

# CANADIAN SCLERODERMA NEWS



SCLERODERMA SOCIETY OF CANADA

JUNE 2010

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Article by Lisa Jewett



Debbie Strang & Joyce Murphy display the quilt that was raffled off in Newfoundland. Thanks to Beverly Blanchette, Jillian Clements, Joyce Murphy and their families. The money they raised will be donated for research.

## **11<sup>th</sup> Annual Scleroderma Conference “Living Well With Scleroderma” Scleroderma Society of Canada**

November 26 & 27, 2010

Westin Nova Scotian  
Halifax, NS  
westin.com

Please register by October 8th.

## 1ST SYSTEMIC SCLEROSIS WORLD CONGRESS

### Scleroderma (SSc) Featured at First World Congress

Over 1,455 doctors, researchers, and patient and pharma' representatives participated in the *1<sup>st</sup> Systemic Sclerosis World Congress* in Florence from February 11 to 13, 2010. Only 500 were expected to register, so the huge turnout, which included about 120 patients, was heartwarming.

In addition to hosting dozens of plenary and concurrent sessions on an unusually wide range of SSc topics, the Congress featured approximately 400 posters and abstracts highlighting recent research results from around the world. The opening address by the UK's Professor Dame Carol Black summarized the history of scleroderma, and the significant progress that has been made, particularly in the last decade, to understand and manage it. She cited, for example, major improvements in clinical expertise, in clinical trial activity, in cross-disciplinary collaboration, in targeted molecular therapies, and in the number and effectiveness of patient support groups as truly positive developments.

Canadian patient representatives included Mare Pacy and her daughter Dee, Catherine Fortune and her husband Tim, Normand Ricard and his wife Annette, Maureen Sauve and her husband David, Joan Kelly, and Bob Buzza. Canadian Scleroderma Research Group representatives included doctors Murray Baron, Janet Pope, Brett Thombs, Mervyn Gornitsky, and Suzanne Taillefer.

Murray and Janet served on the 46-member International Advisory Board that, with the help of basic and clinical research steering committees, designed the overall program. The program was supported by EUSTAR, which is the Trials and Research Group within the European League Against Rheumatism, the 16-member Federation of European Scleroderma Associations (FESCA) that was formed three years ago, and the US Scleroderma Foundation.

A highlight for the Canadian contingent was the opportunity to present the results of our extensive survey of scleroderma patients across Canada. This report was ably presented to the entire FESCA Board of Directors by Maureen Suave. Her presentation highlighted salient points from the 77-page final report. It resonated with Board members, many of whom have scleroderma, from the outset, for it is rare that patients, collectively, present *their* concerns and priorities as a means of influencing research agendas. It is likely that a complementary version of her report will be published in rheumatological journals in Europe and North America, in the spring.

It is not possible on one page to summarize the many presentations that were made at the Congress. The topics were simply too numerous and, in many cases, too complex to do so. It is obvious, however, that scleroderma is emerging from the shadows at an accelerating rate, and that promising research is proceeding apace across many fronts by highly competent people. And, yes, there a 2<sup>nd</sup> Congress, in Spain.



**SCLERODERMA SOCIETY OF CANADA 11<sup>TH</sup> ANNUAL CONFERENCE****NOVEMBER 26, 27, 28, 2010****WESTIN HOTEL, HALIFAX, NOVA SCOTIA**

LIVING WELL WITH SCLERODERMA :

MIND, BODY, SPIRITUAL &amp; ENVIRONMENTAL HEALTH

A WHOLISTIC APPROACH TO MANAGING YOUR DISEASE

**CONFERENCE AGENDA****FRIDAY, NOVEMBER 26<sup>TH</sup>**2:00 - 4:30 PM : HISTORIC TOUR OF PIER 21 HALIFAX : [www.pier21.ca](http://www.pier21.ca) (\$ 6.75)

4:30 - 6:30 PM: REGISTRATION

6:00 PM : SUPPER ON YOUR OWN:

7:00 PM - 10:30 PM : SCLERODERMA WELLNESS FAIR/ CSRG STUDENT RESEARCH PROJECTS, COCKTAIL HOUR ( CASH BAR ), FOOD &amp; ENTERTAINMENT

8:00 PM : WELCOME AND OPENING REMARKS

**SATURDAY, NOVEMBER 27 TH**

7:45 - 8:30 AM : REGISTRATION : CSRG STUDENT RESEARCH POSTERS DISPLAYED ALL DAY

( [www.csrg-grcs.ca](http://www.csrg-grcs.ca))

