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- Scleroderma Society for Residents of Metro Toronto(416)979-7228
- Scleroderma Society for Residents Outside of Toronto1-800-321-1433
- Arthritis Self-Management Program(416)979-7228
- The Scleroderma Society of Ontario Web Pagewww.sclerodermaontario.ca
- The Arthritis Society Web Pagewww.arthritis.ca
- SSC Web Page with link to SSO.....www.scleroderma.ca

STRETCHING... works for me

by Patricia Lott, Scleroderma Foundation, Evergreen chapter, Seattle, Washington, USA

If you have scleroderma, you probably already do some stretching. It is very painful at first when you are dealing with swelling and thickening and more difficult later when atrophy occurs. I will never forget the rheumatoid arthritis patient's comment as my hand therapist worked with me in the OT room "You could kick her under the table," she suggested as I complained more heartily than I intended. Although I did not take her advice, the laugh has helped me over the years...and that devoted OT saved the use of my hands.

Later, stretching became a foundational coping method for living with this disease. I stretch my

fingers, arms, shoulders, lips, mouth and jaw every morning, often when I am still half asleep. Next before I start my day, I do some Kegels while I stretch the feet, legs, back and whole body lengthwise to help prevent injury, particularly if I plan to be active. To protect joints and skin from pressure, I stretch on my foam rubber bed. During the day I stretch what needs the most work and I often do stretches before bed to keep from waking up in pain.

Sometimes something goes wrong and I need to reference Bob Anderson's book, Stretching. Recently pain on the outside of my lower leg threatened to disable my ability to walk. Ready for disappointment, I grabbed the book and headed for the index.

Amazement! Not only does Mr. Anderson provide an excellent stretch for this unusual area but includes instructions for modifying the move to accommodate the acute problem. A lot of the stretches are more like goals than accomplishments for me but it is so reassuring to know moves that will not cause further injury and that can actually relieve pain.

The hardest part for me about stretching is what to know to stretch. Often I experience generalized pain. That is pain in what seems to be bone or joint. I may have disability without an understanding of its origin. Doctors, therapists and chiropractors can help when common sense seems to fail. Not only can they figure out what to stretch but they can also figure out the activities that aggravate the problem. To help stretch my hands and wrists and to avoid those nasty knuckle lesions, I use the inside of my hands and fingers for balancing. I can distribute the pressure by wadding a hand towel up in my hand and take the pressure on the towel and any inner hand surface I can use. I avoid uncomfortable pressure on my fingertips and anywhere else. Since I no longer use a wheelchair, my current stretching activities to maintain flexibility involve at least a 30 minute session in the morning, reminder stretches during the day and another 10-20 minutes before bed. A small price for a better life!! (Always consult your physician before undertaking an exercise or stretching programme).



SCLERODERMA REPORTER

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

September 2006

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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:



So much to report, so little space. The months of May and June brought wonderful successes to your Society. Public awareness in the forms of newspaper stories, radio releases, proclamations and recognition from your local, provincial and federal elected representatives were happening right across the Province. I guarantee you, next year will meet with an even greater understanding of the sufferings of scleroderma patients. Start your planning now. The uninformed public needs to learn. Diagnosed victims of scleroderma, presently unaware of the existence of our Society, must be told that we are here to support and offer help to them.

Our website, www.sclerodermaontario.ca proudly proclaims the unprecedented accomplishments of our fundraisers. A grand total just shy of \$ 100,000.00 has been accumulated from the events in Windsor, Hamilton, Mississauga and Pembroke. More events are just ahead. The time, energy and dedication of each involved volunteer and even more so, of the chief organizers, is most remarkable. Every event achieved previously unattainable goals. All are presently in the planning stages for 2007. The membership-at-large and the Board are in your debt. We can not thank you enough. More research may now be possible.

Dr. Sindhu Johnson, one of our Medical Advisors, did invite members to attend an education exercise in Toronto. The purpose: to teach medical students more about scleroderma. The members present were appreciative of the opportunity. Dr. Johnson advised me that the medical students agreed that the experience of meeting scleroderma patients will stay with them forever, thanks to you Dr. Johnson and to the volunteers. We are most anxious to participate again.

Dr. Janet Pope, another of our medical advisors and a member of the CSRG, organized a one week clinic in London. We were late being informed. Attendance was not what it could have been. Those who did attend were encouraged and most grateful for this experience. Perhaps in another year, it could serve more people. Dr. Pope is the Guest Speaker at our AGM in Mississauga and you will have the opportunity to ask your questions directly.

Nataly Koester is the Chairperson of the Society's Chapter Leader Conference to be held in Kitchener on September the 30th. As always, her attention to detail and her professionalism are very evident even in the planning. The intent: To network with those present and to educate each other on, perhaps, better methods and procedures to accomplish our mission statement. I urge every Chairperson of a Support Group, or their alternate, to make an extra effort to attend. Dr. Nader Khalidi, the arranged Guest Speaker and a member of the CSRG, will talk on "Therapeutics in Scleroderma - an Update" and about his involvement with the CSRG.

