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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 SSOwww.scleroderma.ca

FIRST ANNUAL FUNDRAISING GALA

DINNER / DANCE & AUCTION (Prizes and Draws)

Saturday, March 17, 2007

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

Tickets \$75.00/person or \$750 table of ten. A tax receipt for \$50.00 is provided.

Contact: Carroll Vapsva (905) 822-7868, Jennifer Rai (905) 876-3665

6:00 pm reception and silent auction • 7:00 pm dinner followed by dancing

RHEUMATOLOGY DAY PROGRAM REMINDER

St. Joseph's Health Care London is having their annual Scleroderma Program 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. Program fees are covered by OHIP, however, there is a \$10.00 cost for the program 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 Program

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

BANANA

uses and nutrients from Scleroderma Association of BC newsletter fall 2006

The banana vs apple: The banana is rich in potassium, four times the protein, twice the carbohydrate, three times the phosphorus, five times vitamin A and iron.

constipation - banana in the diet (fibre) can help restore normal bowel action without laxative

heartburn - banana has a natural antacid effect in the body, try for soothing relief

nerves - banana is high in B vitamins that help calm the nervous system

mosquito bites - rub the infected area with the inside of a banana skin to reduce swelling and irritation

ulcers - banana can neutralize acidity, be used against intestinal disorders and coat the lining of the stomach

stress - stress increases the metabolic rate reducing potassium levels; rebalance with high potassium in bananas

strokes - death by stroke can be cut as much as 40% eating bananas as part of a regular diet according to the *New England Journal of Medicine*



SCLERODERMA REPORTER

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

February 2007

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Past PresidentIrene Goodale
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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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HELLO TO ALL:

I am hoping that you enjoyed a wonderful and memorable Festive Season and that you are coping with winter weather as well as possible.

We have three new members on your Board and have already had the advantage of their know how at 2 Board meetings. Carroll Vapsva and husband Vidas have been longtime workers and supporters of your Scleroderma Mission statement and have committed to serving your Board—Vidas has been nominated as the new Treasurer. Maria Colavecchia-Pfuetzner from Burlington is the 3rd new recruit. We are grateful to each of you and to every volunteer working with your Society.

In this Reporter we have increased the font size as well as adjusting our format. Strides, the publication of the Scleroderma Society of Canada will no longer be mailed in its entirety. It is available at www.scleroderma.ca and hard copies can be obtained by calling the toll free number 1-866-279-0632. We will, from time-to-time, re-print informative articles from Strides and include them with the Reporter. We invite suggestions from you, that we might continue to improve this publication.

The Support Group in Mississauga has undertaken the 1st Fundraising Gala Event for your Society. A Dinner and Dance for 300 people with a Silent Auction to be held on the 17th day of March. Well, it was all SOLD OUT by the 17th day of January and extra tables have been added because of the over-whelming ticket demand. All are looking forward to a wonderful, fun-filled evening. The committee deserves a huge congratulations and it is my pleasure, on your behalf, to say CONGRATULATIONS to Carroll Vapsva and her entire group. Their energy and talents will culminate in immeasurable Public Awareness in addition to needed dollars for Research.

Again, I urge each Support Group Chair to visit the website "www.cpsa.on.ca" to search out and prepare a listing reciting the names, address and contact information of each rheumatologist and immunologist in your local city or the major city/cities closest to you. It will contain valuable information to share with present members and those who call you in the future for your help and support. Please, please prepare this list and keep it up-dated. A list of members in your area, is being prepared and will be forwarded to the Support Chairs for your information.

Over the holiday season there were some media releases concerning the expenses incurred annually by Mothers Against Drunk Drivers (MADD). You may recall. I want to assure you that your Society does not pay rent, heat or hydro. We have no full, or even, part-time, help. We have never, nor do we now pay professional fundraisers or telemarketers. All of the work of your Society is carried on by volunteers, much like yourself, who are committed to our Mission Statement, and more specifically, to uncovering the causes and cure for scleroderma. I am truly indebted to each member, their friends, neighbours, associates and family who volunteer their time and efforts in addition to raising funds for research to uncover this illusive cure.



Peter Woolcott

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 _____

Quality of life and functional status in systemic sclerosis compared to other rheumatic diseases (Journal of Rheumatology 2006;33:1117-22)

Dr. Sindhu Johnson et al conducted a trial to assess clinical factors associated with disability and physical health in patients with systemic sclerosis (SSc 82 patients) compared to patients with psoriatic arthritis (PsA 82), systemic lupus erythematosus (SLE 74), rheumatoid arthritis (RA 42) and healthy patients (60). She found physical health relating to quality of life is adversely affected in patients with SSc. Disability is associated with the presence of : 11 tender points, a high skin score, joint and GI involvement. Joint involvement in SSc is more disabling than joint involvement in PsA; and patients with SSc experience more severe pain than patients with RA.

