



SCLERODERMA ASSOCIATION of B.C.

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Issue 2 **SCLERODATA** 2019

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35th SABC Annual General Meeting and Conference



Saturday, October 5th— Port Coquitlam

We invite you to attend the 2019 SABC conference and annual general meeting, held at the **Poco Inn and Suites, 1545 Lougheed Highway, Port Coquitlam, BC** on **October 5, 2019**.



Members spoke and the Conference organizers listened! New this year, we are also incorporating the option of real-time, online video conferencing, in the comfort of your home with family or friends in your community. This ensures those unable to travel to the lower mainland have access to and can partake in, the conference!

First, make sure you are registered. Before the conference, registered members will be emailed a link from **Yes AV**, SABC's audio visual provider. You will click on that link, enter your name and email, and then follow the instructions to install the meeting software on your computer, phone, or tablet. It is just a few simple clicks to join online!

During the conference, you'll have an opportunity to ask questions/comment via a simple chat function!

To participate using the real-time conference streaming option, your home computer or mobile device will need:

Computer Operating System (OS):

- ◆ Mac OS X with Mac OS 10.10 and higher or Windows 7 and higher
- ◆ If not already built in, then external speakers connected to your computer

Mobile device OS:

- ◆ iOS 7.0 or later or iPhone 4 or later or iPad Pro or iPad mini or iPad2 or later or iPod touch 4th generation or iPhone 3GS or Android 4.0X or later or Kindle Fire HD



Program and registration details for both in-person and online participation are described on pages 2 & 3.

We invite and encourage you to join us for this annual opportunity in-person or online to enjoy the company of others, to learn and to share information and ideas! Videos of the sessions will be available on the SABC website after the conference.



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



October 4 & 5, 2019

Poco Inn and Suites, 1545 Lougheed Highway, Port Coquitlam, BC (free parking)

Friday, October 4 Evening 'Meet and Greet' reception

Informal reception on-site in the hotel's **Crossroads Lounge at 6:00 pm**. Full bar service on a 'no-host' basis. 'Appies' provided courtesy of SABC.

Saturday, October 5 AGM and Conference

8:30 *Registration* Conference kit pickup and registration. Coffee/tea/juices/ water available.

9:00 *SABC AGM* Introductions, adoption of agenda, approval of 2018 AGM minutes, receipt of Directors' Report, elections & new business, if any.

MORNING SESSION:

9:30 Dr. Mark Harrison, UBC - Economics and the Functional Side of Stem Cell Therapy

10:30 *Beverage/Chat Break*

10:45 Dr. Sarvee Moosavi, Gastroenterologist - Scleroderma patients and GI issues

11:45 Brief summary of local scleroderma research project

11:55 Gurmej Kaur Dhanda Memorial Scleroderma Community Service Award
Gurmej Kaur Dhanda Memorial Scleroderma Community Scholarship Award

12:00 *Lunch - UBC medical students available for questions*

AFTERNOON SESSION:

1:00 Dr. Trey Petty, Dentist—Dental Treatment for Scleroderma Patients

2:00 *Beverage/Chat Break*

2:15 Tai Chi presentation and participation

3:15 Group Session Breakout: Patient Discussion *or* Supporting of / Caring for Scleroderma Patients

4:15 *Kudos and Adieus*

4:30 *Adjournment*

*Following the conference, an informal no-host dinner will be held in the **Izba Bistro**, an on-site restaurant (for those who signed-up for it when registering).*

Hotel Reservations

If you want to book a room at the POCO Inn and Suites hotel, the room rate is \$159.00 + taxes (includes a \$12.00 voucher for the on-site restaurant). Please specify your reservation is for 'Scleroderma Association of BC' in order to get this block booking rate. Reservations can be made by calling toll free at 800-930-2235 or local at 604-941-6216, or by email at generalreservations@poco-inn-and-suites.com . For more information about the hotel, please visit [hotel website](#)

3 ways to register, 3 ways to pay!

To attend in-person, the registration fee is \$35.00 (\$45.00 after September 15).

You can register and pay by using the SABC website: [Click here to register](#)

Registration/Ticket Information

A - In-person Conference only on Saturday

B - In-person Conference + Friday evening reception

C - In-person Conference + Saturday no-host dinner

D - In-person Conference + Friday evening reception + Saturday no-host dinner

Online video conference

*Helpful hint: When entering info in registration form fields, click on the word 'Select' to enter the info!

