



# SCLERODERMA ASSOCIATION of B.C.

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## Winter **SCLERODATA** 2016-2017

Editor's note: Did you miss the Fall edition? I certainly did. I missed my own deadline of getting it prepared and issued to you, so please accept my apology for the absence of a Fall 2016 issue. This Winter issue includes a few items that were intended for a Fall issue as well as current information and a view ahead to spring events.

### **IN THIS ISSUE:**

- Preview of 2017 SABC Annual General Meeting and Conference, program and registration
- Reports: Creston support group, Bob Saget, Scleroderma Canada national conference
- Surveys: Big Data, support group leaders, caregivers
- June awareness and fundraising activities
- Support group participation
- Advocacy for PAH patients

### **Your Participation is Requested – Research Surveys / Advocacy**

Medical research is important, advocacy is important, therefore your response is important!

Please see pages 7, 8 and 9 of this issue for details.



## **2017 SABC Annual General Meeting and Conference**

**MARK YOUR CALENDAR!**

The Scleroderma Association of BC will be holding its annual general meeting and conference on Saturday, June 10, 2017 in Richmond, BC. As in past years, a Friday evening social get-together has been arranged as a prelude to the actual day of the AGM / Conference. Details are provided in this issue on pages 2 and 3. Further program details and conference information will be included in a Spring issue of *Sclerodata*.



We invite and encourage you to join us for this annual opportunity to enjoy the company of others, to learn and to share information and ideas as a member of the scleroderma community.

### **The Continuing Challenge**



The challenges of scleroderma takes many forms, such as the challenges presented by the impact of the disease on individuals, the challenges that researchers face and the challenge to organizations to meet their goals of support, awareness and fundraising. All of this requires continuing effort from many people, in many ways.



In this issue of Sclerodata you will find information about what people have been doing to meet the challenges of scleroderma and about actions being taken to continue this important work. We encourage you to do what you can – perhaps to volunteer, to complete a survey, to learn more, to talk with others or to offer suggestions to the Scleroderma Association of B.C.



**Scleroderma Association of B.C.**  
**Annual General Meeting and Conference**



**June 9 & 10, 2017**

**Sandman Signature Vancouver Airport Hotel & Resort, Richmond, BC**

located at **10251 St. Edwards Drive, Richmond, BC** (free parking)

**Friday, June 9, 2017**      **Evening 'Meet and Greet' reception**

A reception will be held on-site in the **Sandman hotel's Chop Steakhouse Lounge at 6:00 pm**. There will be full bar service on a 'no-host' basis and 'appies' provided courtesy SABC. Post-reception dining options are available on-site, at the Chop Steakhouse, the Shark Club or Denny's Restaurant.

**Saturday, June 10, 2017**      **The AGM and Conference, all sessions in the hotel's Round Room.**

8:30 *Registration*      Conference kit pickup and registration in the *Round Room*. Research poster display. Coffee/tea/juices/ water available

9:00 *SABC AGM*      Introductions, adoption of agenda, approval of 2016 AGM minutes, receipt of Directors' report, elections & new business, if any.

**MORNING SESSIONS:**

9:30 *Dr. Tiffany Winstone* (topic: esophageal disease)

10:30 *Beverage/Chat Break*

10:45 *Shelley Van Pelt, MSN, RN, CNS*

(topic: The benefits of holistic healthy lifestyle choices and nutrition)

11:45 *Gurmej Kaur Dhanda Memorial Scleroderma Community Service Award and Gurmej Kaur Dhanda Memorial Scleroderma Community Scholarship Award*

12:00 **LUNCH** and *Research Poster Displays by two UBC students, who will be available for questions*

**AFTERNOON SESSIONS:**

1:00 *Dr. Glen Wicks, Optometrist, FAAO* (topic: scleroderma and eye issues)

2:00 *Beverage/Chat Break*

2:15 *Elisa Murru, MSc, MBA and Ashley Grant*, from the Canadian Mental Health Association, BC Division (topic: depression/anxiety issues and support options)

3:15 *Group sessions*: round table group discussions on topics of interest

4:15 *Kudos and Adieus*

4:30 *Adjournment*

*A no-host dinner in the Chop Steakhouse will be held at 5:30 for those who signed up for it when registering.*

**Hotel Reservations**

Twenty rooms (2 queen beds) have been reserved at a special conference rate of \$125 + taxes per night for single or double occupancy. There's a \$20 additional fee for 3<sup>rd</sup> & 4<sup>th</sup> adults. This 'block' will be held until May 9, 2017. Guests can enjoy the facilities in the health club next door, including an indoor pool with 225' water slide. Ample free parking is available in the lot.

