

CANADIAN SCLERODERMA NEWS



SCLERODERMA SOCIETY OF CANADA

FEBRUARY 2010

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11th Annual Scleroderma Conference “Living Well With Scleroderma” Scleroderma Society of Canada

Presentations will concentrate on learning new ways and new skills to manage and cope with some of the daily problems we face with scleroderma. We hope these new skills will contribute to a better quality of life and a more fulfilling life style despite some limitations created by the disease. We will utilize the holistic model of health, concentrating on the mind, body, spiritual dimensions of health and healing. We hope you will consider travelling to eastern Canada next fall to learn how we “Live Well with Scleroderma” here in Nova Scotia. We look forward to your visit with us and hope you will enjoy our warm maritime hospitality.

November 26 & 27, 2010

Westin Nova Scotian
Halifax, NS
westin.com

Registration Fee \$30.00

For more information please contact:

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More details and registration forms will
be in the next newsletter coming out in May.

1ST SYSTEMIC SCLEROSIS WORLD CONGRESS

In February 2010, the 1st World Scleroderma Congress will be held in Florence, Italy. This will be a dual event, consisting of a 3-day congress for doctors, and a one-day event for patients at which rheumatologists will address issues of interest to people who have scleroderma. The Scleroderma Society of Canada is grateful to have four representatives attending this event in Italy. This will be a great opportunity to interact with other support groups from all around the world.



Bamboo Shoots!

A panda walks into a diner, sits down at the counter and orders some food to eat. He calmly eats all his food until he is finished. As he gets up he pulls out a gun and fires a few shots into the ceiling. No one is injured but the owner is furious. Why the heck did you do that?!" The owner yells. As he walking out the door the panda turn around and says: "I'm a panda, look it up." And he leaves. So the owner goes into his back office and pulls out his old dictionary. After blowing the dust off it, he opens it and finds the entry for "panda." It says: "PANDA: native to Asia and a member of the raccoon family. Has black and white markings. Eats shoots and leaves."

15 Immune Boosting Foods

Elderberry

An old folk remedy, extract from these dark berries appears to block flu viruses in test tube studies. And a few small studies done in people show it may help you recover more quickly from flu. But scientists caution that further study is needed. The fruit itself is rich in antioxidants and may also have the ability to fight inflammation.

Button Mushrooms

Don't dismiss the lowly mushroom as nutrient poor: It has the mineral selenium and antioxidants. Low levels of selenium have been linked to increased risk of developing more severe flu. And the B vitamins riboflavin and niacin, found in these mushrooms, play a role in a healthy immune system. Animal studies have also shown mushrooms to have antiviral, antibacterial, and anti-tumor effects.

Acai Berry

Hawked as a "super food" along with produce like blueberries, the little acai berry's dark color signals that it is high in antioxidants called anthocyanins. While the acai is not scientifically linked to specific disease- or illness-fighting ability, antioxidants may help your body fight aging and disease. Acai berries can be found most often in juice or smoothie form, or dried and mixed with granola.

Oysters

Aphrodisiac? Immune boosters? Maybe both, thanks to the mineral zinc that's found in oysters. Low zinc levels have been associated with male infertility. And zinc appears to have some antiviral effect, although researchers can't explain why. However, they do know it is important to several immune system tasks including healing wounds.

Watermelon

Hydrating and refreshing, ripe watermelon also has plenty of a powerful antioxidant, glutathione. Known to help strengthen the immune system so it can fight infection, glutathione is found in the red pulpy flesh near the rind.

Cabbage

This is another source of immune-strengthening glutathione. And cabbage is easy and inexpensive to find during the winter months when it's in season. Try adding cabbages of any variety (white, red, Chinese) to soups and stews to sneak in extra antioxidants and boost your meal's nutritional value.

Almonds

A handful of almonds may shore up your immune system from the effects of stress. A recommended 1/4 cup serving carries nearly 50% of the daily recommended amount of vitamin E, which helps boost the immune system. And they have riboflavin and niacin, B vitamins that may help you bounce back from the effects of stress.

Grapefruit

Grapefruits have a good amount of vitamin C. But science has yet to prove that you can easily get enough vitamin C through foods alone, without supplementation, to help treat cold and flu. However, grapefruit is packed with flavonoids -- natural chemical compounds that have been found to increase immune system activation. Dislike grapefruits? Try oranges or tangerines.

