



Scleroderma Society of Canada

# STRIDES

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## Annual General Meeting 2006

Fredericton, September 23

The Annual General Meeting and Conference brought together 57 people with a common interest, scleroderma.

Physicians, patients, friends and family of patients, representatives of other health organizations and representatives of pharmaceutical companies all shared their knowledge and concerns with a focus on scleroderma.

Those attending this year's AGM added to their knowledge of the disease and its treatment. Presentations and discussions covered a variety of topics, including explanations of the disease, recent scientific studies, expanding knowledge and awareness of scleroderma, research projects taking place and fundraising for research.

The business meeting offered reports on the Society's activities during the past year and determined the new Board of Directors for next year. See page 2 for a complete report. Watch the website for further information as well.

In addition to the meetings and sessions, there were opportunities to meet others and to share stories, to enjoy food and laughter and to learn about what's happening in other parts of Canada and internationally. Aside from the AGM and Conference, people enjoyed seeing the lovely city of Fredericton, in a beautiful part of Canada.



A Very  
Happy  
Holiday  
Season to  
Everyone.

## Report on the AGM and Conference

The Scleroderma Society of Canada held their Annual General Meeting and Conference at the Crowne Plaza Lord Beaverbrook Hotel in the beautiful city of Fredericton, New Brunswick on September 23, 2006.

Prior to Saturday's program, there was an opportunity to participate in a tour of the city on Friday afternoon. The warm, sunny day was perfect for those participating in either the bus tour or the walking tour to enjoy the architecture, scenery and historic buildings of Fredericton.

The AGM started on Saturday morning with greetings of welcome from the Mayor of Fredericton, Brad Woodside, from the Chair of the AGM and Conference, Deanna Cosman and from the President of the SSC, Bob Buzza. A total of 57 people attended.

The program for the day featured presentations from several guest speakers. (complete summaries of the presentations will appear separately) Normand Ricard and Diane Collard, members of the executive of Sclerodermie Quebec, presented a summary of the work being done by their organization. This included a progress report on the amazing fund raising and scleroderma awareness campaigns being carried out in Quebec. Another very significant feature of scleroderma work in Quebec is the research being done by Dr. Jean-Luc Senecal, a noted specialist in scleroderma research who leads a team of researchers at the University of Montreal's Notre Dame Hospital. In his presentation, Dr. Senecal emphasized the importance of early diagnosis of scleroderma and the need for efficient treatment, even though the causes are not yet known.

The next speaker was Dame Carol Black, from London, England. She is a Professor of Rheumatology at the Royal Free Hospital and University College Medical School in London and is an internationally recognized authority on scleroderma. In her presentation on the topic 'Scleroderma – Yesterday, Today and Tomorrow', Dr. Black pointed out that a great deal has been learned about the disease and that scientific research is continuing to reveal useful information about it. She presented details of some of the knowledge that has been gained in recent years. Dr. Black also had a special session in the afternoon in which she responded to questions that had been previously submitted as well as answering many questions from the audience. We were fortunate to have this internationally recognized authority on scleroderma as our featured speaker.

After lunch Suzanne Taillefer, national study coordinator for the Canadian Scleroderma Research Group (CSRG), summarized the work of the CSRG. She emphasized that the gathering of data for the national patient database is expanding, with 464 patients involved so far. Suzanne noted that funding the project is an on-going challenge, with hope for success in recent grant applications.

The final speaker of the day was Dr. Dennis Bowie, a respirologist from Halifax, and an Associate Professor at Dalhousie University. In speaking about scleroderma as a lung disease, Dr. Bowie noted that treatments have improved as a result of increased research and safer and better drugs. Similarly, he pointed out that in cases of scleroderma pulmonary hypertension there are more options today and a better prognosis.

In summary, the audience at the conference learned that even though the complexities of the disease are a continuing challenge to physicians, researchers and patients, there have been advances in managing the disease and in treatments for it. There is expanding hope and interest.

