

## Ontario Support Group Contacts

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Kitchener	..... Penny Pogson.....	(519) 570-4930	
London	..... Sharon Murphy.....	(519) 472-8803	
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Scarborough	..... Naana Daniels.....	(905) 686-7265	..... naanash67@yahoo.com
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Thunder Bay	..... Rose Marie McCracken.....	(807) 344-8345	
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	..... Pamela Mitchell.....	(416) 654-9057	..... pjmitchell@sympatico.ca
Windsor	..... Lucille (Babe) Sliva.....	(519) 945-0108	

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

## 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](mailto:peterwoolcott@sympatico.ca) or (905) 730-0731

## WALKS FOR SCLERODERMA

### WINDSOR

**Walk-Run-Roll-a-Thon**  
Saturday, May 26, 2007  
Ganatchia Trail - 10300 Riverside Drive E.  
Registration begins at 8:30 am and is \$25.00  
Walk begins at 10:00 am  
SILENT AUCTION  
Contact Lucille (Babe) Sliva for details at (519) 945-0108

### HAMILTON

Hamilton Tiger-Cats have joined forces with the Scleroderma Society of Ontario



**Walk 'n Talk**  
Saturday, June 2, 2007  
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 'n Talk**  
Marina Park and Walkway - Pembroke  
Saturday, June 16, 2007  
Contact Carl Stager for details at (613) 732-0046

## RHEUMATOLOGY DAY PROGRAMME REMINDER

St. Joseph's Health Care London is having their annual scleroderma programme on May 22 through June 1, 2007 Monday to Friday 9:00 am - 4:00 pm (two full weeks). The multidisciplinary team (rheumatologist, psychologists, physiotherapists, occupational therapists, pharmacist, social worker and nutritionist) will help the participant understand their illness, learn ways to manage symptoms and cope with them. Programme fees are covered by OHIP, however there is a \$10.00 cost for the programme workbook and handouts. The hospital has accommodation \$30.00/day including parking only walking distance from the hospital (519) 646-6021. Parking at the hospital parking garage is available but limited. If INTERESTED contact them directly.

**Rheumatology Day Programme**  
St. Joseph's Health Care London  
286 Grosvenor Street, P. O. Box 5777  
London, Ontario N6A 4V2  
Contact: Vicky Bossenberry  
Phone (519) 646-6000 Ext.66340 / Fax (519) 646-6317  
[vicky.bossenberry@sjhc.london.on.ca](mailto:vicky.bossenberry@sjhc.london.on.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 \_\_\_\_\_



# SCLERODERMA REPORTER

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

May 2007

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### BOARD OF DIRECTORS

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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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Phone (416) 979-7228, Toll-free 1-800-321-1433  
Fax (416) 979-8366  
Web-Site [www.sclerodermaontario.ca](http://www.sclerodermaontario.ca)  
E-mail [peterwoolcott@sympatico.ca](mailto:peterwoolcott@sympatico.ca)

### HELLO TO ALL:

It's been 2 months since publication of the last Reporter. I am in awe of the total change in the weather. Do you remember February and early March? We deserve the warm stuff and so get out there and enjoy-eh!!!

Allow me to tell you about research for Scleroderma. Dr. Murray Baron, a founding member of the Canadian Scleroderma Research Group (CSRG) has been successful in obtaining two separate grants totaling in excess of three million dollars from the Institute of Musculoskeletal Health and Arthritis. (You can see a summary in this Reporter.) Our Society congratulates Dr. Baron and his collaborators. Be mindful however that each individual member of your Society is deserving of credit and congratulations as well. It is very definitely your membership fees, donations, fundraising events and public awareness activities that have enabled your Society to assist to initiate these projects and to sustain them with funds committed in the amount of \$150,000. Let there be no ambiguity in this matter. Your Society is indebted to you for your untiring efforts. Additionally, let me tell you that we are continuing to support Dr. Andrew Leask from London in his Scleroderma research with \$30,000 again this year. As well, we have received a request to support a separate Scleroderma Research Proposal which will be reviewed at our next board meeting. These are a few of the products of your support. I can not thank you enough.

June is "Scleroderma Awareness Month". Many Support Groups host Fundraising or Public Awareness activities. Some are successful at doing both. I URGE ALL OF YOU to approach the respective heads of your local Council to obtain Declarations or Proclamations in your community that June is Scleroderma Public Awareness Month. Seek out your TV and radio stations as well as the community newspaper. Ask for a scleroderma story time/space. Why not an interview. Opportunity knocks. Reach out to all who don't know about scleroderma and hopefully to sufferers who perhaps know all about their challenge with scleroderma but are unaware of a Society who can offer them support. Stop reading right this minute. Formulate your plan and then follow it.

