



President's Report

Hello All! I hope everyone is keeping well. Here in Mississauga, ON, we are experiencing a considerable amount of snow and some very cold days. Perhaps it is similar where you live. That doesn't mean we have to stay inside. Last Thursday was a beautiful, sunny day here – we haven't seen much sun lately – so I was encouraged to join my friend in Toronto for some window shopping and lunch. With a little effort to make sure I was dressed appropriately and warmly I set out. The city was a pretty sight with the sparkling snow on trees and buildings. We had a great day. The walking was good exercise and I got a good dose of fresh air. You may have your own preferences for outdoor activities in the winter which keep you active and well. Remember that our hands, feet, and heads need to be well protected in cold temperatures.

I would like to draw your attention to a new research initiative. The Canadian Institutes of Health Research (CIHR) have approved a research proposal to estimate the prevalence of orofacial manifestations of scleroderma in Canada. The amount awarded is \$244,000 over a two-year period. Problems that may occur in Scleroderma include diminished ability to open the mouth, dry mouth, and changes in the bones of the mouth and jaws.

I am excited about this study as, for me, personally, this is a major concern. I'm sure many others are also dealing with these problems.

When a research proposal is prepared, patient input is often required. The Canadian Scleroderma Research Group established the Advocacy/Knowledge Translation Committee in 2007. We meet via teleconferencing several times a year. As well scleroderma patients from across the country have agreed to be consultants to respond and review materials as requested by physicians and researchers. This helps researchers provide more patient friendly information about their research and that the research reflects what is important to patients. At this time the consultants are reviewing a draft of a survey for scleroderma patients, care-givers and loved ones, which will be distributed at our annual meeting on September 20th in Ottawa. We hope that when you receive such a survey that you will take the time to complete it and return it to the research team.

Our Conference Committee has prepared the programme for our Conference/Annual Meeting in Ottawa in September, 2008. You can read more about the conference plans in this newsletter as well as the other items I have mentioned and much more.

I would like to say thank you to all those groups and individuals across the country involved in fundraising activities, raising money for research. Keep up the good work and good luck. Thank you to all the volunteers who lead the provincial groups and organize educational seminars locally. Also, I would like to express my appreciation to the Board of Directors of the Scleroderma Society of Canada – all volunteers – who continue to work on your behalf at the national level. **There is much to do, and we are doing it!**

All the best! Keep healthy!

Shirley Haslam – SSC President

Scleroderma Conference and Annual General Meeting

The Scleroderma Society of Canada will hold its annual conference in Ottawa this year, on September 19 & 20, 2008. The Society will conduct its Annual General Meeting as part of the conference. The chair of this year's event is Normand Ricard, president of Sclerodermie Quebec.

The Canadian Scleroderma Research Group (CSRG) is again holding their Annual Scientific Meeting in conjunction with the Scleroderma Society of Canada's AGM and Conference.

We invite you to attend this event. You will be able to hear presentations on topics related to scleroderma and you will have an opportunity to meet patients and professionals who share a common interest in scleroderma.

On Friday of the conference weekend, there will be a chance to tour some highlights of Ottawa in the afternoon and there will be a buffet dinner social event that evening. The conference program on Saturday will feature presentations on research and on a variety of topics related to scleroderma. Afternoon workshop sessions will include topics such as kidneys, Raynaud's, gastrointestinal, lungs, skin, circulation, dental, fatigue and exercise.

Program details and registration forms will be available soon. Updated information will also be available on the Society's website, www.scleroderma.ca. Inquiries may be directed to the following:

for residents of Quebec: Diane Collard at Sclerodermie Quebec, PO Box 2 Sainte-Julie, QC J3E 1X5, ph. 514-990-6789, email: sclerodermiequebec@videotron.ca

for residents of Ontario: Peter Woolcott, ph. 905-730-0731, email: peterwoolcott@sympatico.ca

for residents of other provinces: Aline Laporte, 455 Blake Blvd., Ottawa, ON K1K 1A9, ph. 613-745-7829, email: sclero@sympatico.ca

The conference will be held at the Crowne Plaza Hotel in Ottawa.

