



Scleroderma Society of Canada

## Change of Name

Did you notice the new name for our newsletter? The change from *Strides* to *Canadian Scleroderma News* was a decision of the Board of Directors at their September 30, 2007 meeting. It was felt that the new name better reflects the national scope of the Society.

“Every leaf speaks  
bliss to me,  
fluttering from the  
autumn tree.”

- Emily Bronte



Photo by  
Larry Trush

## President's Message

Shirley Haslam

President - SSC.

A “big” hello to all! Hope everyone had a great summer! As Fall approached, our attention was directed to The Scleroderma Society of Canada Conference and Annual Meeting held in Calgary on Friday, Sept. 28 and Saturday, Sept. 29. Approximately 100 participants attended the conference, during which they were inspired, motivated, and educated by outstanding presenters. As well, the Canadian Scleroderma Research Group held their First Annual Scientific Conference at the same time. The CSRG brought together 74 doctors, medical students, nurses and others in fields of study related to scleroderma research to hear presentations and to discuss common issues which provided opportunities for interaction between patients and professionals.

The joys of attending such an event includes new friendships made, the sharing of stories and celebrating together in a social setting. Thanks to the wonderful Calgary hospitality, participants enjoyed a fabulous bus tour exploring the city of Calgary, on the Friday afternoon, (home made cookies included), followed by line – dancing in the evening. Read more about this in the newsletter.

At our Board Meeting following the conference, we had much to discuss and new initiatives to consider in the areas of communication, awareness, fundraising, research and patient support. We will keep you posted on our website and in our newsletters throughout the year.

We are well into the planning of our Conference and Annual Meeting for 2008, which will be held in Ottawa on Sept 19 and 20. So mark your calendar and watch for more information coming soon.

This is my second year as President. It is a privilege to lead this vibrant group – all volunteers- who work on your behalf to get the message out about Scleroderma. If you have any suggestions or comments, we would love to hear from you. You can reach us at [info@scleroderma.ca](mailto:info@scleroderma.ca) or directly to me at [srunia@sympatico.ca](mailto:srunia@sympatico.ca)

Best wishes to each and every one of you. Keep well.

## Report on the Annual General Meeting and Conference

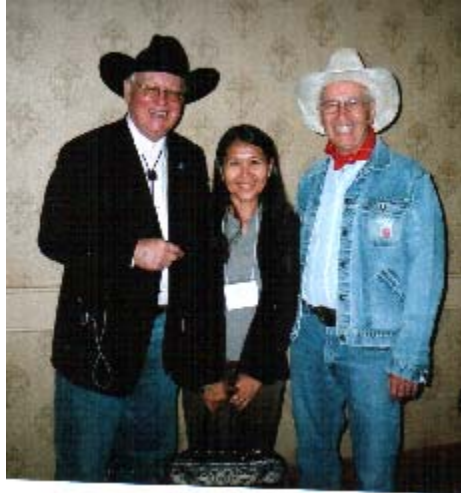


The Scleroderma Society of Canada held their Eighth Annual Conference and General Meeting at the Coast Plaza Hotel and Conference Centre in Calgary, Alberta on September 28 - 29, 2007.

The Friday evening 'meet-and-greet' social function maintained some Calgary tradition by offering a western theme for the evening. The Chinook Country Line Dancers entertained with a lively demonstration of line dancing, which inspired a large group of participants to join in the lessons

which followed. While resting from that exercise, the audience was introduced to a grey-haired old 'cowboy' by the name of Jesse Mannerly (not his real name – rumour has it that his real identity is someone closely connected to the local support group). Jesse had prepared a composition of 'cowboy poetry' for the occasion, the story of his wife and her troubles with scleroderma.

