

CANADIAN SCLERODERMA NEWS



SCLERODERMA SOCIETY OF CANADA

NOVEMBER 2009

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Flu



L-R –Maureen Sauve, John Lewis, Gillian Little, Catherine Fortune,

Marion Pacy, Helen Goerzen

Missing, Normand Richard, Mary Beth Clark

New Board of Directors:

President: Marion Pacy

Vice President: Normand Ricard

Secretary: Helen Goerzen

Treasurer: Catherine Fortune

Research Liason: Bob Buzza

Webmaster: Ron Gullinson

Directors-at-Large:

John Lewis

Maureen Sauvé

Gillian Little

Mary Beth Clark

Conference will be held in Halifax, 2010

MESSAGE FROM THE PRESIDENT

Marion Pacy

The Scleroderma Society of Canada's 10th Knowledge Exchange & Conference was held on October 2 & 3 at the Delta Hotel in Winnipeg was a great success. For those of you that could not attend here is a brief overview of events.

This year the Scleroderma Association of Manitoba hosted the 10th Anniversary of the Scleroderma Society of Canada here in Winnipeg. We started on Friday at 1:00 with two tours. The first was a walking tour from the train station to the Forks called Pestilence, Shamans & Doctors. The tour was lead by Dr Charlotte Ross from the 19th Century. It was a chilly day but 8 brave scleroderma persons enjoyed the walk. Thanks to Marianne who lead the group for the afternoon. The other tour was by bus and was enjoyed by 18 who got a terrific tour of Winnipeg.

Friday evening, the Scleroderma Association of Manitoba welcomed the Canadian Scleroderma Research Group that have doctors, researchers & students from all across Canada, our members of the Scleroderma Society of Canada from BC to Quebec and all interested people from Manitoba to Folkorama at the Delta. We had four different buffets to choose from, Manitoba, Mediterranean, Ukraine & French. During the evening thanks to Jessica & Suzanne from the CSRG we wished well wishes and good bye to our retiring Secretary/Treasurer of the Scleroderma Society of Canada via a web cam. Grant & Maie Dustin have been with the Society since the very beginning. Then we turned the tables, we asked the doctors, students & researchers to ask the patients questions. We had a very interesting question and answer period.

Saturday morning started early with registration & breakfast. The welcome included a powerpoint of the memories of the last ten years, a welcome to Tracey Sperry from the Foundation in the States and then our general meeting with the election of two new people to the board. (See in the newsletter the list of all the board members.) Dr Robinson was kind enough to explain the database that is held at his office at the Health Science Centre. All of the information collected is added to the Canadian Scleroderma Research Groups database. Everyone was very interested in Dr Baron's update on research in the past year. (Please look for an article from Dr Baron in the newsletter).

At 10:30 we started our breakout sessions with Doreen Mulder giving us a few lessons on makeup, her session ran late due to all the questions everyone had. Dr Shane Silver's session also had a lot of questions at the end, he spoke on the skin. Oral Health was covered by Sabrina Gravel.

During Lunch the Andrews-Clay & Rosa Venuta from CIHR (Canadian Institutes of Health and Research) Presented Dr. Baron from the CSRG and Marion Pacy from SSC with the CIHR Partnership Award. We celebrated our 10th anniversary with a wonderful cake with the SSC Logo on top.

In the afternoon breakout sessions Dr Markland spoke on "Are stem cell transplants an option on Scleroderma". Dr Stewart & his wife spoke on Home & Health Support. Dr Shikha Mittoo talk was on lung disease. Johanna Stasiuk was from Physiotherapy. Kidneys were the topic for Dr. Peter Docherty. Tammy Raynor gave us tips on Nutrition. Dr. L. Warren Nielson talk on managing insomnia was a hot topic. Ann Patton was from Occupational. As you can see we had a wide array of speakers and a full day.

We ended the day with the silent auction draw. 30 of us had some energy left and attended Celebration Dinner Theatre.

On Sunday the Scleroderma Society of Canada held their board meeting in the morning and later wished good bye to all of out of town guest that were departing.

I wish to give a huge thank you to all that attended this event. Many filled out the evaluation forms, which I thank you for, these have helped out to plan out next conference in Halifax, November 26 & 27. Of Course I can not thank my volunteers enough. Jackie & Ron for working so hard on the silent auction, Ann for doing all the registration and thanks to all her friends that volunteered. Dr David Robinson who put up with my nagging and emails. A big thanks to Darlene who put up with my non stop organization and working so hard through a difficult time. All those who got picked to introduce the presenters. Thanks to all our guest speakers and the hotel for looking after us. And a huge thank you to anyone I forgot.