Crowne Plaza Hotel

rue 101 Lyon Street,

Ottawa, ON K1R 5T9.

If you reserve a room at the hotel please request the special room rate for the Scleroderma Conference. You may reserve by telephone or online. There are a limited number of rooms available at the preferred rate of \$139.00 for September 18, 19 & 20. If you request a reservation for additional dates, a separate reservation will be required.

Telephone: hotel front desk (not toll free) 1-613-237-3600

Crowne Plaza (toll free service) 1-800-227-6963

Fax: (not toll free) 1-613-237-2351

Website: www.crowneplazaottawa.com

If you wish to reserve a room online, [click here](#) to proceed directly to the hotel's reservation desk. (Or go to the hotel's website, as shown above, and click on 'reservations' on their home page.) Under 'Travel Dates and Traveler Information, enter the dates, room preferences (do not enter 'rate preference'), etc. If you used the 'click here' link to go directly to the hotel's reservation desk, your next step is "Check Availability". (If you used the hotel's website, you will have to enter our conference code – go to the line titled 'Corporate, Group & IATA Identification' and click on the plus sign. In 'Group Booking Code', enter **SCL**, then click on 'Check Availability'.)

SCLERODERMA CONSULTANTS APPOINTED

The CSRG Advocacy/Knowledge Translation Committee recommended that a group of scleroderma patients and loved ones be named as scleroderma consultants. Twenty-seven people from across Canada have agreed to serve. **Their primary task will be to respond to occasional inquiries from researchers seeking a lay perspective about proposed scleroderma research priorities or projects.**

The team includes at least one consultant from every provincial scleroderma support group. Within the 20 who have scleroderma, there is a range of four to 28 years since initial diagnosis. The overall average since diagnosis is 16 years, so it's a highly experienced 'lay' group, with an unusually wide range of interests and work experience.

Our consultants are listed here in alphabetical order by province: **BC:** *Bob Buzza Joan Kelly, John Lewis, Kelly Mauro, Rino Mauro* **Alberta:** *Grant Dustin, Maie Dustin, Ron Gullickson, Gillian Little* **Saskatchewan:** *Shirley Gillander, Louise Goulet, Gerald Shauf*

MB: *Debby Dolan, Mare Pacy* **Ontario:** *Shirley Haslam, Al;ine Laporte, Maureen Sauve* **Quebec:** *Christiane Dubreuil, Johanne Dumont, Josee Fontaine, Lori Jacobs, Louis Ricard, Lise St.-Andre* **NB:** *Deanna Cosman* **NS:** *Mary Beth Clark* **PEI:** *Katherine Dewar* **NFLD/LAB:** *Beverley Blanchette*

SCLERODERMA SURVEY PLANNED

A major survey of scleroderma patients and their loved ones will take place in the fall of 2008. **Results will be used to develop priorities that will influence future research and provide a basis for advocacy work.**

Under the auspices of the CSRG Advocacy/Knowledge Translation Committee, Dr. Brett Thombs and student Sophie Trudeau have completed an initial draft of the survey instrument. The scleroderma consultants listed above and focus groups will offer advice about the draft this spring.

A final version of the survey will be provided to patients and their loved ones at our annual meeting in Ottawa on September 20, 2008. Approximately 300 are expected to complete the survey at that time. Over 1,000 are expected to complete it thereafter. Information about how to participate will be provided in the fall.

New CSRG website !

The **Canadian Scleroderma Research Group** invites you to visit their new website. It provides excellent information about this unique team and the wonderful work being done through their initiatives and dedication.

www.csrg-grcs.ca

There is also a link to the CSRG website through the SSC website, under 'research'.

