

SCLERODERMA REPORTER



SCLERODERMA SOCIETY OF ONTARIO SSO NEWSLETTER
A specific disease association of The Arthritis Society (Ontario Division)

September 2007

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The Scleroderma Society of Ontario Web Page www.sclerodermaontario.ca
The Arthritis Society Web Page www.arthritis.ca
SSC Web Page with link to SSO www.scleroderma.ca

Hospital Bed

The family of Anna Stech has offered to donate an automated hospital bed to a scleroderma patient. It is in new condition. For further details please contact

Peter Woolcott at peterwoolcott@sympatico.ca or (905) 730-0731

Stepping into the Shower with Chronic Illness

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

Some bath items are 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.

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, use liquid soap. Baby baths that contain chamomile and lavender are pure and contain essential oils that are meant to calm fussy babies. 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. 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 the 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. 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. Check 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. This way you do not have to bend or reach or twist your back to reach for items when you need them. And you 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. 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 tedious 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 bath-mat 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 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!

HELLO TO ALL:

Well, where the heck did it go. I hope you enjoyed it because you'll have to wait a year for another. I'm talking about summer eh !!!!



Special thanks to Babe Sliva and her committee in Windsor, the Hamilton gang, as well as the group in Pembroke, for their remarkable energy and efforts to bring about very successful "walks" in their home communities. These events raise public awareness for Scleroderma which saves the Society countless dollars in paid-for promotion additionally to raising large sums of money for research. But---there is an added benefit. It seems that each of these successes strengthens the local support group, grows it in number and strengthens it in companionship. Please don't overlook the plain truth: it is one of the cornerstones of this Society---to search and reach out to every person suffering from scleroderma to assist and give them our support. These fundraisers and public awareness events enable us to reach out. On a sadder note, ill health is forcing Babe to step aside. Your Society is indebted to you Babe, we wish you well and thank you ever so much, for your successes and efforts put forward on behalf of scleroderma.

Our appetite for more research is growing. To that end, you should be aware that we have authorized an additional payment of \$25,000.00 to Dr. Murray Baron, a founder of CSRG, for his continuing work with the compilation of a cross Canada data base. Andrew Leask, a researcher in London Ontario at Western University, was approved for a further sum of \$30,000. Dr. Sindhu Johnson of the Toronto Western Hospital, and familiar to many of you for her support of the SSO, made a verbal and detailed written proposal to the Board for financial assistance to research the "Effectiveness of warfarin on survival in idiopathic and scleroderma associated pulmonary hypertension. A retrospective cohort study". Your Board, after review, approved the full amount of \$50,589.95. Dr. Johnson will provide us with interim written reports and a final report presentation as well as in writing. These monies are the total of sums pledged to date in this fiscal year by your Society for research. Thank you for making this possible.

For your information, several scleroderma sufferers and members of your Society attended the Rheumatology Programme in May at St. Joseph's Health Care Centre London. This is a multidisciplinary programme, with expenses paid for by OHIP save and except for sleeping accommodation and parking, and is carried out over a 2 week period. Keep on the watch for next year's dates. We always receive excellent feedback from the participants. When we know the dates of next year's programme, we will pass them along. The Arthritis and Autoimmunity Research Centre Foundation sponsored a lecture featuring Dr. Simon Carette, Director of Rheumatology at UHN and Mount Sinai. His topic was "The mysteries of scleroderma". Dr. Sindhu Johnson, a colleague of Dr. Carette, also spoke about her vision for the future---in the clinic and in the lab. By invitation of Dr. Johnson, our own Jennifer Rai told all in attendance about her experiences being a wife and mother while living with scleroderma. A welcomed presentation. Thank you Jennifer

As you may be aware, your Board, and more specifically its task force, has been investigating the advantages and disadvantages of leaving The Arthritis Society. After several meetings between representatives of TAS and the SSO discussing our present relationship, your Board unanimously voted in favour of separating from TAS, subject

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DISCLAIMER

The Scleroderma Society of Ontario does not endorse any treatment, drug or diet reported in this newsletter. We wish only to keep you informed. Check any treatment with your doctor.

SCLERODERMA SOCIETY OF ONTARIO

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Fax (416) 979-8366
Web-Site www.sclerodermaontario.ca
E-mail peterwoolcott@sympatico.ca

MEMBERSHIP APPLICATION

Please make cheque payable to the Scleroderma Society of Ontario
Send to: Vidas Vapsva, Treasurer
Scleroderma Society of Ontario
2150 Fowler Lane
Mississauga, Ontario L5K 1B8

Annual Membership Fee is \$25.00
Household Family Membership \$35.00

1. Join: One Year Two Years
2. Renew: One Year Two Years
3. Give a membership to:

(Donor's Name _____)

Name _____ Amount Enclosed \$ _____ Date _____

Street _____

City _____ Prov. _____

Postal Code _____ Phone _____

E-mail Address _____

* tax receipts are issued for full amount of membership

I am a Scleroderma patient.