If you plan to **stay at the Sandman Signature hotel**, reservations may be made by calling the hotel's toll free reservations number, **1-800-726-3626**. Please state **reference number 739752** in order to get our conference special rate.

**SABC 33rd ANNIVERSARY CONFERENCE REGISTRATION FORM JUNE 9-10, 2017**

**Sandman Signature Vancouver Airport Hotel & Resort  
10251 Street Edwards Drive, Richmond BC V6X 2M9**

To register, please mail a completed form for **each** registrant to **David Queen, PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2**, with a cheque for \$25 payable to the '**Scleroderma Association of BC**'.

To **pay** by your choice of **credit card**, please also complete the information on the right below and mail it to the above address *or* email it as a PDF attachment to David at [dq.sabc@telus.net](mailto:dq.sabc@telus.net). You will then receive a PayPal invoice (no account needed) via email for payment.

**SABC 33<sup>rd</sup> ANNIVERSARY CONFERENCE REGISTRATION FORM**

1) _____ Name of <b>registrant</b> (please print)	2) _____ (If different) Name of <b>Credit Card holder</b> as shown on card
<b>Registrant's address, telephone, email</b>	<b>Credit card holder's address, telephone, email</b>
_____	_____
_____	_____
_____	_____

Please check the applicable sections that follow:

- A) **Friday June 9 on-site reception on the stage of the *Chop Steakhouse Lounge* at 6:00 pm** A
- B) **Saturday June 10 lunch in the *Function Room* @ \$25 payable by May 15 or \$35 thereafter** B
- C) **Saturday June 10 on-site no-host dinner in the *Chop Steakhouse* at 5:30 pm** C

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## **NATIONAL SCLERODERMA CONFERENCE**

The Scleroderma Society of Canada's 17th national conference was held in Montreal September 16-17, 2016. It was co-hosted by the national organization and by the long-established scleroderma network in Quebec, Sclérodermie Québec. SABC members attending were Rosanne and David Queen, Melissa Patton and Grant Dustin.

The large program of conference sessions provided a wide variety of topics, with French/English translation services available for the main sessions. In addition, there were meetings for the medical professionals, organized under the

## **Creston Health and Wellness Fair**

As they did in November of 2015, the local scleroderma support group in Creston, under the leadership of Betty Kuny, provided an information table at the 2016 Creston Health and Wellness Fair. The Fair was held on November 5 and Betty reported that their day went well, making contact with people and passing out information. They were pleased to provide a door prize, courtesy of MORRIS FLOWERS. Support group members participating are shown in the

## **Entertainer, Bob Saget, connects with SABC**

SABC Board member Neil Mackie and his wife, Marie, attended the Bob Saget concert in Vancouver last November 11 and had an opportunity to meet the entertainer personally after the performance. Neil tells us that Bob Saget, upon learning that Neil and Marie are active in the scleroderma community here, spent several minutes talking with them about the work being done for the cause.

As some of our readers know, Bob Saget lost his sister to scleroderma several years ago. He raised awareness of the disease by way of directing the movie, 'For Hope', based on his sister's experience with scleroderma. He has also raised millions of dollars for scleroderma research by performing at fundraising concerts over many years. It has been noted that Bob Saget has had a connection with the Scleroderma Association of BC in the past and has always been extremely gracious to our members and volunteers, as he has to

leadership of Dr. Murray Baron of the Canadian Scleroderma Research Group and McGill University. Separate meetings for a Youth Component of the conference were held, following up on last year's initiative for this special feature of the conference.

The Scleroderma Society of Canada has been reviewing its structure and its role in providing leadership and service to the scleroderma community in Canada. This review will result in some changes to the national organization while it continues to maintain a focus on priorities of raising awareness, education and advocacy. Three changes implemented so far are: 1. The name for common reference to the organization will be **Scleroderma Canada**, although the official registered name is still Scleroderma Society of Canada), 2. The logo has changed from the previous logo showing SSC in a blue oval to the new logo shown with this article, and 3. The national conference will be held every-other-year instead of annually, with the next conference scheduled to be held in 2018 in Calgary).

photo, left to right: Myna Kaiser, Betty Kuny and Kathy Evert. Many Thanks to Betty and the team in Creston for doing

such an excellent job of promoting scleroderma awareness!



those who know him in his role of scleroderma goodwill ambassador with several scleroderma organizations in the USA and Canada.



