

Ontario Support Group Contacts

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

- Brantford**Helen Stys(519)753-6132..... helenstys@rogers.com
- Halton**John Littler (Temporary)(905)849-8356
- Hamilton**Audrey Stephenson(905)387-5925
- Kitchener**Penny Pogson(519)570-4930
- London**Sharon Murphy(519)472-8803
- Midland/Orillia** Jeannette Brunelle(705)526-9869.....nettebrunelle@sympatico.ca
- Mississauga**Carrol Vapsva(905)822-7868 vapsva@rogers.com
- Niagara/**
- St.Catharines**Susan Duncan(905)984-6748scleroderma@cogeco.ca
- Ottawa**Aline Laporte.....(613)745-7829sclero@sympatico.ca
- Pembroke**.....Ralph Bergsma(613)735-3313.....rbergsma@sympatico.ca
- Sarnia**Susan Dunn(519)332-0672
- Scarborough**Naana Daniels(905)686-7265naanash67@yahoo.com
- Stratford**Wendy Marshall.....(519)273-1642sparkie@sympatico.ca
- Thunder Bay**Rose Marie McCracken....(807)344-8345
- Tillsonburg**Julie Desplenter(519)842-3451wjdesplenter@kwic.com
- Toronto**Osvaldo Guzman(416)698-4920.....osvaldo.guzman@dgig.ca
Pamela Mitchell.....(416)654-9057pjmittchell@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 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

- QUOTES**
- The severity of the itch is proportional to the ability to reach it.
 - He who laughs last, thinks slowest.
 - Support bacteria, it's the only culture some people have
 - A clear conscience can be a sign of a bad memory

- JOKES**
- It is easier to preach ten sermons than it is to live one.
 - The good Lord didn't create anything without a purpose, but mosquitoes come close.
 - People are funny; they want the front of the bus, the middle of the road and the back of the church.

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 _____

Name _____
Street _____
City _____ Prov. _____
Postal Code _____ Phone _____
E-mail Address _____

I am a Scleroderma patient.
 Yes No

I am interested in helping with a
Support Group _____

* tax receipts are issued for full amount of membership

WALKS FOR SCLERODERMA

WINDSOR
Walk-Run-Roll-a-Thon
Saturday, May 20, 2006
Ganatchio 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 information at
(519) 945-0108

HAMILTON
The Hamilton Tiger-Cats have
joined forces with the
Scleroderma Society of Ontario
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 'n Talk
Marina Park and Walkway - Pembroke
Saturday, June 17, 2006
Contact Carl Stager for details at
(613) 732-0046

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

Reporter by Email

Should you prefer to receive your Reporter by email, please advise Cynthia Busch at cbusch@distributel.net



SCLERODERMA REPORTER

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

April 2006

INSIDE THIS ISSUE

President's Message.....1
Board of Directors.....1
Mission Statement.....2
If there is a WILL, there is a way2
One is the loneliest number2
In Memoriam2
At long last some relief3
Literature Order Form3
Support Group Contacts4
Walks for Scleroderma4
Membership Application4
Quotes & Jokes4
Hospital Bed4
Reporter by Email.....4

BOARD OF DIRECTORS

President / Support Groups & Fund Raising Director.....Peter Woolcott
Vice-President / Research DirectorMaureen Sauve
SecretaryNataly Koester
Past-President / AGM Chair
SSC Liaison.....Irene Goodale
Treasurer / Membership Director.....Kathy Donn
Newsletter EditorPeter Woolcott & Nilton Claudino
Web-Site DirectorCarl Stager
Membership DirectorDorothy Brennan
Research / Public AwarenessDarlene Mattiacci
Support Groups / Public AwarenessMona MacLeod
Fund Raising / Public Awareness & Privacy Policy DirectorCatherine Buntain-Jeske
Fund Raising / Public AwarenessChris May

Advisors:
Senior Director Arthritis Programs
TAS StaffLaurie Hurley
Executive Assistant
TAS StaffCatherine Sweetland
Medical AdvisorsDr. Janet Pope
.....Dr. Elzbieta Kaminska
.....Dr. Sindhu Johnson

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
393 University Avenue, Suite #1700
Toronto, ON M5G 1E6

Phone (416) 979-7228
Toll-free 1-800-321-1433
Fax (416) 979-8366

Web-Site www.sclerodermaontario.ca
E-mail peterwoolcott@sympatico.ca

HELLO TO ALL:



The Society, on your behalf, has expressed condolences to the families of Roy Whitehead and Anna Stech. Roy was the Treasurer of our Society for many years and the widower of a past president who was a scleroderma sufferer. Anna was active in the Halton Support Group working diligently and ambitiously at gaining public awareness and raising research dollars. They have moved on but never to be forgotten. Their efforts, on behalf of your Society—PRICELESS.

