

CANADIAN SCLERODERMA NEWS



SCLERODERMA SOCIETY OF CANADA

FALL 2008

SSC & CSRG Survey

If you have been diagnosed with scleroderma and are interested in shaping the future of research in this field please take time to answer....

THE SCLERODERMA SOCIETY OF CANADA and THE CANADIAN SCLERODERMA RESEARCH GROUP PATIENT SURVEY

We would like to find out what issues are important to individuals living with scleroderma so that we can re-assess our research agenda. This survey has questions about the symptoms that people with scleroderma might experience, as well as psychological, social, employment, and financial issues, and issues related to the ability to obtain appropriate healthcare.

This is a national survey and we hope to reach as many scleroderma patients in Canada as possible.

Response to the survey is voluntary but if you are a scleroderma patient we strongly encourage you to complete the survey. Also, please encourage other scleroderma patients to complete the survey.

To complete the online version please go to the website, www.scleroderma.ca

To receive a hard copy of the survey in the mail, as well as a pre-stamped return envelope, please contact Marielle Bassel at the CSRG, telephone 514-340-8222, extension 3238.

Marielle Bassel is the person you should contact if you have any questions about the Patient Survey. She can also be reached by email: marielle.bassel@mail.mcgill.ca, or by writing to her at the Canadian Scleroderma Research Group, SMBD–Jewish General Hospital, 3755 Cote Ste-Catherine Road, Suite A216, Montreal, QC H3T 1E2.

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MESSAGE FROM THE PRESIDENT

Marion Pacy

I have been on the board of directors for many years now and I am looking forward to the coming year as President. For those that did not get the chance to attend the conference in Ottawa, 2008 was a great success. Thank you Ottawa!!!

The Friday started off with a tour of the city of Ottawa, which was enjoyed by all. I did not attend the tour but had the chance to take a tour of the Parliament Buildings. I was amazed by the sculptures on the columns and walls. My favourite room was the library, the carvings in that room were absolutely amazing.

The Friday evening we attended a reception offered by the Scleroderma Society of Ontario, with a grand attendance.

Up bright and early on Saturday for registration. This year's conference was bilingual, we were given a headset so that some of us could understand both languages. Our speakers hit a broad gamut of topics. The afternoon was held in breakout workshops. I would like to thank all of the speakers for their time and interesting sessions.

A Big thank you to all the volunteers who gave their time and energy to help make the Ottawa conference a success. **THANK YOU!!!**

FROM THE PAST-PRESIDENT

Shirley Haslam.

Hello Everyone.

May I begin by saying that our National Conference in Ottawa, September 19 and 20 was an outstanding success. Participants included patients, caregivers, researchers, student researchers and medical staff. Our speakers provided us with new ideas, new possibilities and continued HOPE for better care. Thanks to the organizing committee for all their hard work. You can read more about the conference in this newsletter.

On Saturday, September 20th, 2009 the Scleroderma Society of Canada also held the Annual Meeting. Along with other business, the new Board of Directors for 2008 -2009 was presented. Our newly – elected President is Marion Pacy. Marion brings a wealth of experience to this role. She has been on the Board of Directors of the Scleroderma Society of Canada since it was established and has held a number of positions. She is currently the Newsletter Editor and Conference Chair for the 2009 National Conference to be held in Winnipeg Manitoba.

It has been a privilege and a pleasure to have been the President during the past two years. I would like to thank all the board members and provincial chairs for their participation and support during my term. The Scleroderma Society of Canada has become a stronger presence in Canada by promoting a greater awareness about scleroderma, providing educational opportunities and literature to patients, care-givers and medical practitioners, and collaborating with researchers and medical doctors in the area of research, specifically the Canadian Scleroderma Research Group.

I wish you all the best of health.

REPORT ON THE 2008 CONFERENCE AND ANNUAL GENERAL MEETING

The Annual General Meeting of the Scleroderma Society of Canada was held as part of the 2008 conference program. In addition to the presentation of the Directors' Report and the Financial Report, the Board of Directors for the coming year was declared. We thank the Board members from last year for their service and for their willingness to serve again for the coming year, and we welcome new Board members John Lewis and Maureen Sauve.