At the risk of sparring boredom v.s. repetition, I again urge you to go to www.cpso.on.ca or to call 1 (800) 268-7096 for an updated list of rheumatologists in your area with their names, addresses etc. and whether or not they are accepting new patients. It should be the responsibility of each Support Group to retain this current list. It is most instrumental when answering those inquiries that we all receive. As well, go to http://scleroderma.org/e_letter_signup.shtm. This accesses a bi-monthly Newsletter from the Scleroderma Foundation in the U.S.A. There is no cost. You will find it very informative and most useful.

Carroll Vapsva is organizing the Annual General Meeting of your Society being held in Mississauga. Dr. Janet Pope as our Guest Speaker has chosen for her topic "Scleroderma in Canada". Make your plans to be in attendance. The day is a Saturday and we will be completed by 1.00pm. Refreshments and snacks have been arranged. Elections for the Ontario Board take place. For a stronger voice and a strengthened Board, please volunteer to sit on the Board as a participating member. I hope to see you in attendance. Take Special Care of Yourself

Peter Woolcott

MEMBERSHIP APPLICATION

Please make cheque payable to the **Scleroderma Society of Ontario**
Send to: Kathy Donn, Treasurer
Scleroderma Society of Ontario
98 Rand St.
Stoney Creek, ON L8J 1A8

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 _____)
Amount Enclosed \$ _____ Date _____

I am a Scleroderma patient.
 Yes No

I am interested in helping with a Support Group _____

Name _____

Street _____

City _____ Prov. _____

Postal Code _____ Phone _____

E-mail Address _____

* tax receipts are issued for full amount of membership

ROLFING

(the process of re-educating the body through movement and touch) From Scleroderma Association of BC Fall 2006

Rolfing systematically releases patterns of stress and impaired function. The primary focus is facilitating the relationship between gravity and the human body. Gravity is the most potent physical force that the body has to deal with. Although most people realize the tremendous force exists, they somehow believe they are immune to it. Gravity's constant effect on any soft, pliable mass is to make it a formless, chaotic and spherical unit. With the human body much broader at the top than at the base, it is greatly affected by gravity when imbalances exist. Most bodies are in a state of imbalance. As we grow older, we often shrink in height and slowly lose flexibility. Our bones stay the same length and our muscles can still function but the connective tissue is what changes most. Connective tissue is the support system of the body...circulatory, digestive, nervous, musculoskeletal and organs are all ensheathed in connective tissue. A healthy and balanced connective tissue system's characteristics are flexibility, elasticity, length and resilience. The tissue absorbs and responds to gravitational force, illness, injury, emotional trauma and plain everyday stress. Any of those factors will immediately, or over time, cause an imbalance in the tissue system. When imbalance exists, the system's healthy characteristics are affected. The imbalance is identified as a shortening, thickening, dehydration of the tissue which impairs joint mobility and muscle function. This is usually felt in the body as chronic pain, discomfort, stiffness or decreased flexibility and impaired movement. Any imbalance in the body, no matter what the cause, is imprinted as change in the internal structure and has a long range and cumulative effect. The body may attempt to return to its original state but without assistance remains misaligned. For instance when someone sprains an ankle, it is natural to protect it as much as possible by shifting as much weight as possible to the uninjured side of the body. This natural response to the injury changes the entire body's relationship to the gravitational field and the neuromuscular system is repatterned as part of this process. The change in the inner system and repatterning can take place from things as simple as the habits of carrying a heavy bag on the same shoulder or holding a telephone between one's shoulder and ear. In order to remain upright, the entire body has to compensate and some muscles are forced to shorten. When a muscle is chronically shortened, it loses its ability to relax, resulting in a constant state of tension. When these changes and patterns occur, the connective tissue needs assistance in order to return to its normal healthy state. Rolfing is of particular benefit at this point.

RESEARCH

The Journal of Rheumatology (vol 33, no 6 June 2006) published "Scleroderma: Health Services Utilization From Patient's Perspective" by Drs. Sindhu Johnson, Simon Carette and Jim Dunne. The study evaluates utilization of the health care system by scleroderma patients.

Dr. S. Johnson of Toronto focuses on scleroderma and associated pulmonary hypertension. Her project centres on this disease as it relates to a person's defence against germs that are not working properly, ultimately attacking the person's own body. The blood pressure in the lungs of some of these people gets very high. When this happens, they develop breathing problems, heart problems and may die. We know that some patients with high pressure in their lungs have an abnormal gene that puts them at higher risk. The purpose of this project is to see if this abnormal gene is present in patients with scleroderma who develop high pressures in their lungs. If we find this abnormal gene, we may be able to find these patients and treat them earlier.