Many Support Groups are as busy as the Canadian beaver organizing public awareness and fundraising events. Your Board is on the same busy track. Chris May has already arranged for a statement to be read at Queen's Park in Toronto. Catherine Buntain-Jeske has arranged for a cousin statement to be delivered in the House of Commons in Ottawa. These announcements publicly acknowledge that the month of June is—"Scleroderma Month"--in Canada and they briefly outline details of the disease and its pervasiveness in our Canadian society. We will attempt to provide you with details of time and date on www.sclerodermaontario.ca. Carl Stager, God bless him, has been instrumental in the production of a 30 second public service announcement telling about scleroderma, now being distributed to every radio station across Ontario. Its cost--nothing. Its value—PRICELESS.

All Support Groups have or will receive a sample package of proclamations to be tailored by them, for a declaration for adoption in your own local area for the month of June. You--yes--that's you, reading this message right now, pick up the phone now to call your local Chairperson and offer your support and assistance to guarantee that your own community recognizes "Scleroderma Month". It would be wonderful to awaken every city, town, village and rural area to the needs and challenges that confront victims of scleroderma on an everyday basis. Union Gas will once again recite in each June billing that it is "Scleroderma Month". New pamphlets, brochures, bookmarks and additional items for education and awareness are on their way. Please, I urge you-- help the Society to help you in your local community.

As I write this message, a questionnaire is being prepared for circulation to each Support Group chair. Hopefully, it will reflect our most sincere efforts to grow and strengthen Support Groups across Ontario. It is short. It is self-explanatory. In larger or smaller groups, take the time necessary to complete and return this questionnaire. Be candid, be honest, be analytical, be suggestive. We will-- as well.

Allow me, for a moment, to talk to you about my very new friend, Nicole Edwards. She is a victim of systemic scleroderma, a Lyme disease sufferer and a recording musician. She was raised in South River, Ontario but moved to Whitehorse, Yukon Territory before developing scleroderma and continues to reside in Whitehorse, a city of 25,000. Ah, the wonders of the Internet-- it introduced us. This young woman is visiting her Ontario family while at the same time receiving hyperbaric oxygen treatments in Hamilton, an alternative treatment that is personal. The benefits for Nicole have been most rewarding. No longer able to play the guitar, she continues her musical career as a vocalist. She has arranged three public awareness events in Ontario on her short visit. You too, would be impressed by her strength and focus to defeat her health challenges. She is a most positive example for all of us and for what we are capable of doing. Nicole, I wish only the most for you.

Now, I am asking again, please, please assist in the organization and support of your local fundraising and public awareness events. Take care.

Peter Woolcott

If there is a WILL, there is a way (by Carey Bornn, St. Paul's Hospital Foundation - from Sclerodata Spring 2006).

We all have achievements in life that we look back on with pride. We worked hard, played hard, put value in our friendships, tried to live our life with integrity and though there may be a few regrets, we try to focus on the positives as much as possible. We learn early in life that more can be accomplished when we are determined and fully committed to the task at hand. We also find out that accomplishing important tasks brings us great satisfaction. When it comes to planning our estate and what will happen when we are gone, the old saying "where there's a will, there's a way" is equally important in achieving success and satisfaction. Each of us needs to have a Will completed before we die so that our wishes can be fulfilled. None of us would want the government to decide how our assets are to be divided. If you die without a Will, that is exactly what will happen. However, a valid, properly completed Will guarantees that the same determination you have in accomplishing what you want to do while you are alive continues after you are gone.

It is also important to note that this final task of distributing your assets through a properly prepared Will is the only way you can decide how to divide your estate to loved ones or to charities that you want to support. It is not good enough to simply tell a friend or jot your intentions on a piece of paper. A valid Will must be properly worded and then witnessed by people not mentioned in the Will.