Wheat Germ

Wheat germ is the part of a wheat seed that feeds a baby wheat plant, so it is full of nutrients. It has zinc, antioxidants, and B vitamins among other vital vitamins and minerals. Wheat germ also offers a good mix of fiber, protein, and some good fat. Substitute wheat germ for part of the regular flour called for in baked goods and other recipes.

Low-Fat Yogurt

A daily cup may reduce your chances of getting a cold. Look for labels listing "live and active cultures." Some researchers believe they may stimulate your immune system to fight disease. Also look for vitamin D. Recent studies have found a link between low vitamin D levels and an increased risk of cold and flu.

Garlic

Garlic offers several antioxidants that battle immune system invaders. Among garlic's targets are *H. pylori*, the bacteria associated with some ulcers and stomach cancer. Cooking tip: Peel, chop and let sit 15 to 20 minutes before cooking to activate immune-boosting enzymes.

Spinach

Known as a "super food," spinach is nutrient-rich. It has folate, which helps your body produce new cells and repair DNA. And it boasts fiber, antioxidants, such as vitamin C, and more. Eat spinach raw or lightly cooked to get the most benefit.

Tea

Green or black? Both are loaded with disease-fighting polyphenols and flavonoids. These antioxidants seek out cell-damaging free radicals and destroy them. Caffeinated and decaf work equally well.

Sweet Potato

Like carrots, sweet potatoes have the antioxidant beta-carotene, which mops up damaging free radicals. Sweet potatoes also boast vitamin A, which is linked to slowing the aging process and may reduce the risk of some cancers.

Broccoli

Easy to find at the grocery store and incorporate into meals, broccoli is an immune-boosting basic. One study reported a chemical in broccoli helped stimulate the immune systems of mice. Plus, it's full of nutrients that protect your body from damage. It has vitamins A, vitamin C, and glutathione. Add some low-fat cheese to round out a side dish with immune-enhancing B vitamins and vitamin D.

The Experience of Fatigue: Sick and Tired of Being Sick and Tired?

Marielle Bassel

Everyone has experienced fatigue at some point or another. It is the sensation of feeling weak or tired, both physically and mentally. When you are fatigued, you have low energy, you need to rest more often, your limbs feel weak and heavy, you have trouble concentrating and paying attention to things, and you no longer have interest or motivation to participate in activities you normally love. Your sleeping pattern is often all over the map, and when you do sleep, it does not leave you feeling refreshed or full of energy. You now need to push yourself to start everyday tasks and even more so to complete them and this frustrates you to no end.

The difference between regular, or acute, fatigue that comes and goes and persistent fatigue from a chronic illness like scleroderma is that the latter is ongoing. You never get a break. Fatigue begins to make other areas of your life difficult, directly affecting your work, your social activities, and personal relationships. Fatigue has an impact on your overall quality of life and this is often apparent to family members and friends. The only problem is that your doctor doesn't know this; he's not asking about it and you are not telling him.

Research has shown that an important barrier to treating fatigue is a lack of communication between physicians and patients. The first question to ask yourself is why you are not talking to your doctor about your fatigue. He or she is obviously knowledgeable when it comes to scleroderma and is dedicated to helping you improve your condition. Is it because you don't believe that there can be anything done to help you? Is it because you don't think fatigue is a legitimate problem? Or is it because you don't want to take time away from other areas that you view as more important, such as your pulmonary hypertension, your Raynaud's, your gastrointestinal issues and other medical problems?

Let's begin by addressing the first concern. You are correct to feel this way since there is a genuine lack of research in the area of fatigue in people with scleroderma. When I began my work with the Canadian Scleroderma Research Group (CSRG), my first project was to look into existing research on fatigue, where I found only a handful of articles from focus groups interviews. In those articles, patients indicated that fatigue was an important part of their disease, one that affected them as significantly as pain and stiff joints and had a major impact on their daily life. Unfortunately, that was the extent of the research that existed on fatigue in scleroderma. In response to this lack of knowledge and information, our team compared data on levels of fatigue in scleroderma to levels of fatigue in other rheumatic disease groups, cancer groups and the general population, areas in which fatigue has been researched more extensively. Our results showed that people with scleroderma had more fatigue than the general population. They had similar levels of fatigue as patients with other rheumatic diseases, such as lupus and rheumatoid arthritis. They also had similar levels of fatigue as cancer patients currently undergoing treatment. Wait a second - cancer patients undergoing treatment? That means a person living with scleroderma has a comparable amount of fatigue to somebody currently undergoing chemotherapy or radiation.