Conferences on Scleroderma Research in 2008

Many scleroderma patients and their families are unaware of the fact that high-level conferences focusing on scleroderma research are increasing in number and scope:

- 1) The well-attended National Conference of the 14,000-member Scleroderma Foundation in the U.S. attracts Canadian scleroderma patients every year. It will take place in Manhattan Beach, California July 25-27, 2008.
- 2) The Annual European Congress of Rheumatology attracts thousands of researchers and pharmaceutical representatives from around the world. Its impressive program will feature major presentations by the EULAR Scleroderma Trials And Research (EUSTAR) Group, which has over 90 active centres devoted to standardizing the assessment and management of systemic sclerosis. The 2008 EULAR Congress will be held in Paris, France June 11-14.
- 3) The 10th International Workshop on Scleroderma Research will also attract researchers from around the world. It will be highly technical in nature. Professor Dame Carol Black, of University College, London, who did such a magnificent job of responding to questions from scleroderma patients at our conference in Fredericton, will serve as co-chair. The Workshop will be held in Cambridge, UK August 2-6, 2008.
- 4) The 9th annual conference of the Scleroderma Society of Canada is expected to attract at least 300 scleroderma patients and their loved ones, as well as 100 researchers and pharmaceutical representatives. An excellent program that provides opportunities for significant interaction between patients and researchers is being developed. Our conference will take place in Ottawa, Ontario September 19-20, 2008

On January 21, 2008, Arthritis Consumer Experts held a major press conference in Ottawa to highlight huge disparities in our national health care system, disparities that adversely affect scleroderma patients, and millions of others. These disparities reflect a two-tier system, one that provides fertile ground for human rights violations. The conference generated extensive press coverage across the country, and some very powerful letters from within the arthritis community. We are indebted to the Arthritis Consumer Experts team for their advocacy efforts. (ACE is a national organization that provides research-based information and education to Canadians with arthritis.)

The press release of January 21 follows:

ACE LAUNCHES NATIONAL REPORT CARD, REVEALING TWO-TIER HEALTH CARE IN CANADA

Disparities in Access Give Rise to Possible Human Rights Violations

(Ottawa, ON) – Arthritis Consumer Experts (ACE) today unveiled their national report card, comparing and grading provinces across Canada on how well their residents are able to access medically necessary arthritis treatments.

Cheryl Koehn, President of ACE, noted that, despite misperceptions, arthritis often impacts young people in the prime of their lives, contributing vastly to work disability and other overall costs to the public system. Several available treatments, if made widely available across Canada, can now halt disease and bring patients back to work, allowing them to contribute as productive members of society.

“When you’re told as a community that treatments that have been peer reviewed, approved by the Common Drug Review, and frequently recommended as medically necessary by physicians are not available to you, yet patients sitting next to you with cancer or HIV/AIDS are getting state of the art treatment, it makes you feel valueless,” said Koehn.

Arthritis research in Canada receives a disproportionately low amount of funding, based on the over 4.5 million Canadians that suffer from the disease. Medical professionals warn that the increasing burden cannot be ignored.

“One in ten doctor visits are a result of arthritis or a major muscular skeletal problem, yet less than two per cent of research funds are directed toward this disease,” said Dr. John Esdaile, Scientific Director of the Arthritis Research Centre of Canada. “The true cost of arthritis is estimated by the Canadian government at 14 billion dollars, which is completely out of line with the small percentage spent on understanding how to decrease the growing burden on our health care system.”

Esdaile noted that many treatments deemed medically necessary by physicians cannot be accessed by patients.

“Patients with money can access treatments that will give them their lives back,” said Esdaile. “Oftentimes, if these same patients rely on the health care system, we as physicians must tell them that the treatments aren’t covered, and essentially that they can’t have their lives back.”

The disparity noted by the medical and patient communities in Canada are a growing concern from a human rights perspective. A lack of access to treatment could give rise to a complaint as a result of discrimination based on disability.

“The risk around arthritis from a human rights perspective is significant from both the perspective of government and private employers,” said Hugh O’Reilly, a Toronto lawyer specializing in benefits and human rights law. “This disease is debilitating, and if not treated in a timely manner, a person will suffer a permanent physical loss. That leads to an enormous risk for a human rights case being brought forward.”

