Distinguished Indeed!

Scleroderma Champion Dr. Janet Pope Receives Prestigious Award

She is one of the world’s leading scleroderma researchers. Dr Janet Pope is a Canadian rheumatologist with a special interest in scleroderma. Professor in the Department of Medicine, Division of Rheumatology and Epidemiology and Biostatistics at the University of Western Ontario, London, Ontario, Canada and Division Head in Rheumatology at St. Joseph’s Health Care, London, Dr Pope obtained her MD and Fellowship in Internal Medi-

cine at the University of Western Ontario and acquired a Fellowship in Rheumatology and Masters of Public Health at Boston University. She then completed a Canadian Arthritis Society Research Fellowship in London, Ontario in scleroderma, and then became a member of the Division of Rheumatology. Her publications and abstracts number more than 500. Recently, Scleroderma Society of Canada CEO, Maureen Latocki, interviewed Dr. Pope about her award and the state of affairs for persons living with scleroderma.

ML Congratulations on receiving the Canadian Rheumatology Association’s Distinguished Investigator Award. The scleroderma community in Canada is very proud of the contributions you have made and continue to make on focusing attention on scleroderma. What does the award mean to you?

JP Thank-you. I am honoured to receive this award. It is always important to be recognized by your peers. I feel that this award although it goes to me is made possible by the workers who support my unit and research, the trainees that have worked diligently to complete projects, all the collaborators, the funders and the patients.

ML You are considered to be one of the few experts worldwide in scleroderma. What are some of the most promising new discoveries or developments that you believe may have significant impact on someone living with scleroderma?

JP There is now treatment for pulmonary arterial hypertension that affects 15% of patients with scleroderma. Treatment can improve survival and quality of life. In future, likely combinations of treatment will be found to be even more effective. There is treatment for some patients with interstitial lung disease (with cyclophosphamide and other immune suppressives) and other treatment trials are underway. There is treatment for Raynaud’s and digital ulcers and for many of the gastrointestinal symptoms. Inflammatory arthritis is treatable. We have come a long way but are not near the finish line – i.e. we have a long way to go.

ML There has been a lot of media attention, of late, on stem cell treatment for scleroderma. What should people with scleroderma and their families know or do before contemplating stem cell treatment?

JP First of all, stem cell transplant was only studied in early diffuse scleroderma subset who had a 50% chance of being alive in 5 years. This means it was studied only in the most severe patients (but...continued on page 3
This is my first column since joining the Scleroderma Society in late December. It has been a very busy first few months as I have been meeting with and hearing from the Board, support group members, clinicians and other stakeholders. The Board has warmly welcomed me and shown their support for my new role.

A first priority has been putting in place a volunteer team to help plan and organize the Scleroderma Canada Congress scheduled for September 27-28, 2013. We have an outstanding group with diverse experience that is keen and committed to make the September Congress in Hamilton a memorable experience for all attendees.

Another priority of the Board was to move quickly to conclude the RFP process that began last summer for the redevelopment of the website. The new site, now live at www.scleroderma.ca, SSC reflects a modern and dynamic organization. By the time you read this, we will have launched a second new website, this one specifically for the Congress. I encourage you to go to www.sclerodermacongress.ca to learn more about what is planned and to register. To encourage early registration, we have specially discounted rates which are in effect until June 30, 2013.

We have had a few quick wins with landing 2 full pages devoted to scleroderma in the March Edition of Hospital News and securing a grant from the Canadian Institutes of Health Research (CIHR) to host a public awareness event in September. I hope we will be able continue this momentum.

Planning is well in-hand for the June Walks. This year’s Walks are taking place on June 8 in Halifax, Ottawa, Hamilton, London and June 15 in Toronto. These 3rd party events are organized by very dedicated volunteers and if you are able, please consider supporting them with a pledge.

While there is certainly no shortage of things to do, I can say unequivocally, that I am excited about what we are going to do together to raise the profile of scleroderma in Canada.