Yes No

I am interested in helping with a Support Group _____

always to membership approval. Several steps have been taken since that decision, all in the best interest of the members and to preserve the integrity of the Society. We have obtained Public Trustee approval, have applied for a proper incorporation and are presently ready with the application to obtain a charitable registered number. Cathy Jeske, a member of our Board and a "Bay Street Lawyer" has completed all of this work --- pro bono. Thank you Cathy. Most recently, TAS has decided to disband all Specific Disease Associations, of which we presently are one, to absorb their members under the Arthritis umbrella and to retain our raised and saved funds of approximately \$367,000.00 for the purposes of TAS. Should we receive membership approval to move into the future as a separate Society with a charitable registered number, TAS will co-operate in this endeavour and release our funds to us for the specific purposes of OUR mission statement. You will receive/ have received a letter and ballot looking for your support of the Board's decision. I ask you for your vote to separate from TAS and to obtain from TAS these funds that so rightly belong to you. Should you have any questions, please feel free to call me at (905) 730-0731 Thank you for your anticipated support.

Peter Woolcott

Recruiting for Board Members for '07/'08 Term

Enclosed you will see the Notice for our next Annual Meeting to be held on September the 29th at the Sir John Colborne Recreation Centre for Seniors in Oakville. I urge you to take best efforts to attend. The committee has been working very hard to make this a successful and enjoyable event. Nominations for Board Membership are accepted prior to the meeting as well as at the meeting itself. We are looking for 2/3 new members and ask you to consider aiding the Society by accepting a nomination. You must be a member in good standing and nominated by a member in good standing. Recently there have been 7 Board Meetings per year and they have all been held in Hamilton except for our AGM. You receive reimbursement for your mileage and all expenses incurred on behalf of your Society. Our present Board Members are looking forward to working with you and to listening to your ideas on how we can improve the Society. Please consider offering your help. If you need further clarification, you can call myself at (905) 730-0731 or any other member of this Board. Thanks for your consideration.



A NO-COST BILLBOARD IN HAMILTON AFTER THEIR WALK



SOME OF THE SUPPORTERS THAT WALKED IN HAMILTON

WINDSOR WALKERS - IN MEMORIAM

Martin Bednarski
Lorraine Pelltier
Marilyn Hunt/Hawkins
Paula Takacs

Daisy Petrie
Joy Watts
Mary Mowatt

HAMILTON WALKERS - IN MEMORIAM

Steve Green
Laura McLean
Jean Doris Sweet
Gary Thomas Wilson

Pat Lepage
Sandra Reinhardt
Lorne Robson
Pamela Whitehead

Julia Cerna
Walter Wazny
Silvia Mason
Marion Hicks

IN MEMORIAM

Rheal Pilon
Douglas Cummings
Donald Glass

Audrey Rheinolt
Delores Polley
Sonia Green

Isabella Fowler
George Kent Dickson
Elizabeth Tower

Jack Joves
Louis Sorokos
Betty Burley

Pip Layfield
Brenda Wise
Dorothy Hughes

Neil Henry
Ruth Robinson
Karen Whitelaw

Scleroderma Society of Ontario Mission Statement

The Scleroderma Society of Ontario is committed to promoting public awareness, advancing patient wellness and supporting research in Scleroderma.

The Scleroderma Society of Ontario is committed to protecting your privacy and maintaining confidentiality of your personal information. We do not sell our membership list to anyone. Save and except for the Arthritis Society of Ontario, we do not trade this information with others that may use it to contact you about their own products or services.

HEALTH

Your questions on GI issues, cosmetic surgery, digital ulcers and pulmonary fibrosis answered, courtesy of The Scleroderma Foundation.

Q: I have systemic scleroderma and would like to have a cosmetic procedure to help with the lines around my mouth. I have heard that Restylane is good for this. Can I have this procedure if I have scleroderma?

A: Restylane is a dermal filler that is commonly used to improve the appearance of deep wrinkles and lines (for example, those around the mouth). It can be quite effective when properly used. Patients have to understand that the improvement is not permanent, that it needs to be reinjected after a few months, and that there is some discomfort and pain associated with the injection. Those who are prone to "cold sores," a common manifestation of herpes infection on the lips or around the mouth, should probably receive prophylactic treatment with an antiviral medicine before the injection. It is my opinion that it is safe to use in scleroderma patients and can improve their appearance. - *Vincent Falanga, M.D.*

Q: Can a gastric pacemaker help with my scleroderma-related gastrointestinal problems?

A: Gastrointestinal problems are extremely common in systemic sclerosis and 95% of patients have some gastrointestinal symptoms. Fifty to 77% of patients have some decreased stomach movement (gastro paresis) and may have symptoms such as bloating, getting full very easily (satiety), nausea and vomiting. In the stomach, as elsewhere in the GI tract, the basic problem probably arises from blood vessels that do not nourish the nerves. This, in turn, results in decreased ability to move food, acids, etc. along the GI tract as well as eventually resulting in replacement of muscle by fibrous (scar) tissue. Treatments such as metoclopramide (Reglan), erythromycin (which stimulates the bowel) and octreotide are often successful. However, when these do not work, a new treatment is occasionally used. This is called "gastric pacing" or "gastric electrical stimulation" and is like a pacemaker for the heart, except it paces the stomach, causing the stomach muscles to push food out of the stomach into the rest of the gastrointestinal tract. This method is only useful for very severe problems and is not yet fully proven in systemic sclerosis but can, occasionally, be very helpful. - *Daniel E. Furst, M.D.*

Q: I have persistent and very painful digital ulcers. What are the latest treatments for this problem? I have heard that Revatio and Bosentan may help. What about hyperbaric treatment that diabetics sometimes use?