7:45 - 9:00 AM : BUFFET BREAKFAST

9:00 – 10:00 AM : WELCOMING REMARKS/ SSC ANNUAL GENERAL MEETING

10:05 – 11:30/55 AM: BREAK OUT SESSIONS

**SUNDAY, NOVEMBER 28<sup>TH</sup>**

8:30/9:00 AM : BUFFET BREAKFAST: SSC BOARD OF DIRECTOR'S

9:00 – 1:00 PM : SSC ANNUAL BOARD OF DIRECTOR'S MEETING

Please let us know if you wish to attend the Sunday Director's Meeting

**AM BREAK OUT SESSIONS:****10:05 - 11:55 AM**

1. “ LIVING WELL WITH SCLERODERMA: A PATIENT’S TOOL BOX ”: DR. BRETT THOMBS, DR. CLINICAL PSYCH., DR. GHASSAN EL-BAALBAKI, DR. CLINICAL PSYCH., & LISA JEWETT, BA (PSYCHOLOGY) & GRADUATE STUDENT, CSRG
2. “ A NATUROPATHIC/NUTRITIONAL APPROACH TO THE DIAGNOSIS AND TREATMENT OF SCLERODERMA AND AUTO-IMMUNE DISEASE ”: DR. SCOTT WOODWORTH, N.D.
3. ORAL HEALTH AND DENTAL PROBLEMS: DR. MERVYN GORNITSKY, ORAL SURGEON, CSRG
4. OCCUPATIONAL THERAPY & PHYSIOTHERAPY MANAGEMENT OF SCLERODERMA:

**DUAL SESSION: 10:05- 11:45/55 AM:**

TREATING THE SCLERODERMA HANDS : KAIRN VON MALTZAHN, OT : 10:05- 10:35

PHYSIOTHERAPIST PRESENTATION : 10:35 - 11:55 AM

**12:00 NOON- 1:30 PM: JOINT SSC/CSRG LUNCH****LUNCHEON GUEST SPEAKERS:**

12:30- 1PM: DR. EVELYN SUTTON, RHEUM., CSRG/CAPITAL HEALTH: BASIC INTRO TO SCLERODERMA

1-1:30 PM: DR. MURRY BARON, RHEUM., DIRECTOR CSRG: QUESTION & ANSWER PERIOD

**1:35 – 2:30 PM**

1. SCLERODERMA AND MULTIPLE ORGAN INVOLVEMENT :GI INVOLVEMENT : DR. GEOFF TURNBULL, GI SPECIALIST
2. LUNG INVOLVEMENT : DR. DENNIS BOWIE, RESPIRALOGIST
3. ENVIRONMENTAL HEALTH : “LINKS BETWEEN ENVIRONMENT AND SCLERODERMA. IMPROVE YOUR ENVIRONMENT ... IMPROVE YOUR HEALTH” : DR. ROY FOX, ENVIRONMENTAL HEALTH SPECIALIST /INTERNIST & DIRECTOR OF THE N.S. ENVIRONMENTAL HEALTH CLINIC
4. “ SCLERODERMA – A DERMATOLOGIST’S PERSPECTIVE ”: DR. LAURA FINLAYSON, DERMATOLOGIST

2:30 – 3:00 PM : SILENT AUCTION & SOCIAL BREAK WITH CAKE & BEVERAGES

**3:00 – 3:55 PM : BREAK OUT SESSIONS**

1. NUTRITIONAL MANAGEMENT OF SCLERODERMA: DIETITIAN CAPITAL HEALTH
2. MANAGEMENT OF MULTIPLE MEDICATIONS: PHARMACIST MEDICINE SHOPPE
3. ACUPUNCTURE : DR. DIANA TONG LEE, DR. AC MED., CMD, ND
4. “ THE EMOTIONAL EXPERIENCE OF WOMEN LIVING WITH SCLERODERMA: RESULTS FROM 16 IN-DEPTH INTERVIEWS ”: EVAN NEWTON, BA (PSYCHOLOGY) & GRADUATE STUDENT, CSRG

4:00–5:00 PM : CLOSING CEREMONY : ALL

ECCUMENICAL SPIRITUAL SUPPORT :

REV. MARK CHERRY

SCLERODERMA IS REFERRED TO AS THE DISEASE THAT TURNS YOU TO STONE . THE BIGGEST STONE IS A MOUNTAIN, AND FOR MOST OF US, SCLERODERMA IS THE MOUNTAIN IN OUR LIVES. “ IF YOU HAVE FAITH AS SMALL AS A MUSTARD SEED YOU CAN MOVE A MOUNTAIN ”.

