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[Scleroderma Society for Residents Outside of Toronto](mailto:sccleroderma@sympatico.ca)1-800-321-1433
[Arthritis Self-Management Program](mailto:sccleroderma@sympatico.ca)(416)979-7228
[The Scleroderma Society of Ontario Web Page](http://www.sclerodermaontario.ca)www.sclerodermaontario.ca
[The Arthritis Society Web Page](http://www.arthritis.ca)www.arthritis.ca
[SSC Web Page with link to SSO](http://www.scleroderma.ca).....www.scleroderma.ca

WALKS FOR SCLERODERMA

June is Scleroderma Month in Canada. Help us bring awareness to this devastating disease by joining us, with your family, friends and co-workers, on a leisurely walk in Windsor, Hamilton or Pembroke. Pledges go a long way for research in Scleroderma. Share in the prizes, incentives, food and music. With your help, the WALKS are getting bigger and better each year!! See you there. STAY TUNED FOR MORE INFORMATION

WINDSOR

Walk-Run-Roll-a-Thon and Silent Auction
 Saturday, May 20, 2006
 Registration begins at 8:30 am and is \$25.00
 Walk begins at 10:00 am at 10300 Riverside Drive East. Using Ganatchio Trail
 Contact Lucille (Babe) Sliva for information at (519) 945-0108

HAMILTON

Walk 'n Talk
 Saturday, June 3, 2006
 T.B. McQuesten Park – 1199 Upper Wentworth Street
 Registration begins at 10:00 am
 Walk begins at 11:00 am
 Contact Peter Woolcott for details at (905) 730-0731

PEMBROKE

Ina Nagle Memorial Walk
 Pembroke Memorial Park
 Saturday, June 17, 2006
 Contact Carl Stager for details at (613) 732-0046

OUT OF THE MOUTHS OF BABES

When I was driving with my three young children one warm summer evening, a woman in the convertible ahead of us stood up and waved. She was stark naked! As I was reeling from shock, I heard my 5-year-old shout from the back seat, "Mom, that lady is not wearing a seatbelt"

My son Zachary, four, came screaming out of the bathroom to tell me he had dropped his toothbrush in the toilet. I fished it out and threw it in the garbage. Zachary stood there thinking for a moment and then ran to my bathroom and came out with my toothbrush. He held it up and said with a charming little smile, "We better throw this one out too because it fell in the toilet a few days ago".

A woman was trying hard to get the ketchup to come out of the bottle. During her struggle, the telephone rang and so she asked her 4-year-old daughter to answer the telephone. "It is the minister Mommy" said the child. Then she said "Mommy cannot come to the telephone to talk to you right now. She is hitting the bottle".

A little boy opened the big family Bible. He was fascinated as he fingered through the old pages. Suddenly, something fell out of the Bible. He picked up the object and looked at it. What he saw was an old leaf that had been pressed in between the pages. "Mama look what I found" cried the boy. "What have you there dear" The young boy's voice answered "I think it is Adam's underwear!"



SCLERODERMA REPORTER

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

March 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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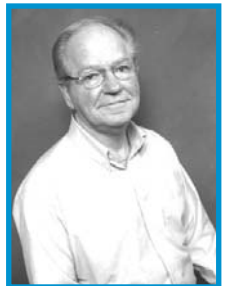
HELLO TO ALL:

Have you noticed the increase in daylight hours? Wiarton Willie has us looking for an early Spring. Now, how Canadian is that eh, mentioning the weather before all else.

Your Board has created a Task Force Committee comprised of Catherine Buntain-Jeske, Chris May, Irene Goodale, yours truly and Maureen Sauve. We have already met on two occasions. This Committee is scrutinizing the ongoing activities of the Society while it takes particular notice of many earlier successes. Its purpose and function is to recognize and establish the necessary benchmarks that will facilitate your Society to achieve realistic goals with rewarding successes over the next few years. The committee members unanimously agree that our support groups are the Society's most valuable asset. They are the life blood that will nurture us into tomorrow. Arguably, there is a depth of experience on the Committee that together with its energy and insight, will allow us to formulate and outline a skeletal plan to assist the current support groups and, additionally, to create and grow support groups when and wherever there is a need. I am asking you to aid and assist. Your wants, needs and ideas are most important. Please take part in this process. Get involved. Call me or email to me your ideas. Together we shall be more successful.

June is 'Scleroderma Month'. Start planning now. Would it not be absolutely wonderful to see stories of Scleroderma in dozens of newspapers throughout the province and also to hear them in our community public service announcements on our radio stations? Perhaps a city hall proclamation. Our focus should be on public awareness. The media in whatever format can be most instrumental in reaching out to so many who are diagnosed with Scleroderma but are unaware of our Society. So many others, everywhere, have never even heard of the illness but may very well be prepared to support our Mission Statement. Social events too, regardless of the magnitude or type, are huge weapons in the arsenal of public awareness to gather support from the informed and the uninformed. Start now! Grow your ideas! Yet to be imagined rewards, will follow.

Another matter comes to mind. There is never enough medical advice to go around. It is mandatory that each physician, practicing in Ontario, register together with any specialty with the College of Physicians and Surgeons of Ontario. There are 190 rheumatologists in Ontario registered by their name, address, telephone number and whether or not they are accepting new patients. This information is available at www.cpso.on.ca or by calling 1 (800) 268-7096. Not all rheumatologists treat Scleroderma. However a good receptionist will be willing to direct you to a rheumatologist who is treating Scleroderma in your area. I urge the support group chairperson to compile such a list of specialists in their community. Keep it current, keep it available, keep it shared.



