSRG students about their posters for this year.

In conjunction with the SSC conference, the Canadian Scleroderma Research Group (CSRG) will be holding its third annual Scientific Conference at the Delta Hotel. As was the case at last year's event, this will provide an opportunity for some interaction between medical professionals and scleroderma patients. Specifically, the program on Saturday provides for an extended lunch time to allow for this interaction.

Delta Hotel

350 St Mary Avenue

Winnipeg, MB

204-944-7287

Toll Free: **1-888-311-4990**

Online Reservation is available.

[www.deltawinnipeg.com](http://www.deltawinnipeg.com)

If you wish to stay at the Delta Hotel please make your own room reservations either by phone or online.

Refer to the Scleroderma Society of Canada conference in order to get the preferred rate which is \$119.00 per night. A limited of rooms have been blocked so reserving early is advised.

Delta Winnipeg is the largest hotel in Manitoba, attached via skywalk to Winnipeg Convention Centre in the heart of downtown. Features include Odyssey Health Club with full fitness facility and three pools, Blaze Bistro & Lounge, Urban Bean serving Second Cup coffee, 24-hour in-room dining, heated underground parkade and much more.

**Saturday: October 3, 2009**

8:00 to 8:30 Registration &amp; Breakfast

8:30 to 8:45 Welcome *"Memory of the past ten years"*

8:45 to 9:30 General meeting

9:30 to 9:45 Dr Robinson *"Scleroderma in Manitoba"*9:45 to 10:15 Dr Baron *"Research Update"***10:15 to 10:30 Coffee****10:30 to 11:15 Breakout**

A. Doreen Mulder

*"Make up - Business, Evening & Corrective Technique"*B. Dr Shane Silver *"Dermatology"*

C. Dr Gornitsky

*"Oral Health Problems for the Scleroderma Patient"***11:15 to 12:00 Breakout**

D. Dr Markland

*"Are Stem Cell Transplants an Option in Scleroderma"*E. Andre Lafreniere *"Managing your Medication"*F. Dr Stewart ]*"Home & Health Support"***12:00 to 1:00 Lunch with CSRG****1:00 to 1:30 Open Forum Q & A****1:45 to 2:30 Breakout**G. Dr Shikha Mittoo *"Scleroderma Lung Disease"*H. Johanna Stasiuk *"Physio Therapy"*I. Dr. Docherty *"Kidneys"***2:30 to 3:00 Coffee****3:00 to 3:45 Breakout**J. Tammy Raynor *"Nutrition & Scleroderma"*K. Dr L. Warren Neilson *"Strategies for Managing Insomnia"*L. Ann Patton *"Occupational Therapy**Appropriate Exercises for Scleroderma"***M. Juvenile Scleroderma**

3:45 to 4:30 Silent Auction – Closing remarks

**Please check the appropriate spaces that you will be attending.**

Registration Fee \$25.00

Includes Friday Supper & Saturday  
Breakfast & Lunch

**Friday**

Tour of Winnipeg \$15.00

Pestilence, Shamans & Doctors  
\$10.00

Friday evening (Buffet- no charge)

**Breakout Session Choices:**

Please select

1.  or  (10:30 to 11:15)

2.  or  (11:15 to 12:00)

3.  or  (1:45 to 2:30)

4.  or  (3:00 to 3:45)

5.  Juvenile Scleroderma

Saturday evening meal at Delta

(no host, individual tabs )

**Or**

Celebration Dinner Theatre \$40.00

# Wellness, Education & Our Future

## Everyone Welcome

### Conference registration

A separate form is to be completed for each person attending.

Payment may be made by check or money order to Scleroderma Association of Manitoba. If you need addition programs or information please call the conference Registrar or our toll free number 1-866-279-0632. Please enclose payment with this registration form and send to:

#### Conference Registrar:

Ann Harwood

961 Crane Ave

Winnipeg, MB

R3T 1V2

Email: [wdharwood@mts.net](mailto:wdharwood@mts.net)

Telephone: 204-477-4310

#### Registration Form

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

Address: \_\_\_\_\_  
\_\_\_\_\_

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

### ANNUAL GENERAL MEETING AND ELECTIONS

#### Nominations

The Scleroderma Society of Canada will conduct its AGM on Saturday morning of the conference.

Part of the AGM will be the election of the Board of Directors for the coming year. Nominations are being accepted for all positions. Please submit nominations to Grant Dustin, Secretary-Treasurer, Scleroderma Society of Canada, 95 Woodfield Road SW, Calgary, AB T2W 5K5, email [mgdustin@telus.net](mailto:mgdustin@telus.net), telephone 403-281-7616.

The Scleroderma Foundation will be holding their conference in St Louis this year in July. Two of our boards members will be attending this event. So look forward to the article that will be in the October issue of Scleroderma News about this event.

