

## ANOTHER MAJOR GRANT AWARDED



On March 15, 2007, the Institute of Musculoskeletal Health and Arthritis (IMHA) approved \$1.8M to increase the number of new scleroderma researchers in Canada over the next six years.

On April 10, 2007, the IMHA, in partnership with Pfizer Canada, approved, subject to resolution of an overlap issue, \$1,497,030 to support a research program involving established and new scleroderma researchers from a variety of backgrounds. This team will address knowledge gaps by focusing on the following immediate goals:

**develop more sensitive classification criteria;**

**create subsets of disease using, among other instruments, autoantibody profiles;**

**develop a disease activity index and a damage index.**

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The team will engage in active Knowledge Transfer and Exchange among the lay and scientific communities and policy makers.

The ultimate objective is to advance the study of scleroderma in Canada, dramatically, and to provide a platform "... for interventional studies aimed at identifying disease-modifying therapies and improving the quality of life of patients with scleroderma."

Our congratulations and thanks to the entire Canadian Scleroderma Research Group and, in particular, Principal Investigators Murray Baron, Anie Philip, Janet Pope, and Andrew Leask, their 14 Co-Investigators, their eight Research Collaborators, their 11 Participating Rheumatologists, and the following Patient Representative Collaborators:

Mary Brachaniec and Bob Buzza (Co-Chairs, Knowledge Transfer Exchange Committee), Shirley Haslam, Phil Hughes, Mare Pacy, and Normand Ricard.

**Over \$3.5 M in scleroderma research funding has been approved by the Canadian Institutes of Health Research since February 2007. This level of support is unprecedented, and heartening. We look forward to sharing results with you.**

*Submitted by Bob Buzza, Research Liaison Officer, Scleroderma Society of Canada*

*[rbuzza@ret.bctf.ca](mailto:rbuzza@ret.bctf.ca) (604) 520 3258 April 22, 2007*



## President's Message

MAY 2007

Hello Members! I think we're all feeling a little warmer now that spring is in the air – for some longer than others. It's wonderful to get outdoors and go for a walk or putter in the garden. Observing daffodils, tulips, hyacinths and other spring flowers bring smiles and I feel so much better.

We are certainly excited about the recent research grants that have been awarded to the Canadian Scleroderma Research Group. On March 15, 2007, the Institute of Musculoskeletal Health and Arthritis (IMHA) approved \$1.8M to increase the number of new scleroderma researchers in Canada over the next 6 years. As well, on April 10<sup>th</sup>, 2007, the IMHA, in partnership with Pfizer Canada approved \$1,497,030 to support a research program involving established and new scleroderma researchers from a variety of backgrounds. You can read more detailed information about these grants in this newsletter. The news of the first grant was announced just after the Mississauga (ON) Support Group held their first annual Gala Dinner and Dance, which raised \$36,000. Such great motivation for us to continue those fundraising activities!

As we look forward to June, which is designated as Scleroderma Awareness Month, many volunteers are visiting their local politicians as well as provincial members of parliament to request them to make a proclamation in council rooms etc. declaring June as Scleroderma Awareness Month. I hope you are one of them. Please let Grant Dustin ([mgdustin@telus.net](mailto:mgdustin@telus.net)) know about your success in this endeavour.

On Saturday, September 29<sup>th</sup> we will be holding our Annual Meeting and Conference in Calgary. Details of this event are in the newsletter. A very informative day has been planned for you. Please check the information and get your registration in. It would be wonderful if we could have representation from each of the provinces and territories

On behalf of the Board of Directors have a great summer and stay well. We look forward to seeing you in Calgary.

Shirley Haslam, President

### LOOKING FOR A CANADIAN CELEBRITY!

Wouldn't it be great if we could find a famous Canadian who would help us bring awareness about Scleroderma across Canada? I'm willing to take action and try to find such a person.

#### **You can help!**

If you have any suggestions or contacts, let me know.

Please contact Carroll Vapsva at [vapsva@rogers.com](mailto:vapsva@rogers.com) or call me at 905-822-7868.