(you will find the poem on page 6)



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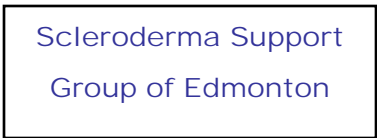
On Saturday morning, the audience of approximately 100 people was welcomed by Ron Gullickson, president of the local host group, the Scleroderma Society of Southern Alberta. The program was chaired by SSC president Shirley Haslam, who introduced the first speaker, Dr. Jan Storek from the University of Calgary Medical School. Speaking on the topic of therapy by way of blood or bone marrow transplantation, Dr. Storek brought information about some of his research on such treatment for autoimmune diseases. The second presenter, and featured speaker, was Dr. Marvin Fritzler, a noted researcher in autoimmune diseases from the University of Calgary. He is also Director of the Mitogen Advanced Diagnostics laboratory in Calgary and is Chair of the Alberta Science and Research Authority. Dr. Fritzler's presentation on advances in the diagnosis of scleroderma, and on other aspects of the disease as well, was very informative and provided encouragement in showing how much work is being done for this disease.

The morning sessions concluded with the business portion of the Annual General Meeting. President Shirley Haslam presented the Directors' Report and Research Liaison Bob Buzza presented a summary of developments in the work of the Canadian Scleroderma Research Group (CSRG). As Past President, Bob Buzza conducted the proceedings for the election of the Board of Directors for the coming year.

A unique opportunity to bring physicians and patients together occurred at our conference during the lunch break. The Canadian Scleroderma Research Group held its First Annual Scientific Conference in conjunction with our Society's conference this year. The CSRG brought together approximately 75 doctors, medical students, nurses and others in fields of study related to scleroderma research to hear presentations and to discuss common issues. The CSRG conference group and the SSC conference group joined at lunch time for mutually beneficial interaction in an informal way, followed by a question and answer session that resulted in excellent dialogue. This gathering of patients and professionals was a notable first such event for Canada in action being taken for the cause of scleroderma.

The afternoon sessions offered choices for those attending our Society's conference. Dr. Sharon LeClerc's session offered clear and current information to help people understand scleroderma and its effects. Dr. Chris Andrews focused on the functioning of the gastrointestinal system, how scleroderma can have an impact on it and possible ways of managing such effects. Carolyn Johns, a physiotherapist, offered a very informative and helpful presentation on exercise strategies for people with scleroderma.

The Scleroderma Society of Canada extends thanks to the local support group, the Scleroderma Society of Southern Alberta, for hosting the conference. We sincerely thank all those attended this event. The conference was a success because of your participation, which required a sacrifice of time, energy and money on your part. Also, special thanks and appreciation are extended to the sponsoring corporations, organizations and individuals for their generous support because this event is only possible with financial assistance. In particular, the corporate sponsors were Actelion Pharmaceuticals Canada Inc., MSL Encysive Canada Inc., Liquid Capital, Trimac, GryzkoHarperBouw Chartered Accountants and RE/MAX Landan Real Estate. Support came from the following organizations: the Scleroderma Support Group of Edmonton, the Arthritis Society of Alberta and NWT and the Alberta Racing Commission.



**Board of Directors for 2007-2008**

- President** Shirley Haslam  
(Scleroderma Society of Ontario)
- Vice-President** Normand Ricard  
(Sclerodermie Quebec)
- Secretary-Treasurer** Grant Dustin  
(Scleroderma Society of Southern Alberta)

- Directors-at-Large**
- Mary Beth Clark  
(Scleroderma Support Group of Nova Scotia)
- Gillian Little  
(Scleroderma Support Group Edmonton)
- Marion Pacy  
(Scleroderma Association of Manitoba)
- Catherine Fortune  
(Scleroderma Society of Ontario)
- Junella Weiss  
(Scleroderma Association of Saskatchewan)

- Webmaster**, Ron Gullickson
- Research Liaison Officer**, Bob Buzza



**New Board for 2007-2008**  
 Junella Weiss, Gillian Little, Grant Dustin, Marion Pacy, Catherine Fortune  
 (Front) Normand Ricard, Shirley Haslam, Bob Buzza  
 (missing is Mary Beth Clark)

## Research Report

presented to the 2007 AGM by Bob Buzza, SSC Research Liaison Officer

We have collaborated with the Canadian Scleroderma Research Group (CSRG) in grant applications to the Canadian Institutes of Health Research since 2004. A Team Development grant of \$99,975 was awarded that year. The following grants have been awarded in 2007:

- 1) A New Investigator grant of \$262,000 to develop and validate a **patient**-assessed disease activity index in systemic sclerosis (SSc).
- 2) A Training Initiative Program grant of \$1,800,000 to examine the underlying causes of SSc, to help identify therapies for SSc and other diseases with a chronic fibrotic component, and to develop new capacity to perform high quality, trans-disciplinary research in multiple aspects of SSc in Canada by training laboratory and clinical researchers.
- 3) A New Emerging Team grant of \$895,865 to create a multidisciplinary, cross-pillar team to perform high impact SSc research using the longitudinal, prospective Canadian SSc patient data base to define subsets, create disease activity and organ damage indices, and validate them using modern statistical techniques.

A number of other grants to SSc researchers such as Quebec's Dr. Jean Luc Senecal have also been awarded. Industry and various universities have committed \$269,000 toward CSRG research. In addition, the SSC and several of its Member groups have committed over \$280,000 to support the work of the CSRG. In particular, the SSC has provided funds to maintain and enhance the CSRG's sophisticated, 680-member data base, which is used for research purposes.

In addition, a SARD Research Alliance Team is applying for a National Clinical Research Network in SARD grant of approximately \$5M. (SARD is an acronym for Systemic Autoimmune Deficiency Diseases.) We are represented on the SARD team. We have also been working with Lupus and Sjogren's representatives to have a survey of SARD patients incorporated in the grant application. Results would be used for advocacy and training purposes.

During the summer, over a dozen students worked with CSRG mentors on a wide range of research projects. Students are also being selected to conduct research this winter. As a result of all this activity, many research articles and abstracts have been and will be published nationally and internationally. These will be featured as posters at our AGM in Ottawa next September.

Members of the SSC and the CSRG have developed an effective and mutually beneficial working relationship. SSC Directors participate in CSRG meetings. An SSC Director serves on the CSRG Board of Governors. Four SSC Directors serve on the CSRG's Advocacy/Knowledge Translation Committee, which SSC VP Normand Ricard chairs. The SSC also has a representative on the CSRG Training Committee, which screens student/mentor grant applications. Newsletter exchanges are in place. Website cross-references are being refined and advertised. Lay language research summaries are being developed and circulated.

Research facilitator Dr. Marwen Naim and statistician Ying Lu have joined Director Dr. Murray Baron and Study Coordinator Dr. Suzanne Taillefer to support the CSRG research teams that have been and are being formed. As many as 44 investigators, rheumatologists and collaborators have been involved in a single grant application, so support and coordination is demanding!

*Respectfully submitted, Bob Buzza, SSC Research Liaison Officer*

### 2007 SCLERODERMA RESEARCH SUMMARIES

**Brief summaries of  
scleroderma research  
undertaken last summer are  
being posted on our website:  
[www.scleroderma.ca](http://www.scleroderma.ca)**

**Technical summaries of the  
same research are being posted  
on a new CSRG website:  
[www.csrg-grcs.com](http://www.csrg-grcs.com)**

## Fundraising Campaign

The Scleroderma Society of Canada has taken on a huge challenge by declaring an objective of raising \$500,000 in the coming year.

This will require the work and support of many people so we are asking for your help. If you have expertise in fundraising or know of someone who does, please contact us. If you have knowledge of businesses, organizations or individuals who may be able to support us in this effort please share this with us. We welcome your assistance and suggestions.

Please contact Normand Ricard, SSC vice-president or Grant Dustin, SSC secretary-treasurer.

Normand Ricard      ricardnormand@yahoo.ca      phone 514-206-5327

Grant Dustin      mgdustin@telus.ca      phone 403-281-7616

### Promoting Awareness

Promoting greater awareness of scleroderma is emphasized in the month of June each year. June this year featured promotional activities taking place in communities across Canada.

