The Scleroderma Society of Canada is pleased to announce its 15th Annual Conference taking place in the beautiful city of Winnipeg, Manitoba. Beginning Thursday, September 18th continuing to Saturday, September 20th, this year’s conference will be held at the Canad Inns Destination Centre Polo Park.

A Scleroderma diagnosis not only possesses its own unique set of challenges, but often brings with it multi-symptomatic, secondary conditions resulting in the need to be assessed and monitored by a wide range of health care professionals, specialists and therapists. In addition to the methods practiced in today’s clinical treatment of the disease, patients often seek out complimentary methods of treatment. On the scientific frontier, more attention is being paid to, not only the physical changes caused by scleroderma, but also the psychosocial and emotional implications it may have.

In an effort to build upon the wide range of treatment methods and disease management strategies, this year’s conference theme, “An Integrated Approach - Creating a United Front”, aims to create an atmosphere of reciprocity. People with scleroderma, their family, friends and caregivers will be able to interchange thoughts, ideas and experiences in the management of scleroderma.

This year’s conference program includes topics such as:
- Chronic pain management
- Disability tax credit services
- Skin care cosmetics
- Musculoskeletal/inflammatory treatment
- Antibiotics
- Gluten-free eating
- Naturopathic medicine
- Speech and swallowing

Keynote speaker includes Dr. Fred Wigley, MD, Director of the John Hopkins Scleroderma Center in Baltimore, Maryland. Dr. Wigley will be presenting a talk on Raynaud’s and Pulmonary Hypertension.

Country music artist, Tenille Nadkrynchny will be singing “Dear Heart” from her new album “Light”.

To learn more about the 15th Annual Scleroderma Society of Canada Conference including how you can register to attend, please visit: www.sclerodermaconference.ca

There’s something to learn for everyone!
Help Us Celebrate June -  
Scleroderma Awareness Month

Scleroderma, or Systemic Sclerosis, is a progressive, chronic auto-immune disease that causes hardening of the skin and can affect internal organs of the body. As many as 16,000 Canadians are estimated to be living with this painful and debilitating connective tissue disorder. It can strike at any age; more than 80% of those afflicted are women usually between the ages of 40 and 60 years.

Scleroderma, in its most serious systemic form, may not only affect the skin, joints, and muscles, but also seriously damage the gastrointestinal tract, lungs, heart, and/or kidneys.

For over 25 years, The Scleroderma Society of Ontario has been creating awareness, educating the public, advancing patient care, and raising funds in support of scleroderma research. To celebrate “Scleroderma Awareness Month of June“, people living with scleroderma, their family, friends and co-workers will be participating in the “Scleroderma Walk / Run in the Park” campaign in the communities of Hamilton, London, Ottawa, and Toronto.

Last year, over $100,000 was raised in Ontario as part of “June’s Scleroderma Awareness” campaign - this year our goal is to reach $250,000.00.

Help us make a difference in the lives of people with scleroderma. Join us this June to walk, run, ride or scoot around the Park for Scleroderma.

Check out page 7 - “Upcoming Events” - for dates, times, locations, and contact information for Scleroderma Awareness events taking place in your community.

Scleroderma Patient Education Update

On April 22 & 24, 2014, at St. Joseph’s Hospital in Hamilton and Toronto Western University Hospital in Toronto, Dr. Alan Tyndall was the guest speaker at the scleroderma patient education seminar, “Scleroderma – An Odyssey for One”. Dr. Tyndall is the Head of the Department of Rheumatology at the University of Basel and Secretary/Founding Member of the World Scleroderma Foundation (Basel). His presentation discussed a patient’s journey through the diagnosis, investigation and treatment of scleroderma. Practical tips regarding symptom management, navigating the health care system and collaborating with the medical care team were discussed.

The event was broadcasted live in Hamilton, and has been uploaded to the Scleroderma Society of Ontario web-site. To view Dr.Tyndall’s patient education session, please visit: http://sso.etherelive.tv/
On Feb 6-8, 2014, the World Scleroderma Foundation hosted its 3rd Annual Systemic Sclerosis Congress in Rome, Italy. This congress emphasized clinically relevant developments with a focus on aspects of care to improve the quality of life for patients with scleroderma world-wide. The combination of formal lectures, small seminars and interactive hands-on workshops ensured a valuable experience for all who attended. The patient program, sponsored by the Federation of European Scleroderma Associates (FESCA), consisted of interactive sessions of lecture and discussion, with consultants and patients speaking on a variety of topics. The patient congress included a round-table networking meeting for leaders of patient groups. Representing the Scleroderma Society of Canada, Maureen Worron-Sauvé (President), participated in patient panel discussions with respect to the Scleroderma Patient-centered Intervention Network (SPIN) and the Canadian national network for organizations representing all those with rare disorders (CORD).