In a recent Patient Survey of Health Concerns and Research Initiatives disseminated by the CSRG to people with scleroderma across Canada, over 600 participants were asked to rate their most frequent symptom and the symptom that had the most impact on their life.

Out of a list of 69 symptoms, fatigue was rated #1 in terms of being both the most frequent symptom and the symptom that impacted people the most.

It is now very clear that people with scleroderma have extremely high levels of fatigue and that it is a frequent and severe problem. But exactly how high are these levels? What percentage of patients suffer from extreme fatigue? And how can we go about finding this out? There are a lot of different questionnaires out there that inquire about fatigue. For example, some ask you to rate your fatigue on a scale of 1-10, but what does a number on a scale mean? What does this actually tell a physician about your experience with fatigue? How will it help in your treatment? My job as a research coordinator is to address the problem of fatigue and to find a unified measure to assess levels of fatigue in patients with scleroderma

Developing and testing treatments to reduce fatigue greatly depends on being able to easily identify patients in need of help, and the method chosen needs to be easy to use in a doctor's office or a clinic. A good way to do this is to develop an interview which is not too time consuming, easy to administer and which already has a fixed criteria to identify patients with fatigue. To achieve this goal, we looked into the well researched area of cancer- related fatigue, and we decided to use a measure that is often used to assess fatigue in cancer populations.

In our study to assess levels of fatigue in patients with scleroderma, which some of you may have already heard about or participated in, our research team calls CSRG patients to ask them about their current experience with fatigue. We first have a few questionnaires in which patients are asked to rate different areas of fatigue on a 1-5 point scale, and then we go into a more in- depth interview, asking more specific questions about fatigue. We ask about the quantity of a patient's fatigue (how long it lasts) as well as the quality (which symptoms of fatigue are the most prominent).

The causes of fatigue are complex. There are many different factors that contribute to it, both psychological and physiological. It is something we refer to as 'multidimensional', which means many different areas may cause it. These factors include the direct effect of the scleroderma burden (skin tightening, breathing problems, inflammatory muscle disease, arthritis and gastrointestinal problems); comorbid medical conditions; lifestyle factors (exercise, smoking, and alcohol consumption); psychosocial factors (stress, coping mechanisms, depression and anxiety) and symptoms that may aggravate fatigue (chronic pain or sleep disturbances). So beyond our assessment, more work is needed to establish the causes of fatigue in scleroderma, including determining which factors may be most easily treated. Research has shown that fatigue is treatable in cancer and other rheumatic diseases, and similar research is needed to develop interventions for patients with scleroderma.

We know that trying to figure out fatigue is a very difficult task, but the goal of our research is to understand people's experience with fatigue, which will ultimately help us with our goal of impacting clinical care. You can help us by agreeing to participate in our study when approached at your annual CSRG visit. Even if there is nothing specific we can do right now, I hope that at least I have helped you to realize that fatigue is an important problem in scleroderma, one that merits serious attention, and a mystery that we're working very hard on to solve.

For those of you who attended the Winnipeg Scleroderma Conference you received free samples of these heatbands. Here is further information for your convenience.

<http://www.tesco-shopping.com/HeatBands.htm>

877-823-5776

Heat bands

Suffering from cold hands and fingers, even Raynauds? HeatBands can effectively assist with this chronic problem. Literally a mini-thermal blanket, they're scientifically designed to utilize body heat to warm fingers and hands and require no other stimulus such as batteries or chemicals. Passively and naturally this remarkable, heat inducing wrist band is proven effective to warm cold hands and fingers. Ingeniously designed by the inventor of compact, warming medical blankets widely used in ambulances and hospitals, HeatBands are scientifically designed with the same care and precision. The secret of Heat bands is a specially designed heat retaining and reflective material imbedded between two specific layers.