Dr. Andrew Leask at the University of Western Ontario in London has been approved by the Scleroderma Society as a new investigator. As such, partial salary support will be provided for five years for research. He is interested in pursuing the effects of fibrotic diseases ie. scleroderma. Fibrosis results in failure of organ function and can affect the kidneys, liver, lungs, skin and blood vessels and in scleroderma is fatal. His work has discovered a potential mediator of fibrosis which is over expressed in fibrotic tissues. The objective of this proposal is to learn what this mediator does and whether it is a good candidate against which to develop anti-fibrotic therapies.

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.

HAPPINESS IS LEARNING by Cynthia Busch

I had the recent opportunity to apply for and be accepted into the Scleroderma programme of the Beryl and Richard Ivey Rheumatology Day Programmes held at the St. Joseph's Health Care in London, Ontario. This course was for two weeks June 5 to June 16, 2006, 9:00 am to 4:00 pm. Similar programmes are offered in other provinces. I hope all those suffering from this disease will be able to attend what is offered in their province. Each year a refresher course is held for graduates of this course to learn updated information. Once accepted, I looked forward to what I would be exposed to, to help myself better understand and manage this disease. Upon completion, I truly was not disappointed. It is unfortunate our health system does not incorporate educational classes to all suffering from any illness to complement patient care.

On arrival the first day those in our class were brought into, what was to be, our classroom for the next two weeks. We were given our first week schedule and a thick binder which contained all the information we would be covering for the programme. Course topics were medicine, psychology, social work, physiotherapy, occupational therapy, pharmacy, nursing and nutrition. Instructors were staff from the different disciplines that came to give us up-to-date information geared specifically for the scleroderma patient. Each instructor was very open to questions and encouraged class participation during their presentation. Most time was spent on psychology and occupational therapy. Psychology covered skills for relaxation through deep breathing and using a relaxation CD. We also covered stress on illness, chronic illness and emotions, chronic pain, self-esteem, sexuality and four sessions on cognitive therapy which helped us analyze our thought processes. Occupational therapy covered pacing and energy conservation, foot, hand and face care, joint protection, community resources, body mechanics and finally assistive devices for self care and homemaking. The sessions gave us knowledge to pace - pace - pace and take care of our bodies. Physiotherapy classes provided exercises to improve movement. I especially enjoyed pool therapy in our second week.

The schedule for each week provided one rest period per day. This hour allowed us to go for a walk, read, practice relaxation or see an instructor for a one-on-one appointment. At the end of the first week family members were invited to have a session together to discuss their concerns about the impact of this disease in their life. The following week there was a second group meeting with the class and family members to discuss how our families could best help us manage our disease.

Another bonus to all I have mentioned is the bonding of those in our class to each other. We shared two weeks understanding how this illness had affected us physically and emotionally. It was comforting to have all this information and accessibility to experts for two full weeks. If problems or concerns arose at a later time, we were encouraged to contact any instructor for assistance. Parting was difficult but we have continued the friendship.

Again, if you have the opportunity to enroll in such a programme, put it on your to do list. My thanks to all staff at St. Joseph's Health Care in London for their efforts and time to provide those with scleroderma the opportunity of a lifetime, knowledge and the best memories. Knowledge is power.

FUNDRAISERS WALKED IN 2006 WERE IN MEMORY OF

Julia Cerna, Amy Hicks, Marion Hicks, Pat LePage, Ina Nagle, Steve Newton, Sandra Reinhardt, Lorne Robson, Diane Stone, Stanley Stys, Jean Doris Sweet, Walter Wazny, Ron & Pam Whitehead

LITERATURE ORDER FORM

- Understanding & Managing Scleroderma.....FREE
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.
- Helpful Hints: Living with Scleroderma.....\$2.00
A compilation of helpful information submitted by Scleroderma Foundation (USA) members.
- Sjogren's Syndrom.. UPDATED 2003.....\$0.25
A general overview of Sjogren's
- What Causes Scleroderma?.....\$0.25
Also available in Spanish. Discusses the Scleroderma "puzzle".
- Perspectives on Living with Scleroderma.....\$16.00
By Mark Flapin, Ph.D. Features Dr. Flapin's insightful articles on coping, including his personal story. 233 pages

- Successful Living with Scleroderma: Guidebook.....\$15.00
New! By Robert Phillips, Ph.D. Dr Phillips is Director for the Center for Coping.
- The Scleroderma Book (2005) 2nd edition.....\$20.00
By Maureen Mayes, M.D. A definitive guide for patients and their families.

- Pulmonary Hypertension...UPDATED 2003.....FREE
A general overview of PH in Scleroderma

Book #	Price	Quantity	Total

Please enclose cheque or money order payable to:
Scleroderma Society of Ontario
393 University Ave Suite #1700
Toronto, ON M5G 1E6
(Prices subject to change without notice)

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