For more details about the 3rd Annual Systemic Sclerosis World Congress including access to scientific and medical research abstracts, please visit: www.sscworldcongress.org

Highlights from the 3rd Annual Systemic Sclerosis Congress in Rome, Italy

Meet and Contact the Staff

The Scleroderma Society of Canada officially moved into its new headquarters at 41 King Williams St., Suite #206, Hamilton, ON, L8R 1A2

(Left to Right)

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VICTORIA BEZIC
Social Media Co-ordinator
Victoria Bezic, a scleroderma patient herself, will be responsible for Facebook, Twitter & Instagram updates. If you have information you would like to share through our Scleroderma Society social media channels, please contact Victoria at socialmedia@sclerodermaontario.ca

SUSAN DOCHERTY-SKIPPEN
Newsletter Editor
Susan Docherty-Skippen is pleased to return to the Scleroderma Society. If you have an article suggestion or personal story you would like to share through the Scleroderma Connection Newsletter, please contact Susan at: susan@sclerodermaontario.ca
Right now, only 60% of treatments for rare disorders make it into Canada and most get approved up to six years later than in the USA and Europe. People with rare disorders in Canada are missing out on treatments that could save or significantly improve their lives. This needs to change.

The solution is for Canada to create an Orphan Drug Regulatory Framework. The United States and most countries in Europe have already created one, but Canada is lagging behind. The Canadian framework will allow drug companies to apply to bring their treatments to Canada at the same time as the USA and Europe. It will also create an opportunity for Canadians to participate in clinical trials at the same time as they happen in the rest of the world.

In addition, the Orphan Drug Regulatory Framework is the first step towards Canada taking a leadership position in personalized medicine. Targeted drugs (i.e., based on your genetic code) are now being created to treat specific forms of diseases such as breast cancer and lung cancer. Without this framework, Canadians may not be able to access treatments for their specific disease that are available elsewhere. Imagine if there was a life-saving treatment for your specific type of cancer that was available in Europe and the USA but was not available in Canada, simply because we did not have an Orphan Drug Regulatory Framework?

The good news is, Health Canada has already developed the Orphan Drug Regulatory Framework and announced it in 2012. It is ready to go. Unfortunately, it has never been published and approved. On the occasion of Rare Disease Day on February 28th, and as part of the Rare Disease Conference that took place in Ottawa on March 3rd, a petition has been created to support the approval of the Orphan Drug Regulatory Framework.

To read full article originally published by the Canadian Organization for Rare Disorders (CORD) and to learn more about the Orphan Drug Regulatory Framework and the petition to approve the Orphan Drug Regulatory Framework, please visit: www.raredisorders.ca/currentIssues.html
Researchers Identify Biomarker in Helping Curtail Pulmonary Arterial Hypertension (PAH) Caused by Scleroderma Progression

Pulmonary Arterial Hypertension (PAH) is a frequently encountered complication of Systemic Sclerosis (SSC). PAH is also the leading cause of morbidity and mortality among SSC patients. Despite some progress in new detection methods, standard right heart catheterization still remains the most effective means of diagnosis of PAH with Systemic Sclerosis. However, the need for the detection of biomarkers in blood and serum at early stages of the disease still remains unmet. If researchers can solve this particular diagnostic need, it could significantly aid in the early-stage detection of SSC and prevent progressive deterioration.

According to research carried out at The University Medical Center, Utrecht, the Netherlands, the circulation of peripheral blood cells in SSC patients have been found to secrete an excess of signaling protein, CXCL4, compared to healthy controls. CXCL4 has thus been assumed as a direct link (clinical biomarker) for both SSC and PAH — a much awaited finding for the medical community. Now, this connection offers the potential for developing a therapeutic target for SSC.

“CXCL4 is associated with the progression and clinical observable characteristics of SSC, and thus provides a tool for clinicians to identify those patients in need of aggressive therapy and...to avoid unnecessary side-effects for those who have a milder form of the disease.”

Dr. Radstake, Department of Rheumatology and Clinical Immunology, University Medical Center Utrecht

Commenting on the usefulness of detecting CXCL4 levels in SSC patients, Dr. Radstake, lead study researcher, said in an interview to Medscape, “CXCL4 is associated with the progression and clinical observable characteristics of SSC, and thus provides a tool for clinicians to identify those patients in need of aggressive therapy and ... to avoid unnecessary side-effects for those who have a milder form of the disease. Moreover, the identified roles for CXCL4 in SSC spark our knowledge of the pathogenic pathways in this terrible condition. Now, we and other groups will have to further unravel the precise roles for CXCL4 in SSC and possibly other fibrotic and immune-mediated conditions.” He further added, “The clinical relevance of this work is pretty high, as there is no current effective therapy available for SSC. Also, there are no biomarkers [that] are able to predict which patient will have severe disease or those who will not. This is important, since therapy that is available as kind of last resort for these patients (e.g., cyclophosphamide or autologous stem cell transplantation) has a high rate of mortality and/or morbidity. We definitely believe that CXCL4 might be a novel target and the first to really tackle the underlying problem that drives this terrible disease. There are multiple efforts underway to further develop CXCL4 as a clinical target for therapeutic intervention.”