- over 84 municipalities officially declared June to be 'Scleroderma Awareness Month'
- a scleroderma conference (Halifax)
- proclamations in the Legislative Assembly (BC and Ontario)
- proclamation in the House of Commons
- displays of posters and literature and sale of pins and notecards

### MEETING WITH THE MINISTRY OF HEALTH

On June 11<sup>th</sup>, 2007, Shirley Haslam and Normand Ricard from the SSC, representatives from Lupus Canada and from the Sjogren's Society of Canada met with Dr. Jo Kennelly, Chief Policy Advisor for the federal government Ministry of Health. These representatives had an opportunity to discuss the following three major concerns, which their committee had set as common priorities.

These are as follows:

1. A far greater priority and percentage of allocated funds needs to be given to research about autoimmune diseases.
2. The CIHR grant applications need to be processed in a reasonably efficient time frame.

Health Canada needs to find a way to expedite the review and approval of established and novel treatments. A representative from the CIHR and the Public Health Agency of Canada also attended the meeting. The concerns expressed by the representatives generated considerable discussion, with agreement to hold follow-up meetings. Dr. Paula Stewart from Public Health will be the contact person. Further efforts will continue in the coming year.

## Change On The Range

by Jesse Mannerly (Cowboy Poet)

Tomorrow we'll get up early and we'll learn somethin' new,  
I expect there have been changes, more than a few.  
We'll hear from the doctors and all about the SSC,  
But tonight let's just set a spell – and hear some cowboy poetry.

Many years ago, on a bright Alberta spring day,  
The wife was out in the corral, feedin' some hay.  
I was watchin' and figured she was workin' up a sweat,  
She's small but a darned good worker, on that you can bet.

A cold wind was blowin' and she was warmly dressed  
So I wondered why she stopped – could it be to rest?  
I went to her and she showed me her hands – all turned blue.  
Amazed, I said Ethel, "What the heck is wrong with you?"

Well, she spit downwind and peered from 'neath her big hat,  
Sort of offish, like that green-eyed Felicity – her favourite old cat.  
"It's the darndest thing," she said, "Something totally new."  
"Not sure when it started, or how – I haven't got a clue."

"Maybe your underwear is hitched too tight." was my sage advice.  
That look again. "Don't joke with me Jesse. I won't tell you twice."

A strange thing this was and it seemed there was no explanation.  
But I knew somethin' besides me was causin' some aggravation.

It happened again and again, her hands goin' white, then blue.  
I'd never seen the likes – it was plumb scary, that's for true.  
We was some worried so figured her doctor better have a say,  
But we weren't hollerin' 'Yahoo' about a trip to the city that day.

The doctor had a look at Ethel, 'specially her hands and her feet,  
Then asked her some questions – "What are your habits? What do you eat?"

He went out to talk with a doctor friend – a short time he was gone.  
When he returned, he said "Ethel, you have Raynaud's  
Phenomenon."

Ray's what? We looked at each other in a dumbstruck kinda way.  
Never heard of Raynaud's Phenomenon – what could a body say?  
So we asked what to do. Was there a pill to take, would it bring harm?

The doc said, "Ethel, you'll have to cope with this, mostly keep warm."

A few years went by, with most things stayin' the same,  
Cows and calves, fences to fix – and the old mare still lame.  
Ethel out helpin' with chores, except in the winter cold,  
Hired the neighbour's kid at times – I must be gettin' old.

Then wouldn't you know it, as if that Raynaud's thing wasn't enough,  
Ethel's fingers and hands were gettin' all swollen, tight and tough.  
She could hardly tighten the cinch on her saddle or get a grip on the reins.  
Agein' is one thing but these were some mighty strange aches and pains.

The skin on her arms got real stiff and hard, like old boot leather,  
And sore! Why, she could hardly stand the touch of a feather.  
Now Ethel, she's not one to complain, to feel low or to whine,  
So I knew it was bad when she said, "Jesse, I ain't feelin' so fine."

At meal time, Ethel could really chow down – had a darned good appetite,  
But now she had trouble to eat and swallow – somethin' sure wasn't right.  
The troubles continued, like the bad luck we had in 1982,  
So back to her doc we went for help, to see what he could do.