## GALA DINNER AND AUCTION

On Saturday, March 17th, 2007 the First Annual Fundraising Gala Dinner & Auction organized by the Mississauga Scleroderma Support Group (ON) was held, with phenomenal success. Over three hundred people attended the dazzling evening of wining, dining and dancing. A spectacular silent auction of over 50 items generated lots of enthusiastic bidding. Our mystery entertainer, "Elvis" serenaded us with a number of familiar songs while the guests danced



### Front Row: L to R

Shirley Haslam - President, Scleroderma Society of Canada

Jennifer Rai - Gala Dinner Committee member

Rosemary Vincec - Gala Dinner Committee member.

Carroll Vapsva - Gala Dinner Committee Chair

Carolyn Lewis - Mississauga Support Group member

### Back Row: L to R

David Sweet, MP, Ancaster - Dundas - Flamborough - Westdale

Peter Woolcott - President, Scleroderma Society of Ontario

### Forefront

Jeff Taylor - violinist

## Scleroderma Conference

**Scleroderma Society of Canada**  
**Annual General Meeting and Conference**  
**September 28-29, 2007**

**Coast Plaza Hotel and Conference Centre**  
 1316 – 33<sup>rd</sup> Street NE, Calgary, AB T2A 6B6  
 telephone: 403-248-8888 toll free: 1-800-661-1464  
 fax: 403-248-0749

If you reserve a room at the hotel please request the special room rate for the conference (\$119.00).

A limited number of rooms are reserved for our conference so we recommend booking early.

### Program

#### **Friday, September 28, 2007**

1:30-4:30 pm guided bus tour of Calgary – optional, \$15.00 for basic tour plus optional entrance fee to  
 Canada Olympic Park ski jump tower or Hall of Fame (\$6.00)  
 and Fort Calgary visitors' centre (\$7.50)

6:00-7:30 pm dinner at hotel restaurant (no-host, individual tabs)

7:30-10:00 pm 'meet-and-greet' social event (casual Western dress encouraged)

#### **Saturday, September 29, 2007**

8:00-9:00 am Continental breakfast and registration

8:15-9:00 am Presentation by Dr. Duncan Stewart *"What is Pulmonary Arterial Hypertension?"*  
 (Optional: This session is part of the CSRG program but is also available for SSC people to attend.)

9:00-9:15 opening remarks, welcome, introductions

9:15-10:00 presentation by Dr. Jan Storek *"High dose cytotoxic therapy with blood or marrow  
 transplantation for autoimmune diseases"*

10:00-11:00 presentation by Dr. Marvin Fritzler *"Advances in Scleroderma Diagnostics:  
 What Difference Will it Make?"*

11:00-11:15 stretch/coffee

11:15-12:00 Annual General Meeting AGM business and CSRG report

12:00-1:00 lunch (SSC and CSRG people will combine for lunch)

1:00-1:30 open forum Question/Answer session featuring a panel of doctors to answer patients' questions

1:30-2:30 breakout sessions: A. Dr. Sharon LeClercq – Scleroderma: Understanding the Disease  
 (choose one) B. Carolyn Johns – Exercise Strategies for People with Scleroderma  
 C. speaker to be announced – topic on gastrointestinal issues

2:30-2:45 move/coffee

2:45-3:45 breakout sessions: A. Dr. Sharon LeClercq – Scleroderma: Understanding the Disease  
 (choose one) B. Carolyn Johns – Exercise Strategies for People with Scleroderma  
 C. speaker to be announced – topic on gastrointestinal issues

3:45-4:00 closing remarks

6:00-8:00 dinner at hotel restaurant (no-host, individual tabs)

Scleroderma Society of Canada  
**Annual General Meeting  
 and Conference**

September 28 – 29, 2007

**Registration**

Registration Fee: \$25

Includes continental breakfast and  
 buffet lunch.

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

Please check the appropriate spaces on the  
 registration form.

Payment may be made by cheque or money  
 order payable to Scleroderma Society of  
 Canada. Please enclose payment with the  
 registration form(s) and send to:

Kath Orr – Conference Registrar  
 1704 – 47<sup>th</sup> Avenue SW  
 Calgary, AB T2T 2S2  
 Phone: 403-243-5319  
 Email: [keorr@shaw.ca](mailto:keorr@shaw.ca)

For financial consideration regarding fees please contact  
 Grant Dustin at 403-281-7616.