Maureen Latocki

The Scleroderma Society of Canada Board of Directors met in March. Highlights of the meeting included approval to fund the redevelopment of the Scleroderma Society of Canada website and the development of a website for the Annual Scleroderma Canada Congress. The Board accepted, with regret, the resignation of Louann O’Dwyer (Alberta) who stepped down as a Director for personal reasons.

The Scleroderma Society (UK) was founded in 1982 to provide support for both people with scleroderma and their families. Since its birth, the Society has developed considerably and continues to expand its activities, membership numbers and the services it offers. The Society is a UK registered charity and from its inception in 1982 until 2012, operated on an entirely voluntary basis by a team of dedicated volunteers and trustees. 2012 saw the appointment of the Society’s first paid member of staff, brought onboard to direct the Society forward to fulfill its potential. Professor Dame Carol Black as President and Professor Chris Denton and Professor Ariane Herrick are Vice Presidents. Besides a cadre of volunteers, the Society has a 5 member Board of Trustees. The Society’s three priorities are:

Support - Their services include a free helpline, an annual conference, a network of local groups across the UK, a members’ assistance fund, an online discussion forum, a popular quarterly newsletter and an extensive range of literature on scleroderma.

Awareness - They participate in World Scleroderma Awareness Day, attend relevant medical conferences in the UK and worldwide and participate in the work of FESCA (the Federation of European Scleroderma Associations).

Research - The Society, its volunteers and fundraisers, raise vital funds used for scientific and medical research into the causes and possible treatments for scleroderma.
not so severe that a major organ was already severely damaged). The next thing to note is that we don’t know the benefit in the long term and with a stem cell transplant, the complications such as infection lead to death in 10% over the first year and there has been no benefit in smokers. However, there was a survival benefit by two to three years compared to cyclophosphamide. The data are only available for the European trial (ASTIS) as the US trial is still following patients for survival.

So, in my practice, at most 1% of patients would be like the patients who were included in the stem cell transplant trial. Until we have more data due to the mortality associated with the transplant, it is to be considered experimental therapy but more data will be collected from the patients in the trial to determine the long term risk and benefit. Other transplants such as lung (for interstitial lung disease or pulmonary hypertension) and kidney have been done in scleroderma with success in patients with end stage organ involvement who meet other criteria.

ML Where does Canada rank among other countries in making investments in scleroderma research? What are the opportunities for Canada to take a leadership role in scleroderma research?

JP The federal government and the Scleroderma Societies of Canada and Ontario and other provinces have helped to support the Canadian Scleroderma Research Group (CSRG) which is a database of more than 1000 scleroderma patients where we have learned several things about scleroderma. However, funding for scleroderma is very poor in Canada. It is more common than MS but the latter has more funding. We need to improve awareness and advocate for funding.

ML If you could speak directly to patients and families, what would you like them to know?

JP Well, I do speak to patients and families in my clinical care and in my research studies. However, I think they should know that there is hope, there is a lot we can do to help symptoms and for most people it is not as bad as what they have read on the internet. The survival has improved even over the time I have been in practice.

**From London to Chicago – Erin Zubick’s Story**

**by Jennifer Hryniw**

Shortly after Erin & Matt Zubick were married, Erin started experiencing unusual symptoms. She went for tests and received a devastating diagnosis—scleroderma, a destructive autoimmune disease with no cure.

The newlywed had always dreamed of being a mother, but one doctor asked her why she’d want to have kids if she wasn’t going to be there to raise them. Today she’s the proud mother of four children. She makes the most of every birthday, graduation and holiday, never sure how many more she’ll see.

After 17 years she’s long outlived original expectations, but the disease has kept progressing in painful ways. In all this time, she’s never known any real hope of a change for the better. Now a new option has brought fresh hope. Stem cell transplants are being used to treat scleroderma with amazing results. She was disappointed to learn that in Canada, stem cell transplants aren’t yet used to treat scleroderma, but she kept researching her options. She learned of a study for scleroderma patients taking place at Northwestern Memorial Hospital in Chicago with Dr. Richard Burt.

