

SCLERODERMA REPORTER



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

November 2007

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Scleroderma Society for Residents of Metro Toronto	(416)979-7228
Scleroderma Society for Residents Outside of Toronto	1-800-321-1433
Arthritis Self-Management Program	(416)979-7228
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

EXERCISING WITH SCLERODERMA

by Carolyn Johns, physiotherapist (from Canadian Scleroderma News)

Benefits of good posture

- allows one to breathe fully
- distributes body weight evenly
- decreases stress on muscles, ligaments and joints thus decreased risk of injury
- helps keep body organs healthy
- increases energy available
- promotes good circulation

Goals of Exercise

- decrease pain and stiffness
- help lose weight
- increase strength
- improve sleep
- improve cardiovascular fitness/endurance
- maintain joint/soft tissue range of motion (ROM)
- maintain cartilage and bone health
- reduce stress and anxiety

Scleroderma Articles for Sale

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 PO Box 78025, Westcliffe Postal Outlet, Hamilton, Ontario L9C 7N5

Five piece rosewood wine kit	\$20.00 each
Wrap around blue blanket	\$20.00 each
Over the shoulder/arm tote bag	\$6.00 each
Felt beverage zippered container	\$5.00 each
Thank you notes with envelopes	\$5.00 per dozen
Lip balm (cherry or vanilla)	\$2.25 each
Hand warmers	\$2.00 each
Scleroderma pen	\$2.00 each
Scleroderma pin	\$2.00 each
Car magnet	\$2.00 each
Wrist band	\$2.00 each
Hand grips (for opening jars)	\$1.50 each

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 _____

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BOARD OF DIRECTORS

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Vice-President	Catherine Buntain-Jeske
Past President	Peter Woolcott
Secretary	Barbara Williams
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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.

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HELLO TO ALL:

Hey !!!! It's that time of the year. I am taking this opportunity to wish you and your loved ones, a very Merry Christmas and a Happy, Healthy and a full year free from stress and worries. Arguably, we live in the best Country in the world. My wish for you-- is to enjoy this privilege.

At our last Board Meeting, after 3 years as President of your Society, I moved aside. I write this report to you as the Past President. Many of you have already had the pleasure of meeting with our new President, Maureen Sauve, a very strong supporter and active worker for the tenets of our Mission Statement. Her experience both on the Board as well as in the community at large will enable her to move our Agenda forward with giant steps. Please join with me to wish Maureen and her very capable Board Members, the very best in their endeavours on our behalf.

At the Annual General Meeting, two additional members of your Society accepted nominations to sit on the Board. Brittany Stager, a recent college graduate in Marketing and long time granddaughter of Carl, came aboard to work on the Website and Public Awareness. I am looking forward to the fruits of her efforts and expertise. As well, Barb Williams from Burlington, has joined to act as Secretary and Membership Director. Her skills developed in the corporate world and accomplished computer wizardry will serve the Board well. I am positive and delighted that these additional volunteers to your Board will strengthen an already strong Board to assure the Society of continuing successes.

The results of the ballot circulated to the membership with respect to the question of separating from TAS were 100% in favour of the separation. There was a 75% return of ballots. At the AGM, the following motion was unanimously approved by the voting members in attendance:

- #1 Confirming the steps taken to date in making application for Articles of Incorporation incorporating the SSO as a not-for-profit corporation in the Province of Ontario and further to establish and finalize all by-laws, rules and constitution as may be necessary.
- #2 Authorizing the directors, officers and/or their representatives to execute such documents and all things necessary to apply to CRA to become a registered charity
- #3 Authorizing the directors and officers, upon receiving the Charitable Status to request that The Arthritis Society of Ontario pay over to SSO any funds that are being held by TAS on account of SSO. The Board Members thank you for your support.

The Task force is working to honour all of the items in the resolution as passed unanimously.



Dr. Peter Lee was the Keynote speaker at our AGM - His topic - "Scleroderma, Through the Looking Glass".

