



Scleroderma Society of Canada

March, 2007

Spring

Strides

Pursuing Our Issues Together, Nationally

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In November 2006, representatives from lupus, scleroderma, and Sjogren's decided to arrange a meeting with Tony Clement, the Minister of Health. Because of the overlap between his portfolio and the ministers responsible for women's and aboriginal issues, they were contacted, as well.

Unfortunately, Minister Clement has not yet agreed to meet with us, and referred us to a Senior Medical Officer, instead. We have followed up with her. We have also arranged a meeting with the critic for disability issues, Dr. Carolyn Bennett.

SARD representatives have now sent their package to the Minister of Health, the ministers dealing with women's and aboriginal issues, and the Senior Medical Officer. In addition, Grant Dustin has delivered the package to the Prime Minister's constituency office in Alberta. The package includes facts about the nature, extent, and impact of autoimmune rheumatic diseases, our

support groups, and our research activities.

The major concerns we are expressing are threefold:

- 1) Approximately 35% of health care costs in Canada arise from autoimmune deficiency diseases, but only five per cent of the overall research budget is devoted to them;
- 2) It can take over a year for grant submissions with the potential to provide more effective diagnosis and treatment to be processed;
- 3) It takes far too long to gain approval for established or novel treatment options.

Anyone wishing a copy of our package is urged to contact BobBuzza at 604 520 3258, or rmbuzza@ret.bctf.ca or 413 - 2 Renaissance Square, New Westminster, BC V3M 6K3

Canadian Scleroderma Research Group (CSRG) Update

Progress made by the CSRG since it was formed in 2004 is good news for every scleroderma patient in Canada. Even better news is anticipated in the coming months.

As of February 2007, 16 members of the CSRG had received ethics approval and had entered baseline data on a total of 520 scleroderma patients. Within that cohort, 280 have already had their one-year review, and 79 have had their two-year review. Other doctors, such as Quebec's Jean Luc Senecal, are beginning to add data, as well. One of the largest and most comprehensive scleroderma patient data bases in the world is well established, is expanding, and is being utilized.

It has already been used to generate 20 wide-ranging articles and abstracts that have been published nationally and internationally. A 'key word' summary suggests the range: predictors of depressive symptoms; comorbidity estimates; health service utilization; predictors of medical outcomes; gastrointestinal manifestations; lung disease and pulmonary function; hand range of motion; cutaneous involvement; disability, pain and dyspnea (labored breathing).

The data base has also been used to underpin grant applications. In March 2004, the CSRG was awarded a Team Development Grant of **\$99,974** by the Canadian Institutes of Health Research (CIHR). Our Society was a collaborator on that application, and others, and has provided funding to develop and maintain the central patient data base of clinical and laboratory results. In February 2007, the CSRG was awarded **\$262,500** to develop and validate a **patient-assessed** disease activity index in systemic sclerosis (SSc).

We are awaiting the results of other significant grant applications to the CIHR. Results of an application on February 1, 2006 in the amount of **\$1.8 M** are expected by April 2007. (Note the time lag!) This Training Initiative Program Grant proposal focuses on skin disease and musculoskeletal rehabilitation. The objective is to develop new capacity to perform high quality, trans-disciplinary research in multiple aspects of

SSc in Canada by training laboratory and clinical researchers to do so.

Results of an application in June 2006 for a New Emerging Team Grant in the amount of **\$1.5 M** will be known in the next few months. The proposal is to create a multidisciplinary, cross-pillar team to perform high impact SSc research. The team will use a longitudinal, prospective data base to define SSc subsets, create disease activity and organ damage indices, and validate them using modern statistical techniques.

In September 2006, a proposal concerning the Impact of Orofacial Manifestations in the amount of **\$246,897** was submitted. The goal is to raise awareness of the oral health problems experienced by patients with SSc, so that they can be prevented and treated. A decision is expected this spring.

Several individuals in the diverse CSRG have undertaken and are undertaking complementary SSc research, privately, as well. In addition to the foregoing initiatives, a clinical research team known as the Systemic Autoimmune Rheumatic Disease (SARD) Research Alliance has been formed. It, too, is seeking research funds to address autoimmune and, by definition, SSc issues.

In summary, there is a cadre of approximately 30 highly qualified and respected doctors and researchers across the country working with many others to improve diagnosis and treatment, and to speed the day that SSc is conquered. Patient representatives are working closely with them.

As a direct result of a meeting of the CSRG on February 23, 2007, it is on even firmer ground to pursue its collective mission, which is to perform research in SSc. Society representatives Bob Buzza and Grant Dustin attended that meeting. During it, Bylaws and Rules of Procedure were adopted, agreements governing use of the CSRG Registry Data Base, the services to be provided by recruiting rheumatologists, and authorship policies pertaining to all publications using data from the CSRG central data base were approved. Chairs of Standing Committees were appointed.