Full of hope, she overcame major medical hurdles to be accepted into the study. Then she faced a financial obstacle: even with a major discount, the cost of the transplant was $125,000. Then there were the hotel, transportation and food costs for the three month treatment. A community of friends and family gathered around her and formed Team Erin Zubick to help raise money to help lighten the burden. With a simple web presence and social media, they got the word out, and so far have raised more than $120,000.

They’re hoping the best is yet to come. Erin starts treatment soon, and this story is to be continued!
Coping with Stress

By SPIN Research Group

Dr. Linda Kwakkenbos, Behavioural Health Research Group (BHRG), The Lady Davis Institute (LDI). LDI is the research arm of Montreal’s Jewish General Hospital, a teaching hospital of McGill University. Linda joined the Institute in the summer of 2012 to continue to pursue her research related to psycho-social and quality of life issues among scleroderma patients. As a post-doctoral fellow, she now coordinates the Scleroderma Patient centered Intervention Network (SPIN), an international team of researchers, clinicians, scleroderma patients, and patient advocates devoted to developing and implementing patient centered care that targets important issues related to quality of life and well-being among people with scleroderma.

Living with scleroderma can have an impact on many aspects of your life, through symptoms of fatigue, pain, and limitations in every day activities. You may need to make adjustments in your work environment, pay regular visits to the hospital and take medications according to a schedule. Coping with scleroderma is a daily challenge! Not surprisingly, having a health condition like scleroderma may cause symptoms of stress, such as low mood, worry, and irritability. These stress symptoms can develop when you feel overwhelmed by physical symptoms such as pain and fatigue, or because of challenges related to managing your scleroderma and treatments.

Many supportive interventions exist that help people in coping with many different health conditions. Elements of these programs may be helpful to better cope with symptoms of scleroderma as well, such as relaxation exercises, managing worry, or balancing activity and rest. These kinds of supportive interventions, however, have not been designed and tested to meet the specific needs of people with scleroderma.

The Scleroderma Patient-centered Intervention Network (SPIN), led by Dr. Brett Thombs, a researcher at the Lady Davis Institute for Medical Research of the Jewish General Hospital and McGill University in Montreal, are working to change this. SPIN is an organization designed to develop and test interventions to help people with scleroderma cope with important problems, such as stress symptoms. Patient organizations from around the world, including the Scleroderma Society of Canada and Canadian provincial patient organizations, along with top researchers from Canada, the US, the Netherlands, and France are involved in SPIN.

Recently, SPIN investigators met with Dr. Dan Bilsker, a Vancouver psychologist and lead author of the Positive Coping with Health Conditions (PCHC) workbook. The PCHC workbook outlines a generic intervention that teaches skills to cope with stress for people living with chronic illnesses. During the meeting, it was discussed how elements from this workbook could be adapted for people with scleroderma. To gain more insight on how to best gear the SPIN intervention for people living with scleroderma, two focus group discussions were held in Hamilton, Ontario. Two more groups are planned to take place in Montreal, Quebec.

During these focus groups, elements of an intervention to cope with stress were introduced and demonstrated to people with scleroderma. After the demonstration, participants discussed the topic’s relevance to living with scleroderma, and how these elements may need to be adapted for people with scleroderma. Currently, the group is reviewing the outcomes of the first two focus groups, and these results will further guide the development of a supportive intervention to cope with stress from scleroderma.

For more information contact spin@jgh.mcgill.ca or KwakkenbosL@gmail.com
Connecting Across Canada

The Canadian Scleroderma Research Group (CSRG)
Dr. Murray Baron, CSRG Director

The Canadian Scleroderma Research Group (CSRG) is made up of Canadian clinicians and researchers dedicated to improving the understanding of Scleroderma and its symptoms in order to better treat people affected by this rare, too often incapacitating, and potentially deadly disease affecting mostly women in their forties and fifties. The Group, under the direction of Dr. Murray Baron, was created in 2004 thanks to grants from the Canadian Institutes of Health Research (CIHR), nonrestrictive grants from Actelion and Pfizer pharmaceuticals, and generous donations from Scleroderma Society of Canada, Scleroderma Society of Ontario, Cure Scleroderma Foundation, and Sclérodermie Québec.