Application has been made to CRA for the registered charitable number and acknowledgement has been received from CRA. The stated wait time is 6-9 months. Our anticipated target date for separation is April 1st 2008 and we believe it is achievable thanks to all of the hard work of Cathy Jeske and the members on her committee. The representatives of TAS have been working with us as well and all steps taken by SSO have



been completed in accordance with their requirements. This separation is with their assistance and support both of which they have committed and promised will continue after the separation has been finalized.

I want you to know and I believe that it is important for everyone to understand that while this matter of the separation has been progressing in accordance with our plan, our paid membership has improved measurably, additional funds have been expended on research with more to come in the near future, plans for repeat and additional fundraising events are on-going and plans for possible additional public awareness are underway. Thanks to your continuing support and encouragement, all of this has been made possible.



Thank you Joyce Mackie and the Halton Support Group for hosting the 2007 Annual General Meeting for Scleroderma Society of Ontario

I would like to say that my term on the Board, both as President and originally as Fundraising Director, has been a growing experience for me. I have learned a little bit more about scleroderma and how it can convert an otherwise typical, family lifestyle into day-to-day challenges for mundane, routine chores that many of us just take for granted. It has allowed me to meet with so many sufferers of scleroderma and to be accepted as a new friend or an acquaintance. But mostly, it has humbled me and hopefully made me more respectful of others wherever I find myself. I will always thank you.

Peter Woolcott

Measuring Disease Severity and Damage in Scleroderma Patients

from Sclerodata Fall 2007 p. 3

Dr. Kevin Keen along with co-investigators Dr. Jenny Walker, Dr. Murray Baron and collaborator Dr. Jim Dunne, are interested in the behaviours of scleroderma, pertinent to the severity, disease activity and resulting damage. Patient management for any disease involves one or more of pharmaceutical therapy, surgical intervention, physiotherapy, occupational therapy, social or psychological support. However chronic disease management implies ongoing assessment of the patients' disease state. Severity, activity and damage indices can be based on subjective evaluation, i.e. physician's assessment and patient's reported quality of life or an objective evaluation i.e. lab tests, Rodnan skin score by a rheumatologist and patient reports of days lost to a normal range of activities.

Dr. Gierrson (Sweden) developed a severity scale for scleroderma using five organ systems while Dr. Medsger (USA) developed a scale using nine organ systems. Dr. Medsger's list is made up of general (weight loss and hematocrit), peripheral vascular, skin, muscle, joint/tendon, gastrointestinal tract, lung, heart, kidney. Dr. Medsger's severity index scores each of the nine body systems separately using a scale by scoring normal 0, mild 1, moderate 2, severe 3 and endstage 4. This scale makes it difficult for a rheumatologist or family physician to keep track. It would be easier to just add up the scores for all nine organ systems and call the result a global score. There is not a rationale to why this simplified approach has not been implemented. Missing from Dr. Medsger's nine body systems is 'immunological' along with combining existing muscle and joint/tendon as 'musculoskeletal' to be included in the proposed Canadian study. Indices have been developed to assess severity, activity and damage with each index constructed from lab tests, physician examination of disease signs and patient reported symptoms.

Noting the differences between Gierrson's and Medsger's approach to scoring organ systems raises the question 'What to do in Canada?' The SSRU has created a national scleroderma registry with over 600 patient entries from across Canada. Two projects are underway to develop measures of disease severity.

Activity index (patient assessed) is undertaken by Marie Hudson, MD, McGill University with funding of \$64,085 (ends August 2008) + \$262 from CIHR.

Damage index (Physician assessed with lab results) Start up in September 2007 by Dr. Jenny Walker MD, FRCPA Calgary University, Murray Baron MD, FRCPA McGill University and Kevin J. Keen PhD University of Northern BC with funding of \$7,500 from SABC with a possibility of matching funds.

To be created from the national scleroderma registry, the Canadian scleroderma damage index may have limitations in the completeness of data and no longitudinal data for survival such as in the Gierrson scale. It would encompass eight organ systems namely gastrointestinal, heart, immunological, kidney, lung, musculoskeletal, peripheral and skin.