The afternoon sessions concluded with the business portion of the Annual General Meeting. Reports were presented and an election resulted in the new Board of Directors for the coming year.

President	Shirley Haslam	( Scleroderma Society of Ontario)
Vice-President	Normand Ricard	(Sclerodermie Quebec)
Past-President	Bob Buzza	(Scleroderma Association of BC)
Secretary-Treasurer	Grant Dustin	(Scleroderma Society of Southern Alberta)
Directors-at-Large	Mary Beth Clark	(Scleroderma Support Group of Nova Scotia)
	Tammy Gangl	(Scleroderma Society of Southern Alberta)
	Gillian Little	(Scleroderma Support Group Edmonton)
	Marion Pacy	(Scleroderma Association of Manitoba)



Back: Normand Ricard, Gillian Little, Bob Buzza, Tammy Gangl, Grant Dustin  
Front: Marion Pacy, Shirley Haslam, Mary Bether Clark

### **The Canadian Scleroderma Research Group (CSRG) Why it is important to get involved in the patient database?**

In her presentation at the AGM, Suzanne Taillefer (national study coordinator for the CSRG) presented information to indicate the progress being made by this research group. She also emphasized the importance of patient involvement in the work being done by the CSRG.

*A large part of the work of the Canadian Scleroderma Research Group is to establish a national patient database. Patients are interviewed and tested in centres across Canada to gather data.*

#### **TYPE OF DATA COLLECTED**

The patient's history – When the disease started, when diagnosed, how it effects each organ, how it affects function, psychological, work and pain aspects, and resource utilization

The doctor's exam – Measures specific to scleroderma like “skin score”, joint count, disease activity, severity and damage

Laboratory Investigations – Routine blood tests but also results of X-rays, echocardiograms, CT scans, pulmonary function tests, etc...

**Serum** sample collected at each visit.

### CHARACTERISTICS OF SAMPLE

464 patients enrolled between September 2004 and September 2006

Data entered in the database on 420 patients

205 patients seen for visit 2

Just started seeing patients for visit 3

Low refusal rate for patients

87% females, mean age = 56 y.o.

Mean duration since diagnosis = 7.3 years ( $\pm$  8.1)

About 80% fulfill the American College of Rheumatology Criteria for Scleroderma

### AREAS OF RESEARCH SO FAR

Disease severity

Disease activity

Functioning

Lung

Comorbidity measurement

Subsets (limited vs. diffuse)

Antibodies

Psychosocial

Capillaroscopy

100 new patients will be seen each year

**Thanks to all patients that are involved and asking for more patients to be involved.**

### PARTICIPATING RHEUMATOLOGISTS

**Dr Jones**

Edmonton, AB

**Dr Dunne**

Vancouver, BC

**Dr Markland**

Saskatoon, SK

**Dr Docherty**

Moncton, NB

**Dr Baron, Dr Mathieu Dr Senécal**

Montreal, QC

**Dr Rahman**

St John's, NL

**Dr LeClercq & Dr Abu-Hakima**

Calgary, AB

**Dr Robinson**

Winnipeg, MB

**Dr Bookman & Dr Johnson**

Toronto, ON

**Dr Pope, London & Dr Khalidi,**

Hamilton, ON

**Dr Smith**

Ottawa, ON

**Dr Sutton**

Halifax, NS

## Questions & Answers that Dr Black gave at AGM

**Scleroderma can be cared for by either dermatologists or rheumatologists, or other specialists. Skin treatments rarely help for severe disease. Surgery should be approached with great caution. Ulcers on the hands & feet continue to plague many scleroderma patients. Has any new treatment been found to speed up the healing process?**

Sildenafil may help

Bosentan prevents ulcer formation

**Is there any research suggesting that hyperbaric chamber oxygen treatment can be beneficial for some scleroderma patients? One of our members had severe scarring on his arms. His skin was virtually impenetrable. After about 20 chamber treatments, his skin is now pliable. Another member found her lung function improved greatly after 6 treatments.**

Very restricted availability

Some individual success

**What symptoms & pulmonary test levels determine if a scleroderma patient should be on oxygen? Is it important to start oxygen therapy early to help prevent worse lung involvement? Does oxygen help with lung fibrosis? Is oxygen normally used to treat PAH in scleroderma patients?**

There is no evidence that oxygen prevents or helps with lung fibrosis, and it should be used at rest only if the O<sub>2</sub> saturation is less than 90%.