6:00 PM : SUPPER ON YOUR OWN

**Accommodations**

Westin Nova Scotian

1181 Hollis Street

Halifax, NS

B3H 2P6

If you wish to stay at the Westin please make your own room reservations either by phone or [online](#).

When booking by phone please indicate that you are booking for the Scleroderma Society of Canada Conference in order to get the preferred rate which is \$139.00\* A limited number of rooms have been blocked so reserving early is advised. Please check out the Westin’s facilities at [westin.ns.ca](http://westin.ns.ca)

\* Group rate is available until October 26, 2010

Local – 902-496-8585 (not toll free)

902-993-7846 (toll free)

Fax - 902-425-2717

**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

Helen Goerzen ([helengo@mymts.net](mailto:helengo@mymts.net))

A registration form must be completed for each participant attending the conference.

Registration fees include a “buffet and wine”(cash bar available) social gathering on Friday night, a wellness fair, with over 20 exhibitors on Friday night, breakfast and lunch on Saturday, as well as nutrition breaks.

Please complete the registration form below and return it with payment (cheque or money order) by October 8<sup>th</sup>, 2010 to:

Shayla Kennedy – Conference Registrar

8 Orion Drive

Easter Passage, NS

B3G 1J8

For information:

Email: [shayla.kennedy@hotmail.com](mailto:shayla.kennedy@hotmail.com) or [scleroderma.ns@gmail.com](mailto:scleroderma.ns@gmail.com)

Phone: 902-225-7139

**Registration Form:**

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

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

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

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

\_\_\_\_\_ Conference Registration Fee \$30.00

\_\_\_\_\_ Student Registration Fee \$20.00

**Breakout Session Choices:**

(Please indicated your 2 session preferences per time slot)

1. \_\_\_\_\_ or \_\_\_\_\_ (10:05 am – 11:55 am)

2. \_\_\_\_\_ or \_\_\_\_\_(1:35 pm – 2:30 pm)

3. \_\_\_\_\_ or \_\_\_\_\_ ( 3:00 pm – 3:55 pm)

**Dietary Needs** - (If you have dietary needs please indicate these below so that appropriate meal choices and preparations can be made)

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Arrangements are being made to tour the Pier 21 Site on Friday. Individuals will pay the \$6.75 at the site. For planning purposes please indicate if you are going to take part in this tour.

\_\_\_\_\_ Tour of Historic Pier 21 ([www.pier21.ca](http://www.pier21.ca))

## Getting Under the Skin: A Look at Body Image in Scleroderma

By Lisa Jewett

You walk into a room and feel eyes shifting to where you stand. You look around and see people turn, smile awkwardly, or shift away. Thoughts race through your head. “Are they looking at the tightened skin on my face? Or is it my swollen and bent hands? Do they notice my disfigurements?” How do you respond? Sit down and face them, walk away, or try and avoid their stares?

Living with scleroderma means not only learning how to cope with the medical symptoms of the disease but also how to deal with other people’s reactions. Unwanted attention, questioning stares, and misunderstanding all go hand in hand with the appearance-related changes that are common in scleroderma. The bodily changes associated with scleroderma are diverse and unique, which makes dealing with them all the more challenging.

Feelings about body image are an important part of self-esteem for most people, whether living with a chronic illness or not. Given this, it is not surprising that dissatisfaction with body image can detract from overall quality of life. So what do we know about body image among people living with scleroderma? Unfortunately, the answer is, not very much. Most research on body image comes from studies of people with eating disorders and weight issues, which are typically not the focus for someone with significant visible disfigurements, as in scleroderma.

My goal as a Master’s student and trainee with the Canadian Scleroderma Research Group (CSRG) is to address this current gap in a much-needed area of research. Specifically, my projects aim at uncovering what aspects of body image are relevant for people with scleroderma and how best to measure them. Body image is a complex concept, with many definitions and dimensions, so clearly identifying and targeting specific aspects of interest are highly important, as well as establishing proper measurement of each. Furthermore, when developing questionnaires, it is essential to make them feasible to administer, by keeping them simple and as short as possible so that you, the respondents, can realistically fill them out!

