

STRIDES



May

Scleroderma Society of Canada

2006

Scleroderma Society of Canada Annual General Meeting and Conference

September 23, 2006

at the

Lord Beaverbrook Hotel

659 Queen Street, Fredericton, NB E3B 5A6

Toll free: 1-866-444-1946

Room cost: \$120 plus taxes

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The program will include Friday afternoon and evening activities.

The keynote speaker on Saturday will be **Professor Dame Carol Black**, who is an international authority on scleroderma. In addition to her presentation she will offer a question and answer session. **You are encouraged to submit your question(s) for Dr. Black to:**

Bob Buzza, President, Scleroderma Society of Canada
413 – 2 Renaissance Square
New Westminster, BC V3M 6K3
Phone: 604-520-3258 Fax: 604-521-3284
Email: rmbuzza@ret.bctf.ca

Registration Fee - \$25 (includes lunch and continental breakfast)

Please complete registration form included in this issue.

For more information please contact:

Deanna Cosman, conference chair
1963 Route 845
Summerville, NB E5S 1G9
Phone: 506-763-2105
Email: cos55@nb.sympatico.ca

Grant Dustin
95 Woodfield Rd SW
Calgary, AB T2W 5K5
Phone: 403-281-7616
Email: dustin@spots.ca

or

October newsletter
will be the highlights
of the AGM &
Conference.

Answers from
Dr Black

2006 ANNUAL GENERAL MEETING PROGRAM

Crowne Plaza Fredericton Lord Beaverbrook Hotel
659 Queen Street, Fredericton, NB E3B 5A6
Tel: 1-800-561-766 Email: info@fredericton.com

Located in the historic downtown area on the banks of the St. John River.

Friday, September 22

Guided historic area walkabout **or** scenic bus tour in the afternoon.
Hospitality room meet-and-greet-and-refresh in the evening.

Saturday, September 23

Continental breakfast and registration, followed by a welcome from Mayor Brad Woodside, introductions, and report updates.

The following will be the conference presentations:

Normand Ricard on '*Sclerodermie Quebec Programs*' and
Dr. Jean-Luc Senecal on '*Scleroderma Research Results*'

This 700-member organization is raising \$5M for scleroderma research! Normand Ricard is an SSC Director, Sclerodermie Quebec VP & Chair of its Corporate Campaign. Dr. Jean-Luc Senecal has headed its research team since 1999.

Professor Dame Carol Black on '*Scleroderma – Yesterday, Today, and Tomorrow*'

Dr. Black will offer a second session, '*Answers to Audience & Presubmitted Questions about Scleroderma*'

Dr. Black is President of the Royal College of Physicians and is an international authority on systemic sclerosis (scleroderma).

Suzanne Taillefer on '*Canadian Scleroderma Research Group Update*' and

Dr. Peter Docherty on '*The Effects of Pulmonary Arterial Hypertension on Scleroderma Patients*'

Suzanne Taillefer is the Study Coordinator of the Canadian Scleroderma Research Group. Dr. Docherty is a fully participating member of the CSRG.

The business portion of the **Annual General Meeting of the Scleroderma Society of Canada** will follow the presentations by speakers.

Reports from the Directors and the Secretary-Treasurer will be presented, a fee will be set, and elections for the 2006-2007 Board of Directors will be held. The meeting is open to everyone.

Annual General Meeting Registration Form

Name: _____

Address: _____

Phone: _____

Email: _____

Registration fee: \$25.00

(payable to Scleroderma Society of Canada)

Please return your registration to:

Grant Dustin _____ or
95 Woodfield Road SW _____ register online at
Calgary, AB T2W 5K5 _____ www.scleroderma.ca
Email: dustin@spots.ca (see AGM news item)
Phone: 403-281-7616

After receiving your registration, we will send you a registration confirmation with a program outline, asking you to check off the activities you are going to participate in, and to send payment for the bus tour or whatever is else is required.

Do You Have Questions About Scleroderma?

Dr. Carol Black, featured speaker at this year's Annual General Meeting and Conference will offer a Question & Answer session, in addition to her keynote address.

She will receive your questions in advance of the conference and will reply to a selection of them at this session.

We invite you to submit your question/questions.

Please send your questions, in writing, to Mr. R. M. Buzza,

413 – 2 Renaissance Square,

New Westminster, BC

V3M 6K3,

fax 604-521-3284, or

email rmbuzza@ret.bctf.ca.

Nominations for Board of Directors

Nomination(s) for the position(s) indicated below for the Board of Directors, to be elected at the Annual General Meeting of the Scleroderma Society of Canada, September 23, 2006.

President _____

Vice-President _____

Secretary-Treasurer _____

(nominations may be submitted separately for the above)

Secretary _____

Treasurer _____

Director-at-Large _____

Submitted by _____

(name of person submitting the nomination)

I have contacted the person(s) being nominated and they agree to this nomination.