O<sub>2</sub> can be used at night to exclude desaturation during sleep, if saturations are in the low 90's.

**What is the long term outlook for patients taking Tracleer (Bosentan) who have scleroderma? I have been taking it for 3 ½ yrs for PAH. My liver enzymes are affected, but not the ones normally affected by taking Tracleer. Have there been other side effects like this with long-term use? My doctor says I don't have any other options except taking Tracleer. I am not a candidate for lung transplant.**

There are several treatments for PAH and often drugs are combined.

**When I was told, after a CT-scan, that I had inflammation of the lung, it was suggested that I undergo chemo-therapy at some future stage. Why was this, and what should be done now?**

Cyclophosphamide and/or azathioprine can be useful in some patients with inflammation and fibrosis in the lung.

**What's the best way for lay people to find out what's being done internationally to improve diagnosis and treatment for scleroderma patients? How is research shared between professionals in Europe & North America?**

The web is confusing. We need a central, current source of reliable information.

Patient groups— their web sites, newsletters.

Hospital departmental literature.

Research is shared person-to-person, and through

international workshops and conferences, recently in Boston 2006, Scleroderma International Research Workshop, report not yet out.

**For 20 years, I've had localized scleroderma plaque AND linear growing. Is this normal? Also, my eyes have been burning, swelling, & hurting for a year. Could this be from scleroderma? Nothing seems to help it.**

Usually morphea/linear scleroderma stops sooner

Burning eyes: unlikely to be related to the localised SSc

**What is the most significant research breakthrough in scleroderma research in recent years?**

Treatment of pulmonary hypertension

Better understanding of the disease process

**In terms of your personal experience, approximately what percentage of researchers are actively involved in scleroderma research?**

Complex: so much research in other areas helps SSc

Why is it so difficult for researchers to work together to find the origin and the cure?

Some do work together very well.

Perhaps some worry about priority and are wary of revealing their work in progress

**What, if any, is the direct evidence that stress is a recognizable factor in the cause of scleroderma? In the event that it is a factor, how significant can it be?**

No direct evidence

Can you recommend some way to relieve an itch associated with CREST Syndrome?

**I've had it for approximately 4 years. For 3 years, it was everywhere. For the past year, it is not itchy on my back, outside of arms, & lower legs. The dermatologist thought it might be caused from skin tightening & irritating nerve endings.**

Many factors lead to itching

My most successful treatments:

Atarax (hydroxyzine 25mgs r.d.s.)

Low dose steroids

Topical tacrolimus

**I suffer from finger ulcers from Raynaud's Phenomenon & scleroderma. I had my right index finger amputated three years ago, & still suffer quite severe nerve pain daily. My entire right hand is pins-&-needles & I'm weak up to the elbow. I also lost part of my left index finger to dry gangrene. Should doctors treat finger ulcers aggressively when they first develop to avoid amputation & gangrene? What treatments & drugs do you recommend?**

aggressive treatment is often indicated

i.v. prostacyclin, digital sympathectomy, sildenafil, clopidogrel

**I have scleroderma. Should I be taking out or putting in certain foods for my diet? Also, I have several calcium-deposit bumps. Should I stop taking calcium "for my bones" pills?**

Continue to take the calcium

No dietary change helps calcinosis

**What is the best treatment for slow motility of the bowels for scleroderma patients? Does diet make any difference, or are there certain foods which help, or some to avoid? Can the bowels just stop working, & then what is the treatment?**

Domperidone 10mgs t.d.s.