Carroll Vapsva and that highly energized committee in Mississauga achieved the impossible—impossible for all who preceded. This group organized and sold out a hugely successful Dinner/Dance with a Silent Auction raising, after all expenses, in excess of \$37,000 for scleroderma research. Mark your calendar for April 5th 2008 for the 2nd Annual Gala Event and the best time of your life. Again to Carroll and the committee ---a most sincere thank you and giant congratulations.

Hamilton, Windsor and Pembroke are staging their Walks while dove-tailing their efforts with public awareness. Your support is always most encouraging for the organizers. Make a special effort to attend. You will enjoy the day with friends and family. The weather will be great. I guarantee it.



Peter Woolcott

## Scleroderma has \$1,800,000.00 approved for research

We are delighted to report that the Institute of Musculoskeletal Health and Arthritis (IMHA) has approved research funding to the Canadian Scleroderma Research Group (CSRG) in the amount of \$1,800,000. The CSRG proposal was submitted February 1, 2006. Principal investigator Dr. Murray Baron was advised March 15, 2007 of the results of the peer review process. Up to \$300,000 for each of six years (\$1.8M) has been approved.

This financial amount will be supplemented by a wide range of grants from other sources. The Scleroderma Society of Ontario (SSO) has already supplied funding of \$50,000 and will continue to provide \$25,000 per annum for four additional years to support the CSRG's extensive clinical database.

Progress in scleroderma research has been slow with poor integration between basic and clinical scientists.

The foregoing funds will be used to increase the capacity to perform scleroderma (SSc) research in Canada. Mentors will be provided to young researchers in specific fields at multiple sites. This community of new researchers will complete their training and continue to interact which will ensure cross fertilization of ideas from one discipline to another. They will acquire the expertise to run independent research programmes on multiple aspects of scleroderma in both clinical and laboratory settings and will become part of an expanded CSRG.

The CSRG was formed in 2004. This highly respected consortium of researchers and rheumatologists at multiple sites in Canada has an established commitment to integrated transdisciplinary research. Its rheumatologists see scleroderma patients at 15 sites and then enter detailed data into a central database that already includes one of the largest such cohorts in the world. Expansion to include the new trainees will increase its capability. Scleroderma patients will undoubtedly benefit from their work but so will those coping with other systemic autoimmune rheumatic diseases (SARD) such as lupus and Sjögren's syndrome patients.

Our congratulations to Dr. Baron and his team comprised of four principal applicants, four co-applicants and 21 collaborators.



Photo taken by the Mississauga News

## GALA March 17th, 2007

Names from left to right:

Shirley Haslam, Jennifer Rai, Rosemary Vincec, David Sweet, M.P., Carroll Vapsva, Carolyn Lewis, Peter Woolcott, and violinist, Jeff Taylor.

## IN MEMORIAM

Frances Mackenzie	Sheila Zatimed	Terry Agambar	Ina Nagle	Eldon Tinney
Gary McLean	Zora Crnich	Robert Burnfield	Anne Amos	Sonia Green
Omira Calabrese	Lillian Hurren	Edith Smith	Julie App	
Gale Deering	Robert Grover	Nancy Chapman	Gary Ferguson	
Amos Pino	Delores Polly	Audrey Reinholt	Bessie Richardson	

### 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.

## ANOTHER MAJOR GRANT AWARDED

On March 15, 2007 the Institute of Musculoskeletal Health and Arthritis (IMHA) approved \$1.8M to increase the number of new scleroderma researchers in Canada over the next six years.

On April 10, 2007 the IMHA, in partnership with Pfizer Canada, approved, subject to resolution of an overlap issue, \$1,497,030 to support a research programme involving established and new scleroderma researchers from a variety of backgrounds. This team will address knowledge gaps by focusing on the following immediate goals:

- 1) develop more sensitive classification criteria
- 2) create subsets of disease using among other instruments autoantibody profiles
- 3) develop a disease activity index and a damage index

The team will engage in active knowledge transfer and exchange amount the lay and scientific communities and policy makers.

The ultimate objective is to advance the study of scleroderma in Canada dramatically and to provide a platform "...for interventional studies aimed at identifying disease modifying therapies and improving the quality of life of patients with scleroderma."

Our congratulations and thanks to the entire Canadian scleroderma research group and in particular principal investigators Murray Baron, Anie Philip, Janet Pope and Andrew Leask and their 14 co-investigators and their eight research collaborators, their 11 participating rheumatologists and the following patient representative collaborators Mary Brachaniec, Bob Buzza and co-chairs of the Knowledge Transfer Exchange Committee Shirley Haslam, Phil Hughes, Mare Pacy, Normand Ricard.

## A prospective controlled study evaluating the effects of osteopathic treatment on patients with idiopathic pulmonary hypertension and pulmonary hypertension secondary to scleroderma

What is osteopathy - osteopathy is a holistic treatment that uses manual palpation techniques to improve and restore overall function. Osteopathy has been used to treat various forms of chronic pain. The purpose of this study is to investigate the effects of osteopathic treatment on people with idiopathic pulmonary hypertension or pulmonary hypertension related to scleroderma.