Completing a Will is usually quite simple to do and often not as expensive as we think it might be. It is not a task that we should procrastinate on. There are serious consequences of not having a valid, up-to-date Will should we have a sudden major health issue or accident. Now is the time to consider to whom we wish to distribute our assets and which charities we wish to help. It may also be a good time to talk to a financial advisor about the taxes that may be payable at your death and what your options might be to minimize those taxes to preserve your assets. The information above is of a general nature and **not** a substitute for legal advice.

One is the Loneliest Number (By Rona Jaffe, M.Ed. - from Sclerodata Spring 2006)

I have heard friends, colleagues and clients say that living with a chronic illness can be a pretty lonely experience. Let's face it, you may be surrounded by people who do not face the same challenges you face and if that is not tough enough, you cannot get sympathy or support from people who do not know that you need it. On the other hand, disclosing your condition to everyone is not always a good idea either. So what is a person to do?

Here is my answer: Build allies and find advocates. Consider these three ways and you will benefit from cultivating allies and advocates in your life...

1. You will almost certainly feel less isolated, particularly when your health gets shaky, having allies. This means that you have people whom you like and trust, to talk to about your situation.
2. You will benefit from another's response. For instance, if you are unsure whether your condition is creating a problem at work, you can get someone else's perspective.
3. You will have people who will 'go to bat' for you. Because your health can be variable and unpredictable, you need to know that there are people who are willing to pick up where you left off. You will feel good asking because you know that you will return this in whatever capacity possible.
4. Participation in a support group, having a close understanding of each others challenges and having social interaction with a supportive network of fellows, can be as uplifting as taking a happy pill. One of the best guards against depression is having others to talk to, knowing they truly understand as even the most loving family member or friend cannot. Ideas and tips may be discussed providing enlightenment and a wonderful positive flow of energy from learning that you are not helpless, there are ways to try and help yourself. You feel stronger just in the realization that the chronic condition you are living with is not in charge of you, but rather you are in charge of it. If you are unable to participate in a support group for lack of transportation, if you cannot host an occasional meeting, or if health issues actually keep you from joining with your fellows, do not hesitate to ask for a telephone buddy. Keeping in touch once in a while or on an agreed upon schedule, with a supportive, understanding fellow living with similar issues to those you must cope with, will work wonders. REACH OUT !!

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

- | | | | |
|----------------------|------------------------|----------------------|---------------------------|
| Sarah Caton | James Percy | Terry Goldwin | Roy Whitehead |
| Mike Ludgate | Gerry Armour | Joyce D'Souza | Anna Stech |
| Joyce Bamford | Petrie Pekarska | Donna Hallet | Nora Roberts |
| Dorothy Sheel | Kathy Stillaway | Sarah Hauser | Winnifred Crowther |

At Long Last, Some Relief by Lori Jacobs

I have always had a health problem. It started with my digestive tract when I was a little girl. I was so constipated that I had to be hospitalized. I did not know that I was constipated because I never felt the urge to go, sometimes for a week or more. The doctor told my mother that there was nothing physically wrong with me, that I was "just stubborn". So that was the beginning of my physical ailments that I manifested in my mind because I was "just stubborn".

Then there were dozens of bouts with bronchitis and the appearance of small patches of skin discolourations on my arms and legs, like a concoction of milk and Pepsi. It seems my joints were always sore, sometimes even infected, although I did not do anything to get an infection. In my teens, I would venture out into the cold with no hat and an open coat to be cool like my friends. Boy, the cold could really hurt me. My friends would say "Hey, what is wrong? "You got no blood?" Being a North American Indian, that was a strike against my pride and "Indian ness" so I would suffer the consequences in silence. After all, it was all in my head! Or was it?

I never knew I had scleroderma until I was having my second child when I was 26 years old. I was working as a data entry operator in Montreal, back in the days when the main computer of a company took up a whole room. The temperature of that room had to be kept very cold so that the computers would not overheat. My fingers were blue but I kept on punching those keys, until a co-worker put a scare into me, saying I must have a heart problem because her brother had the "same thing" and died of heart failure. So I went through emergency, was diagnosed with scleroderma and pregnancy and was sent home with a photographed page of a medical book that predicted I would be dead in five years. That was 24 years ago. Boy, talk about stubborn!