Diet can help

The bowel can stop working and there are ways to help this.

**I have scleroderma & am told that I have a loop in my bowel or pseudo-obstruction. My stomach gets very hard, bloated and extended. I eat small meals, & often feel full after a few bites. I have thrown up after eating. If a patient is unable to have surgery for this, what options are there?**

Domperidone 10mgs r.d.s., Erythromycin 250mgs daily, Dietary manipulation

PEG, PEJ, PN

**What are the early symptoms & warning signs of kidney involvement & failure for patients with scleroderma? A friend who had scleroderma recently died. It seemed to happen within a month.**

Headaches, Nausea, Feeling of sudden 'ill health'

**How soon is prostacyclin therapy effective?**

**Why is it given as a last resort ?**

- The effect is variable.
- It is given at different times depending on the problem.

**Does the drug Cyclophosphamide-Cytosin show promise in slowing skin thickening and lung function deterioration?**

Some

**What alternative treatments have proven to be beneficial?**

None proven

**How important is it for people with scleroderma to participate in clinical trials and contribute to data bases?**

- Very important

**What is being done to inform general practitioners, interns, medical students, and those in the nursing profession of the symptoms and repercussions of scleroderma?**

Many avenues – medical journals, specialised units, patient organisations etc – it is a rare disease posing special difficulties for education.

**What life style changes help people cope more effectively?**

Pacing oneself

Exercise within capability

**How closely is scleroderma related to other autoimmune diseases such as lupus, Sjogren's, myositis, and vasculitis, to name a few?**

Quite closely, but there are significant differences

**Is it possible to go into remission from scleroderma and, if so, for how long, on average?**

Yes: variable course in individual patients

## PRESIDENT'S MESSAGE

Greetings to all!

For this first message in the newsletter as your new President of the Scleroderma Society, I would like to tell you a little about myself. For many years I have been a volunteer in various scleroderma groups, having served on the Board of Directors of the Scleroderma Society of Ontario and The Arthritis Society: Ontario Division. I also co – chair a support group in my home area, Mississauga, ON. As President of the Scleroderma Society of Canada, I look forward to the opportunity to participate at a national and global level.

As a scleroderma patient, I feel I have a fairly good understanding about what we deal with in our day to day lives. The past 20 years have not been easy when it comes to managing day to day living – many days are good, but there are those days, well, what need I say. I have always maintained that a positive attitude is crucial and that one needs to take control of managing the disease. My belief is to live as “normal” a life as possible and do all I can keep myself “feeling good”.

So I have accepted the challenge, but it is not one I can do alone. We are all in this together, all part of the team: your local support group, in your community, at the provincial level and the national level. At the AGM on September 23<sup>rd</sup> in Fredericton, a group of eight members from across the country accepted the challenge to be Board Members. We are ready.

On behalf of all members, I express a most sincere thank you to Bob Buzza for his incredible work as President over the last five years. We are pleased that he will stay on as Past – President for this coming year and focus his energy in the research area.

To keep you informed, this newsletter and subsequent newsletters will include information about the speakers and the events from the AGM in Fredericton, and much more. As well don't forget to check our website.

Keep smiling,  
Shirley Haslam

### What Do I Get For My \$4.00?

You become a member of the Scleroderma Society of Canada by joining one of the provincial scleroderma organizations that are part of the SSC. Four dollars of that group's membership fee goes to the national organization (the SSC). What are the benefits of belonging to the Scleroderma Society of Canada?