Dr Murray Baron, who founded the CSRG, was elected as Director of it for the next five years. His term is renewable, once. The fourteen rheumatologists who had entered **complete** data within the last 12 months on more than five patients and Bob Buzza, representing our Society, were elected to the Governing Council. It will determine policies and programs. Bob and Society representatives Grant Dustin and Shirley Haslam were appointed as collaborators. Other representatives will be appointed as well.

The CSRG is dispersed across at least 15 institutions in Canada. The group functions essentially on a 'virtual reality' basis. Liberal use is made of email exchanges about a wide range of SSc issues. Exchanges are pointed, and result in a sharpening of options warranting further attention. Exchanges are an ongoing form of in-service education that results in considerable agreement about 'best practice'. Patients benefit.

Meetings are infrequent. To keep costs to a minimum, they are typically held in conjunction with Canadian or US rheumatology meetings. Although a nominal fee is paid to defray patient data entry costs, nothing is paid for the time devoted to CSRG work. Grant applications, alone, take a great deal of time. They sometimes exceed 60 closely-typed pages, and may cite over 200 references. As many as 40 applicants, co-applicants, and collaborators may be involved. Competition is stiff. Only 15-20 per cent can be funded.

SSc patients face a myriad of problems. Many feel that too little is being done for them, personally, and they are likely right. However, there has never been a greater emphasis on SSc within the medical and research communities. Diagnosis and treatment **are** improving. Significant research **is** being undertaken.

Please visit our website at www.scleroderma.ca) for further information and more information on the CSRG under "Research."

The CSRG, in particular, deserves our wholehearted support.

*Respectfully submitted, Bob Buzza, Research Liaison,
Scleroderma Society of Canada rmbuzza@ret.bctf.ca*

Feb '07

Annual General Meeting and Conference

The Scleroderma Society of Canada will hold its Annual General Meeting and Conference on September 29, 2007 in Calgary, Alberta. We invite you to attend this event, which will feature presentations on topics related to scleroderma as well as being an opportunity to meet other patients and professionals with common interests. In addition to the full program on Saturday, September 29, there will be Calgary tours arranged for Friday afternoon and a "Meet and Greet" social event Friday evening. Details of the program will be available at a later date. For more information please contact Grant Dustin, 95 Woodfield Road SW, Calgary, AB T2W 5K5, telephone 403-281-7616, email mgdustin@telus.net.

The AGM/Conference will be held at the Coast Plaza Hotel and Conference Centre in Calgary. If you reserve a room at the hotel please indicate that you request the special room rate (119) for the Scleroderma Conference.

Coast Plaza Hotel
and Conference Centre
1316 – 33rd Street NE
Calgary, AB T2A 6B6

Telephone: 403-248-8888

Fax: 403-248-0749

Toll free: 1-800-663-1144

President's Message

February, 2007

Happy New Year!

I trust everyone enjoyed a wonderful holiday season with family and friends. The New Year is well underway and we are all experiencing winter weather, more extreme in some areas than in others. Winter can be a challenging time. Bundle up well, keep warm and get outside when possible, if you are able to do so. It's important to keep moving: walk, dance, swim, stretch, lift weights or other indoor and outdoor activities that interest you.

The SSC continues to be very active on your behalf. Bob, Normand and I are on a committee with representatives from Lupus Canada and the Sjogren's Society of Canada developing a plan of action to meet jointly with the Federal Minister of Health and other MPs, with the purpose of creating awareness about our diseases and discussing health care issues related to them. Another committee is working with Maie and Grant planning our AGM to be held in Calgary, on September 29th. You can read more about this event in your newsletter. With respect to scleroderma research, two representatives from SSC will be attending the Canadian Scleroderma Research Group meeting on Feb. 22nd. Check out the report about research by Bob Buzza, our Research Co-coordinator, in this newsletter.

Across the country, many provincial and support groups are gearing up for various spring and summer fundraising events: dinners, walks, garage sales etc. On March the 17th, I will be attending the Annual Gala Dinner and Dance, a fundraising event organized by the Scleroderma Society of Ontario. Check the SSC Website for information about this event and other fundraising activities. There are groups preparing educational seminars, drawing on the medical and other health professionals in their respective areas .to provide an opportunity for Scleroderma patients to get together for discussion, networking and seminars.

The SSC board of Directors welcomes your comments, stories and suggestions. You can reach us at the SSC address which is info@scleroderma.ca. You can also e- mail me at srunia@sympatico.ca.

Keep well.