## Friday Tours

### 1. Muddy Water Tours - Pestilence, Shamans & Doctors \$10.00

Ever wonder what it would be like to be ill in centuries gone by?

Learn from a famous Victorian doctor about plagues, diseases and discoveries that changed Canadian history.

History of the Grey Nuns in St. Boniface, medicines of First Nations people and the hidden potency of medicinal plants are just a few of the doctor recommended lessons you will receive.

**2. Tour Winnipeg, (\$15.00)** the wonderful city of trees! This tour includes the Forks National Historic site, Winnipeg's historical "meeting place", with its unique outdoor historic site and indoor market of shops, cafes, and restaurants. Across the new Esplanade Riel Bridge, you will visit Winnipeg's French Quarter (St. Boniface) and the beautiful St. Boniface Cathedral, the oldest cathedral in Western Canada. The Cathedral's cemetery features the grave of Louis Riel, the famous Métis leader and founder of Manitoba. You will tour through the Exchange District, with its exceptional collection of terra cotta and cut stone architecture. This thriving and unique neighborhood is home to an array of restaurants, nightclubs, art galleries and Winnipeg's theatre district. Its cobblestone streets and friendly pedestrian environment also contribute to its popularity as a period backdrop for today's movie industry. You will also see the Legislative Building, the beautiful homes of Wellington Crescent, and Winnipeg's 393-acre Assiniboine Park where you will have the opportunity to walk through the unique Leo Mol Sculpture Garden, which features bronze sculptures, porcelains, paintings and sketches by celebrated Winnipeg artist, Leo Mol.

## Saturday Evening

### 3. Celebrations Dinner Theatre

If you've ever wondered what it would be like to be front and centre when the infamous Rat Pack performed at the Sands Hotel in Vegas during the late '50's and early '60 here's your chance.

Frankie and Dino are the best of friends and two of the hottest acts in Vegas. They are also two of the worst poker players in town and find themselves loaded with gambling debts to their casino boss and suspected mobster, Hombly Hills Malone. To top that off, Frankie falls in love with the mobster's wife. Now they have only 24 hours to get the girl, win back the money, pay off their debts and do the 6 shows a night they are contracted to perform. Its either that or rob the casino, fake their own death, become showgirls or perhaps all three.

In tradition of the Sinatra Rat Pack movies of Robin and the 7 Hoods and the original Ocean's 11, Celebrations'/Jubilations' Luck Be A Lady takes you back to the glorious, ring-a-ding-ding, days of Vegas in the 50's and 60's with the timeless music of Frank Sinatra, Dean Martin, Sammy Davis Jr. and many other Vegas standards. It was a time of showgirls, late nights, single malt scotch, good friends and laughter!

On the Saturday night we would leave the Delta hotel by bus at 5:30.

## Available resources

We have several Pamphlets available upon request. These can be requested through our website [www.scleroderma.ca](http://www.scleroderma.ca) or 1-866-279-0632

**Scleroderma – Quick Facts** -A general overview of scleroderma in point format. This pamphlet will probably be most useful as a handout at such venues as malls, trade shows, and/or health shows.

**What is Scleroderma?** - A general overview of scleroderma but contains more information than in the Basic Facts pamphlet. This will probably be useful to give to people requesting general information on scleroderma or to put in medical offices.

**Managing Scleroderma** - Deals with general issues in coping with scleroderma and the effects of the disease.

**Raynaud's Phenomenon** - A general overview of Raynaud's as it affects scleroderma patients.

**Pulmonary Arterial Hypertension** - Specific information on pulmonary hypertension in scleroderma patients.

**Gastroesophageal Reflux Disease** - Specific information on gastrointestinal issues of scleroderma patients and some of the resulting complications.

**Medical Tests** - General list of medical tests that physicians may request in diagnosing and treating scleroderma.



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## Dry Mouth Survival Tips

- Eat soft, moist foods if you have trouble swallowing or with your teeth chipping and breaking.
- Sjögren's patients should eat smaller, more frequent meals to stimulate saliva flow.
- Avoid salty, acidic or spicy foods and carbonated drinks that may be painful on your dry mouth or interfere with digestion in Sjögren's.
- Help prevent dental decay by using oral products containing the sweetener xylitol.
- For dry mouth, increase your intake of liquids during the day. Remember that small sips of water work best.
- Sjögren's patients should avoid mouthwashes and rinses that contain alcohol or witch hazel. These ingredients can aggravate oral dryness and burning.
- Chew sugar-free gum or suck on hard diabetic or sugar-free candies to help increase saliva.
- Apply vitamin E oil or moisturizing gels to dry or sore parts of the mouth or tongue for long-lasting relief. Use the liquid oil or punch holes in vitamin capsules.