1. receive *quarterly issues of the newsletter, Strides*
  - provides helpful information
  - provides updates on developments in Canada and internationally
2. Support the work of the SSC
  - advocates for the interests of scleroderma
  - supports efforts to raise funds for research
  - serves as a channel for donations
  - organizes a national annual conference
  - conducts an annual campaign to promote greater awareness of the disease
  - works collaboratively with provincial scleroderma organizations
  - provides information to patients and to the public



### 'Tribute to Linda Shauf'

Along with all the positive aspects on the day of the AGM, there was unfortunately also a note of sadness. Former SSC Board member Linda Shauf passed away two days before the conference. A victim of scleroderma, Linda succumbed to the illness while in hospital in Regina. Recognition was given for her work with the Scleroderma Society of Canada and with the Scleroderma Association of Saskatchewan. (details below)

#### Taken in part from the Weyburn Review

##### Linda Isabel Shauf

I, Linda Isabel Shauf of Estevan, passed away in Regina on September 21, 2006. I was born to Harry and Lena Ivan on May 4, 1952. I am survived by my best friend and devoted husband of 35 years, Gerald, loving daughter, Michelle (Josh) Bock and treasured granddaughters, Claudia and Monica Bock, mother Lena Ivan, siblings, Hazel (Marcel) Glowatski, Carol Grev, Jean (Paul) Cragg, Edna (Wayne) Donnelly, Allan (Colleen) Ivan, Elmer (Sharon) Ivan and Norma (Greg) Boucher, in-laws Loris Shauf, Dale (Audrey) Shauf, Marvin (Colette) Shauf, JoAnn (Barry) Larsen, Brian (Carol) Shauf, Murray Shauf, numerous nieces, nephews, relatives and many good friends. I became involved with the Scleroderma Association of Saskatchewan in 1991 and became group president in October 2000. I was also involved with the formation of the Scleroderma Society of Canada and met many dear people all working towards a common goal for Scleroderma - finding a cure, raising funds for research, and promoting awareness.

"You may be here for only a short while. But, in whatever part you play, be remembered as part of a legacy changing someone's life for the better. It's that legacy that never dies."

Memorial donations can be made to the Scleroderma Association of Saskatchewan, c/o Gerald Shauf, treasurer, 465 Willow Bay, Estevan, Sask. S4A 2G3. Ph: 634-3433. Email: glshauf@sasktel.net.

### Hope comes from.....

"The hope, the worth, the joy we find in this life must be a real thing, not a sham. The hope has to come from the truth, no matter how hard or ugly it is, no matter how much it hurts."

Stephen May, commenting on his dislike for illusion and escapism in art

*Several of the people who attended the Society's recent AGM and Conference in Fredericton took time to visit the Beaverbrook Art Gallery. The gallery offers a great variety of interesting displays, including a display featuring several paintings by Stephen May, and quotations from some of his writing. This quotation reminds one of the message presented by some of the conference speakers who spoke about the realities of scleroderma and the hope for the future.*

quoted from

Lt.-Gov. Dr. Hermenegilde Chiasson, *Stephen May: Embodiments*

(Fredericton, NB: The Beaverbrook Art Gallery)

**Disclaimer**

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.

**SCLERODERMA SOCIETY  
OF CANADA**

95 Woodfield Rd SW  
Calgary, Alberta  
T2W 5K5  
Email: mgdustin@telus.net

Phone: 1-866-279-0632  
Fax: 403-238-2773  
Email: scleroderma@illicomanitoba.ca



Scleroderma Society of Canada

[WWW.SCLERODERMA.CA](http://WWW.SCLERODERMA.CA)

[INFO@SCLERODERMA.CA](mailto:INFO@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.**

**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.**

- 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.

Pamphlets on a variety of topics are available, free of charge, by contacting one of the Member support groups or the Secretary-Treasurer of the Society.

Scleroderma – Basic Facts
What is Scleroderma?
Managing Scleroderma
Raynaud’s Phenomenon
Pulmonary Arterial Hypertension
Gastroesophageal Reflux Disease
Medical Tests

Grant Dustin  
95 Woodfield Rd SW  
Calgary, AB T2W 5K5  
Phone: 403-281-7616  
Email: mgdustin@telus.net