YES ___ NO ___

Nominations may be submitted to:

Grant Dustin, Secretary-Treasurer,

Scleroderma Society of Canada

95 Woodfield Road SW

Calgary, AB T2W 5K5

fax: (403) 238-2773

email: dustin@spots.ca

Delta South MLA Val Roddick introduced 12 BC scleroderma reps in the Legislative Assembly April 26th and read into-the-record a strong statement about the disease, and Joan's role in forming the Scleroderma Association of BC in 1984. The intent was to raise awareness about the disease.



In the British Columbia Legislative Assembly and a statement about scleroderma was read and entered in Hansard. Also in BC, proclamations were issued in Kelowna, Kitimat, Port Coquitlam, Powell River, Vancouver and Williams Lake. In Saskatchewan, eight cities will be issuing proclamations. In Alberta, the mayor of Calgary will be issuing a proclamation and requests for proclamations have been sent to many other municipal districts. Manitoba has also received their proclamation. There will be many more across Canada. We will report on the results of the campaign in the October issue of Strides.

June Awareness Campaign

June is "Scleroderma Awareness Month". Last year, a variety of activities to promote this were organized by our provincial groups and a national poster campaign was sponsored by the Society.

There will be a national poster campaign again this year so watch for the posters in your area, displayed in medical clinics, hospitals and other public areas.

Proclamations to recognize June as Scleroderma Awareness Month were issued in several provinces last year, by municipal and provincial government authorities. We are hoping to have more proclamations issued this year. Arrangements include announcements to be made in the Legislative Assembly of Ontario, by Ontario MPs in the House of Commons and by the mayor of many towns and cities across Canada. On April 26, twelve representatives from the Scleroderma Association of BC were introduced in the British Columbia Legislative Assembly and a statement about scleroderma was read.



**WHEREAS scleroderma is a mystery disease that affects thousands of Canadians;
and**

WHEREAS scleroderma affects women four to five times as frequently as men; and

WHEREAS scleroderma can disfigure, disable and kill; and

WHEREAS there is no known cure for scleroderma; and

WHEREAS featuring June as Scleroderma Awareness Month raises public awareness about the disease and the need for research to eradicate it

THEREFORE I,, Mayor, on behalf of the City Council of, hereby proclaim June as

SCLERODERMA AWARENESS MONTH



Pins and Notecards



Two new items have been produced to help promote greater awareness of scleroderma, lapel pins and gift notecards.

The lapel pin is in the shape of a ribbon (similar to the lapel pin used for other disease awareness campaigns) – blue with the word scleroderma on it. It's available in English or in French.

The notecards come in a package of 8 cards, with envelopes. The cards are blank on the inside, with an original painting of flowers on the cover. There are eight different paintings, the work of Jocelyn Barber, a Vancouver artist who is a scleroderma patient.

The pins and notecards may be purchased from your provincial support group contact person. They may also be purchased from the Society by contacting Grant Dustin, Secretary-Treasurer of the Society. Pins are \$3.00 each, notecards are \$6.00 per set.

New Book Available

“The Scleroderma Book – A Guide for Patients and Families, 2nd edition”, was recently written by Dr. Maureen D. Mayes and published by Oxford University Press. This book is widely recognized as an excellent resource for information on scleroderma. It is practical, thorough and easy to use.

Copies of the book are available through the provincial Member organizations, and through the Secretary-Treasurer of the Scleroderma Society of Canada.

Looking For New Editor for “STRIDES”

Seeking a Newsletter Editor

We are in need of a newsletter editor and a layout person to assist the editor. Are you interested? Do you know of anyone who might be interested in this position?

Marion (Mare) Pacy has been the editor of our newsletter, *Strides*, for the last four years. She is stepping down, taking a well-deserved rest. We sincerely thank Mare for the fine job that she has done in producing the newsletter.

For any information that you
need please call
our toll free number
1-866-279-0632.

If you have anything you would
like to see in STRIDES, please
call the toll free number
or email me at

Scleroderma@illicomanitoba.ca

Disclaimer

SCLERODERMA SOCIETY OF CANADA

95 Woodfield Rd SW
Calgary, Alberta
T2W 5K5

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Phone: 1-866-279-0632

Fax: 403-238-2773

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Scleroderma Society of Canada

WWW.SCLERODERMA.CA

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. 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 those affected by this disease, and to support research dedicated toward a cure.

Membership

Why be a member of the Scleroderma Society of Canada? Are you a member? What is the fee?

If you are a member of a provincial scleroderma organization, you are automatically a member of the Scleroderma Society of Canada. Our provincial Member organizations charge an annual membership fee, out of which they return \$4.00 per person to the national organization. There are 1200 to 1300 such fee-paying members across Canada, yielding about \$5,000.00 as the annual operating budget for the Scleroderma Society of Canada.

The Scleroderma Society of Canada provides a national voice for scleroderma, and represents Canadian scleroderma interests internationally. It provides a communication link among the 14 regional organizations, it promotes greater awareness of the disease and it supports scleroderma research. Our Society is a collaborative supporter of the Canadian Scleroderma Research Group.

We are staffed entirely by volunteers, so we are able to function on a small budget, however we need your help to continue our work. We need more members, so please join one of the provincial groups. Information on each group is provided on our website under 'support', or you can contact the Scleroderma Society of Canada.