# News and Announcements

## June Events

June is Scleroderma Awareness Month and there will be awareness / fundraising events taking place in our province and across Canada. Here are some of the plans for activities in BC. If you know of other events planned for this purpose please contact us.

## Events in British Columbia

### 6th Annual Scleroderma Ride for Research

Sunday, June 18th – bike ride and walk in Stanley Park, Vancouver. Rosanne and David Queen will again be hosting this event to promote awareness of scleroderma and to raise funds for research. Members, family and friends of the Scleroderma Association of BC are invited to come out that day for the 30 km ride, or 10 km ride, or a walk in the park.

### Walks

Scleroderma supporters across Canada are in the process of organizing walks (or runs or bike rides) to be held in June to promote greater awareness of the disease and to raise funds in support of research and the work being done to continue the fight against this disease. Walks being organized in BC are:

- Smithers - June 4, 1:00 pm, meet at Main St. and Hwy. 16. For more information please contact Pati Struthers, ph 250-847-9190

- Valemount - June 4, 10:00 am registration, 11:00 am walk, meet at Centennial Park. For more information please contact Teresa Colosimo, ph 250-566-4172.

This event combines walking for scleroderma, arthritis and ALS (note: Wear your sparkle and bling!)

### National June Awareness Campaign - walk, run, ride

Scleroderma Canada is promoting the national campaign again this year for communities to host a walk, run or ride for fundraising and promoting awareness. Such activities last year resulted in total fundraising of \$357,607 across Canada. Their goal this year is \$500,000! Scleroderma Canada has information and assistance for anyone interested in organizing an event for this campaign. Or, as they suggest, anyone can take part in a Virtual Walk! You can read more about this in Scleroderma Canada's recently issued newsletter, available online at [https://issuu.com/sclerodermacanada/docs/scleroderma\\_canada\\_fall\\_2016\\_v15\\_lr?e=27946123/43529963](https://issuu.com/sclerodermacanada/docs/scleroderma_canada_fall_2016_v15_lr?e=27946123/43529963).

## Canadian Organization for Rare Disorders (CORD) conference

The Canadian Organization for Rare Disorders will be holding Rare Disease Day 2017 Conference on March 30-31, 2017 at the Sheraton Vancouver Wall Centre, 1088 Burrard Street in Vancouver. More information is available by contacting CORD, telephone 1-877-302-7273 or at their website, [www.raredisorders.ca](http://www.raredisorders.ca).

## Websites for Scleroderma Organizations

British Columbia ([www.sclerodermabc.ca](http://www.sclerodermabc.ca)), Canada ([www.scleroderma.ca](http://www.scleroderma.ca)), United States ([www.scleroderma.org](http://www.scleroderma.org)), United Kingdom ([www.sruk.co.uk](http://www.sruk.co.uk)), Australia ([www.sclerodermaaustralia.com.au](http://www.sclerodermaaustralia.com.au))

\*Scleroderma Canada's recently issued newsletter is available online at [https://issuu.com/sclerodermacanada/docs/scleroderma\\_canada\\_fall\\_2016\\_v15\\_lr?e=27946123/43529963](https://issuu.com/sclerodermacanada/docs/scleroderma_canada_fall_2016_v15_lr?e=27946123/43529963)

## New Video: Genome 101

The Scleroderma Association of B.C. has recently released a video that was made at the 2016 SABC conference. It features Dr. Kevin Keen of the University of Northern British Columbia giving a presentation on the topic 'Genome 101 and The Scleroderma Association of BC Research Project'.



"It's a pacemaker for your heart. Plus, you can download apps for your liver, kidneys, lungs, and pancreas!"

The video may be viewed by going to the SABC website, [www.sclerodermabc.ca](http://www.sclerodermabc.ca) and selecting the YouTube link on the home page. Other videos are also available via that link.