### Inclusion criteria

1. Scleroderma associated pulmonary hypertension or idiopathic pulmonary hypertension
2. Age 18-70 years
3. Able to provide consent to treatment
4. Have stable signs and symptoms for a minimum of three months

### What is involved

- Prior to the study you will be asked to fill out a brief questionnaire (SF-36 form), perform a six minute walk test and book an osteopathic evaluation.
- Three more osteopathic treatments will be booked for you.
- Upon completion of the last treatment, eight days after and then three months later, you will be asked to fill out the brief questionnaire again, perform a six minute walk test and an osteopathic re-evaluation.
- Total time needed to complete this study is six hours.

For more information please contact Pam Ennis (647) 880-7263 or Claire Biafore (416) 858-9933

## 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. Sjögren's Syndrome.. UPDATED 2003.....\$0.25  
A general overview of Sjögren'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 (2005) 2nd edition.....\$20.00  
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 \$ \_\_\_\_\_



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SCLERODERMA SOCIETY OF ONTARIO SSO NEWSLETTER INSERT  
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May 2007

## Scleroderma Voice March 2007 - questions and answers

**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 (gastroparesis) 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. *by Dr. Daniel E. Furst*

**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 (eg. 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. It is my opinion that it is safe to use in scleroderma patients and can improve their appearance. *by Dr. Vincent Falanga*

**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 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 bio-engineered 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. *by Dr. Vincent Falanga*

**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 - 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. *by Dr. Kevin K. Brown*

# The Gastrointestinal Tract In Scleroderma

**Mouth** - This occurs in approximately 40% of patients and is associated with sicca or dry mouth. Dry mouth can be a result of medications (eg. antidepressants). There is also decreased salivary flow. This impairs early digestion because saliva contains enzymes to help break down food. It also prevents the normal cleaning of teeth so that dental caries and periodontitis (inflammation of the gums) may occur. Dental checkups are difficult because patients struggle opening their mouth wide. Treatments are good dental hygiene, brushing, increased fluids with meals and occasional medication eg. oral pilocarpine (Salagen).

**Esophagus** - Esophagus involvement can cause heartburn, dysphagia (difficulty swallowing), bleeding and aspiration (taking bits of food into the lung) with pulmonary problems. Barium swallow x-rays and video x-rays often test esophageal involvement. Manometry is used for muscle measurement. Endoscopy examines the esophagus visually. Patients with esophageal symptoms should avoid being overweight and eliminate smoking, drinking coffee, non-herbal and some herbal teas, eating chocolate or acidic foods such as orange or tomato juice. Tight clothing should be avoided and 6" blocks to raise the head of the bed can help prevent reflux while sleeping.

**Stomach** - The stomach is involved in only 10% of patients but can be associated with bloating, satiety (early fullness), abdominal pain, nausea and vomiting. Testing for the stomach is the same as for the esophagus. Scanning techniques are sometimes used to examine stomach function. Radioactive food and Geiger counter like instrument tracts movement down the GI tract. Monitoring pH measures acidity for up to 24 hours.

**Small intestine** - When the small intestine becomes involved, nausea, vomiting, bloating, diarrhea and malabsorption (poor absorption of nutrients) can occur. The latter can result in weight loss and malnutrition. When muscle function of the small intestine is impaired, food remains there longer and allows an overgrowth of bacteria. This results in a breakdown of bile and other enzymes that help absorb food. Fat may not be absorbed and may cause diarrhea as well as weight loss, bloating and abdominal pain from gas build up. Rotating antibiotics such as amoxicillin, ciprofloxacin, ampicillin, metronidazole and tetracycline are often used.

**Large intestine** - The large intestine is involved in 39% of patients. The muscles become weak and constipation and bloating can occur. Diarrhea from malabsorption in the small intestine can also occur. Constipation needs to be treated with fluids and bulk. Diarrhea needs to be treated by treating the poor absorption in the small intestine. In some patients, fecal incontinence (the ability to control stools) occurs. This very rare complication can be treated by controlling stool bulk but extremely rarely may benefit from surgery. Gas may be a problem and may be helped by eliminating milk products and sugar. Boiling milk and special milks such as Lactaid may help. In very severe cases, a special diet called "gluten free" may be needed.

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**Research facts for your information** - T cells become involved with skin inflammation in the early stages of scleroderma. There is evidence that the outbreak of T cells within the skin may lead to autoimmunity. Regulatory T cells are cells that suppress inflammation and prevent autoimmunity in normal individuals.

Systemic sclerosis is more commonly found in women.

Excessive collagen in skin and internal organ scarring are the most serious problems in scleroderma.

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