To read full article originally published by the Pulmonary Hypertension News, please visit: www.pulmonaryhypertensionnews.com/2014/04/28/cxcl4-chemokine-predicts-scleroderma-progression/
Gala Raises $50,000 in Support of Scleroderma Research

The Mississauga Support Group of the Scleroderma Society of Ontario held its eighth annual gala on April 5 at the Oasis Convention Centre with more than 500 people in attendance. $50,000 was raised in the fight against a potentially fatal autoimmune disease.

Special thanks to AM900 CHML broadcaster Bill Kelly who served as the event’s Master of Ceremonies. The evening featured opening speeches from Scleroderma Society of Ontario Vice-President Rebecca Wissenz and Dr. Zareen Ahmad from the Scleroderma Program, University Health Network and Mount Sinai Hospital, Toronto, ON.

Sclérodermie Québec 7th Annual Chocol-Champagne Fundraising Event

Sclérodémie Québec held its 7th annual fundraising event November 21st of last year at Espaces Dalhousie, in the Old Port of Québec City. Champagne was served upon arrival to over 200 guests who enjoyed a variety of wines and a scrumptious array of chocolate delights. Over $22,000 was raised in support of scleroderma.

More Ways to Help

On Feb. 25th 2014, Members from the Scleroderma Association of Manitoba hosted a “Lia Sophia Jewelry “Party”. Jewelry Consultant Cathy Arnason, generously donated sales commissions in support of Scleroderma research.

On June 8th, 2014, The Scleroderma Association of Saskatchewan is pleased to be hosting a Raffle & Steak Night at “The Tap”, 4245 Rochdale Blvd. Regina, SK. Two gorgeous hand-made quilts (made by Shirley Gillander) and five $100 University of Regina gift cards will be raffled off during the Steak Night.

For further information please contact: Louise Goulet (306) 584-1950 or Shirley Gillander (306) 525-6377.
Upcoming Events!

JUNE 6th - 7th, 2014
Scleroderma Association of British Columbia (SABC)
30th Annual Conference & AGM
Kintyre Room, Best Western Plus Abercorn Inn, 9268 Bridgeport Rd, Richmond, BC.
For program information, visit:

JUNE 7th, 2014
 Hamilton Walk/Run for Scleroderma
Registration @ 10:00 a.m.; Walk @ 11:00 a.m.; BBQ follows
T.B. McQuesten Community Park, 1199 Upper Wentworth St., Hamilton, ON, L8W 2N6. For further information contact: The Hamilton Scleroderma Support Group: info@sclerodermaontario.ca

London Walk for Scleroderma
Registration @ 10:00 a.m.; Walk @ 11:00 a.m.; BBQ follows
For further information contact: Stephanie Odd: doyles@marcus.on.ca

JUNE 8th, 2014
Regina, SK - Scleroderma Raffle & Steak Night
The Tap, 4245 Rochdale Blvd. Regina, SK
Two gorgeous hand-made quilts (made by Shirley Gillander) and five $100 University of Regina Ram Rider Gift Cards will be raffled off during the Steak Night.
For further information and help sell raffle tickets, please contact: Louise Goulet (306) 584-1950 or Shirley Gillander (306) 525-6377

JUNE 11th, 2014
HAPPY 25TH ANNIVERSARY OTTAWA!
The Ottawa Support Group is pleased to host an afternoon cocktail reception in celebration of their 25th Anniversary. Over the years, over 550 people with scleroderma have attended support group meetings, and many more have been helped by telephone conversations and home visits. For further information, please contact Catherine Fortune: catherine.fortune@sympatico.ca

JUNE 14th, 2014
Ottawa Walk for Scleroderma
Registration @ 10:00 a.m.; Walk @ 11:00 a.m.; BBQ follows
Vincent Massey Park Ottawa, ON, K1S 5B7.
For further information, please contact: Karen Nielsen: knielsen@gmail.com

Toronto Walk for Scleroderma
Registration @ 10:00 a.m.; Walk @ 11:00 a.m.; BBQ follow
Parkland, Bayview Woods, Steeles, Toronto, ON M2J 1B1.
For further information, please contact: Melissa Hatcher: torontosclerodermawalk@gmail.com

