



HAVE YOU DONE THE SURVEY?

WHAT SURVEY?

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You know, the one that was explained on the cover of the last issue of this newsletter. The one that is being done by scleroderma patients across Canada. The one that is very important for future scleroderma research! The **national scleroderma patient survey**, presented by the SSC and the CSRG (Canadian Scleroderma Research Group).

Scleroderma patients, please complete a survey by April 30, 2009.

- 1) Complete the survey online at www.scleoderma.ca. The survey does **not** have to be completed at a single sitting, so pace yourself.
- 2) Complete and mail a hard copy of the survey. Copies are available by contacting Marielle Bassel by phone @ 514 340 8222, extension 3238 or by email @ marielle.bassel@mail.mcgill.ca or by writing her @ *Canadian Scleroderma Research Group, SMBD-Jewish General Hospital, 3755 Cote Ste-Catherine Road, Suite A216. Montreal, QC H3T 1E2*. Marielle provides prepaid return envelopes, too!

Survey preparation involved professional researchers and twenty-three patient representatives from across Canada. The survey includes not only questions about symptoms that patients may experience, but also about psychological, social, employment, financial and health care system issues.

Statistical analysis of survey results will begin in May. A team of patient representatives will meet in September to interpret results and to draft plans to utilize them for the benefit of scleroderma patients everywhere. Survey results will be used to further our understanding of scleroderma, to set research priorities and to support advocacy initiatives. Results will **not** 'gather dust' as many studies do – and that is why **we're seeking as many returns as possible**.

Thank you for helping to make this survey a success.

MESSAGE FROM THE PRESIDENT

Marion Pacy

Hello Everyone, I hope those that got to go to warmer places had a good time this winter and those of us that had to stay and tough out the cool weather stayed warm. I treated myself to a new hat this winter. It looks more like the Hudson Bay trapper hats but more trendy but very warm.



I hope everyone has marked their calendar in October for the Scleroderma Society of Canada's Conference here in Winnipeg, Manitoba.

I promise it will be warmer!!!!!!

Wanted Newsletter Editor for the Canadian Scleroderma News

**If interested please email Marion Pacy at
scleroderma@simplyconnected.ca**

The last newsletter I will be doing will be in October
so please get in touch soon.

WANTED: SECRETARY

**There is an opening for the position of Secretary of the
Scleroderma Society of Canada.**

If you are interested in this position, which pays absolutely nothing but offers excellent opportunities to work with others of common interests, please contact the present Secretary, Grant Dustin at 95 Woodfield Road SW, Calgary, AB T2W 5K5, telephone 403-281-7616, email mgdustin@telus.net.

Thanks for the Help!

In the campaign to battle this disease, as in any such campaign, many resources are required, particularly the resources of people and money. The efforts of many people and financial support from many sources are helping to make a difference.

Donations are essential in meeting our objectives of supporting research and creating greater awareness of scleroderma and its impact. The Scleroderma Society of Canada receives donations from individuals, groups and businesses who want to help in the fight against this disease. As a national organization that acts as an advocate for the interests of scleroderma and helps to serve the needs of those affected by scleroderma, the Scleroderma Society of Canada is grateful for the contributions of talent, time and funds from many people across the country. Thanks for the help!

Provincial scleroderma organizations conduct many fundraising activities that often result in funds being donated to scleroderma research through the SSC in addition to supporting their own programs. Individuals often initiate activities for the purpose of fundraising for scleroderma. Here are some examples that deserve our attention and appreciation.

- “Friends of Basil Bell” Charity Golf Classic event in Barrie Ontario, summer, 2008, organized by Nicole Bell-Webster.
- “Lily’s Supporters of Scleroderma” golf tournament in Ottawa, summer 2008, organized by Claudette Bower and Cathy Griffin.
- Lynn Brunelle runs to raise funds for scleroderma, in honour of her mother who suffers from the disease. Lynn ran the Disneyland Half Marathon last summer and the Disney World Half Marathon in January of this year.
- ‘Spencer Skate for Scleroderma’ annual skating fundraising event in Richmond, BC organized by the Scleroderma Association of BC. (more info at www.sclerodermabc.ca)
- Scott Mudry from Kimberley, BC plans an extensive walk through BC and beyond to raise awareness and funds for research.
- The scleroderma support group in Mississauga, Ontario organizes an annual Dinner Gala event that is a big fundraiser for scleroderma. The next one is April 4, 2009. (more info at www.sclerodermaontario.ca)
- The Riverbend Ladies League golf group in Red Deer, Alberta held a golf tournament last summer to raise funds for scleroderma.
- Jaime Boal organized a ‘Walk for Colby’ fundraising event in Merrickville, Ontario. Her 5-year old son Colby has scleroderma.

These are just some examples. Perhaps you know of others. Why not tell us about them and we’ll add them to the list in the next issue? Please send them to the editor.