Should such a case come forward, provincial governments and private employers providing drug plans for employees would be at risk of violation.

“Arthritis is the Rosa Parks of diseases. People with arthritis have been sitting at the back of the bus for a long time, and today is the day to change that,” concluded Koehn.

The media coverage is very encouraging and lets hope some more provincial and national media pick up on this in the days ahead. The CNW Group broadcast of the interviews which can be viewed at http://cnw.pondeserver.com/story_details.asp?fn=180 was excellent.



Doctors at a hospital in Brooklyn, New York have gone on strike. Hospital officials say they will find out what the Doctors' demands are as soon as they can get a pharmacist over there to read the picket signs!"

**A letter to the editor of the Vancouver Sun in relation to drug access
in regards to the ACE press release**

BC arthritis drug access rated low. January 22, 2008

The report released in Ottawa on the sorry state of ready access to relief for those suffering from arthritis in British Columbia, and across Canada, has created a long-overdue focus on this issue.

It is difficult to realize just how important this issue is, to realize the depth of impact, the depth of need, unless you happen to be one of the many patients living with arthritis in one of its guises, or as is sometimes the case, an overlapping of them.

Scleroderma is one of the subset conditions tucked under the arthritis umbrella.

Being diagnosed myself in 1982 (given up to five years to live at the time) I have had the privilege of forming friendships with hundreds of other patients in the 25 years since. Unfortunately, too many of them were not lasting friendships – we don't talk about the fact that arthritis kills.

- We know what it is like to live with a debilitating, life-altering and life-threatening condition.
- We know what it is like to be told that we don't count.
- We know what it is like to be told that we don't qualify for research because our numbers are small, that we are not 'cost effective.' We don't talk about the fact behind our small numbers.
- We know what it is like to finally come in to a time of hope, where new medications formulated to help us, remain out of our reach.

Heartfelt thanks to the advocacy group ACE for the helping hand, for helping us extend our reach.

Joan Kelly, Co-founder

Scleroderma Association of BC

www.sclerodermabc.ca

Systemic Sclerosis and Oral Health



Dr. Mervyn Gornitsky,
BSc, DDS, FRCD(C)

Systemic Sclerosis (SSc) or Scleroderma is a disease of connective tissue that can affect many parts of the body including skin, joints, lungs and kidneys. It affects about 1 in 4000 adults, mainly women. The **Canadian Scleroderma Research Group (CSRG)** is a group of rheumatologists, clinicians, and researchers funded by the *Canadian Institutes of Health Research (CIHR)* since 2004 who joined forces to better understand Scleroderma and its symptoms. The group has a registry of more than 750 Canadian adults with Scleroderma. Patients are assessed yearly by a rheumatologist part of the Group, and answer a series of questions related to their symptoms, quality of life, and history. They also undergo a series of laboratory investigations to assess the severity and activity of their disease.

Scleroderma and the mouth

One area being looked at by the group is the mouth. Problems that may occur in Scleroderma include diminished ability to open the mouth, dry mouth and changes in the bones of the mouth and jaws. Limitations of jaw movements cause oral hygiene and nutritional concerns. Other consequences are increased oral infections, cavities and gum disease. Care of the mouth and teeth must be stressed. Loss of teeth either due to decay or gum disease could be disastrous in a person with limited oral opening. Dentures would be difficult to fabricate and retention would be compromised. The aesthetical and nutritional impacts on patients of not being able to wear dentures along with other symptoms of the disease could result in mental depression. Excellent oral hygiene must also be stressed. Visits to a dentist should be at three-month intervals. Fluoride varnishes applied to the teeth will help reduce decay. For dry mouths, *Salagen*® 5 mgs 30 minutes prior to eating and before bedtime may help increase salivation. For patients with limited dexterity, the toothbrush could be modified with a ball cemented on the handle to allow for handling. Electric toothbrushes may be more convenient and more efficient. Repair of decay in the dental office could be accomplished with instruments used for children, especially in those patients with limited oral opening. Sensitive oral tissues must be handled with care.