St-Colomban Tournoi de Golf
Vous êtes invités à la 12e édition du tournoi de golf. Club de Golf Bonniebrook, 207 Côte St-Paul, St-Colomban, QC, J5K 1Z6.
For information and reservation:
Éric Canuel: eric.canuel@sympatico.ca ou au (450) 569-7284
Luc Tétreault: tetreault.luc@hydro.qc.ca ou au (514) 229-1264
Richard Tremblay: sirtinc@videotron.ca ou au (514) 994-7478

JUNE 15th, 2014
Vancouver - 3rd Annual Scleroderma Bicycle Ride for Research
Ceperley Park Picnic Area, Second Beach, Stanley Park, Vancouver, BC. All are welcome - whether you ride, walk or “scoot”.
For further information contact: Rosanne, SclerodermaRide@shaw.ca

JUNE 21st, 2014
Nova Scotia Walk/Run for Scleroderma
Registration@11:30a.m.;5K@12:30p.m.;1K@1:00p.m.; BBQ follows
DeWolfe Park, 150 Waterfront Drive, Bedford, NS, B4A 4K5.
For further information contact: Jason Doucette jadoucette@eastlink.ca or walkintheparkfor@gmail.com

AUGUST 9th, 2014
SSO / Scleroderma Foundation Tri-State Patient Education Conference!!
FREE (lunch included)
Niagara Falls Memorial Medical Center, Niagara Falls, New York, US, Buffalo, New York.
Guest speakers include Dr. Lee Shapiro and Dr. Janet Pope.
For more information on event, please visit, buffalosed.com/sclerodermatristate.org

SEPTEMBER 6th, 2014
Tournoi de Golf – Outasouasi Troisième Édition!
Club De Golf Royal Papineau, 65 Ch Du Golf, Notre-Dame-de-la-Salette, QC J0X 2L0
Pour information et réservation:
Céline Thibault ou Marc Sarrazin: (819) 454-2932

SEPTEMBER 13th, 2014
Hamilton, ON - Charity Golf & Dinner Auction
Flamborough Hills Golf & Country Club, 71 Regional Rd. 52 Hamilton, ON, L0R 1J0.
For further information & reservations contact:
Jason Worron: (416) 989-1163 or Mike Rice: mwrice@hotmail.com or (905) 741-8852

SEPTEMBER 18th - 20th, 2014 - SAVE THE DATE!
Winnipeg - 15th Annual Scleroderma Canada Conference:
“An Integrated Approach- Creating a United Front”
Canad Inn Polo Park, 1405 St Matthews Ave, Winnipeg, MB, R3G 0K5.
For further information & reservations contact:
www.sclerodermamanitoba.com

OCTOBER 16th, 2014
Soirées-Bénéfice - Dixième Édition du Souper-Bénéfice
De Trois-Rivières, qui se tiendra le 16 octobre prochain au Musée québécois de culture populaire.
Pour information, veuillez contacter:
madame Dolorès Dupuis au (819) 378-2869

NOVEMBER 29th, 2014
London Curl for Scleroderma
13812 Ten Mile Road RR#3, Ilderton, Ontario, N0M 2A0
For further information & reservations contact:
Alex McNaughton: curlforscleroderma@gmail.com
Summer 2014

Scleroderma Society of Ontario Newsletter

I wish to make a donation:
- $100
- $50
- $25
- Other: $_________

Name: ____________________________

Address: __________________________

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Please make cheque to the order of:
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Please sign and return with your donation.

*This information will remain confidential.

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Dr. Sandhu Johnson & Dr. Peter Lee
Mount Sinai Hospital, Joseph & Wolf Lebovic Health Complex
60 Murray Street, 2nd Floor (Main), Toronto, ON, M5T 3L9
Tel: (416) 586-4800

Dr. Janet Pope
Western University / St. Joseph’s Hospital London
Rheumatology Clinic Room 2-101
268 Grosvenor St., London, ON, N6A 4V2
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Dr. Douglas Smith
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1967 Riverside Dr. Box 37, Ottawa, ON, K1H 7W9
Tel: (613) 738-8400 • Fax: (613) 738-8336

Dr. Ronald Laxer or Dr. Elena Pope
University of Toronto/The Hospital for Sick Children
555 University Avenue, Toronto, ON, M5G 1X8
Tel: 1-877-252-9900 • Email: helpdesk@ehch.ca

Helpful Resources:

Scleroderma Society of Canada
Tel: 1-866-279-0632 • www.scleroderma.ca

Scleroderma Foundation (United States)
www.scleroderma.org

Pacific Lung Health Centre
www.pacificlung.com

Sjogren’s Syndrome Support Group
www.sjogrens.org

Raynaud’s Association
www.raynauds.org

Arthritis Self-Management Program
(416) 979-7228

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