In summary, it is likely the Canadian scleroderma damage index study may deliver posters for CRA, ACR or CAN meetings with the possibility of a report available for the SABC AGM next year. Limitations exist in the need for about 600 patients (globally) and in dependence upon international consensus of rheumatologists.

MARK YOUR CALENDARS

The Mississauga Support Group is hosting their -

Second Annual Fundraising Gala Dinner/Dance and Silent Auction

April 5, 2008

6.00 p.m. reception and auction • 7:00 p.m. four course dinner

LOCATION:

Oasis Convention Centre • 1036 Lakeshore Road, East, Mississauga, Ontario L5E 1E4

TICKETS:

\$75.00 each (\$50.00 tax receipt provided)

Contact Carroll Vapsva at (905) 822-7868 OR email at vapsva@rogers.com

Tickets available until March 15, 2008

If you can provide any help in acquiring silent auction items and/or sponsorships for the event, your assistance is greatly appreciated. Join us for an evening of fun, dancing, entertainment and chances for great door prizes and draws. Hope to see you there!

IN MEMORIAM

The Scleroderma Society of Ontario gratefully acknowledges the generous donations made recently from family and friends in memory of the following people:

- | | | | | | |
|-------------------|----------------|----------------|-----------------|-----------------|-----------------|
| Basil Bell | Rosa Di Meo | Pip Layfield | Agostina Prebeg | Norris Rumble | Elizabeth Tower |
| Thelma Des Roches | Amy Dyer | Charles Legate | Audrey Reinholt | Bill Sauve | Karen Whitelaw |
| Marie Desroches | Gayle Friendly | Karen Morgan | Ruth Robinson | Donald Seguin | Steven Wood |
| Alyce DeVas | Sonia Green | Ina Nagle | Elsie Rumble | Antonio Tiberia | |

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.

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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A specific disease association of The Arthritis Society (Ontario Division)

November 2007

Scleroderma: What gets better and why, part 1

By Dr Lee S. Shapiro, New York from Strides 2003, issue 5, winter edition

Knowledge is power

I truly believe that with this disease, knowledge is power and ignorance is not bliss. The most treatable features of scleroderma in any part of your body are the early features and this is likely always to be the case. The well informed patient may not always do well but he or she will always do better than those who keep themselves in the dark.

Let's begin at the beginning

The natural history of scleroderma starts before the diagnosis is made, sometimes years before. The individual develops an awareness of altered bodily function (such as frequent heartburn, shortness of breath, stiffening or blanching of the fingers) or changed appearance, but the cause is not yet known to the individual so afflicted. Denial of symptoms may lead to delay in pursuing medical attention. As in so many other illnesses, the answer becomes more apparent over time. With diagnosis instead of relief, the patient's unease persists and may worsen because of uncertainty as to one's fate.

The physician has several responsibilities to you, the scleroderma patient

1. obtaining an accurate, detailed medical history - This includes knowing what problems have already occurred, how they have affected your functional abilities, your normal home and work activities. We must get a sense of the pace of the disease progression. Diffuse and limited disease is sometimes misdiagnosed on a first visit.
2. what is your support system - are you on your own or is there a spouse or companion to help you with difficult tasks.
3. are you adjusting psychologically - fear, anger, insomnia and hopelessness are issues that must be addressed.
4. conducting a careful physical examination - The physician must examine you physically with equal care with focus on the skin. The extent of skin thickening over time is important telling about your disease and response to therapy. The goal is to categorize your illness as limited, diffuse or scleroderma overlapping with another connective tissue disorder such as lupus or polymyositis.
5. ordering appropriate tests - To make a proper diagnosis, antibody studies are helpful. The anticentromere antibody is strongly associated with limited scleroderma and Scl70 antibody is seen with diffuse disease - but the antibodies are not in themselves diagnostic and they are not always present even in the face of obvious disease. ECG, echocardiogram, chest x-ray, pulmonary function studies, muscle enzymes and barium studies of the gastrointestinal tract help define the extent of the disease. Disease categorization can provide a forecast of what the future may bring and help misplaced worries.
6. physician's attitudes toward scleroderma have changed - As recently as 1987, in a rheumatology journal a physician wrote "most physicians dread the prospect of caring for patients with systemic sclerosis because of the multitude of difficulties these patients present and unsatisfactory therapeutic armamentarium available." There is an increasing awareness that some features of scleroderma may improve over time, even without treatment.