## **Scleroderma Support Groups in BC**

There are a number of regional support groups in BC and the Yukon, each doing what they can to provide a service for local patients and caregivers and to represent the interests of the scleroderma community. The list of support groups shown on the back page of the Sclerodata newsletter and on the SABC website indicates that many areas are served by this network but there are still some places where patients may wish to access a support group but the opportunity doesn't exist for them. The Fraser Valley is one area that does not presently have a support group. A scleroderma patient who lives in Hope is interested in meeting other scleroderma patients in her general area. If you live in the Fraser Valley area and have an interest in a scleroderma support group, or know of someone who might be interested, please contact us (contact information at the top of the cover page of this newsletter). Also, the SABC is still seeking a replacement to serve as the support group representative for local groups in Maple Ridge, Kelowna and Surrey. **Volunteers needed. Easy work. No experience required.**



## **St. Paul's Pulmonary Fibrosis Support Group**

The next support group meeting will be on March 7, 2017. Meetings are held at St. Paul's Hospital, 1081 Burrard Street, Vancouver. All meetings are in Dining Room 1 – Fourth Floor Providence Wing – Beside the Cafeteria. Meetings run from 1:00 to 3:30 pm. All patients with pulmonary fibrosis of any kind or level of severity, caregivers and significant others are welcome to attend. Meeting dates this year are scheduled for March 7, May 23, July 18, September 12, November 21 and December 12.

The support group meetings offer an opportunity to meet and mix with other patients and to hear a presentation from a guest speaker, with time for questions. The meetings are hosted by Fran Schooley, who is the clinic coordinator for the Scleroderma Lung Clinic, which is part of the Pacific Lung Health Centre at St. Paul's Hospital. Information about the Pacific Lung Health Centre and the Scleroderma Lung Clinic may be found on their website, <http://pacificlung.ca/scleroderma-lung-clinic>. Information about the clinic and support group meetings may be found on the SABC website or by contacting Fran Schooley at 604.806.8818 Extension 2, or email [fschooley@providencehealth.bc.ca](mailto:fschooley@providencehealth.bc.ca). Please leave a message on Fran's phone at night if you plan to attend.

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## **Calling on all scleroderma patients affected by Pulmonary Arterial Hypertension (PAH)!**

Scleroderma Canada is working with the Pulmonary Hypertension Association of Canada to advocate to governments across Canada to ask that all PAH patients have immediate access to all Health Canada-approved treatment options like Uptravi (selexipag).

Scleroderma Canada wants to speak with patients who are either currently being treated with Uptravi or are eagerly awaiting publicly funded access to this new treatment option to lend their voice to our advocacy efforts. If you or someone you know is interested in learning more, please email [info@scleroderma.ca](mailto:info@scleroderma.ca) or call 1-866-279-0632. Together we are making a difference! #TakeActionPAH

### **Two sources for more information on this are:**

1. Scleroderma Canada's recently issued newsletter, available online at [https://issuu.com/sclerodermacanada/docs/scleroderma\\_canada\\_fall\\_2016\\_v15\\_lr?e=27946123/43529963](https://issuu.com/sclerodermacanada/docs/scleroderma_canada_fall_2016_v15_lr?e=27946123/43529963)

& 2. The excerpt below is from an article ('Rare lung disease patients fear ...'), printed in the Vancouver Sun, November 17, 2016. It presents the issue of access to drug options for the

treatment of pulmonary arterial hypertension patients. The full article may also be viewed at <http://www.vancouversun.com/business/cnw/release.html?rkey=20161117C7481&filter=4005>



### **Rare lung disease patients fear lengthy negotiation trend will delay access to another new therapy, putting lives at risk**

- PAH physicians, patients and caregivers urge governments across Canada to uphold funding recommendation and grant swift access to life-extending treatment option

VANCOUVER, BC and HAMILTON, ON, Nov. 17, 2016 / CNW/ - Canadians affected by pulmonary arterial hypertension (PAH), including those living with scleroderma, are pleased with

*Continued...*

the recent Common Drug Review (CDR) recommendation to reimburse Uptravi (selexipag). However, the community fears access to this treatment option – the third new PAH therapy approved by Health Canada in recent years – will be delayed due to a lengthy negotiation process through the pan-Canadian Pharmaceutical Alliance (pCPA). Another Health Canada-approved PAH treatment, Opsumit (macitentan), was recommended for public funding by the CDR in January 2015, yet still remains out of reach due to unsuccessful pCPA negotiations, giving patients reason to be concerned that Uptravi may follow in its path.