Back Row: Catherine , Maureen, Gillian, John

Front Row: Mary Beth, Shirley, Marion

New Board of Directors:

Past President: Shirley Haslam	Directors-at-Large:
President: Marion Pacy	John Lewis
Vice President: Normand Ricard	Maureen Sauvé
Sec/Tres: Grant Dustin	Gillian Little
Research Liason: Bob Buzza	Mary Beth Clark
Webmaster: Ron Gullinson	Catherine Fortune
	Junella Weiss

Some comments from those attending the Society's annual conference were that it was '...a huge success...', '...it was exciting, with lots of feelings of hope and community...', '...a very valuable experience...my expectations were not only met but exceeded...'

The conference, held at the Crowne Plaza hotel in Ottawa on September 19 & 20, was attended by nearly 400 people! This was not only the largest Canadian scleroderma conference in our history, it was also the first time we've had a bilingual conference. People attended from most provinces, with a large number of delegates from Quebec and Ontario.

The Canadian Scleroderma Research Group (CSRG) held their Second Annual Scientific Conference in conjunction with the SSC conference. Students who have been doing research related to scleroderma displayed posters of their work and were available for discussion of their projects. Many people did the rounds and read the articles on each of the posters that the students had worked so hard on.

Those attending the conference had the opportunity to meet others who share an interest in scleroderma and they were able to attend sessions featuring excellent speakers whose topics covered a wide range of scleroderma issues. Talks on kidneys, PAH lungs, skin problems, caregivers, Gastro, Dental problems. Four other breakouts were given in French. We heard rave reviews about all of the breakout sessions throughout the day.

By all reports, the conference was very worthwhile for those attending and we want to express our thanks to the co-host organizations and to all the individuals who worked to make this event such a success. Sclerodermie Quebec and the Scleroderma Society of Ontario were co-hosts for the event, with conference committee members from each of those groups: Normand Ricard (chair), Diane Col-lard, Aline Laporte and Catherine Fortune.

Financial support for the conference is essential and is very much appreciated. We sincerely thank all those corporations, organizations and individuals who helped in this way. Sponsors included:

Sclerodermie Quebec, the Scleroderma Society of Ontario, Actelion Pharmaceuticals Inc., the Government of Canada, Rx&D – Canada's Research-Based Pharmaceutical Companies, Revera Group, Certified General Accountants of Ontario, Bank of Montreal Financial Group, McNeil Consumer Health Care (Guelph) and Ottawa Tourism, plus financial support from individuals.

2009 will be the 10th Conference for the
Scleroderma Society of Canada.

It will be held in Winnipeg, at the Delta Hotel
Information for this will be in the February 2009 issue
Canadian Scleroderma News

Or

Early information
scleroderma@simplyconnected.ca
1-866-279-0632



Study in Oral Health

Dr. Mervyn Gornitsky has been awarded \$244,000 to study oral health in scleroderma. He also has been studying saliva samples from scleroderma patients to determine, in part, if the disease is associated with increased oxidative damage and, if so, if saliva analysis can help determine disease severity and possibly help determine treatment modalities. It took a year to obtain forty samples for a pilot study with trainee Michael Benarroch, but 300 samples are needed for a larger study, which will also include a control group of 600. At the recent meeting in Ottawa he asked for volunteers with scleroderma. By the end of the day, 70 additional patients had provided saliva samples - which was heartening and remarkable response!

Canadian Scleroderma Research Group

Just an update,

Since September 2004 till September 2008, The CSRG has **889** patients that have been registered into the database, 87% of them are women of an average age of 57.

For more on the CSRG, including more information on the patient database and on the student research projects, please visit their website, www.csrg-grcs.ca.

ADVERTISING IN NATIONAL MAGAZINES

In September, we placed a scleroderma ad in two national magazines, Maclean's and their French issue counterpart, L'actualite. The ad in Maclean's was in the September 29 issue and the ad in L'actualite was in the October 1 issue.

The half-page advertisements were designed to reach scleroderma patients in Canada and to invite them to participate in the national Patient Survey (please see the news item on the front page of this issue). In addition to the ads, we arranged to have a website link with both the SSC and with Sclerodermie Quebec, such that viewers of the magazines' website were linked with our websites.