A One-of-a-kind Registry

Thanks to the participation of over 1418 patients to date, a secure one-of-a-kind online registry of Canadian patients diagnosed with Scleroderma has become CSRG’s primary research tool, allowing many researchers to better study several aspects of the disease.

In the past few years, the CSRG, along with other International Scleroderma Groups, have contributed to redefining the criteria associated with the disease (C. Coulter, et al., 2013; J. Fransen et al., 2012; SR. Johnson, et al., 2012; M. Hudson et al., 2010;). We expect an official revised version of the American College of Rheumatology Scleroderma diagnostic criteria in the coming months. We are confident that these new criteria will improve the diagnostic process, allowing earlier and therefore more efficient medical interventions for Scleroderma patients. Our Group has also focused their energy on better understanding lung and renal problems, specific antibodies, and psychosocial impact of the disease. You can read more about our latest publications on our website.

Joining Forces Nationally and Internationally

Our quest to better grasp the complexity of Scleroderma and its many symptoms has encouraged us to join forces with other Groups, collaborating not only with the best specialists in Canada but also with many well respected clinicians and researchers around the world.

• The McGill Systemic Auto-immune Rheumatic Diseases (McGill SARDs) Group is an example of an initiative on the national level. McGill SARDs will allow us to more easily compare our Scleroderma patients to Canadian patients with other rheumatologic diseases such as Lupus, Early Rheumatoid Arthritis, and Inflammatory Myositis in order to not only identify differences but also commonalities between these diseases. With the help of another Group called CANCoRC, we also hope to broaden this initiative to include other rheumatologic cohorts in Canada, such as Osteoporosis, Spondyloarthritis, Vasculitis, and Ankylosing Spondylitis. Stay tuned to find out more about these ongoing initiatives.

• INSYNC is another example of how the CSRG has been collaborating with other Groups also interested in better studying Scleroderma, but this time, on an International level. Establishing this group of groups will allow us to compare our Canadian patients to patients with the same disease in countries such as the USA, Spain, Australia, and Germany. You can also read more about INSYNC on our website.

Challenges to Come

With the end in 2013 of both our 5-year CIHR Team grant and our 6-year CIHR Training grant, we face major financial challenges. However, we are constantly seeking new funding that would allow us to continue to keep our online registry of patients alive and pursue our research activities, both national and international, for many years to come. Sadly, funding has become scarce and more and more difficult to obtain from both government and pharmaceutical sources, and consequently, donations are for the time being our only hope to continue our activities.

We encourage you to please visit our new CSRG website to find out more about our publications, as well as many of our research projects and activities.

Suzanne S. Taillefer, CSRG National Coordinator
Maura Buchignani, CSRG Research Nurse
May 3rd, 2013
A new study supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), part of the National Institutes of Health (NIH), has identified a peptide that, in lab tests, protects against fibrosis. Fibrosis, a thickening of the skin and/or internal organs, is a potentially fatal characteristic of diseases including scleroderma and idiopathic pulmonary fibrosis.

The peptide, dubbed E4, is derived from endostatin, a component of the protein collagen XVIII. Endostatin has been studied as a cancer treatment because of its ability to prevent angiogenesis, or the formation of blood vessels, which enables cancers to grow and spread. NIAMS-supported scientists identified endostatin as a possible therapy for fibrosis based on earlier observations showing the protein was elevated in fibrosis; however, it was uncertain whether endostatin worsened or improved fibrosis, says investigator Carol A. Feghali-Bostwick, Ph.D of the Scleroderma Center at the University of Pittsburgh School of Medicine. When they tested it in human cells and human skin induced to become fibrotic, they found its effect was to improve fibrosis. This prompted them to look for the specific part of the endostatin fragment that was having the beneficial effect on fibrosis.

"We designed short peptides, stretches of amino acids, that matched or corresponded to different regions of endostatin to try to find out which region is really responsible for the reduction of fibrosis," says Dr. Feghali-Bostwick. When they evaluated the peptide E4 in healthy human skin cells that were induced to become fibrotic, the skin remained normal. E4 also protected the skin and lungs of mice from thickening. In addition, the researchers found the peptide could reverse existing damage.