In January 2016, Health Canada approved Uptravi for the long-term treatment of idiopathic PAH, heritable PAH, PAH associated with connective tissue disorders (including scleroderma), and PAH associated with congenital heart disease, to delay disease progression in adult patients with Functional Class II or III. In October 2016, the CDR recommended that Uptravi be publicly funded for patients whose disease is not being adequately controlled with a first- and second-line therapy. The hope is that publicly-funded access to Uptravi will be successfully negotiated through pCPA, but physicians, patients and caregivers are concerned that any delay will impact the prognosis of those who require this treatment option.

*“PAH patients have high hopes for Uptravi as a new treatment option to slow the progression of this rare but very complex and serious lung disease that significantly limits life expectancy,” says Maureen Worrone-Sauvé, Vice President of Advocacy, Scleroderma Canada. “Our fear is that if we are faced with another lengthy negotiation process, as with other PAH drugs, patients will be denied access to a treatment option that may be urgently needed by some, and seen as a last resort by others.”*

To date, none of the recently approved treatments for PAH are accessible to patients in Canada through public funding, with the exception of Opsumit, which is only publicly funded in Quebec. This delay in access to treatment restricts PAH physicians’ ability to exercise the individual clinical judgment that is essential to the optimal management and long-term health of those living with this complex disease. As the first oral prostacyclin receptor agonist, Uptravi is a new form of treatment that can address patients’ diminished quality of life and potentially slow the progression of their disease. For patients who are unable to be treated with an intravenous prostacyclin, Uptravi may be their last hope.

While the prognosis for PAH patients has improved somewhat in recent years, it remains poor despite currently

available treatments. Many patients remain significantly ill with moderate-to-severe symptoms and progressive right-ventricular heart failure. The average survival in adult PAH patients following diagnosis is estimated at only five to seven years, which means they do not have time to wait for the necessary treatment options to be made accessible to extend their already limited life expectancy.

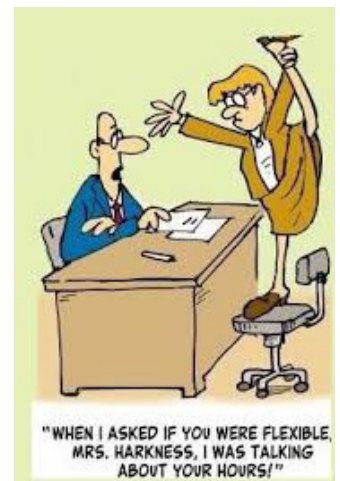
“It is unacceptable that PAH patients who rely on public drug funding are prevented from accessing Health Canada-approved treatments and, as such, we as PAH specialists are unable to exercise the individual clinical judgment that is essential for the optimal treatment of this serious and fatal disease,” says Dr. Sanjay Mehta, MD, FRCPC, FCCP, Director of the Southwest Ontario Pulmonary Hypertension Clinic at the London Health Sciences Center in London, Ontario, and Chair of PHA Canada. “Our community is very concerned that the trend to delay and deny public funding of the newest, most effective PAH treatments is taking treatment decisions out of the experienced hands of PAH medical experts. We strongly urge governments across Canada to immediately fund Uptravi and ensure all PAH patients have timely access to optimal therapy to improve and extend their lives.”

## **About Pulmonary Arterial Hypertension**

*In PAH, the arteries (blood vessels) of the lungs become narrowed by scar tissue, sometimes to the point of being completely closed. Those affected by PAH suffer from high blood pressure in the lungs, which results in strain and enlargement of the heart, which ultimately leads to heart failure and death. PAH is a common complication of scleroderma, a chronic hardening and contraction of the skin and connective tissue. PAH shares many symptoms with other diseases, which often leads to lengthy delays in diagnosis, and misdiagnosis. There is currently no cure for PAH, and if left untreated, patients live an average of only two to three years. Please visit [www.phacanada.ca](http://www.phacanada.ca) or [www.scleroderma.ca](http://www.scleroderma.ca) for more information.*

SOURCE Pulmonary Hypertension Association of Canada

For further information: please contact: Jamie Myrah, PHA Canada, 604-682-1036 ext. 101, [jmyrah@phacanada.ca](mailto:jmyrah@phacanada.ca); Anna McCusker, Scleroderma Canada, 289-396-3039, [anna@sclerodermaontario.ca](mailto:anna@sclerodermaontario.ca)



# Research Surveys

## Is 'Big Data' a big deal for health care in Canada?

You are invited to participate in a survey that is being undertaken by Arthritis Research Canada to learn more about patients' and the public's views about the use of large data sets ('Big Data') for research purposes. Big Data, in health care, is large and complex sets of data that have information routinely collected on patients' health and their use of health care systems, such as their reason for visiting a hospital, laboratory results, doctor's notes, and medication prescribed.