	<input checked="" type="checkbox"/> To pay by credit card	<input checked="" type="checkbox"/> To pay by cheque
To attend in-person, enter quantity for A,B,C or D then click Get Tickets	Enter your card details when prompted	Mail cheque payable to "Scleroderma Association of B.C." to David Queen, PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2.
To attend online, enter quantity then click Get Tickets	Free	Free

You can register and pay by using your online banking website:

	<input checked="" type="checkbox"/> To pay by e-transfer
To attend in-person	<p>Add the following e-transfer recipient information: Name: Scleroderma Association of B.C. Contact method: Email DQ.SABC@telus.net Notify By: Email Add in the optional 'Message' box: (This will serve as a registration form for the person named) Name , Address , Telephone number, Email address The letter for your participation: A B C D (see descriptions above) If you are a scleroderma <i>patient</i> or a <i>supporter</i> If you would like to receive the <i>Sclerodata</i> newsletter and <i>The Bulletin</i> magazine</p>

You can register by mail to David Queen, PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2:

	<input checked="" type="checkbox"/> To pay by credit card	<input checked="" type="checkbox"/> To pay by cheque
To attend in person	Provide your card details on form (next page) and mail to above address	Mail cheque payable to "Scleroderma Association of B.C." to David Queen, PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2.

SABC Member Updates

Synergy with Three Update: New Website & *The Bulletin*

In the last issue of this newsletter we mentioned SABC's newly formed partnership with Scleroderma Manitoba and Sclerodermie Quebec with the goal of enhancing member support and communication.

We are excited to share that SABC has, with the help of Sclerodermie Quebec, improved our website www.sclerodermabc.ca and with additional financial support from Actelion, published our first magazine, *The Bulletin*, helping to raise scleroderma awareness by distributing to SABC members, rheumatologists, hospitals and family clinics throughout the province.

If you did not receive your copy of the *The Bulletin*, please email SABC at scleroderma@telus.net to ensure you are kept up to date with all things scleroderma in BC.

What is next?

- In our never ending effort of keeping the website current, SABC is hoping to include more 'scleroderma patient/supporter stories'. If anyone would like to share their story related to scleroderma, please contact Rosanne Queen at 604.984.9425 or rq.sabc@telus.net
- Coming this Fall! The next issue of *The Bulletin*
- Continuing to work on more timely access to the latest scleroderma research and information
- Continuing to update our SABC membership lists. Thank you to all members who emailed scleroderma@telus.net your updated contact information!

SABC 35th ANNUAL CONFERENCE REGISTRATION FORM

1) _____
Name of **registrant** (please print)

2) _____
(If different) Name of **Credit Card holder** as shown on card

Registrant's address, telephone, email:

Credit card holder's address, telephone, email:

Please circle the letter designating your participation:

- A - In-person Conference only on Saturday
- B - In-person Conference + Friday evening reception
- C - In-person Conference + Saturday no-host dinner
- D - In-person Conference + Friday evening reception + Saturday no-host dinner

Are you a scleroderma patient or a supporter? _____

Would you like to receive the *Sclerodata* newsletter and *The Bulletin* magazine? _____

SABC Member Updates Con't

John Lewis' Legacy, Med Students at the Conference

So why do we facilitate the attendance of UBC medical students at our annual conference?

Because of the vision of one man, John Lewis, a scleroderma patient and member of the SABC Board.

In 2007 John started participating as a Community Educator in UBC's Patient and Community Voices Project. The project consisted of a group of UBC faculty, students and community members who believed bringing patient and community voices into the education of future health providers was essential. It was through this involvement John came to realize the valuable contribution scleroderma patients could provide to the education of BC's future physicians by representing the 'Face of (hands of, feet of, skin of...) Scleroderma' at UBC's Health Science Fair. The Fair was an opportunity for students and faculty to learn about the experiences of living with an illness or disability from patients and community members, and their interactions with health professionals and the health care system.



In the spirit of increasing even more awareness of scleroderma to students, faculties and other community groups, John organized 7 SABC members to join him at the 2009 Fair. The Fair gave the members an opportunity to tell their individual stories and the students were encouraged by the members to ask any questions, feel their hands, review videos and informational posters about scleroderma. Their booth was well received as many students had never even heard of Scleroderma before. UBC medical student feedback after the Fair was overwhelmingly positive.



Students said, "Just to hear the lived experience from someone's mouth is always great ... 10 minutes of that seems to be worth about 2 hours of it coming from an instructor's mouth ...".