A: The digital ulcers in scleroderma are due to poor blood supply and are often precipitated by trauma. Although some of them can be quite resistant to treatment, there are good general measures that can help. Good wound care, dressings that avoid further trauma, debridement (removing dead or contaminated tissue) are part of the solution. For those who still have difficulty healing, several options are available. Both Revatio and Bosentan are drugs that can improve the blood supply, and there is some evidence that they can be of help. Coverage of the wound with bioengineered skin is underutilized, although readily available. Hyperbaric oxygen has been around for a very long time. Like the other options, it will not help unless one is also implementing optimal wound care. - *Vincent Falanga, M.D.*

Q: What are the current treatments for pulmonary fibrosis associated with scleroderma, and does Revatio help?

A: Most scleroderma patients have some pulmonary disease, with pulmonary hypertension (PH) and interstitial lung disease (ILD) or pulmonary fibrosis being most common. From 25 to 90% of scleroderma patients will have some pulmonary fibrosis, and it is notoriously difficult to treat. However, a recent study suggests that taking cyclophosphamide (Cytoxan) for 12 months is of benefit. The study suggested three important things: that cyclophosphamide may slightly improve lung function, decrease breathlessness, and improve quality of life. Another medication under active study is mycophenolate mofetil (CellCept). While sildenafil (Revatio) may benefit patients with pulmonary hypertension, there is no information to suggest that it directly treats the pulmonary fibrosis. - *Kevin K. Brown, M.D.*

LITERATURE ORDER FORM

- | | |
|--|---|
| 1. Understanding & Managing SclerodermaFREE
New! By Maureen Mayes, M.D.,M.P.H., & Khanh T. Ho, M.D. This booklet is intended to help persons with scleroderma, their families and others interested in scleroderma to better understand what scleroderma is, what effects it may have, and what those with scleroderma can do to help themselves and their physicians manage the disease. | 7. The Scleroderma Book (2005) 2nd edition\$20.00
By Maureen Mayes, M.D. A definitive guide for patients and their families. |
| 2. Helpful Hints: Living with Scleroderma\$2.00
A compilation of helpful information submitted by Scleroderma Foundation (USA) members. | 8. Pulmonary Arterial Hypertension (PAH)FREE |
| 3. Sjögren's Syndrome.. UPDATED 2003\$0.25
A general overview of Sjogren's | 9. Scleroderma, What Is It?\$2.00
By Jennifer Hinkley |
| 4. What Causes Scleroderma?\$0.25
Also available in Spanish. Discusses the scleroderma "puzzle". | 10. Scleroderma - A Treatable Disease.....\$3.00
By Dr. Joseph Korn. Published in "The Cleveland Clinic Journal of Medicine" |
| 5. What's Funny About Having Scleroderma?\$2.00 | |
| 6. Successful Living with Scleroderma: Guidebook\$15.00
New! By Robert Phillips, Ph.D. Dr Phillips is Director for the Center for Coping. | |

Book #	Price	Quantity	Total

Please enclose cheque or money order payable to:
Scleroderma Society of Ontario
RR #3 Pembroke, ON K8A 6W4
Attn: Carl Stager
(Prices subject to change without notice)

Subtotal \$ _____
Shipping & Handling \$ **\$3.50**
Total \$ _____



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September 2007

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 the 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). In February, the CSRG was awarded \$262,500 to develop and validate a patient-assessed disease activity index in systemic sclerosis (SSc).

An application on February 1, 2006 in the amount of \$1.8 M was successful. 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.

An application in June 2006 for a New Emerging Team Grant in the amount of \$1.5M was also successful. 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.

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.

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.

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.

Scleroderma Articles For Sale

Hand Warmers	\$2.00 each
Scleroderma Pens	\$2.00 each
Hand Grips (for opening jars)	\$1.50 each
Lip Balm (cherry or vanilla flavoured)	\$2.25 each
Felt Beverage Zippered Containers	\$5.00 each
Tote Bags for over the Shoulder/Arm.....	\$6.00 each
Car Magnets.....	\$2.00 each
Wrist Bands.....	\$2.00 each
Five Piece Rosewood Wine Kit	\$40.00 each
Wrap-around Blue Blankets.....	\$20.00 each
Thank-You Notes with Envelopes	\$5.00 per Dozen
Scleroderma Pins	\$2.00 each

Each article has the scleroderma logo and most are produced in our blue colour. The prices quoted include taxes and postage. To order write to: Scleroderma Society of Ontario P.O. Box 78025, Westcliffe Postal Outlet, Hamilton Ontario L9C 7N5

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.
9. **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.