We are requested to have the anticipated  
 number of participants for the Scleroderma  
 Conference and AGM by the end of August.

Please send the completed form to the  
 conference registrar by August 31, 2007.

***Special thanks to our sponsors:***



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**Registration Form**

Name \_\_\_\_\_

Address \_\_\_\_\_  
 \_\_\_\_\_

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

Email \_\_\_\_\_

**Breakout Session Choices**

(Please select two in order of preference.)

\_\_\_\_ “Scleroderma: Understanding the disease”

– Dr. Sharon LeClercq

\_\_\_\_ “Exercise Strategies for People with Scleroderma”

– Carolyn Johns

\_\_\_\_ Topic on gastrointestinal issues and nutrition –  
 speaker TBA.

**Fees**

Please check the appropriate spaces below

\_\_\_\_ Registration Fee \$25.00

\_\_\_\_ Basic Bus Tour \$15.00

\_\_\_\_ Friday evening meal no host

\_\_\_\_ Saturday evening meal no host

(Evening meals are individual tabs but we need to  
 confirm numbers to reserve hotel restaurant space.)

### What causes night leg cramps? What can you do about them?

A muscle cramp is an involuntary, sustained tightening (contraction) of one or more of your muscles. It can result in intense pain and an inability to use the affected muscles. Night leg cramps are contractions of the leg muscles, usually in the back of the lower leg (calf). They often occur just as you're falling asleep or just as you're waking up.

The exact cause of night leg cramps isn't known. Some experts believe they may be due to abnormal processing of electrolytes — essential elements and chemical substances your body needs for basic functions — by muscles. Almost everyone has occasional leg cramps. But they occur most often in older adults. Common causes of night leg cramps include:

- Muscle overexertion
- Prolonged sitting
- Dehydration
- Pregnancy
- Diabetes
- Decreased potassium levels
- Neuromuscular disorders, such as Parkinson's disease
- Certain medications, such as albuterol, niacin, diuretics, and some calcium channel blockers and antipsychotic medications
- Alcohol use

If you do get a leg cramp, you may be able to make it go away by:

- Walking on the affected leg
- Massaging the affected muscle
- Straightening your leg and flexing your foot toward your knee until you feel the calf muscles stretch
- Applying a cold pack to the affected muscle
- Taking a hot bath

To help prevent night leg cramps:

- Drink plenty of fluids during the day.
- Stretch your leg muscles before bedtime.
- Get adequate potassium in your diet.

If you have frequent and severe leg cramps at night, talk to your doctor. Treatment results vary. But the most effective treatments based on current research are:

- Vitamin B-12
- Gabapentin

Night leg cramps should be distinguished from another common cause of night leg discomfort called restless legs syndrome, a condition in which your legs have a creepy, crawly or fidgety sensation unless you move them. The sensation often worsens as night approaches. Restless legs syndrome is a neurologic condition that requires different treatment from that of night leg cramps.

## Scleroderma Hints.

Scleroderma can cause the mouth area to shrink and harden, which can impair chewing, brushing, flossing, and dental work. Facial exercises can help; ask your dentist or physical therapist for mouth exercises. Use child-size toothbrushes. Try to find a dentist familiar with Scleroderma dental problems.

Dentists should use pediatric-size molds for impressions, provide tooth rests to ease the stress of keeping your mouth open, and arrange hand-signals for the patient to signal any discomfort during dental procedures.

For tooth extractions, see an oral surgeon so that the jaw can be relaxed manually while you are under anesthesia.

Scleroderma Lips: Deep lines around the lips worry many scleroderma sufferers but unfortunately [collagen injections](#) and laser treatment are not advisable as they may cause scarring. Tightening of the skin of the face may lead to microstomia - a small mouth. [Facial and mouth exercises](#) may help. "Disappearing lips" can be a very upsetting cosmetic problem and a reputable plastic surgeon may be able to perform an operation called a mucosal advancement.