For making this project possible, we thank Bob Buzza for negotiating the arrangements, Cameron Dustin for the graphics work on the ad, Marie-Claude Beaudry at Maclean's for efficient completion of arrangements and Sclerodermie Quebec (via Normand Ricard) for generous funding.

Flu Vaccine and Scleroderma

By Thomas Medsger, M.D. (originally published in "Best of the Beacon" 1999)

A number of questions with regard to flu occur to patients with scleroderma and other diseases affecting the immune system. Will getting the flu activate scleroderma? Will a flu shot prevent the flu and other infections? Is there any risk of a scleroderma flare from getting a flu shot? Which scleroderma patients should consider getting a flu shot?

In patients with systemic lupus erythematosus, there is some evidence that infections can trigger a disease flare. This is not the case in persons with scleroderma, so there is no particular risk that a flu shot will worsen scleroderma. The vaccine is safe since it is composed of killed rather than live virus particles. Persons with egg allergy should not receive the flu vaccine, since the virus used to prepare the vaccine is grown in eggs. Also, if you have or suspect that you have an infection, it is best to wait until the infection has passed before receiving a flu shot. Some patients develop a low-grade fever and muscle aching, particularly at the site of the shot, during the first several days after the flu injection, but serious reactions are extremely rare.

The flu vaccine is newly prepared each year, based on the particular types or "strains" of flu that caused the largest number of cases in the previous year. Thus, the most common 1994-1995 "flu bugs" are used to prepare the 1995-1996 vaccine. Patients may therefore still develop flu caused by a strain of virus not included in the vaccine. The best time to get the flu shot is in the fall of each year (late September or early October), when the vaccine becomes available. Even January or February is not too late to receive protection for the end of the flu season.

It is recommended that all patients with chronic systemic diseases get flu shots. Therefore, all persons with systemic sclerosis (not localized forms of scleroderma) should receive an annual flu vaccination. The primary problem with getting the flu is that it is capable of causing pneumonia. Scleroderma patients with any form of pre-existing lung disease are especially at risk. Furthermore, viral infections such as influenza are frequently followed by bacterial infections, which can be even more damaging. Patients who produce watery, clear phlegm during a viral illness are at risk to next develop thick/discolored (green, yellow, brown, or gray) phlegm, which may be a sign of bacterial infection. If you have a cold or other respiratory infection that results in discolored phlegm, be sure to ask your physician if you need antibiotic treatment.

The most common bacterial pneumonia is pneumococcal pneumonia. A specific vaccine (Pneumovax) is available, which is capable of producing immunity to many common strains of Pneumococcus. This protection lasts a minimum of five years after which time re-vaccination is necessary. All patients with scleroderma lung disease should also get Pneumovax, especially if they are receiving medications that are recognized to dampen the immune system's capability to respond to infections. Such medications include cortisone, methotrexate, Imuran, Cytosan, and a number of others.

For each scleroderma patient, a physician must make a decision about whether the flu and Pneumovax vaccines should or should not be given and must order the vaccinations. I have provided general guidelines above, but each physician has his/her own approach to this issue. You should discuss this topic with your rheumatologist or primary care physician.

Gastroesophageal Reflux Disease Diet

Purpose

The esophagus is the tube that carries food from the throat to the stomach. However, it is not just a simple tube. The lower esophagus has a specialized muscle around it that usually stays tightly closed, opening only to allow food and liquid into the stomach. It acts to prevent the reflux of stomach acid into the esophagus.

Symptoms occur when this specialized muscle weakens and allows stomach acid to splash up into the esophagus. These symptoms include heartburn, chest discomfort, and bitter fluid flowing up into the mouth. Chest discomfort can occur. If the stomach juice trickles into the breathing tubes, hoarseness, cough, and even shortness of breath can occur. This entire problem is called GERD (Gastroesophageal Reflux Disease). A number of factors, including certain foods, may cause the lower esophageal muscle to relax, causing GERD.

Nutrition Facts

A diet designed to prevent or reduce acid reflux is usually easy to follow. The basic food groups of cereals, vegetables, fruits, dairy products, and meats can be eaten with only a few limitations. A vitamin C supplement may be needed if an individual does not tolerate citrus foods such as orange, tomato, etc.