When I first started reviewing the literature on different aspects of body image, I came across the topic of body image avoidance. It involves the avoidance of objects and/or situations because

they cause distress or concern about the body. This can entail avoiding social situations where attention is given to appearance or hiding certain body parts that might provoke anxiety during everyday interactions. Ironically, the fear of being negatively evaluated or judged by others based on appearance can sometimes lead to what others perceive as defensive or avoidant behaviors and may actually bring out negative responses from others. This might be described as a vicious cycle where uncomfortable attention is given to disfigurements from scleroderma, and attempts to avoid this attention can make a person with disfigurements appear standoffish or otherwise uneasy, which impacts relationships negatively.

So far, avoidance or anxiety related to body image has only been measured in women with concerns about weight, even though it is clearly important for people dealing with physical changes from injuries or diseases like scleroderma. Due to the fact that body image avoidance has only been studied in women with weight issues, the questionnaire used to measure it, is specific to those concerns. Our task was to adapt this original tool in order to make it applicable to the experiences of people with scleroderma. A team of experts who work in the field helped to create new items that resulted in a scleroderma-specific body image avoidance questionnaire. Some examples of items from this questionnaire include asking respondents how frequently they wear clothes that hide changes to the skin, or how often they hide their hands so that people cannot see them.

In addition to body image avoidance, other relevant body image issues for people with scleroderma include feelings of discomfort in social settings due to appearance, as well as dissatisfaction with particular body parts. These two topics have been examined in individuals with disfiguring burn injuries, through a questionnaire developed specifically for that group of people. That questionnaire, however, has items that are less central for scleroderma (e.g., how satisfied are you with the appearance of your legs), in addition to being repetitive and quite lengthy; therefore making it less realistic to administer to people who are also answering many other questionnaires, such as those who participate in the CSRG Registry. Given this, we undertook another project that involved adapting the original questionnaire measuring social discomfort and body image dissatisfaction in burn victims, to make it more applicable to the scleroderma situation and more easily completed by respondents. This entailed only keeping items that were specifically related to

scleroderma, such as those asking about dissatisfaction with the hands and face, in addition to reducing the number of repetitive items about social discomfort. We developed a shorter, six-item questionnaire, found that it was as accurate as longer versions, and we are currently integrating it into the CSRG questionnaire package.

These projects related to uncovering and measuring important body image dimensions in scleroderma are just the beginning. They constitute a necessary first step to take before we can move toward our ultimate goal, which is to adapt or create educational material that targets coping with important body image issues for people with the disease. To date, no interventions have been specifically developed for scleroderma, but there are sources of information that exist for other groups that can be useful for scleroderma.

One organization, Changing Faces ([www.changingfaces.org.uk](http://www.changingfaces.org.uk)), is a non-profit group from the United Kingdom whose main goal is to provide support for individuals touched by disfigurement and to increase public awareness about issues surrounding disfigurement. Changing Faces focuses largely on issues related to body image avoidance and social discomfort due to appearance. For instance, the organization provides workshops that teach strategies on enhancing overall self-esteem and on learning how to manage the reactions of others in different social settings. Additionally, Changing Faces has produced and made available resources, including DVDs, booklets, and guides, designed for both healthcare professionals and individuals living with disfigurements. We are planning to build on this work from Changing Faces to develop interventions for scleroderma based on their principles and from information that we plan to gather by essentially asking people with the disease to tell us about their lived experiences with respect to their body image.

Knowing your body to look a certain way for many years of your life and then suddenly seeing disfiguring physical changes can be devastating. Body image is an important part of identity and learning how to accept and deal with significant changes to your appearance is no small task. Acknowledgement and attention to this matter is the first step, but there is still much more to be done.



**Scleroderma Society of Canada**

phone (toll free): 1-866-279-0632  
Information: info@scleroderma.ca

**Board of Directors:**

**President:** Marion Pacy

**Vice President:** Normand Ricard

**Secretary:** Helen Goerzen

**Treasurer:** Catherine Fortune

**Research Liaison:** Bob Buzza

**Webmaster:** Ron Gullickson

**Directors-at-Large:**

John Lewis

Maureen Sauvé

Gillian Little

Mary Beth Clark

**Contact List for Each Province**

- British Columbia - Joan Kelly - 1-888-940-9343
- Edmonton - Gillian Little - 780-434-3517
- Southern Alberta - Grant 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 - Louise Goulet, 306-584-1950.
- 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

**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

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

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