Fibrosis occurs when cells known as fibroblasts start making excess collagen, fibronectin and other proteins, leading to thickening of skin and hardening of organs, says Dr. Feghali-Bostwick. “Usually when that thickening occurs, particularly in internal organs, the organs cannot function properly and ultimately that’s what results in death.”

The eventual goal of the research, reported in the journal Science Translational Medicine, is the development of therapies that will prevent or reverse fibrosis and preserve organ function, she says. While such a therapy is likely still years away, the identification of E4, and its effectiveness in laboratory studies using human skin, is an important start.


Source: National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) website www.niams.nih.gov/...
The Scleroderma Association of British Columbia (SABC) lost dear friend and fellow Jeannette Stach in March

Jeannette was the inaugural President of the SABC, formed in 1982. Her dedication to the group’s formation and activities, and her participation on the Board of Directors continued for the rest of her life.

Jeannette was diagnosed with scleroderma in 1979. She endured its many challenges in her calm, quiet way with admirable determination and an always positive outlook. Jeannette was a deeply loved friend to so many of us and will always be remembered.

The Scleroderma Association of Saskatchewan (SASK) is hosting a Steak Night on June 2nd to kick off Scleroderma Awareness Month. Tickets are selling quickly and we hope to have 120 guests in attendance. Our evening will include door prizes and a 50/50 draw. Each year the City of Regina hangs our very large SASK banner on the pedway downtown. The banner is 1 metre wide and 12 metres long and reads: SCLERODERMA AWARENESS JUNE 1-30

At our April Self Help Group meeting we had the pleasure of Dr. Nicole Fahlman, rheumatologist, as our guest speaker. Dr. Fahlman is very knowledgeable about scleroderma and was a most gracious presenter. Her topic’s included cause and treatment of digital ulcers, calcinosis, and how scleroderma may affect the heart.

For a fall project, we will raffle 2 beautiful quilts made by our member Shirley Gillander. Her work is superb as you can see in the photos. We hope to have a few art pieces donated as well.

We are excited to attend the Scleroderma Canada Congress in September. Three members have already booked their flights. We hope to see many of you there.

Louise Goulet, President, Scleroderma Association of Saskatchewan
On Saturday, April 20, 2013, The Mississauga Scleroderma Support Group hosted a little “Sex” in the City of Mississauga. The lecture held at The Living Arts Centre, Rogers Theatre in Mississauga featured two guest speakers. Dr. Lemmese Al-Watban, MD, CCFP, Women’s Health Specialist presented Scleroderma and Sexuality. The second speaker, Ms Lisa Jewett, MSc, Jewish General Hospital and McGill University, Coordinator of The Scleroderma Patient-Centered Intervention Network (SPIN) presented Scleroderma and Sexuality: Appearance Changes and Body Image. After each presentation a considerable discussion was generated by the audience. You could say we “opened the book on Sexuality”. Dr. Al-Watban’s presentation covered the topics of sexuality and sensuality, included factors affecting sexual performance and suggestions for coping with problems related to and improving sexual activity. Lisa Jewett talked about the impact of Appearance Changes and Body Image, as well as strategies for coming to terms with changes. If you would like a copy of the materials, you may contact Maria Szoke at mszoke@providencecorp.ca. Thank you to everyone who attended the event. Contributed by: Maria Szoke, Member of the Mississauga Scleroderma Support Group.

In its 7th year, the Mississauga Gala and Auction attracted over 600 people to the Oasis Convention Center on Saturday, April 6 for dinner and dancing with a deejay and live entertainment. While the final numbers are not yet in, all signs point to a new fund-raising record in excess of $150,000 for the evening. Started in 2006 by Gala organizer Vidas Vapsva’s late wife Carol, the annual event has since raised over $500,000 to advance scleroderma research and education. Media personality Rod Black was again the evening’s outstanding emcee. A live and silent auction included two Air Canada tickets to anywhere in North America the carrier flies, an autographed Wayne Gretzky jersey with a chance to meet Gretzky, two suite tickets to the Toronto Maple Leafs game, a Chopard diamond necklace valued at $4,500 from Oakville’s Knar Jewellery, a dinner for eight cooked at your home by the Arrogant Chef and two 47-inch high-definition TVs. Planning is already underway for next year’s event.
Sclérodermie Québec (SQ)
Spring is on its way at Sclérodermie Québec with many events

Our support groups continue their wonderful work in Québec regions!