I have the CREST syndrome of limited scleroderma. Over the years, I have taken calcium channel blockers to help with the Calcinosis and heart and blood pressure medication to help with the Raynaud's. I have had a severe swallowing problem, Esophageal dysfunction, so I just did not eat until I was so ravenous that I did not care if the food got stuck in my throat, then I would suffer. I have had tons of creams and potions to alleviate the tightening skin on my hands and arms, Sclerodactyly and by rights, I should own stock in all the cosmetic companies whose makeup I have used to camouflage the tiny red veins on my face, Telangiectasia. I even had to take thyroid medication because I was tired all the time and take antibiotics when my joints flared up. When all the medications failed to do what the doctors said they would, they would just put me on another type of medicine or add another medication to combat side effects. I was getting fed up being used as a guinea pig, for I knew that the doctors really did not know what scleroderma was all about or how to treat it. I have read countless books on nutrition, vitamin and mineral supplements and even tried traditional alternative medicines of my people, the Mohawks, with limited success.

With all the advances in modern medicine to alleviate the symptoms of scleroderma, I never really experienced any long lasting relief. So I kept on searching, telling myself that maybe that next fad would work for me. Alas, that miracle never materialized. I am no doctor or health professional but I know that I needed to take responsibility for my own health care. What I did learn was that despite our ethnic backgrounds and cultural differences and similarities, we as North Americans are eating ourselves sick.

In our everyday, fast paced, convenience oriented, junk food society, 70% of us do not eat the minimum recommended daily nutrients that our bodies need to keep healthy. So when we deprive our bodies these basic nutrients, we open ourselves up to a wide range of illness and disease.

Research shows supplementation can substantially improve health by bridging the nutritional gap. Fifty percent of us already use some form of nutritional supplement and 80% of cancers are diet related.

We feel sick so we go to our doctor, get a prescription, go to the pharmacy and get a bunch of pills to make us feel better. How long do the pills sit in our stomach before they are actually absorbed into our body to do its work? Some estimate that less than 25% of the pills we ingest actually get into the system.

Everyone knows that our health care professionals are probably the most important people in our lives besides our families, because we trust our health to them. What I now know is that every time a doctor writes a prescription and it is filled by a pharmacist, both get a cut from the company whose drug name brand appears on your prescription.

We, as patients, sometimes allow ourselves to become prisoners to our afflictions instead of building partnerships in our health care regimen with our doctors, nurses and pharmacists.

The biggest revelation of all my research was that diseases and illnesses begin in our colon, a holding station for bodily waste products before they are excreted from the body. Our bodies store toxins/poisons in the colon.

In the summer of 2003, I came across a product that turned my life around. It was actually a Mother's Day gift from my son. It is called Reliv, a soy based vitamin and nutritional supplement in powdered form. Soy! Yuck! That is what I said too. I am such a cynic and sometimes my own worst enemy, but I told myself that I cannot stop searching for what might work for me. Besides, Hippocrates said it best, "Let food be thy medicine and medicine be thy food." After it sat on my kitchen shelf for a while, I took it out, dusted it off and finally gave it a try. My first shake was the test and I was hooked, not from the taste but how it made me feel.

Check out their website at www.reliv.com or for more information please contact Lori (450) 638-1831 or email me for more information at ljacobs@paulcomm.ca

DISCLAIMER **The Scleroderma Society of Canada does not endorse any drug or treatment. Information that is provided is intended merely to keep people informed. The manifestations and severity of scleroderma vary. Individualized medical management is therefore essential. It is recommended that all drugs and treatments be discussed with one or more doctors or health care providers to assure evaluation and treatment.**

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. | 6. Successful Living with Scleroderma: Guidebook.....\$15.00
New! By Robert Phillips, Ph.D. Dr Phillips is Director for the Center for Coping. |
| 2. Helpful Hints: Living with Scleroderma.....\$2.00
A compilation of helpful information submitted by Scleroderma Foundation (USA) members. | 7. The Scleroderma Book.....\$20.00
By Maureen Mayes, M.D. A definitive guide for patients and their families. |
| 3. Sjogren's Syndrom.. UPDATED 2003.....\$0.25
A general overview of Sjogren's | 8. Pulmonary Hypertension...UPDATED 2003.....FREE
A general overview of PH in Scleroderma |
| 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 | |

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 \$ _____