Yesterday, Today and Tomorrow by Dr. Dame Carol Black, London, UK from Sclerodata Spring 2007.

Localized scleroderma - good progress in clinical expertise with centres and clinics world wide and a consortium participating in lots of collaboration. Localized scleroderma does not convert to systemic scleroderma and is usually self-limiting and in childhood can be a major problem.

Progressive scleroderma - includes disease of the blood vessels or vascular disease. It is interstitial because you have gaps where fibrosis occurs e.g. lungs, kidneys etc. Great strides have been made in treatment of Raynaud's phenomenon and also in prognosis. Ulcerations can be helped to heal rather than so often leading to amputation. Laser therapy benefits telangiectasis. Progress is not good enough in renal and pulmonary areas.

Interstitial disease - thickens up skin, heart, lung and kidneys impeding normal function. The heart and gut receive symptomatic treatment only (test material is impossible to collect). Clinical diagnosis of Raynaud's is remarkably improved and helpful. Scleroderma is no longer treated as one disease but rather segregated as microvascular, exocrine, pulmonary, cardiac, skin sclerosis and renal. Subsets of scleroderma tell the patient what they are most at risk for, ie. limited cutaneous, diffuse cutaneous, CREST or sine scleroderma. Lungs must be watched constantly for progress or deterioration. Autoantibodies are predictors. High resolution CT scan of the lungs is required. Pulmonary function tests to be done annually. This condition may stabilize, regress and stabilize again.

Genes - can be important in scleroderma development. The profile of the gene gives important information in tissue damage. In 1970 cells would continue to make more collagen. In 2006 there are 8-10 more target information improvements. Now we can block endothelin with bosanten. Oral bosanten is good for the treatment of digital ulcers. Sildenafil (vasodilator) is a good option for treatment of ulceration and Raynaud's phenomenon. There is better outcome in survival of pulmonary hypertension with drug intervention. In avoiding toxicity cyclophosphamide does some good but is not the answer for interstitial lung disease. If we could treat scleroderma early on when skin is itchy and puffy, there would be a far better outcome.

IN MEMORIAM

- | | | | | |
|-----------------|-------------------|-----------------|-----------------|---------------|
| Marjorie Miller | Edith Smith | Marcel Rochette | Bryan Martin | Nancy Shannon |
| Gary Ferguson | Frances Mackenzie | Gary McLean | JoAnn Robinson | Elsie Mace |
| Eldon Tinney | Omira Calabrese | Rose Hatala | Sarah Hauser | Donna Horton |
| Marianna Guidi | Juanita Campbell | Heather Mason | Corine Bereskin | Gail Lavalie |
| Anne Kendall | Gail Friendly | Jose Mari Gozon | Evelyn Dyer | |

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.

This is a poem composed by Barbara Williams (member of the Halton support group) which she presented at the Halton support group Christmas luncheon.

The Scleroderma Holiday Rant

This is the season when we count our good fortunes,
Send greetings to friends and control our food portions!
But what if you live with a serious illness?
How do you balance the good with the badness?
So I thought and I thought and here's what came through.
There are good points and bad points, some many,
some few.

So, what are the benefits of evil Scleroderma?
Well how about skin that is so much firmer,
than that of my friends who are about the same age.
And even on days when I feel a slow rage
I'm grateful for other things and 'though not so brave.
I am pleased that my upper arms don't shake when I wave.

My weight has decreased and I'll take that as a plus,
and my friends when they visit don't expect a big fuss.
Sure the meds are annoying as they grow in number,
there are some before meals and then more before slumber.
But before I get fed up and flush them away,
I remember I'm lucky to have this disease today.
I hate to think of how I would fare,

In generations past without all of this care.
So, calcinosis, sclerodactaly (don't you hate these big words?)
Finger ulcers, dry eyes and that gadawful GERD.
Make me wonder about this mysterious disease,
But darn, now the worst is I can no longer eat cheese
Because of my kidneys, the doc said "no more,
And also no chocolate" (which I simply adore).

When I think of the losses, like sports and career.
I find it hard to hold back my tears.
But then I think of my family and my many dear friends,
who are always there and on whom I depend.
I may never have known their true kindness and love,
Had I been able to continue in my previous groove.

So it is what it is and it could even be worse.
Which is what I am trying to say in this verse.
So, Scleroderma be dammed, it's the holiday season
Good tidings, good friends and plenty of reason,
To recount our blessings and keep in our mind
That the only thing that matters is ... that what we give to others comes back in kind.

**** NOTE **** STRIDES will no longer be included in with the SCLERODERMA REPORTER. You can obtain a copy by going to the website www.scleroderma.ca or by calling 1-866-279-0632 to receive a hard copy.