**Lay summary of Dr. Baron's presentation to patients
during the 2009 Annual Meeting of the Scleroderma Society of Canada
(Winnipeg, MB)**

Dr. Murray Baron, Ms. Mireille Guirguis & Dr. Suzanne S. Taillefer

The Canadian Scleroderma Research Group (CSRG) patient registry now has over 1000 patients from all over Canada, some seen for their sixth annual visit this year. The Group has many publications and also many summer students and trainees involved in our studies and they all depend of our data collection.

The CSRG research is mainly divided into 2 areas: Clinical and Laboratory. *Clinical Research* uses mostly information that we collect annually and that we keep in a central database. This information is taken from the patients we have seen, but also include some extra studies involving new questionnaires, exams and interviews. *Laboratory Research* mainly looks at fibrosis which is scar tissue, and blood vessels.

Three laboratories are presently working on **fibrosis**: (1) Dr. Leask and Dr. Parapuram are working with a protein called Akt which is involved in fibrosis, and PTEN which suppresses the effects of Akt. With skin cells of CSRG patients they will determine if fibrosis is due to loss of PTEN. This can lead to drug therapy for fibrotic diseases like SSC. (2) Dr. Philip, Dr. Finsson and Dr. Man have been working on fibrosis and have made many advances in this field using CSRG skin biopsies. (3) Dr. Roughley, Dr. Mort & Dr. Recklies, along with their trainee Yuen Yee Ho, have been working on proteoglycans (PG) that form part of the substance outside of cells in many tissues. They are trying to find a way to measure these PGs to know if the fibrosis is actively going on or whether it has already happened.

Three other laboratories are focusing on the **vascular aspect** of the disease: (1) Dr. Van Eeden's laboratory studies cytokines, which are chemicals by which cells communicate. Cytokines play a large role in blood vessel activity. To study this, blood from 400 CSRG patients is being used. (2) Dr. Servant and Monique Arts, his trainee, are currently trying to reproduce a protein in blood that occurs only in scleroderma patients that stimulates skin cells and other fibroblasts to produce excess collagen. They are trying to see if this substance stimulates the cells in the walls of blood vessels. (3) Dr. Trifiro and his trainee Daniele DiCapua are now using a method to cut out blood vessels from skin biopsies of CSRG patients in order to know if the genes that produce some of the receptors on the surface of the blood vessel cells are functioning abnormally. If so, we may be able to design therapy to make them function normally.

What Do We Know About Sleep? Sleep in Health and Illness Dr Warren Nielson

Although there has been little research into sleep problems in people with Scleroderma, tiredness in general and sleep problems specifically, do appear to be common in those with this illness. It is likely fair to say that, for many of those with Scleroderma, help with sleep problems is an unmet need.

Sleep is more than just a time of inactivity and rest. Our sleep/wake cycle or circadian rhythm is involved in regulating a number of important physiological functions such as blood pressure, muscle strength, cardiovascular efficiency, body temperature, etc. Lack of adequate sleep increases the risk of mood problems, cardiovascular disease, obesity, diabetes and infections. Sleep in Scleroderma is known to be affected by gastroesophageal reflux, pulmonary fibrosis and restless legs syndrome. However, other symptoms such as pain and pruritus (itchiness) are also likely to disrupt sleep.

Sleep is divided into stages based on the electrical activity of the brain (i.e., brain wave patterns). The first four stages are called Non-Rapid Eye Movement Sleep (NREM). After we fall asleep we gradually move into deeper stages of sleep. The deepest of these (stages 3 and 4) are sometimes called “restorative” sleep because they are related to physical restoration. As the night progresses we move back into lighter stages of sleep including Rapid Eye Movement (REM) sleep. This stage, which first occurs about 90 minutes into sleep, is most linked to emotional rejuvenation. It is during REM sleep that we dream. Throughout the night we cycle back and forth through these different stages.

The most common sleep disorder is insomnia. Between 30 and 35% of people have at least occasional insomnia. For about 15% insomnia is more severe and is a significant problem. Insomnia is about 1½ times more common in women than men. There have not been any large-scale studies of insomnia in those with Scleroderma so we do not know exactly how common it is in this group.