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

WINTER WORTHY MOISTURE THERAPY - Courtesy of Homemakers Magazine

At this time of year, cold weather outside and dry heating inside combine to rob your skin of moisture – especially in sensitive spots such as heels, hands and cuticles. Here are a few moisturizing products to help keep your skin (and hair) in good repair.

Face and lips

- Kiehl lip balm SPF15
- Biotherm oleo source Radiance Elixir, dry skin formula

Face and skin

- LaRoche-Posay, a favourite of dermatologists, for severely dry, irritated, sensitive skin

Chapped hands

- NeoStrata Moisture Fusion Ultra Replenishing Mask (for face but terrific on hands)
- Dermaglow Miracle Nails
- Sephora Nourishing Cuticle Oil
- A/G Saturate Moisture Glove
- Glysolid treatment for dry, chapped or cracked hands (feet too)

Cracked heels

- Gehwol Med salve for cracked skin (good for the tiny cracks on fingertips too)
- Dr. Scholl's Pedicure Essentials cracked skin repair cream
- Allpresan Cream Foam3 Extra intensive care for rhagades (deep cracks in callused heels)

Dry, brittle hair

- Pure & Simple Organic Lemon/Rosemary Conditioning Shampoo and Nourishing Hair Mask
- Pantene Pro-V Winter Rescue Moisturizing Shampoo
- Schwarzkopf Professional bc Moisture Mask

PULMONARY ARTERIAL HYPERTENSION

Simon Stewart has written a 56 page pocketbook guide to pulmonary arterial hypertension. In its forward, Professor Carol Black describes it as "packed with essential and accessible information" and notes that "advances in the field ...mean that a hitherto rapidly fatal disease is now, for many patients, a controllable condition." Specialist commentator Keith McNeil concurs noting that patients "once faced with a devastating disease and little prospect of effective treatment can now achieve very significant gains in both their prognosis and quality of life."

This guide is intended for medical practitioners, rather than the general public. However because pulmonary hypertension is recognized as a lethal complication of all forms of systemic sclerosis, it may be of interest to scleroderma patients, in particular.

It is distributed in North America by Taylor and Francis, 200 NW Corporate Blvd, Boca Raton, FL, USA 3343, telephone (561) 994-0555 or email orders@crcpress.com. Your local bookstore may be able to order a copy for you.

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.

In Memoriam

- | | | | |
|------------------------------|-------------------------|----------------------|---------------------------|
| Pamela Behan | Robert Fong-Jean | George Kirk | Ina Nagle |
| Corrine Bereskin | Isabella Furano | Doris Long | Gladys St. Michael |
| Marguerite Birmingham | Terry Goldwin | Gail Lavillie | Kathy Stillaway |
| Evelyn Dyer | Linda Hayes | Heather Mason | Joe Takacs |
| Ian Fleming | Donna Horton | Barbara Moore | Paula Takacs |
| | | | Hermann Voelsgen |

The next annual AGM meeting will be held on Saturday October 21, 2006 10:00 am – 1:00 pm at the Erin Mills United Church, 3010 The College Way, Mississauga, Ontario, L5L 4X9. More details to follow.

CANADIAN SCLERODERMA RESEARCH GROUP (CSRG)

The CSRG after applying for a grant for \$300,000 to the Canadian Institutes of Health Research were told only two submissions of 14 were accepted. For your information the national CSRG is comprised of the following Canadian physicians: Dr. M. Baron, Dr. M. Bell, Dr. A. Bookman, Dr. P. Docherty, Dr. C. Douglas, Dr. J. Dunne, Dr. M. Fritzier, Dr. M. Hudson, Dr. N. Jones, Dr. E. Kaminska, Dr. S. LeClercq, Dr. A. Mason, Dr. J. Pope, Dr. E. Sutton and Mr. R. Buzza.

Fifteen centres have agreed to participate and are actively recruiting patients for the CSRG database. The database is housed on a computer at GEREQ in Montreal. Each site enters the data via the web from their own site – this allows for immediate correction of errors and missing information.

WHY DATA COLLECTION

- Scleroderma occurs between 30-120 per million population
- **patient's history** (disease onset, when diagnosed, affect on each organ, how it affects function, psychological aspects, work aspects, pain aspects)
- **doctor's exam** (the doctor's findings for all body organs, measures specific to "skin score" – drawing up a pinch of skin to measure thickness)
- **laboratory investigations** (routine blood tests, x-rays, echocardiograms, CT scans etc.)

STANDARDIZED TEST RESULTS BLOOD SAMPLES CONSENT

- test results must be done and be reported the same way
- blood is withdrawn, frozen and shipped to Calgary in bulk by Fedex
- written, informed consent is required of all patient participants

UNBELIEVABLE MATH PROBLEM

Using a calculator

1. key in the first three digits of your telephone number (not the area code)
2. multiply by 80
3. add 1
4. multiply by 250
5. add the last four numbers of your telephone number
6. add the last four numbers of your telephone number again
7. subtract 250
8. divide by 2

... Do you recognize the answer?

LITERATURE ORDER FORM

1. 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.
2. Helpful Hints: Living with Scleroderma.....\$2.00
A compilation of helpful information submitted by Scleroderma Foundation (USA) members.
3. Sjogren's Syndrom.. UPDATED 2003.....\$0.25
A general overview of Sjogren's
4. What Causes Scleroderma?.....\$0.25
Also available in Spanish. Discusses the Scleroderma "puzzle".
5. 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

6. Successful Living with Scleroderma: Guidebook.....\$15.00
New! By Robert Phillips, Ph.D. Dr Phillips is Director for the Center for Coping.
7. The Scleroderma Book.....\$19.00
By Maureen Mayes, M.D. A definitive guide for patients and their families.
8. 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**
 Total \$ _____