To be eligible to participate in this study, you must be a Canadian resident, 18 years of age or older and have access to a device with internet connection. The link to the survey is <https://survey.ubc.ca/s/BigDataSurvey/langeng/>.

Research assistant Lynn Nowoselski is asking health organizations to encourage participation in this online survey, which has the purpose of understanding patients' knowledge and opinions about the use of Big Data in Canadian health research. Specifically, researchers hope that this survey can help them to learn the following:

- Current levels of knowledge about Big Data
- Willingness to participate in projects using Big Data
- Major concerns about the use of Big Data
- Interest in learning more about health research using Big Data
- Preferred modes of receiving more information about Big Data.

Lynn points out that the survey will take approximately 20 minutes to complete. The information provided in this survey will remain strictly confidential and accessed only by members of the study team. Participation will be anonymous and data will be pooled for analysis to ensure complete privacy. This study has received ethics approval by the University of British Columbia ethics board. The research is being carried out under the leadership of Dr. Linda Li, Professor, Department of Physical Therapy, UBC and Senior Research Scientist, ARC.

The link to the research project website is <http://www.arthritisresearch.ca/precision/project6>.

## Surveys for Support Group Leaders & Caregivers

There are two surveys presently taking place under the direction of principal investigator Dr. Brett Thombs, Department of Psychology, McGill University. One has a focus on scleroderma support group leadership and effectiveness. The other is designed to help develop effective support services for informal caregivers of scleroderma patients. Details of these surveys are available in the recently published Scleroderma Canada newsletter, available online at [https://issuu.com/sclerodermacanada/docs/scleroderma\\_canada\\_fall\\_2016\\_v15\\_lr?e=27946123/43529963](https://issuu.com/sclerodermacanada/docs/scleroderma_canada_fall_2016_v15_lr?e=27946123/43529963).

### Survey for Support Group Leaders (past or present)

If you have served as a scleroderma support group leader, or are presently the leader of a scleroderma support group, you are asked to complete this survey. If not, but you know of someone who fits this description, please pass it on. This covering information comes from Nicole Pal, co-investigator.

My name is Nicole Pal, I am a research assistant working with Dr. Brett Thombs, the Director of the Scleroderma Patient-centered Intervention Network (SPIN) and Vanessa Delisle, a doctoral student at McGill University, on the Scleroderma Support Group Leader Project.

In collaboration with Scleroderma Canada and the Scleroderma Foundation in the United States, we are working towards the development of a scleroderma support group leader training program to help make scleroderma support groups more effective and accessible. To help in the development of this program, we have created a survey that focuses on the experiences of past and current scleroderma support group leaders to help identify potential training and support needs.

If you are a current or past scleroderma support group leader we hope that you will fill out our survey. If not, we ask that you please pass the recruitment sheet on to any current or past scleroderma support group leaders that you

*Continued...*



## Surveys Continued...

know of. Additionally, if you have any access to social media platforms (Facebook groups, websites, newsletters) we would greatly appreciate your help in promoting this survey by posting the recruitment notice.

The survey can be completed from online anywhere and will take approximately 15-20 minutes to complete. Participation is completely voluntary, and all responses will be kept anonymous. Participants must be 18 years of age or older, must be diagnosed with systemic sclerosis (scleroderma), and must be a current or past scleroderma support group leader.

The link below will bring you directly to the survey if you wish to complete it now: [https://survey.co1.qualtrics.com/SE/?SID=SV\\_9zX1Ozg8uGD3z5H](https://survey.co1.qualtrics.com/SE/?SID=SV_9zX1Ozg8uGD3z5H)

If you have any additional questions or concerns about the survey, please do not hesitate to contact me at [nicole.pal@live.com](mailto:nicole.pal@live.com) or Ms. Vanessa Delisle, at [vanessa.delisle@mail.mcgill.ca](mailto:vanessa.delisle@mail.mcgill.ca) or call (1) 514-340-8222 ext. 26812

### Survey for Caregivers

If you have been, or are presently, an informal (i.e. support on an unpaid basis) caregiver of a person diagnosed with scleroderma, you are asked to complete this 30-40 minute survey about your experiences providing support. Information gathered will be used to work toward developing, testing and distributing effective support services to informal caregivers. Here is the link to the survey. [https://survey.co1.qualtrics.com/jfe/form/SV\\_cJ9hOPiYjxdxPIX](https://survey.co1.qualtrics.com/jfe/form/SV_cJ9hOPiYjxdxPIX)

If you have any additional questions or concerns about the survey, please do not hesitate to contact the members of the research team for this survey: Ms. Danielle Rice, telephone (514) 340-8222 ext. 6811; email [daniell.rice@mail.mcgill.ca](mailto:daniell.rice@mail.mcgill.ca) or Ms. Mara Canedo, email [mara.canedo@mail.mcgill.ca](mailto:mara.canedo@mail.mcgill.ca).