The only sleep disorder that has been documented to be more common in patients with Scleroderma is Restless Legs Syndrome (RLS). This involves unpleasant sensations of tingling or prickling in the legs, particularly in the calves and is relieved by moving them. As you might expect, people with this problem have difficulty falling asleep and staying asleep. In the general population, RLS affects between 5 and 15 percent of people (depending on the study group). In those with Scleroderma, the incidence is higher at about 22%. Although RLS is not curable, there are a number of drugs that can help, particularly those that increase a neurotransmitter called dopamine. Stretching, hot baths, massage and avoidance of alcoholic or caffeinated drinks can also help. Sometimes, RLS is due to iron or vitamin deficiency and iron, vitamin B12 or folate supplements may be prescribed.

Insomnia is defined as “difficulties initiating, sustaining or obtaining qualitatively satisfying sleep that occur despite adequate sleep opportunities and result in notable waking deficits” (Edinger, 2004). The most important thing to do to treat insomnia in people with Scleroderma or other chronic illnesses is to treat the underlying disease. When the disease is better controlled symptoms are fewer and less severe and hence less likely to impact on sleep. Another important consideration is whether the medications the person is taking may be causing or contributing to the sleep problem. Sometimes medications can be changed to reduce the effect on sleep. Mood disorders are also a common cause of insomnia, particularly anxiety and depressive disorders. For some people, napping can also make nighttime sleep more problematic. In general, naps should be limited to no more than 20 minutes. Longer than that and they are increasingly likely to interfere with sleep at night.

In addition to insomnia associated with chronic illness some people can develop what is called “primary chronic insomnia”. This is when people have developed an unhelpful sleep pattern where they are more “revved up” than is normal at bedtime. This condition is usually diagnosed using a sleep diary and sometimes an overnight sleep recording.

Insomnia typically involves a vicious cycle in which the person becomes increasingly worried about not sleeping after having had difficulty sleeping on previous nights. Such a person may become anxious at just the thought of not sleeping, thus making it even more difficult to fall asleep. More time is spent in bed “trying to sleep” but less time is spent actually sleeping. Some sleep experts have called this “insomnia brain” where negative thoughts spread like wildfire and it becomes increasingly difficult to turn them off. A negative conditioning process occurs in which your bed and bedroom become cues for anxiety and distress about not sleeping. What steps can be taken to break this cycle of negative conditioning and anxiety? One thing you can do is to go to bed only when you are sleepy. If you don’t fall asleep within 20 minutes, get out of bed and go to a different room. Engage in something relaxing until you feel sleepy again and then go back to bed. Relaxation techniques (e.g., deep breathing, progressive muscle relaxation, meditation) can help you settle down and make it easier to fall asleep. A more intensive approach called “sleep restriction therapy” can also help reset your sleep/wake cycle. With this approach, sleep is first limited to 4 or 5 hours and more time is added each night until a normal night’s sleep is achieved. To deal with negative thoughts you can learn to challenge exaggerated negative thoughts like “I’ll never fall asleep without take a pill” or “My day tomorrow will be ruined if I don’t fall asleep soon” and replace them with more realistic, balanced thoughts. Together, all of these strategies are called “Cognitive-Behavioural Therapy” and this approach has been shown to be the most effective way to treat insomnia – even better than sleeping pills. However, no approach is perfect and some people may require medication to help them sleep. If you have a sleep problem that persist and is distressing to you, talk to your doctor about your options.

Of course, prevention of sleep problems is best. In addition to what has already been discussed, here are some suggestions to maintain good sleep habits:

Select a standard “wake-up” time

Stick to it regardless of how much sleep you get on a given night

Will help you develop a more stable sleep pattern

Have a “wind-down” time before you go to bed

Use the bed only for sleeping (sexual activity is the only exception)

3. Don’t worry, plan, etc. in bed
4. Limit your use of caffeinated foods and drinks (coffee, tea, soft drinks, chocolate)
5. Limit your use of alcohol - you may get to sleep faster but you will have poor quality sleep
6. If you can, try some moderate exercise – but not in the evening
7. Try a light bedtime snack (cheese, milk, peanut butter, yoghurt)
8. Make sure your bedroom is quiet and dark

Make sure your bedroom temperature is comfortable (temperature above 24C is too hot; 18-19C is thought to be optimal)

Scleroderma and Sadness: The Inside Scoop

Evan Newton

You're in your mid-30s, you're happily married, you have a couple of kids at home. Your job is stressful but absorbing. And then your fingers start to swell, to bend, and change texture. They become painful. The skin on your face changes. These changes are disturbing and bewildering, and as you're shuffled around from doctor to doctor, each unable to give a firm diagnosis, your health continues to deteriorate. When the diagnosis of scleroderma is finally made, whatever relief you feel from finally having a name for your condition is surpassed by the worries that come with being diagnosed with a chronic disease. A disease that neither you nor your friends have heard of. A disease that's disfiguring. That can be fatal. For which there is no cure.