April 13th and 27th:
Support groups from Estrie and Granby had their spring conference

In June, the annual picnic will be held at the Mont St-Hilaire. Another way to get together and talk of the disease

Finally, on June 26th
Sclérodermie Québec will organize another fundraising event!

A comedy play named “La puce à l’oreille”- with famous Quebecer actors (such as Benoît Brière, Martin Dainville and Luc Guérin) will be held at the Old-Terrebonne Theater.

This event is another opportunity for people to learn about scleroderma and raise funds for research. You can get more information about this event on the blog section of our website: www.sclerodermie.ca or you can contact us by phone 514-990-6789 or by email: sclerodermiequebec@videotron.ca

13 et 27 avril : Les groupes d’entraide d’Estrie et de Granby ont réalisé leur conférence de printemps

En juin aura lieu le pique-nique annuel au Mont-St-Hilaire. Une autre façon de se réunir pour échanger autour de la maladie

Enfin, le 26 juin Sclérodermie Québec organise une représentation-bénéfice !

Une comédie de boulevard intitulée « La puce à l’oreille » avec des acteurs québécois réputés (tels que Benoît Brière, Martin Dainville and Luc Guérin) aura lieu au théâtre du Vieux-Terrebonne.

Cet événement est une nouvelle occasion de faire connaître Sclérodermie Québec tout en co lectant des fonds pour faire avancer la recherche. Pour plus d’informations sur cet événement, consultez notre blogue sur www.sclerodermie.ca ou en nous contactant par téléphone au 514-990-6789 ou par email: sclerodermiequebec@videotron.ca
## Making and Strengthening Connections

### UPCOMING EVENTS

#### ONTARIO EVENTS 2013

**HAMILTON, ON**

**June 8, 2013  A Walk in the Park for Scleroderma**

**Hamilton** - This year’s walk is planned for TB McQuesten Park.

For more detail, please contact David Sauvé 905-543-1577 ext. 3 or at davidsauve@cogeco.ca

**September 14, 2013  5th Annual Scleroderma Charity Golf Tournament, Dinner and Auction**

The location for this year’s event is the Flamborough Hills Golf & Country Club.

For more detail, contact Jason Worron at 905-670-1163 or at jworron@stainlessprocess.com

**September 27 and 28, 2013  Scleroderma Canada Congress**

The Scleroderma Society of Canada’s annual conference will be held this year in Hamilton at the Sheraton. More details to come.

**September 29, 2013  Scleroderma Society of Ontario Annual General Meeting**

**LONDON, ON**

**June 8, 2013  A Walk in the Park for Scleroderma**

This year’s walk is planned for Gibbon’s Park (Victoria St. entrance) along the Thames River in the heart of the City of London. Registration starts at 10:00am. The Walk is to begin at 11:00am. BBQ to follow (donations accepted).

For more information is available at http://www.walkrunlondon.com or on Facebook: www.facebook.com/walkrunlondon and Twitter: @walkrunlondon.com Contact Paul or Stephanie Doyle 519-474-1012 Email: info@walkrunlondon.com

**OTTAWA, ON**

**June 15, 2013  A Walk in the Park for Scleroderma**

This year’s walk is planned for Vincent Massey Park. Register online at the Running Room site www.events.runningroom.com/site/?raceId=9236

For more detail, contact Karen Nielsen 613-795-9570 or at knielsen0@gmail.com

**September 14, 2013  1st Annual Golf Fund-raiser**

The location for this year’s event is the Meadows Golf & Country Club.

For more detail, contact Krisstina Davis 613-797-9850 or at davisk@algonquincollege.com

**TORONTO, ON**

**June 15, 2013  2nd Annual A Walk in the Park for Scleroderma**

This year’s walk is planned for East Don Parkland.