How do they work? Ingeniously, the specially designed wristbands insulate the skin of the wrist retaining heat that would normally be expended through natural heat loss. Instead, natural body heat is retained and steadily reflected back promoting the flow of warm blood to the hand and fingers. Obviously, warmth is critical for relief from cold hands and fingers for anyone and in particular Raynaud's victims.

Comfortable, each wrist band is 2.75 inches wide (7 centimeters) wide and sized to be universal fit for girth. The underside, or skin side is a comfortable, safe, absorbent lining. Heatbands are designed to be worn casually all day and are super lightweight, so other than warmer fingers and hands, you'll forget you're even wearing them. The self adhesive strip means you can adjust the bands to the most comfortable fit. May also be removed and replaced easily.

Clean looking and aesthetically tasteful Heat Bands have a durable, waterproof exterior so may be worn virtually unnoticed just about anywhere. Tough enough to be worn during sports activities and sensible for use at home, and the office. This product is very versatile and is available in Neutral (natural skin tone) or black. These hygienic bands are normally used one per day and are available in convenient packs of: 14, or 60 - No more cold hands.

The Scleroderma Pain Puzzle: Putting the Pieces Together

Orit Schieir, MSc.

I first became interested in scleroderma while working as a research assistant in arthritis for a busy rheumatology center. The first time I walked through the scleroderma clinic, I looked around and was amazed by the diversity I saw; some people had visible skin changes; some people's hands were flexed inward; some people had assistive devices and/or needed oxygen and others had no discernable symptoms. The rheumatologist came out to grab the next chart and I quickly asked: "Does it hurt?" The rheumatologist looked at me and answered: "Does what hurt?" I answered: "Scleroderma; does it hurt?" The rheumatologist said: "Good question. I don't really know because we don't talk a lot about pain with scleroderma patients."

Several questions about pain peeked my interest, but, primarily, I wondered why a rheumatologist might not know very much about pain in scleroderma. A knee-jerk explanation might be that the doctor wasn't very knowledgeable about scleroderma and/or didn't pay very close attention to their patients. This, however, wasn't the case. The rheumatologist was a recognized scleroderma expert; one who had devoted more than 20 years to improving the care and treatment of persons with scleroderma.

A review of the literature related to pain in scleroderma as well as some of the general rheumatology literature helped shed some light on this issue. I found hundreds of research studies on pain in many of the rheumatic diseases, particularly arthritis. It was clear from all work that had been done in this area, that pain is widely recognized as an important problem in arthritis that is routinely assessed and treated. Comparatively, I found very little research related to pain in scleroderma. Also, compared to arthritis where pain can be presumed to be associated with joint pain, a single definable source, pain in scleroderma may arise from many different sources. These can include: i) skin changes, which are universal in scleroderma and commonly lead to tightening, inflammation and itching in areas throughout the body; ii) vascular problems, such as Raynaud's attacks, which are experienced by 95% of people with scleroderma, and digital ulcers, which are present in up to 50%; iii) gastrointestinal problems, including problems of the esophagus, stomach and intestines, that are present in up to 90%; iv) joint problems and contractures that are present in 24-97%, v) muscle aches or weakness in 70-96%; and vi) tendon friction rubs, usually in the diffuse type of scleroderma, in up to 35% of people. This can make it very difficult for the doctor as well as the person with scleroderma to detect the exact source of pain, and subsequently treat it effectively.

It was very clear that more research aimed at better understanding pain in scleroderma was needed. The biggest issue with the existing research studies on pain in scleroderma (besides how little there was) was that these studies were performed in small numbers of patients.

Given how differently scleroderma can present itself in different individuals, larger numbers of patients were needed to try and get at a stable picture of the pain experience in scleroderma. I was very fortunate to join the Canadian Scleroderma Research Group (CSRG), a pan-Canadian collaboration of rheumatologists, different types of researchers and scleroderma patient advocates, with the largest and most detailed scleroderma patient registry in the world.

Our research team performed a study of nearly 600 patients with scleroderma who saw their rheumatologist and answered questions about pain related to their scleroderma in the last week. We studied the number of individuals who reported at least some pain, the severity of the pain, and the specific scleroderma symptoms that predicted pain in all people with scleroderma, as well as separately in people with different types of scleroderma (limited/CREST scleroderma or diffuse scleroderma). We were also interested in looking at whether having other health conditions related to pain, like depression, osteoarthritis, and / or chronic back pain, would affect our findings.