Special Considerations

The lower esophageal muscle can be weakened by factors other than food. The following recommendations may be helpful in reducing symptoms:

1. Stop using tobacco in all forms. Nicotine weakens the lower esophageal muscle.
2. Avoid chewing gum and hard candy. They increase the amount of swallowed air which, in turn, leads to belching and reflux.
3. Do not lie down immediately after eating. Avoid late evening snacks.
4. Avoid tight clothing and bending over after eating.
5. Eat small, frequent portions of food and snack if needed.
6. Lose weight if overweight. Obesity leads to increased reflux.
7. Elevate the head of the bed six to eight inches to prevent reflux when sleeping. Extra pillows, by themselves, are not very helpful.
8. The following foods aggravate acid reflux, and should be avoided:
 - fatty or fried foods
 - peppermint and spearmint
 - whole milk
 - oils
 - chocolate
 - creamed foods or soups
 - most fast foods

9. The following foods irritate an inflamed lower esophagus and may need to be limited or avoided:

- citrus fruits and juices (grapefruit, orange, pineapple, tomato)
- coffee (regular and decaffeinated)
- caffeinated soft drinks
- tea
- other caffeinated beverages

10. Spicy or acidic foods may not be tolerated by some individuals.

Food Groups		
Group	Recommend	Avoid
Milk or milk products	skim, 1% or 2% low-fat milk; low-fat or fat-free yogurt	whole milk (4%), chocolate milk
Vegetables	all other vegetables	fried or creamy style vegetables*, tomatoes
Fruits	apples, berries, melons, bananas, peaches, pears	citrus*: such as oranges, grapefruit, pineapple
Breads & grains	all those made with low-fat content	any prepared with whole milk or high-fat
Meat, meat substitutes	low-fat meat, chicken, fish, turkey	cold cuts, sausage, bacon, fatty meat, chicken fat/skin
Fat, oils	none or small amounts	all animal or vegetable oils
Sweets & desserts	all items made with no or low fat (less than or equal to 3 g fat/serving)	chocolate, desserts made with oils and/or fats
Beverages	decaffeinated, non-mint herbal tea; juices (except citrus); water	alcohol, coffee (regular or decaffeinated), carbonated beverages, tea, mint tea
Soups	fat-free or low-fat based	chicken, beef, milk, or cream-based soups
*Individually determined		

This material is designed for information purposes only. It should not be used in place of medical advice, instruction and/or treatment. If you have specific questions, please consult your doctor or appropriate health care professional.

NEW WEBSITE FOR CAREGIVERS

www.caregiver-connect.ca

We all know something about the important work done by caregivers as they provide help to others. Now there's a new source of help for them.

The Victorian Order of Nurses (VON) has established a new website that provides a great variety of information and assistance to caregivers. Here's the announcement, as stated in their website.

VON Canada Launches New Bilingual Web Portal for Canada's Three Million Caregivers

September 16, 2008 OTTAWA, ON – Today, VON Canada (Victorian Order of Nurses) launched a groundbreaking new tool for Canada's nearly three million caregivers: "Caregiver Connect...from Caring to Sharing/De l'entraide au partage...aidants en réseau." This innovative bilingual web portal will provide access to information and resources that caregivers need to care for themselves, to provide better quality care to their family members and/or friends, and to connect and share with other caregivers through a virtual discussion forum.

"VON Canada supports caregivers and provides care for families and individuals from Newfoundland to British Columbia - we know first hand the questions and challenges that caregivers encounter," said Dr. Judith Shamian, President and CEO of VON Canada. "Caregivers are an essential part of the Canadian health care system –providing over \$5 billion in savings on health care costs. But caregiving can be isolating – and one of the goals of Caregiver Connect is to enhance autonomy, independence, and quality of life for caregivers and for those whom they provide care. The new Caregiver Connect portal is a one-stop shop of vital information for Canada's caregivers."

When a caregiver visits www.caregiver-connect.ca – he or she can check out the latest information related to a specific health condition, click on links to Government of Canada programs, find information on working and caregiving, legal and financial assistance and home care programs, and connect with fellow caregivers and experts in the virtual meeting place of the portal's caregiver communities.



Scleroderma Society of Canada

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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 - 905-544-0343

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 - 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

Website: www.scleroderma.ca

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

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.