Respectfully submitted,

Shirley Haslam

It is with sadness that we report the passing of Pam Mullin of Fredericton, New Brunswick. Pam started the New Brunswick scleroderma support group in the early 1990's and was the leader of that group until a few years ago. She and her husband, Sam were key people in helping to organize and host our Society's AGM and conference that was held last September in Fredericton. On behalf of the Scleroderma Society of Canada and its Member organizations we extend our sincere sympathies to Sam Mullin and family members.



Patient-Assessed Disease Activity Index

Great news! The CIHR has awarded a grant of approximately \$262,000 to Dr. Marie Hudson and her co-applicants to develop and validate a **patient**-assessed disease activity index in systemic sclerosis (SSc).

The index will be useful "... in epidemiological research to identify important and potentially reversible aspects of SSc". It will be helpful in establishing eligibility for and measuring outcomes in upcoming clinical trials. It may also be used in clinical practice to guide decision-making and meet regulatory requirements.

The index will complement the **physician**-assessed disease index that will be developed if the CIHR approves the New and Emerging Team grant application that was submitted last June.

Patient-assessed disease activity indexes are relatively rare, but "... have been shown to perform as well as standard physician and laboratory measures of disease activity in several rheumatic diseases." **Patient** indexes provide a practical, less time-consuming means of assessment, are made at one point in time, rather than at different times, are less costly and invasive, are less likely to be subject to missing data and, because patients participate in the development process, tend to enhance validity.

Ethics approvals for this project are now being sought. In the first year or so, Dr Hudson, MD, MPH and her team will recruit about 30 patients for interviews and about 15-20 caregivers for focus groups in Montreal, London, and Saskatoon, as well as an additional 80 patients for pre-testing. During a two-year validation phase, the instrument and questionnaires will be administered to all the patients during two consecutive visits.

Co-Applicants on this project are Murray Baron, MD, Russell Steele, PhD, and Sharon Wood-Dauphinee, PhD.

Our sincere congratulations to the entire team, and our thanks to everyone who will help develop the index.

Bob Buzza, Research Coordinator, Scleroderma Society of Canada



Two references in Dr Hudson's application are of interest;

1) Using conservative estimates, SSc is thought to affect over 16,000 Canadians. (Previous estimates were in the 9,000 range.)

2) The Canadian Scleroderma Research Group patient registry, which now includes about 500 registrants, is described as one of the largest cohorts in the world. (Kudos to everyone who has registered, so far.)

Stepping into the Shower with Chronic Illness

We all know that staying clean and presentable costs us much more in pain and fatigue than our healthy counterparts. It's been years since I've been able to take a relaxing soak in the tub, because I rarely have a crane available to get me out. Therefore, I'm strictly a shower girl. For those of you who can relate to the problems associated with the endurance marathon of taking a shower, I'd like to share some of my adaptations.

Preparation is key. Be sure to have all necessary items within reach, as you'll have more energy and wits to find them before your shower than afterwards.

I find some bath items more helpful than others. For instance, using a 2-in-1 shampoo with built-in conditioners saves you a step in hair care and limits the amount of stretching and holding your arms over your head. Some of the brands who carry these combination products are Suave, Pantene, and Prell. Your own personal preference will tell you which to choose; however, I prefer the Pantene Pro-V version. Using bar soap presents two problems. They are often drying, which causes skin issues for some. In addition, that wet bar of soap can easily slip from your grasp during shower time, causing you to have to bend and reach for it on the tub/shower floor. This can cause muscle strain and even lead to falling in the shower. To prevent these issues, I use liquid soap. I personally prefer the baby baths that contain chamomile and lavender. They are pure and contain essential oils that are meant to calm fussy babies, but they also work to

calm a fussy and achey me. You can find these baby bath products in either Johnson & Johnson's form or in the cheaper store brand, located in either the baby items section or in the standard soap aisle.

Fluffy towels are worth the investment, even on a fixed budget. When used to wrap your hair turban-style, the thicker the towel, the shorter time you need to raise your arms to towel-dry your hair yourself. I also find that using strategically placed hair bands, barrettes, or other hair clasps during the initial drying time cuts down on styling time.

You may not think you are "disabled" enough to warrant my best secret weapon in showering: the shower chair. However, even if you walk fine and can stand unaided, a shower chair will lengthen your endurance for a relaxed, comfortable shower. Mine stays in the tub/shower and is the same color as the tub so as not to be an eyesore. Shower chairs can be large or small, and can be bought sturdy enough to hold up to at least 450 pounds. They can be purchased at your nearby living aids store. I recommend checking out yard sales and flea markets first to see if you can get one cheaper.