The results of this study showed that pain complaints are very common in scleroderma; 5 of every 6 individuals reported at least some pain related to their illness in the last week and more than 1 in 3 rated their pain as moderate or severe. People with the diffuse type of scleroderma reported only slightly worse pain than people with the limited/CREST type of scleroderma, but the difference was very small. Having more Raynaud's attacks, active ulcers (open sores), more swollen joints and gastrointestinal problems were all related to worse pain complaints. In addition to scleroderma symptoms, we found that also having painful conditions other than scleroderma like depression, osteoarthritis and/or chronic back-pain, was related to the severity of pain complaints.

This study showed that pain was as common and as severe in individuals with scleroderma as in individuals with other rheumatic diseases like arthritis where pain is commonly talked about, routinely monitored and treated. This study therefore supports the need for improvements in pain management in patients with scleroderma.

This study however, was just the tip of the iceberg in terms of the work that needs to be done to understand and eventually treat pain effectively in scleroderma. Studies that look at changes in scleroderma symptoms and pain over time will help come to decisive cause and effect conclusions about sources of pain. Basic science research on pain in scleroderma will also help clarify physiologic processes that can potentially be targeted for treatment. There are also some psychosocial and behavioral treatments for pain that have shown some benefit in arthritis like cognitive behavioral therapy, relaxation, biofeedback and exercise that should be tested in people with scleroderma. Lastly, patients and scleroderma health providers need to work together. Open communication between patients and physicians can help increase awareness about scleroderma pain and can help develop strategies to alleviate pain and improve overall quality of life in scleroderma.

Winter Relief

Whether you spend the winter hibernating inside or braving the chill of the great outdoors, chances are your skin is suffering during the coldest months of the year. For people with lupus who may already be dealing with photosensitivity, skin rashes or lesions, and side effects from medication, winter's freezing temperatures, low humidity, and wind exposure just make things worse. It's no surprise that people find themselves battling dry, cracked skin and "winter itch."

In winter, the atmosphere loses moisture, and the resulting climate can strip skin of the layer of oils, cells, and lipids that normally shield us. Dry indoor heat doesn't help, since it causes humidity to evaporate. If you don't have a humidifier in your home or office, try leaving a small bowl of water on the radiator to create moisture in the air.

Even the products we use can aggravate existing problems. Antibacterial cleansers, fragrances, and some sunscreens can dry skin, leaving it vulnerable to flaking and even bleeding.

Luckily, there are steps you can take to protect your skin in even the harshest conditions. The trick is to preserve and boost your skin's natural moisture without sacrificing sun protection. Although temperatures may have dropped, the sun's UVA and UVB rays can still cause photosensitivity and burns, especially when they reflect off snow and ice. High altitudes also strengthen the sun's power.

Start with your soap. Even if you have oily skin, liquid and antibacterial soaps can cause serious dryness issues. For winter, switch to a mild soap with skin cream (like Dove), or glycerin soaps like Neutrogena, to help prevent loss on the most basic level. If you use bath oil, don't use it in the tub. Instead, rub onto damp skin immediately after you bathe (Be extra careful not to get any in the tub where it can make you slip.).

While you're in the shower, turn the heat down. A lukewarm shower is much easier on your body than a hot one -- though we admit this may be hard to do when it's 30 below outside. If you must take a hot shower, be sure to replace any lost moisture with a thick body lotion, applied while your skin is still damp. Some dermatologists recommend a "shielding" lotion, like SkinCareMD, which creates a barrier between your skin and the elements. A cream formula with mineral oil, coconut oil, or other emollient also works.

Don't forget sunscreen. Because most sunscreens are inherently drying, it can be hard to find a winter moisturizer that contains enough SPF. Some of the newest body lotions are made with an SPF of 15, and make a nice base to start. Apply your regular sunscreen generously and often in addition to your regular skin care routine. The extra protection is well worth it -- sunscreen prevents skin damage and the weathering effects of the harsh winter sun.

Finally, don't forget to drink -- water, that is! It's easy to ignore hydration in the winter, but that water bottle is just as crucial in January as it is in July. Try to drink at least eight glasses of water per day, to keep your cells hydrated and help your skin regenerate, resulting in happy, healthy winter skin, inside and out.





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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.