A 2-year study to better understand oral health in Scleroderma

Dr. Gornitsky is an Oral Surgeon and a member of the CSRG. He graduated in Dentistry from McGill University in 1953. He and his co-applicants, Drs. Baron, Hudson, Steele and Dagenais, recently were awarded \$244,000.00 by the CIHR to study oral health in SSc. The objective of their 2-year study is to estimate how often the oral and dental manifestations of scleroderma occur and the impact of these on the quality of life. Patients followed by the **Canadian Scleroderma Research Group** will be recruited for this study and their characteristics will be compared to those of men and women without Scleroderma. The results of this research study will facilitate the development of future projects related to the treatment and prevention of mouth and dental problems in SSc. This is a multisite project involving dentists and rheumatologists in Calgary and Edmonton (AB); Saskatoon (SK), Winnipeg (MB); London (ON); Halifax (NS); and Montreal (QC). Dentists in these sites will examine and record mouth opening, saliva production, incidence of decay and periodontal disease, as well as take radiographs to assess changes in the bones of jaws and joints.

This will be the largest study ever done in this area encompassing 180 scleroderma patients and 360 controls throughout Canada. Results will be transmitted to other rheumatologists and dentists through scientific meetings, abstracts and journals, as well as patient groups, e.g. the *Scleroderma Society of Canada* (SSC) and provincial groups, via their newsletters and websites.

If you suffer from Scleroderma and would like to find out more about this project, please contact Audrée Janelle-Montcalm by phone at: 514-340-8222, ext.: 3423 or by email at: a.janelle.montcalm@gmail.com.

Prescriptive compliance:

A woman in Arkansas brought her baby in to see the doctor, and he determined right away the baby had an ear ache.

He wrote a prescription for ear drops. In the directions he wrote, "Put two drops in right ear every four hours" and he abbreviated "right" as an R with a circle around it.

Several days passed, and the woman returned with her baby, complaining that the baby still had an earache, and his little behind was getting really greasy with all those drops of oil.

The doctor looked at the bottle of ear drops and sure enough, the pharmacist had typed the following instructions on the label: "Put two drops in R ear every four hours."

Testing, testing, 1, 2, 3, 4, 5

Doctors use these tests to aid in scleroderma diagnosis.

by Elaine Furst, R.N., M.A. and Daniel Furst, M.D.

Scleroderma is a complex disease and it's often difficult to diagnose, requiring testing, testing and more testing. Once diagnosed, doctors order additional tests to measure the response to medications and other treatments. Finally, doctors administer tests to determine whether the disease is progressing. What is the purpose of all these tests?

We've put together a list of some of the tests you're most likely to encounter during your doctor visits, what they measure, and how they're performed so you won't be just a pincushion, but an informed pincushion.

Test: Skin Score:

How Performed: The doctor gently "pinches" your skin in 17 different places on your body, such as your forearm, upper arm, face, hands, fingers, thighs, etc. The doctor can assesses the amount of skin thickness on a scale of 0 (normal) 3 (very thick).

What the doctor looks for: When the doctor adds the score he can see the severity of your skin involvement, the higher the skin score, the more severe your disease may be, especially in the first three years. Higher scores indicate that internal organs such as the lungs are also being affected. The highest score possible is 51 and 0 is normal.

Test: Blood (ESR,ANA,anti-Scl-70, BUB, creatinine, anti-centromere)

How Performed: Blood is taken from your arm. If hard skin makes this procedure difficult for you, ask the phlebotomist to wrap your arm in warm, wet towels to soften the skin and open blood vessels. (be sure to wear warm clothes to your appointment)

What the doctor is looks for: Blood tests of various kinds will indicate whether or not there's inflammation in your system, (ESR—Eosinophil Sedimentation Rate) whether your immune system is active, (ANA-Anti-Nuclear Antibody) differentiate between scleroderma and other autoimmune diseases(Scl-70, anti DNA antibody) and measure how well your kidneys are working. (BUN-blood urea nitrogen, creatinine) While there are numerous other blood tests, these are the most common ones most useful to diagnosing scleroderma.