Another preparation for your best shower is a dual shower head that includes a hand-held shower. This way you can stand under the shower spray for all-over rinsing, train the spray on a particular set of muscles that ache, or you can hold the spray while seated and direct it where you need it. These basic dual heads range in cost from \$20-30, and are available from health product catalogs or your local department store. You will more than likely need assistance installing your new shower apparatus. It is simple to do, but requires the ability to stand and hold your arms up for an extended time.



Another good preparation is to install one or more suction-cup baskets to the wall of your shower which you will be facing. Be sure that the bin you choose has holes in the bottom so water can drain out. Once I am settled on my shower chair, there is a suction-cup plastic bin facing me at seated eye level which holds all my shower items: shampoo, razor, liquid soap, washcloth, etc. This way I do not have to bend or reach or twist my back to reach for items when I need them. And I always know where they are, brain fog or not!

Once you have all the shower items you will need at hand, it is time to take the plunge. If you have a walk-in shower, so much the better. However, for those of us with tub showers, caution is needed in entering/exiting the tub. For many, the most dangerous moment is getting in or out of the shower, and for most, getting out after expending a lot of energy is a tenuous process. If you use a cane for strength or stability, make use of it when climbing in or out of the tub. Regardless of your shower configuration, be sure that you have a non-slip absorbent bathmat outside your tub, and non-slip surfaces on your tub floor, whether adhesive or built-in.

Once you have settled in your shower, let the warm water melt your muscle cramps away as you rest for a minute, and then carry on, with all the bath paraphernalia you need right at hand. A long-handled bath brush, preferably with a wide handle as well for easy grip, will help in washing those feet that seem, oh, so far away. After you're pink and clean, step carefully out of your shower and wrap yourself in the one thing I missed in my preparation paragraphs: a thick, cozy, terrycloth robe with a hood. Let the robe absorb the water and go take a rest if you need it. Your clothes will always be there when you're up to it!

With the right preparation, your shower time will become less of a chore and more of a luxury!



Clearing the Fog

Many people with fibromyalgia or scleroderma experience unclear thinking or cognitive dysfunction. They become forgetful, lose their train of thought, forget words or mix them up. There's no known cause for it, and the only treatment for it is following some basic memory and communication tips.

Below are some common-sense pointers that can help you clear the fog.

1. **Repeat yourself.** Repeat things to yourself over and over again. Repetition will keep thoughts fresh in your mind.
2. **Write it down.** Whether you write in a calendar, in a notebook or on sticky notes, if you're afraid you won't remember something, putting pen to paper can help.
3. **Pick your best time.** If there is something you need to do that requires concentration and memory, such as balancing your checkbook or following a recipe, pick your best time to do it. Many people with fibromyalgia say they perform best early in the day.
4. **Get treated.** Depression, pain and sleep deprivation can influence your ability to concentrate and remember. Getting your medical problems treated may indirectly help your memory.
5. **Engage yourself.** Reading a book, seeing a play, or working a complex crossword or jigsaw puzzle can stimulate your brain and your memory.
6. **Stay active.** Physical activity, in moderation, can increase your energy and help lift your fibro fog. Speak to your doctor or physical therapist about an exercise program that is right for you.
7. **Explain yourself.** Explain your memory difficulties to family members and close friends. Memory problems often result from stress. Getting a little understanding from the ones you love may help.
8. **Keep it quiet.** A radio blasting from the next room, a TV competing for your attention, or

background conversation can distract your attention from the task at hand. If possible, move to a quiet place and minimize distractions when you are trying to remember.

Go slowly. Sometimes memory problems can result from trying to do too much in too short a period of time. Break up tasks, and don't take on more than you can handle at once. Stress and fatigue will only make the situation worse.

The Scleroderma Society's toll-free number, 1-866-279-0632, has been transferred to a different location but remains in service, using the same number as stated above, and as listed on the Society's publications.

There may have been some interruption during the transfer. If you experienced any difficulty getting a connection to this service recently, we apologize for that. The service is now based in Caledonia, Ontario under the direction of Irene Goodale.



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.

scleroderma@
illicomanitoba.ca

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Scleroderma Society of Canada

Back issues of *Strides* are available on the website (www.scleroderma.ca, under 'contact us', go to 'publications')

Any one wishes the latest issue of *Strides* please contact us through the 1-866-279-0632 or email scleroderma@illicomanitoba.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 research toward finding a cure and to provide support and information to those affected by the disease.

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.

Pictures from Gillian Little in Alberta on Donations that were received for their support group.



Gloria Swanson who approached Branch 215 of the Ex Service women here in Edmonton. They donated \$2000 to be used for support and awareness of Scleroderma.



Elizabeth and David Chomik Grand Prairie Trumpeter Lions Club, who donated \$900. Swan City Breakfast Lions Club, who donated \$500 and Grand Prairie Lions Club, who donated \$200.