For more detail, please contact Melissa Hatcher and Jenny Hatcher at torontosclerodermawalk@gmail.com

Walkers and pledgers can sign up at http://www.events.runningroom.com/site/?raceId=9285

Starting at sunset on Saturday June 15th, the Toronto CN Tower will become a blue and white beacon of light to symbolize Scleroderma Awareness Month in Canada. The 8 minute light show at the top of each hour will be in honour of all Canadians who have been touched by this little known disease.
UPCOMING EVENTS

BRITISH COLUMBIA EVENTS 2013

May 31, 2013  Annual SABC & friends “No Host” Dinner & Social
6:30 pm “Fernridge Room” Sandman Signature Inn 8828 201 Street, Langley BC (southeast side off Highway 1 & 200th St.)

June 1, 2013  SABC 29th Annual Conference & AGM
Willoughby Room, Sandman Signature Inn
8828 201 Street, Langley BC

Sept 8, 2013  “Grandma’s Gala” 5th Anniversary Luncheon
hosted by Dr. Dhar & Mrs. Harv Dhanda, honouring Gurmej Kaur Dhanda 12 – 3 pm at the
South Hall Wedding & Banquet Palace 8273 Ross Street, Vancouver BC

Sept 22, 2013  2nd Annual Scleroderma Ride for Research
Hosted by Rosanne and David Queen, Stanley Park, Vancouver, BC

October (date tba)  5th Annual Community & Patient Fair for Health Professional Education

December 1, 2013  Christmas Luncheon (details to be announced)
PoCo Inn and Suites, 1545 Lougheed Highway, Port Coquitlam, BC

For more information on BC events please visit  http://www.sclerodermabc.ca/coming_events.html

SASKATCHEWAN EVENTS 2013

June 2, 2013  Steak Night Kick-off for Scleroderma Awareness Month
The Scleroderma Association of Saskatchewan (SASK) is hosting a Steak Night on June 2nd.
The evening will include door prizes and a 50/50 draw.
For more information contact Louise Goulet at louise.goulet@sasktel.net

NOVA SCOTIA EVENTS 2013

June 15, 2013  Second Annual “Walk in the Park for Scleroderma” Walk
DeWolfe Park in Bedford, Nova Scotia

QUEBEC EVENTS 2013

June 15, 2013  11th Annual Charity Golf Tournament - Bonniebrook Golf Club
$135 includes golf, cart, dinner The number of places is limited so book quickly. Contact http://sclerodermie.ca/

June 26, 2013  Sclérodermie Québec presents the comedy “La puce à l’oreille”
with famous Quebecer actors (such as Benoît Brière, Martin Dainville and Luc Guérin) will be held at the Old-Terrebonne Theater.
This event is another opportunity to get people to know better about the scleroderma and raise money for research.
You can get more information about this event on the blog section of our website www.sclerodermie.ca or
you may contact us by phone 514-990-6789 or by email at sclerodermiequebec@videotron.ca

Social Networking and Scleroderma

If you are on Facebook, here are a few pages you may be interested in:

1. Scleroderma Society of Ontario --> Please visit our Facebook page and use it to keep others posted on Scleroderma news, upcoming Scleroderma public awareness and fundraising events taking place in Ontario or to let others know about your Scleroderma story.
2. If you have a Twitter Account, follow us @ Scleroderma_SSO
3. Scleroderma Foundation --> Visit this Facebook page and get connected to our Scleroderma friends in the United States.
Scleroderma Society of Canada Group Contacts

Scleroderma Society of the Atlantic Provinces

Newfoundland & Labrador
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Scleôdermie Québec

Web-site: www.sclerodermie.ca
Marielle Pelletier - email: scleriel@videotron.ca
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Aude Gilone - email: agilone@gmail.com
Karine Ferland - email: sclerodermiequebec@videotron.ca

Scleroderma Support Group of the Provinces

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Scleroderma Society of Ontario
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Scleroderma Association of British Columbia

Scleroderma Association of British Columbia
Telephone: 1-888-940-9343 or (604) 940-9343
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