10th Annual Scleroderma Knowledge Exchange Conference Scleroderma Society of Canada

Scleroderma

Wellness, Education & Our Future
Everyone Welcome
Patients - Family - Caregivers

. October 2 & 3, 2009

- Delta Hotel, Winnipeg, Manitoba
- Registration Fee \$25.00

Topics: Juvenile scleroderma, Occupational Therapy tips, Health support, Pulmonary Hypertension, Make up, Oral Health & much more.

For Registration & more information please contact:

Ann Harwood—Conference Registrar

Phone: 477-4310

Email: wdharwood@mts.net

Scleroderma Association of Manitoba



2009 will be the 10th Conference for the

Scleroderma Society of Canada.

It will be held in Winnipeg, at the Delta Hotel

This year Friday will have a tour of Winnipeg in the afternoon and we hope to hold some focus groups for those interested. Friday evening the Scleroderma Association of Manitoba will host the meet & greet with a light supper and great entertainment. Of Course, the members of the CSRG will be joining us for the Friday evening meal and entertainment.

Saturday will be a full day with workshops and displays. In the evening, you will have a choice to stay at the hotel and have a no host dinner or attend an evening at Celebration Dinner Theatre.

We will have information on Nutrient, Exercise, Skin, Home & Health Support, Kidneys, Physio, Occupational, Oral Health, Lungs and more.

Our programs and more detail agendas will be available in May. We will have information on our focus groups, workshops, and fun times at the dinners. Please plan to attend!!!!!!

On page four you will find a phone number and email address for Ann our Conference Registrar. If you want to make hotel reservation please tell the Delta you are attending the Scleroderma conference.

"Delta Winnipeg is the largest hotel in Manitoba, attached via skywalk to Winnipeg Convention Centre in the heart of downtown. Features include Odyssey Health Club with full fitness facility and three pools, Blaze Bistro & Lounge, Urban Bean serving Second Cup coffee, 24-hour in-room dining, heated underground parkade and much more.

For Reservations, call 1-888-311-4990."

Scleroderma Day Program, London, Ontario

Further Details:

This is a 2 week, multidisciplinary group for people with scleroderma. A doctor's referral is required. This 2-week program is covered under OHIP for those in Ontario. Other provincial plans may provide coverage. Participant's are responsible for their own room/travel costs. There are a number of accommodations available. Please call Vicky at the number above.

When: April 27th - May 8, 2009

Where: St. Joseph's Health Care, 268 Grosvenor Street, London,
Beryl & Richard Ivey Rheumatology Day Programs

Who: Contact Vicky Bossenberry

Phone: 519.646.6340

Fax: 519.646.6317

Email: vicky.bossenberry@sjhc.london.on.ca

Information Sources

Websites

www.srfcure.org Scleroderma Research Foundation

The Scleroderma Research Foundation, based in San Francisco, was founded in 1987 by Sharon Monsky. The website has information on the disease and on research being done.

www.scleroderma.org Scleroderma Foundation

This is the national scleroderma organization in the United States. The website has a great deal of information. To receive their free eLetter click on the link at the bottom of the home page or look under 'News'.

www.sclerodermasociety.co.uk Scleroderma Society of the United Kingdom

There's an interesting article in the latest newsletter (October 2008 , p.5 &6), 'Progress in Scleroderma' by Dr. James R. Seibold; also 'Living With Scleroderma' by Sheila Proctor on p. 7. On this UK website the menu on the left advertises 'Our New Booklet'. This is available and may be helpful to some.

Measures for Preventing and Treating Dry Skin

Alavi A, Coutts P, Crozier D, Sibbald RG,.

- Keep bathing to a minimum when your skin is dry. Baths should not be too hot or longer than 10 minutes as they dry out the skin more than showers.
- Avoid irritants such as harsh detergents or cleansers.
- Do not over-scrub, or use excessive amounts of soap when washing. Mild soap (Dove, Oilatum Soap, Oilatum Shower & Bath Oil, Petro-Phylic Soap) or soap substitutes (Spectrogel, Cetaphil) are less drying than regular soap.
- Apply creams and ointments immediately after bathing while the skin is still damp.
- Choose a sunscreen with a moisturizing base and an SPF of at least 15. Apply the sunscreen FIRST, before using any other skin creams.
- DAILY: Use lubricants that are oil based or oil and water based to prevent the loss of moisture from the skin (eg. Glaxal base, Clinaderm cream, Prevox Moisturizing Lotion, Prevox Protectant Cream, Oilatum Shower & Bath Oil, Vaseline) along with hydrating agents that trap water on the skin's surface, such as Uremol cream or lotion, Lachyrin lotion and Dermalac cream.
- Treating sensitive skin around the eyes, use bland creams without perfumes, which can cause allergic reactions.
- REGULARLY coat lips with petrolatum-based ointment sticks.
- To treat itch, keep creams containing menthol in the refrigerator. Over the counter anti-itch creams that are non-sensitizing include those that contain menthol, phenol, camphor and/or pramoxine such as Sarna-P Lotion, Pramox cream and lotion. Use as needed to control itch.
- Non-comedogenic creams are recommended for use on dry skin in hairy areas and on acne prone skin, as these agents do not block the pores (Lubriderm lotion, Marcel Aquarelle, Wibi lotion, Cetaphil lotion, Moisturel lotion, Lancome lotion).
- Cracks (fissures) on the heel can be sealed with petrolatum or Prevox Protectant Cream to prevent further moisture loss and stinging. Humectants with 20% urea (eg. Uremol 20 Cream or Dermal Therapy 25%) are most effective in healing this area.
- Where there are open wounds because of dry skin, it is better to use only lubricants until the wounds heal because the active ingredients in hydrating agents (lactic acid, urea) may sting.
- Dry skin, especially on the feet, may indicate neuropathy (check for diabetes) or a fungal infection (have your Doctor perform a fungal scraping.).
- If the skin is red and inflamed, a coexisting dermatitis might require a topical steroid prescription.
- Avoid clothing containing wool or nylon, which may trigger pruritis (itch). Use cotton next to your skin.