The doc was so puzzled – he admitted he couldn't figure it out.  
This was a lot tougher to deal with than a bad spell of gout.  
So a specialist was next. 'Rheumatologist' it said on the door.  
She studied Ethel's charts and tests, then checked her some more.

She described Ethel's condition and sorta put us at ease.  
"It's called scleroderma", she said "a rare but serious disease."

Ethel looked at me kinda wide-eyed, like a calf bein' branded.  
I guess we were both wonderin' what fate she'd been handed.

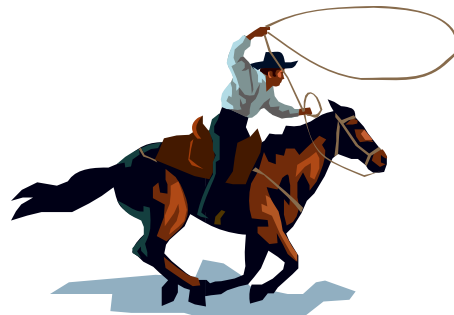
Life around here used to be simple – pretty much meat and 'taters.

Now it's a lot of blood tests, channel blockers and vasodilators.

Ethel has tried a lot of different treatments, some work, some don't,  
It's frustratin'. We've struggled and worried, but give up we won't.

Sometimes we wonder who dealt the cards in this here game,  
No matter. Whatever the hand, we'll play it out and attach no blame.

Life can show us some things mighty fine - some scary and strange,  
But we'll keep doin' the best that we can, here at home, on the range.



## EXERCISING WITH SCLERODERMA

Presented by Carolyn Johns, physiotherapist,

Speaker at the 2007 conference

### Benefits of Good Posture

- Distributes your body weight evenly
- Decreases stress on muscles, ligaments, and joints - decreased risk of injury
- Helps keep body organs healthy
- Allows you to breathe fully
- Promotes good circulation
- Increased energy available

### Goals of Exercise

- Maintain joint/soft tissue range of motion (ROM)
- Decrease pain and stiffness
- Increase strength
- Maintain cartilage & bone health
- Improve cardiovascular fitness/endurance
- Help you to lose weight
- Make you feel better about yourself
- Reduce your stress and anxiety
- Improve your sleep

### SARD – Systemic Autoimmune Rheumatic Diseases

Since the Consensus Conference on Systemic Autoimmune Rheumatic Diseases (SARD) conference was held in December, 2005 in Toronto, a number of initiatives are taking place as a result of goals established at that conference:

A grant application for the establishment of a new Clinical Research Network is being established. This will be the Systemic Autoimmune Rheumatic Diseases (SARD) Research Alliance.

The development of a SARD report card is being pursued as an integral part of the grant application.

The goals of this report card are:

- to highlight the strengths and gaps in SARD diagnosis and treatment
- to put SARD on the national and provincial health care agendas in Canada.

Representatives from the SSC are participating at the committee level in these initiatives to ensure that the needs of patients are realistically addressed.

### New Gadgets

#### Palm Peeler

Breakthrough vegetable peeler lets you peel without gripping a peeler.

Palm Peeler slips over your middle finger to put the power of peeling right in the palm of your hand! Contoured peeler's soft rubber grip is gentle on your finger. Just run your palm away from you, along vegetable to be peeled; stainless steel blade does the work. Top-rack dishwasher-safe.

\$7.99 at Home Outfitters.





## Scleroderma Society of Canada

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email (webmaster): info@scleroderma.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, therefore individualized medical management is essential. It is recommended that all drugs and treatments be discussed with one or more doctors or health care providers to assure proper evaluation and treatment.

Website: [www.scleroderma.ca](http://www.scleroderma.ca)

*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 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

### 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 - Paulette Zielinski - 514-631-3288

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

So please send these in.

[scleroderma@simplyconnected.ca](mailto:scleroderma@simplyconnected.ca)

Back issues of *Strides* are available on the website ([www.scleroderma.ca](http://www.scleroderma.ca),

(under 'contact us', go to 'publications')

please contact us through the 1-866-279-0632 or email: [scleroderma@simplyconnected.ca](mailto:scleroderma@simplyconnected.ca)