By: Chris Clay The Mississauga News

## Almost \$80,000 raised to battle disease

**April 14, 2009 01:13 PM** - The word on the rare, autoimmune disease known as scleroderma is getting out to the public.

And the Mississauga Support Group of the Scleroderma Society of Ontario is largely to thank for that. The 35-member group has annually organized a gala fundraiser for the past three years and has seen a tremendous growth in the amount of money raised and the number of people who attend.

At the 2009 gala, held earlier this month at the Oasis Convention Centre, 750 people attended and almost \$80,000 was raised. It's a big increase from the inaugural event, when 350 people came out and more than \$37,000 was donated.

Funds raised go towards research into the chronic, progressive autoimmune disease of the connective tissue that generally causes a hardening of the skin.

Those living with the illness, which usually strikes women between the ages of 30 and 50, also suffer from poor circulation and skin discolouration, a hardening of internal organs, reduced finger functionality and have difficulty with movement and swallowing.

Scleroderma affects hundreds of people in Ontario and about 16,000 across Canada.

"It's been a bad year with the economy being just terrible," said Rosemary Vincec, who organized the gala with Vidas Vapsva, Mary Lou Bothelo, Jennifer Rai, Janice Borg and Maria Szoke. "Even though everyone is suffering, we still managed to get a big group of people out and spending money on a good cause."

Money was raised through auctions and a raffle, with items up for bid including tickets to the Toronto Raptors and to watch the band Coldplay live in concert. There was also a hockey stick signed by members of the Toronto Maple Leafs, a hat signed by Port Credit's Matt Stajan (a forward with the Leafs), jewellery, original art and even a barbecue.

While raising almost \$80,000 was gratifying, said Vincec, increasing awareness about the disease was even better.

"We really feel that the word is getting out and I think that's part of the reason the (gala) numbers are growing," she said. "We meet so many people who don't know anything about scleroderma and then when we see them again they know so much more about it. Hopefully, one day it will be a household name."

This year's event was bittersweet as one of the support group's founding members, Carroll Vapsva, died last year due to complications from the disease.

The date has already been set for the 2010 gala. It will be held March 27 at the Oasis.

For more information, visit [www.sclerodermaontario.ca](http://www.sclerodermaontario.ca).



Shirley Haslam, Past -President of the Scleroderma Society of Canada, and her husband, Peter Hodgkinson, were on hand to greet guests as they arrived at the Gala.



**Scleroderma Society of Canada**

phone (toll free): 1-866-279-0632  
phone (sec-treas): 403-281-7616  
fax: 403-238-2773 email  
(sec-treas): mgdustin@telus.net email  
(webmaster): info@scleroderma.ca

*The mission of the Scleroderma Society of Canada is to promote awareness of scleroderma, to support those affected by this disease, and to support research dedicated toward a cure.*

**Objectives of the Scleroderma Society of Canada**

- Provide information about scleroderma and promote awareness
- Provide information about scleroderma research
- Support and seek funding for scleroderma research
- Assist Regional support groups

**Board of Directors:**

**Past President:** Shirley Haslam

**President:** Marion Pacy

**Vice President:** Normand Ricard

**Sec/Tres:** Grant Dustin

**Directors-at-Large:**

John Lewis

Maureen Sauvé

Gillian Little

Mary Beth Clark

Catherine Fortune

Junella Weiss

**Research Liason:** Bob Buzza

**Webmaster:** Ron Gullickson

The Scleroderma Society of Canada does not endorse any drug or treatment. Information it provides is intended merely to keep people informed. The manifestations and severity of scleroderma vary. Individualized medical management is therefore essential.

The Society of Canada strongly recommends that all drugs and treatments be discussed with one or more doctors or health care providers to assure proper evaluation and treatment.

**Contact List for Each Province**

British Columbia - Joan Kelly - 1-888-940-9343

Edmonton - Gillian Little - 780-434-3517

Southern Alberta - Maie Dustin - 403-281-7616

Manitoba - Marion Pacy - 204-422-6114

Ontario - Maureen Sauve - 905-544-0343

Ottawa - Aline Alporte - 613-745-7829

Kahnawake - Lori Jacobs - 450-638-1831

Sclerodermie Quebec - Diane Collard - 514-990-6789

New Brunswick - Deanna Cosman - 506-763-2105

Saskatchewan - Gerald Shauf - 306-634-3433

Nova Scotia - Mary Beth Clark - 902-423-3942

Prince Edward Island - Katherine Dewar - 902-892-8895

Newfoundland & Labrador - Beverley Blanchette - 709-722-1470

Arthritis Montreal - Paulette Zielinski - 514-631-3288