Normal range of values:

AA: under 1:40

Scl-70: negative

Anti-DNA antibodies: under 200 Ig

BUN: under 20 mg/dl

Creatinine: under 1.2 mg/dl

Test: Lung Function

In one test, the patient blows into a machine that measures how much air your lungs hold, (TLC—total lung capacity) how much airflow there is FVC-forced vital capacity and FEV1-forced expiratory volume) and how well the lungs extract oxygen from the air (DLCO-carbon monoxide diffusing capacity). These tests are often repeated annually or even more frequently. Another test is a high resolution CAT scan of the chest to detect any abnormalities in the lung tissues. This is like an X-ray, with significantly less radiation, plus uses computers to make a picture of the lungs.

The CAT scan helps picture inflammation, lung scarring, and blood vessels. Sometimes your doctor needs cells from the lung or needs to look for infection within the lungs. Then bronchoalveolar lavage (BAL) can be used. In this test, you are given a medicine that makes you forget the procedure. A small tube is passed down the throat through the mouth and into parts of the lungs (called lobes). Sterile fluid is introduced into an area of the lung and removed by suction. The fluid will contain inflammatory cells or organisms (infection) that can be analyzed.

What the doctor looks for: Normal FVC is over 80% of predicted. Normal DLCO is over 80%. Normal TLC is over 80%.

Test: Echocardiogram

How Performed: This is a non-invasive ultrasound test of the heart in which sound waves are bounced against the heart to get a picture of the heart chambers as well as heart function. You lie down and have special conductive jelly put on your chest over your heart. The ultrasound machine is rolled over the jelly and a picture of your heart is projected on a screen and copies of the picture are made. In addition, certain pressures and heart functions can be measured.

What the doctor looks for: The echocardiogram allows your doctor to analyze your heart efficiency, whether there might be increased lung problems reflected in increased heart pressures and whether there is abnormal fluid around the heart. (pericardial effusion)

Test: Endoscopy

How Performed: After being given anesthesia, a tube using fiber optics is introduced into the stomach (upper endoscopy) or lower intestine (colonoscopy) in order to visualize the esophagus, stomach and colon and take tissue samples.

What the doctor looks for: The esophagus may have narrowing (strictures) that doesn't allow food to pass. Narrowing may also lead to ulcers that cause pain and bleeding. In addition, due to the acid that sits around in the esophagus that doesn't move food along, the esophagus may exhibit cellular changes that may be pre-cancerous. This condition is called Barrette's esophagus and samples of the cells will be taken for examination. The stomach may exhibit ulcers and dilated blood vessels (watermelon stomach) that can bleed. The colon can be scanned for bleeding, polyps and cancers.

We hope that these explanations will help you understand the tests and how they help your physician comprehend your disease and help you cope with it.

.For more information:

Gottesman, Karen, *The First Year: Scleroderma*, An essential guide for the newly diagnosed. Marlowe & Company, New York. 2003.

Mayes, Maureen, *The Scleroderma Book*, 2nd edition. Oxford University Press, New York. 2005.

This article was re-printed with kind permission from the December 2007 issue of *Scleroderma VOICE*, the publication of The Scleroderma Foundation. www.scleroderma.org



Scleroderma Society of Canada

95 Woodfield Road SW,

Calgary, Alberta

T2W 5K5

phone (toll free): 1-866-279-0632

phone (sec-treas): 403-281-7616

fax: 403-238-2773

email (sec-treas): mgdustin@telus.net

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

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 - Maureen Sauve - 905-304-8787

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

Back issues of *Strides* are available on the website (www.scleroderma.ca,

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

please contact us through the 1-866-279-0632 or email: scleroderma@simplyconnected.ca