## Medical File

### Is Hoarseness a Symptom of Scleroderma?

In answer to the question, this reply was presented some years ago by William Swedler, MD, Rheumatologist, Cook County Hospital, Chicago, USA. (Thanks to Joan Kelly for submitting this item to Sclerodata.)

Hoarseness is often caused by problems in or around the voice box (larynx) affecting the vocal cords. The vocal cords are flaps of tissue which open and close as we breathe and speak. To open and close properly they need a soft supple covering, good joint movement (yes, there are small joints in the voice box), and strong muscles with good nerve supply.

Scleroderma may cause tightening of tissues over the voice box which can reduce motion in the vocal cords. Some ulcers can occur in this area and if arthritis is a problem the vocal cords will not move well. Sometimes in scleroderma patients, muscle weakness can occur due to muscle inflammation or damage to the nerves feeding the muscles. If hoarseness persists for several weeks, then see an ENT specialist or other physician who can look at the voice box using a mirror or scope. They may find a problem easily correctable.



## SABC Board of Directors 2016 / 2017

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Board member without portfolio	Susan Ashworth	778-837-4540	alyosha303@gmail.com
Board member without portfolio	Michele Gervais	604-875-9337	gordmich@telus.net
Board member without portfolio	Neil Mackie	604-999-8729	neilmack@telus.net
Board member without portfolio	Dianne McPhee	604-513-5875	diannemcphee@shaw.ca

*note: Joan Kelly is not on the Board of Directors but continues to serve as the SABC 'Office Contact'. Joan may be contacted by telephone at 604-940-9343 or 1-888-940-9343, fax 604-940-9346, or by email at scleroderma@telus.net*

## Community Contact Representatives

Campbell River	Sharon Watson	250-923-6171
Creston	Betty Kuny	250-428-8875
Kelowna	<i>Seeking Representative</i>	
Kamloops	Darla Martin	250-554-4636
Maple Ridge	<i>Seeking Representative</i>	
Nelson	Sylvia Reimer	250-352-2005
New Westminster	Melanie Ross	778-867-0736
Penticton	Barb Creighton	250-770-7836
Prince George	Donna Pilkington	250-962-9260
Quesnel	Leah McAnena	778-466-1073
Surrey	<i>Seeking Representative</i>	
Smithers	Pati Struthers	250-847-9190
Valemount area	Teressa Colosimo	250-566-4172
Victoria	Susan Goss	250-479-8586
Vernon	Lisa VanDyk	250-542-5231
Williams Lake	Cecelia Jaeger	250-392-3656
Yellowknife	Helen White	867-873-5785

### Disclaimer

The Scleroderma Association of BC does not endorse any drug, treatment or diet material presented in this newsletter. We aim to keep you informed, sharing news from various sources. Always inform your doctor of new vitamin or herbal remedies before including them in your diet.

### Sclerodata

As stated in the previous issue, our newsletter 'Sclerodata' may still be received in print form but may also be received as an email attachment (just send us your email address if we don't have it yet).

## Membership Renewal

Annual member fees are due May 1<sup>st</sup>. Please remit by cheque for full value of your contribution, payable to Scleroderma Association of BC, PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2. For online payment options, please contact the office for further information.

*Please note: Tax receipts are issued for donations only.*

(please complete this form and enclose with payment)

### Membership Form

Date: \_\_\_\_\_ Name: \_\_\_\_\_ Scleroderma patient? yes ( ) no ( )

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail address: \_\_\_\_\_

Member fee: \$20.00 Donation: \$ \_\_\_\_\_ Memorial gift: \$ \_\_\_\_\_

(for acknowledgement, please include name & address)

Total amount enclosed: \$ \_\_\_\_\_

Change of address/phone/other notations: \_\_\_\_\_