Scleroderma can get better over time

Scleroderma was once thought to be a disease which progressed relentlessly. The disease was called progressive systemic sclerosis.

It was then noted that many individuals with the CREST syndrome or the limited form showed no evidence of disease progression over years or even decades. Also individuals with diffuse disease did not endlessly progress. Skin thickening peaks after anywhere from two to five years. The skin stabilizes and often thins. In only a small minority, the skin thinning is so complete that the disease appears to have disappeared entirely.

In most everyone with diffuse disease progression of skin thickening does not stop after a few years and in the majority, detectable though not complete thinning does occur. If the skin thins, then joints, muscles and tendons may also operate more easily.

Why does spontaneous improvement occur in some skin areas and not others

The pattern of improvement is not random. Skin thinning almost always begins in areas that have been affected last - usually the upper chest, abdomen, and upper arms. The areas first involved - the fingers and hands - are the last and the least likely to improve.

Why should this be so? One answer is that the body has enzymes that can digest collagen but these enzymes work most effectively on collagen that has recently been produced. Mature collagen is more resistant to enzymatic digestion because the collagen fibres form crosslinks which weave them together more tightly.

Recent studies from Switzerland show that low tissue oxygen tension may in itself be a trigger for activating fibroblasts, the cells which produce collagen. In scleroderma, the fingers suffer first from deficient blood supply.

How white cells, mast cells and fibroblasts function in scleroderma

In an individual with early diffuse disease, a skin biopsy from an area of newly thickened skin will usually show not just bundles of extra collagen and diminished blood vessels but also collections of white cells. These white cells have been identified as activated T-lymphocytes.

These white cells produce signals which in turn activate fibroblasts to over produce collagen.

These white cells are present only in the early inflammatory phase of scleroderma, the phase the hands are puffy, the joints most achy and the itching most severe.

Not just lymphocytes infiltrate the skin but also mast cells. These cells probably account for much of the itching due to their release of histamines.

In later disease, the lymphocytes and mast cells disappear from the skin and the swelling subsides and the itching resolves or decreases.

Unfortunately, the fibroblasts that were activated continue to over produce collagen. The signals that transformed them have a long lasting effect.

Therefore if we are to treat the skin effectively, we must either do so early when the process is more one of inflammation than of fibrosis or we must develop better ways of turning off fibroblasts or accelerating the activity of enzymes which digest collagen. We must do so in ways that do not poison normal fibroblasts, thin normal skin or weaken all the internal structures in which collagen is an integral part.

LIVING WELL WITH CHRONIC LUNG DISEASE

adapted from Scleroderma fall 2007 p. 4

for more information on COPD contact www.livingwellwithCOPD.com

Respiratory challenges such as interstitial lung disease, chronic obstructive pulmonary disease (COPD), and asthma may result in overwhelming exhaustion, inactivity, feelings of helplessness and a negative lifestyle cycle. There are breathing techniques and body positions to reduce shortness of breath, coughing and relaxation techniques and recommended exercises to help build strength, flexibility and cardiovascular endurance. Regular exercise is of utmost importance. A vicious downward spiral can occur when we avoid exercise of shortness of breath. Principles of energy conservation (the six P's) are listed below.

1. prioritize your activities
2. plan your schedule within your limits
3. pace yourself
4. position your body and arrange your environment to reduce shortness of breath
5. purse lip breathing when doing activities requiring effort *
6. positive attitude

* purse lip breathing - technique to reduce shortness of breath.

Inhale slowly through your nose until you feel that your lungs are filled with air. Make sure to take longer to breathe out than you did to breathe in - without forcing your lungs to empty.