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 (2005) 2nd edition.....\$20.00
By Maureen Mayes, M.D. A definitive guide for patients and their families. |
| 3. Sjögren's Syndrome.. UPDATED 2003.....\$0.25
A general overview of Sjögren'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 \$ _____



SCLERODERMA REPORTER

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

February 2007

Patients Need Patience

The title of this piece is a little phrase that has been running through my head for some time. But these three words, though they represent an important reminder to me, can be easily misunderstood.

By saying “patients need patience,” I am not saying that those with Scleroderma need greater patience. Instead, the title of this piece is a reminder to those of us who love and care for someone who has Scleroderma that we need to work to have greater patience toward those with the disease.

This is a lesson I’ve learned first hand.

When my mom, Viola, was dealing with the ravages of Scleroderma, she would talk about all the pain and itchiness she felt all over. I have to admit there were times when it was very difficult for me to be patient with her.

Dealing with the stresses of advocating for her, helping my father, tending to the needs of my workplace, and trying to keep my own affairs in order sometimes kept my focus divided - as a result I wasn’t really sensitive toward what my mom was dealing with.

The difficulties of my daily life, coupled with my mom’s concerns, sometimes made me tired. And being tired sometimes made me impatient.

If you’re in this position today, maybe you know what I mean. It can be very difficult to put ourselves in the shoes of someone with a chronic illness.

We know what it’s like to have pain - maybe some back or knee pain - but we have little idea what it would be like to have this pain continuously and in such a way that aspirin or rest can ever take it away.

I’m sure we even deal with itchy skin every now and then. But scratching or some type of cream can alleviate the irritation. The problem for some people with Scleroderma is that no amount of scratching or ointments will make it feel better.

It is important that we remember the words: Patients need patience.

Though it can be hard, we need to work to develop a sensitive heart toward those with Scleroderma. A sensitive heart means we have more than sympathy toward those we know with the disease. Developing a sensitive heart means we are empathetic toward patients.

The difference between sympathy and empathy is simple. Sympathy means we have a mutual understanding or are sharing a feeling or circumstance. Empathy means we are vicariously experiencing the situation of another.

Developing this empathy (which leads to patience for patients) begins with educating ourselves about the physical and emotional aspects of this disease. It’s not enough to know about Scleroderma, we have to share in the experience of it with those we love and care for.

We may never have to walk a mile in the shoes of our loved ones. But we should strive mightily to put our arm around them and patiently walk this mile with them.

Remember: Patients need patience.

Joseph P. Camerino
Chair, Board of Directors
Scleroderma Foundation

The Tinkerbell Effect

How Optimism & Action Can Bring You Back to Life

By Roberta M. Diddel, Ph. D.

We're all taught that optimism is good for you, but did you know that psychologists have proven that fact? Studies in the new field of positive psychology have shown that people who are optimistic are healthier, live longer, are more successful, more creative, more popular, recover more quickly from trauma, and are less likely to suffer from anxiety and depression.

There are several reasons why optimistic people do better, but one main reason is that optimism leads people to be open to experience and makes them more willing to try new things. The person who tries something is more likely to succeed than the one who doesn't. As basketball star and politician Bill Bradley said, "You miss 100% of the shots you don't take."

Positive people also tend to draw others to them, because it's easier to be around someone who's optimistic. That may explain why optimists live longer - they seem able to gather support from others and ask for help when they need it.

Optimism also serves as a buffer against stressors, like illness, pain and fatigue. Chronic illness makes it hard to enjoy and to stay involved in life and relationships. Positive thinking helps to combat the temptation to withdraw, becoming focused on how bad one feels and how dismal the future seems.

Optimism is also connected with a trait called

resilience. Resilient people manage difficulties better because they tend to believe they can overcome life's challenges, feel their needs are important, seek out opportunities to laugh, and have fun. They are able to put fear and pessimistic thoughts out of their minds for periods of time in order to take the pleasure they can from life.

Resilience is as much about *doing* as thinking, because without activities, life becomes devoid of meaning and we become disengaged. So you may not need to *be* optimistic, as long as you *act* optimistic, since most of the benefits of positive thinking stem from living life actively and staying engaged socially.

We are a little like Tinkerbell, the fairy from Peter Pan who begins to die after drinking poison. We can save her only by clapping to show that we believe in her. It's not enough just to believe; we must act.

This then, is the Tinkerbell Effect - creating life through activities that express our values and use our strengths, that bring us closer to others and to our purpose in life. So get out there every day and clap.

Dr. Diddel is the executive director of Psychology Works, a non-profit organization educating people with chronic disease and their families about how to adapt to the emotional and social impact of illness. She has been quadriplegic since a spinal cord injury in 1973.