**On June 3, 2007  
the Scleroderma Association of Saskatchewan**

**5<sup>th</sup> Annual Scleroderma Awareness Brunch  
- "Goin' Country"**

~Sunday June 3<sup>rd</sup>, 2007

~Time: 12:00 noon-3:00pm

~Travelodge Hotel-Imperial  
**Ballroom (lower level) 4177 Albert St.  
South Regina, SK (parking in back)**

~Motivational speaker Dr. Todd Sojonky

~Entertainment: Roberta Nichol, Eastview  
Getalong Linedancers

~Door prizes, Silent Auction, **All proceeds  
will be donated to scleroderma research in  
Linda's Shauf's name.**

~Advance tickets only

~For tickets, information and donations  
contact:

~Sandy MacPheat Ph: 775-0826

~Sharon Matson Ph: 789-0472

~Donated items for the silent auction and door  
prizes are needed. Please contact your local  
businesses, family and friends to see if they  
will make a donation.

~Everyone is welcome to attend.

**June 9th, 2007  
Nova Scotia Scleroderma Support Group**

**LIVING WELL WITH SCLERODERMA  
NEW INFIRMARY HOSPITAL, HALIFAX,  
NOVA SCOTIA  
ROYAL BANK THEATER**

**AGENDA**

- Pre-registration & Sign up for
- Welcome & Introductions:
- General medical talk on Scleroderma & Q & A Dr. John Hanley, Rheumatologist

**STRESS MANAGEMENT WORKSHOP**

**PART ONE**

Living well with a Chronic Illness  
"Health & Wholeness: Body, Mind & Spirit"  
Dr. Robert Rutledge & Dr. Tim Walker

**LUNCH - TBA**

**PART TWO**

Living well with a Chronic Illness  
" Practicing Health and Wholeness: Body, Mind & Spirit"  
Dr. Robert Rutledge & Dr. Tim Walker

**Afternoon Break Out Sessions**

- What Occupational Therapy can offer to the Scleroderma Patient
- Scleroderma and special Nutritional Needs
- Dental Hygiene Problems & Dental Health
- Finish up Afternoon Sessions by
- Final wrap up: Royal Bank Theater
- Lupus patients are invited to attend these sessions especially the two part mini workshop on stress management
- This conference is free to all participants.
- Pre-registration and signing up for sessions is required by calling Amada Dillon at the Halifax Arthritis Society Office, locally at : 902- 429-7025, Or Toll free at : 1-800-321-1433
- For more information about the conference call locally: Mary Beth Clark at :( 902 ) 423-3942.



**SCLERODERMA SOCIETY  
OF CANADA**

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Calgary, Alberta  
T2W 5K5

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Phone: 1-866-279-0632  
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www.scleroderma.ca  
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Scleroderma Society of Canada

Back issues of *Strides* are available on the website ([www.scleroderma.ca](http://www.scleroderma.ca),  
(under 'contact us', go to 'publications')

Anyone who wishes the latest issue of *Strides* please contact us through the 1-866-279-0632 or email: [scleroderma@illicomanitoba.ca](mailto:scleroderma@illicomanitoba.ca)

The Scleroderma Society of Canada does not endorse any drug or treatment. Information that is provided 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.


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

**Objectives:**

- Provide Information and raise awareness about Scleroderma
- Provide information about scleroderma research.
- Provide information to persons seeking more information.
- To provide support to patients and their families
- To acquire funds from public and private sources for medical research.

**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 - Peter Woolcott - 905-730-0731  
Ottawa - Aline Alporte - 613-745-7829  
Kahnawake - Lori Jacobs - 450-638-1831  
Sclerodermie Quebec - Diane Collard - 450-922-3777  
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 - Jean Roger - 514-631-3288



We would like to invite the readers to send a note into our newspaper editor that would include their ideas, comments, suggestions, notice of something happening in their area for scleroderma, etc.

We would also like to have a 'letters to the editor' section. So please send these in.  
[scleroderma@illicomanitoba.ca](mailto:scleroderma@illicomanitoba.ca)