The combination of the physical progression of the disease and the diagnosis itself can be devastating. The recognition of the undeniable burden of having scleroderma has prompted research aimed at better understanding the psychological experience of people with the disease. My role as a master's student with the Canadian Scleroderma Research Group (CSRG) is to do exactly that: to look at the emotional and psychological experience of people with scleroderma.

My first step was to look at what past research had been done on depression and mental health in people with scleroderma. I found that no research has been done on major depression, which is a psychiatric diagnosis. Different studies, however, have found that between 36% and 65% of patients have high levels of "depressive symptoms" or "distress." A study by the CSRG also found that worse disease is related to greater distress.

But all this research has been done by collecting data at single time points. Scleroderma is a disease that changes over time, so to look at mental health at a single time point may not be getting the whole picture. This problem led me to the first project of my master's studies. We wanted to know how mental and physical health related to each other over time. We looked at the course of both depressive symptoms and physical disability in people in the CSRG registry over a four-year period. We found that while physical disability worsened somewhat over the four-year period, symptoms of depression remained stable. The way we understand this is that a diagnosis of scleroderma can be a scary, distressing thing, but that once this diagnosis is given, people learn to accept and take into account the uncertain future of their life with the illness. As a result, even if their scleroderma gets worse, mood for many people largely stays stable.

However there is still a problem with this research. In every study so far, depression has been measured by a questionnaire, in which you, the participants, are asked to rate the severity of symptoms on a number scale, with a final number coming out at the end to indicate the severity of your mood. Is it okay to give a number to such a subjective experience? Questionnaires are also known to inflate the number of people who appear to have clinical depression in terms of a psychiatric condition. And furthermore, when we use questionnaires, even if somebody has a high score, we technically can't say they are experiencing "depression"! Since we don't know the nature of their distress, we can only say that they are experiencing "significant depressive symptoms." In order to say that someone is suffering from "clinical depression," they have to complete a structured interview for major depression.

This is a much more time-consuming process that requires training to administer, but is considered the “gold standard” of depression diagnosis.

Recognizing the need to use this technique, our research team is currently conducting a study in which patients in the CSRG are contacted by phone to complete both a questionnaire designed to evaluate depressive symptoms and a structured interview for major depression. The purpose of this is to see how a diagnosis by a quick and easy-to-use questionnaire and the more rigorous interview match-up. Although they’re really supposed to be measuring the same thing, we think the interview is going to find a much smaller number of people who experience clinical depression in strict psychiatric terms.

So, is this semi-structured interview, the so-called ‘gold standard’ of depression diagnosis, the be-all and end-all of depression research in scleroderma? Do we now have everything we need to know about the psychological experience of those with scleroderma? I don’t think so. I think there are more fundamental questions to ask than simply deciding whether or not someone has met the official psychiatric criteria for major depression.

What is “depression” anyways? The term is widely used and troublesome; you can find a movie depressing, or feel depressed on a rainy day, or be so depressed that you end up hospitalized. The term “demoralization” has been introduced in medical research to describe a similar but distinct syndrome as “depression” that is often seen in the medically ill. It is a state of hopelessness, disheartenment, apathy, and sadness, which, unlike major depression, is seen as a fairly typical reaction to a difficult situation. Most importantly, it differs from major depression in that it is not considered to be a bonafide psychiatric disorder. The point is that different words besides “depression” have been used to describe emotional distress, and that not all distress lies on a continuum of being more and less depressed. These issues led me to develop the core project of my master’s thesis. The question I’m setting out to answer is this: what is the nature of the emotional distress experienced by people with scleroderma? Instead of using a questionnaire that gives a number to your experience, or using a structured interview with verbatim questions and confined answers, instead of simply trying to determine whether someone deserves the label of depressed or not, I’m taking a very different approach. I’m tackling this question by using in-depth interviews with people with scleroderma. These interviews are long (between one and two hours), and will take place in participants’ homes. I’ll ask participants to describe their emotional and psychological experience in their own words. Perhaps scleroderma patients will more often describe a state closer to demoralization than depression. I’ll also ask what aspects of the disease have the biggest impact on their mood, and to consider what it means to them to experience this distress. I’m also interested in hearing what they do about their distress, and how they cope with it.