John was able as a member of the Lougheed Burnaby Lions Club, to secure a donation to SABC of \$500.00 to continue this effort of ensuring patient-student interactions. Because SABC continues to acknowledge John, his work and his vision of patients contributing to physician education, current SABC members Dianne McPhee and Grant Dustin attend the Lions Club's annual barbeque and accept, in John's memory, the same generous donation allowing SABC to include UBC medical students in our annual conference.

So this 35th conference, we again encourage patients to please seek out the friendly faces of our student invitees, introduce yourself and to honor John, tell your story and answer their questions. Because like our disease, opportunities for future physicians to experience patients like us, are rare.

Thanks again to John and the Lions Club for continuing to facilitate the attendance of medical students at our conference.



June Awareness Highlights

June Awareness / Fundraising Activities BBQ , Ride for Research & Walks

Scotiabank Community Day Hot Dog Lunch

Friday, May 31st – North Vancouver (Lonsdale Scotiabank Branch)

SABC says a big thanks to all those who joined us in raising \$2753.50 and thanks to Scotiabank for matching it to make \$6,000 for scleroderma research. A big thank you to Susanne Kingshott, Assistant Manager & her gang at 1357 Lonsdale, Nicole & Anroe of O'Canadawg and the residents of the North Shore.



8th Annual Scleroderma Ride for Research

Sunday, June 16th – Vancouver (Ceperley Picnic Site in Stanley Park)

Rosanne and David Queen report the Scleroderma Ride for Research raised over \$50,000 for the St. Paul's Scleroderma Research Project! They had over 90 join them in the sunshine. The oldest being 90 years old, the youngest 7 weeks old. It was followed by a great potluck lunch.

They were also joined by a few from the research team. The Team talked about the ongoing research and clarified that none of the money raised goes to salaries or expenses for the primary researchers; every dollar goes to the necessities of conducting the research.

A special THANK YOU for a great day to Park Insurance, Open Road Audi Boundary and to all those that supported our ride! The Kamloops contingent raised over \$2000!



June Awareness Highlights con't

2nd Annual Scleroderma Walk in the Park for Research

Sunday, June 23rd - Victoria (West Shore Parks and Recreation, Picnic Shelter, Lower Field)

Linda Barnes reports the 2nd Annual 2019 Victoria Walk in the Park for Scleroderma was another wonderfully successful day of spreading awareness and raising money for research! Close to 100 people either participated in the walk or volunteered as course marshals, set up crew, silent auction coordinators, first aid attendants and behind the scenes supporters! Over \$11,000 was raised for ongoing research at St. Paul's Hospital.

Thanks to all who donated, walked and cheered. You are all a part of making Scleroderma awareness a vital part of finding a cure!! A very special thank you to Tim Horton's, West Shore Parks and Recreation, CFX radio, and the organizing committee of Corrine King, Rhonda Schellengberg, Mena Westhaver, Angelina Loglisci, and Sandy Clarke, and to all the families and friends that travelled from all over the Island to be with us.

Look forward to even bigger and better things next year!



3rd Annual Scleroderma Walk in the Park for Research

Saturday, June 29th - Valemount (Centennial Park—5th Ave)

Way to go Valemount! Teresa Colosimo reports the Valemount walk had an incredible turnout with over 60 participants and raising over \$4700. They also raised additional funds from our bake sale and raffle, all thanks to those who donated.

The day started off with poor weather but they beat the cold with hot coffee provided by Tim Hortons who kindly donated enough coffee for all. The sun came out for part of the walk and everyone had a great time. After the walk we enjoyed a wonderful potluck lunch, played games and had an amazing afternoon.

Teresa cannot believe the support that she received from family, friends and community!



News and Announcements



Supporting Scleroderma Research - Decisions, Decisions

How do we decide what research studies to start to and continue to support?

SABC is fortunate to have members with medical research expertise (aka: Team Research) who are tasked with reviewing all requests for research study support whether it be financial or simply memoranda of support. Many research study grant applications now require written confirmation of patient organization's support.

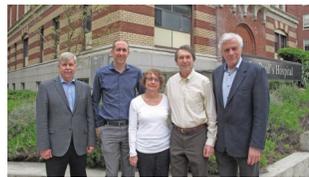
Based on Team Research's recommendations, the SABC Board then votes whether or not the proposed study is one SABC members should support.