FOODS FOR A HEALTHIER IMMUNE SYSTEM

What you eat (and don't eat) could make a difference in how well your body defends itself against day-to-day germs. To help your body fight off cold and flu bugs, you'll want to follow a fairly commonsense healthy diet -- lay off the empty calories, and focus on nutrition-dense foods like fruits, veggies, whole grains, lean proteins, and healthy fats. And there are a few key food items you just might want to stock up on.

5 Foods to Fight Colds and Flu

Research is in the early stages, but studies suggest a few key foods and nutrients may help boost the immune system. Here are five great examples:

Apples: They're a great source of quercetin. Research suggests this mighty flavonoid may offer some defense against the influenza virus.

Mushrooms: Early research suggests that a key compound in mushrooms may help rev up the body's production of killer cells -- the kind that defend against viruses as well as cancer.

Green tea: Catechins in green tea get most of the credit for this brew's health powers. One particular type of catechin, epigallocatechin gallate (EGCG), seems to interfere with the influenza virus's ability to replicate.

Garlic: Rich in immune-system-friendly allicin and other types of sulfur compounds known as thiosulfinates, garlic has a wide range of germ-fighting potential against bacteria, viruses, parasites, and fungi.

Almonds: Why? Because of the vitamin E -- a nutrient your immune system *requires* in order to function. But most people don't get enough E from their diets.

Vitamin E

Benefits

- Vitamin E is an antioxidant that may help prevent heart disease, Alzheimer's, and two common vision stealers -- macular degeneration and cataracts.
- Tip: Take your E with C (1,200 mg). These two antioxidant vitamins work together to prevent the oxidation that causes clogs in blood vessel walls.

Cereal: raisin bran, corn flakes (1 cup)	20 IU
Almonds (1/4 cup)	14 IU
Sunflower seeds (1/4 cup)	12 IU
Spinach, cooked from frozen (1 cup)	10 IU
Hazelnuts (1/4 cup)	8 IU
Safflower oil (1 tablespoon)	7 IU
Red bell pepper (1 cup)	4 IU
Avocado (1/2 medium)	3 IU
Olive oil (1 tablespoon)	3 IU
Mango (1 medium)	3 IU
Tomatoes, canned (1 cup)	3 IU

Potassium**Benefits**

Potassium helps regulate blood pressure and maintain normal heart and artery function. It also reduces the risk of stroke.

Potato, baked, with skin (1 medium)	1,082 mg
Sweet potato, baked, with skin (1 medium)	694 mg
White beans, canned (1/2 cup)	595 mg
Yogurt, low fat (8 ounces)	531 mg
Beets, cooked (1 cup)	519 mg
Halibut, cooked (3 ounces)	490 mg
Banana (1 medium)	422 mg
Kidney beans, canned (1/2 cup)	328 mg
Raisins (1.5-ounce box)	322 mg
Salmon, cooked (3 ounces)	319 mg
Blackberries (1 cup)	233 mg

Calcium**Benefits**

Calcium is essential for strong bones and teeth and helps prevent arthritis. But that's not all this mineral is good for: Calcium helps your brain communicate with your nerves, regulates blood pressure, and may reduce the symptoms of PMS and the risk of colon cancer.

1,000–1,500 mg of calcium per day from food and supplements -- but not all at once. Your body can only absorb 500–600 mg at a time, so divide it into two or three doses over the course of a day.

Tip: If you take a calcium supplement, take it with vitamin D (they're often combined in one pill) to help absorption -- and with a little magnesium to reduce the constipation sometimes caused by calcium. *Don't* pair calcium with iron or fiber supplements, which can interfere with your body's ability to absorb the bone-building mineral.

Peaches, frozen and sweetened (1 cup)	235 mg
Red bell pepper, raw (1 medium)	152 mg
Broccoli florets, cooked (1 cup)	101 mg
Strawberries (1 cup)	97 mg
Green bell pepper, raw (1 medium)	96 mg
Papaya (1 cup)	86 mg
Kiwifruit (1 medium)	70 mg
Orange (1 medium)	70 mg
Cantaloupe (1 cup)	59 mg
Mango (1 medium)	57 mg
Brussels sprouts, cooked (4 medium)	52 mg



Scleroderma Society of Canada

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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.