What this really comes down to is answering the question, “What’s really going on in the minds of people with scleroderma?” After all, if something’s going to be done about this distress, if it’s going to be treated, we first need to know what it is we’re treating.

If I can shed some light on this, if I can make it just a little bit clearer, I’ll be satisfied.

Lowering Salt in Your Diet

Everyone needs some salt to function. Also known as sodium chloride, salt helps maintain the body's balance of fluids. Salt also functions in many foods as a preservative, by helping to prevent spoilage and keeping certain foods safe to eat. But nearly all Americans consume more salt than they need, according to the 2005 Dietary Guidelines for Americans. These guidelines are published every five years by the U.S. Department of Health and Human Services and the U.S. Department of Agriculture.

The natural salt in food accounts for about 10 percent of total intake, on average, according to the guidelines. The salt we add at the table or while cooking adds another 5 to 10 percent. About 75 percent of our total salt intake comes from salt added to processed foods by manufacturers and salt that cooks add to foods at restaurants and other food service establishments.

Q. What is the daily recommended amount of sodium for adults?

A. The amount of salt in a food is listed as “sodium” on the Nutrition Facts Panel of food labels. The Dietary Guidelines recommend that the general population consume no more than 2,300 milligrams of sodium a day (about a teaspoon of table salt). Most food labels shorten the word “milligrams” to “mg.”

Q. What steps can I take to lower my salt intake?

- Eat more fresh fruits and vegetables.
- Consume foods that are rich in potassium. Potassium can help blunt the effects of sodium on blood pressure. The recommended intake of potassium for adolescents and adults is 4,700 mg/day. Potassium-rich foods include leafy, green vegetables and fruits from vines.
- Flavor food with pepper and other herbs and spices instead of salt.
- Choose unsalted snacks.
- Read food labels and choose foods low in sodium.
-

Q. How can I tell if a food is low in sodium or high in sodium?

A. The Nutrition Facts Panel that appears on food labels also lists the “% Daily Value” for sodium. Look for the abbreviation “%DV” to find it. Foods listed as 5% or less for sodium are low in sodium. Foods listed as 6% to 20% contain a moderate amount of sodium. Anything above 20% for sodium is considered high. Try to select foods that provide 5% or less for sodium, per serving.

Q. Are salt substitutes safe?

A. Many salt substitutes contain potassium chloride, which could be harmful to people with certain medical conditions, such as diabetes, kidney disease, and heart disease. Check with your doctor before using salt substitutes.



Know the Difference between a Cold and H1N1 Flu Symptoms

<u>Symptom</u>	<u>Cold</u>	<u>H1N1 Flu</u>
Fever	Fever is rare with a cold.	Fever is usually present with the flu in up to 80% of all flu cases. A temperature of 100°F or higher for 3 to 4 days is associated with the H1N1 flu.
Coughing	A hacking, productive (mucus-producing) cough is often present with a cold.	A non-productive (non-mucus producing) cough is usually present with the H1N1 flu (sometimes referred to as dry cough).
Aches	Slight body aches and pains can be part of a cold.	Severe aches and pains are common with the H1N1 flu.
Stuffy Nose	Stuffy nose is commonly present with a cold and typically resolves spontaneously within a week.	Stuffy nose is not commonly present with the H1N1 flu.
Chills	Chills are uncommon with a cold.	60% of people who have the H1N1 flu experience chills.
Tiredness	Tiredness is fairly mild with a cold.	Tiredness is moderate to severe with the H1N1 flu.
Sneezing	Sneezing is commonly present with a cold.	Sneezing is not common with the H1N1 flu.
Sudden Symptoms	Cold symptoms tend to develop over a few days.	The H1N1 flu has a rapid onset within 3-6 hours. The flu hits hard and includes sudden symptoms like high fever, aches and pains.
Headache	A headache is fairly uncommon with a cold.	A headache is very common with the H1N1 flu, present in 80% of flu cases.
Sore Throat	Sore throat is commonly present with a cold.	Sore throat is not commonly present with the H1N1 flu.
Chest Discomfort	Chest discomfort is mild to moderate with a cold.	Chest discomfort is often severe with the H1N1 flu.



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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

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.