The SABC Board receives update reports from scleroderma studies we support, like SPIN-SHARE below:

All of SPIN's staff, investigators, and patient participants are very grateful to the Scleroderma Society of BC. I'm attaching a letter expressing our gratitude and a summary of how we used the funding that you provided to us in December 2017. Thanks for your ongoing support!
 Brett D. Thombs, Ph.D.
 Professor, Faculty of Medicine, McGill University
 Senior Investigator, Lady Davis Institute of Medical Research, Jewish General Hospital



SABC is noted as a supporter in research publications, like St. Paul's *Promise* magazine:



Kevin J. Keen, PhD (medical statistician)
 Christopher J. Ryerson, MD (respirologist)
 Fran Schooley (clinic coordinator)
 Pearce G. Wilcox, MD (respirologist)
 James V. Dunne, MD (rheumatologist)

Any questions about the research SABC members support? Feel free to reach out to Team Research members: Michele Gervais, Tiasha Burch and Veronika Boyeva (contact info on page 9).



News and Announcements Con't

Sharing Info about Scleroderma-Friendly Health Professionals

Do you know a healthcare professional who is knowledgeable about scleroderma? Whether it is a doctor, dentist, or physiotherapist, we want to know!

We are compiling a list of healthcare professionals for the scleroderma community. Help us make this possible by sending us your healthcare professional's name. We will ask them for permission to be added to our website.



Please email veronikaboyeva@gmail.com with their information.



St. Paul's Pulmonary Fibrosis Support Group



The next support group meeting will be on **August 20, 2019**.

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 1:30 to 3:30 pm.

All patients with pulmonary fibrosis of any kind or level of severity, caregivers and significant others are welcome to attend.

Information about the Scleroderma Lung Clinic at St. Paul's Hospital and support group meetings may be [scleroderma-lung-clinic](#) or on the SABC website or by contacting Fran Schooley at 604.806.8818 Extension 2, or email fschooley@providencehealth.bc.ca.

Next group meetings: October 22, December 10th, 2019, February 11, April 14 and June 23, 2020.



Article

My Scleroderma Conference Trip Was Just What the Doctor Ordered

Excerpt from *Scleroderma News*, May 28, 2019 by Kim Tocker (a New Zealand scleroderma patient).



The last two weeks have been extremely challenging. Living the scleroderma lifestyle means I never know what is around the next corner. Waking up brings a daily surprise, sometimes good, and other times not so pleasant. I have learned to go with whatever the disease presents me with each morning.

However, no matter how adaptable I think I am, kidney infections seem to sneak up on me. I felt one coming on suddenly a fortnight ago; the signs were obvious about 60 minutes before its onset. In addition to the dread I felt, I knew that in six days, I would fly to Wellington to attend the Scleroderma NZ National Seminar 2019. I needed to be treated with antibiotics as soon as possible if I were to have a chance of attending.

While sitting in the emergency room at 4 a.m., with IV fluids and antibiotics running through a drip, I considered whether traveling the following week would be worth it. I have learned over the years that pushing myself when I am unwell is unhelpful and can cause a delay in my healing. Deciding to go was tricky, but in the end, my husband, Max, and I chose to make the trip. We set out with trepidation, my suitcase laden with all manner of prescription medications just in case — and a hope that all of the action wouldn't exacerbate my symptoms.

After an early night, Max and I set out to the conference the next morning. As we made our way into the seminar room, I was hit with a massive wave of friendliness and welcoming smiles. I experienced an innate feeling of belonging. I was with "my people."

We learned a lot from the speakers and came away feeling empowered. I felt unwell at times but managed OK. However, something happened that I hadn't expected. That feeling of belonging while in the presence of "my people" gave me a superpower that changed something for me.

It is difficult to explain precisely what shifted, but the change was one of healing and it was helpful. Gathering with other scleroderma warriors in one room offered a sense of belonging and a powerful feeling of kinship. This experience held me together inside because I knew that I was surrounded by others who fully understood my daily experience of living with scleroderma.

Thank you to all of the New Zealand scleroderma warriors who came to the weekend and love to those who couldn't make it. Whether we talked or not, your presence was part of something bigger for me, and I am eternally grateful.

I am so happy I made it to the weekend — as it turns out, it was just what the doctor ordered!

Note: Scleroderma News is strictly a news and information website about the disease. It does not provide medical advice, diagnosis, or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website. The opinions expressed in this column are not those of Scleroderma News or its parent company, BioNews Services, and are intended to spark discussion about issues pertaining to scleroderma.

SABC Board of Directors 2018 / 2019

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Disclaimer

The Scleroderma Association of B.C. does not endorse any drug, treatment, or dietary material presented in this newsletter. Always discuss alternative medical options with your doctor before including them in your treatment plan. Although we aim to keep you informed and engaged, the opinions shared through this newsletter are not those of the Scleroderma Association of B.C. and are intended to spark discussion.

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).