



SCLERODERMA ASSOCIATION of B.C.

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Issue 2 **SCLERODATA** 2020

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Highlights

Another Successful Scleroderma Awareness Month

For World Scleroderma Day, on June 29th, Canada Place, BC Place Stadium and Telus World of Science were lit up in scleroderma “blue” to show our support for all those living with scleroderma around the world.



And throughout the entire month of June, people across BC and Canada participated in our virtual event “**Move for Scleroderma**”. Congratulations to all the scleroderma patients and their supporters who participated! Participants engaged in an activity of their choice, in a location of their choice. They walked, galloped, golfed, kayaked, cycled and hiked, many with their 4-legged furry friends, in support of scleroderma awareness and research. This virtual event included 5 teams of 21 participants. 250 supporters donated in June, raising a total of \$47,546.

Check out these two videos on SABC’s website, capturing everyone “keeping scleroderma hope afloat” and “moving for scleroderma”, showing how we all joined together in spreading awareness and raising funds to support scleroderma research!

[Hope Afloat](#)

[Move for Scleroderma](#)



Due to Covid-19, Rosanne & David Queen conducted a virtual cheque presentation in the amount of \$43,000 to the SABC Research Project. The balance raised will be held for other research projects across Canada.

Highlights cont'd



Kamloops



Pemberton



Valemount



Vancouver



White Rock

Move for Scleroderma!



Richmond



Whistler



Vancouver



Victoria



Victoria



North Vancouver



Vancouver



Deroche



North Vancouver



Vancouver



Fort Mac, AB



Deroche

SABC AGM & Conference

Your 2020/2021 SABC Board of Directors

On October 3rd via Zoom, SABC President Rosanne Queen thanked the 2019/2020 board members and other volunteers throughout the province who continue to bring public awareness to scleroderma. We also said goodbye to long time board member Grant Dustin and to now doctor, Veronika Killow.

Returning Directors of the Board were confirmed as: Tiasha Burch, Michele Gervais (vice president), Jeff Gammon (secretary), David Queen, Patrick Livolsi (treasurer), Pat Thomasson (patient liaison), and Rosanne Queen (president).

A warm welcome to new Board Members: long-time SABC member Beth Miller and new member medical students Valerie Doyon, Jessica Jun and Grace Kim.

Conference Speakers and Social Time

Fifty-eight (58) patients and their supporters registered for the virtual conference this year. The morning included presentations from two conference speakers: Dr. Alyson Wong and Dr. May Kazem. The conference concluded with an opportunity for attendees to 'socially meet' using Zoom's break-out rooms and talk about various topics of interest.

Check out [SABC Highlights](#) to watch these presentations on interstitial lung disease and what to expect with scleroderma over time.

ZOOM MEETING



Good to Know

Keeping Connected with One Another!

Online Holiday Luncheon



SABC would still like to hold its **annual Holiday luncheon**, albeit virtually this year. Even though we are unable to gather together in person, we would still like the opportunity to socialize/ connect with each other this holiday season.

Click on this link **by November 15th** and let us know what day works best for you to join us from the comfort of your home! [Cast Your Vote](#)

1. Type in your name in the empty box
2. Find the date and time best for you and click on the corresponding **Blue** box
3. Don't forget to click the green **Send** box!

We invite and encourage all members to join us for this annual tradition to toast the holiday season, meet some new faces and simply enjoy the company of others, learning and sharing information as a member of the scleroderma community!

Results of the poll with dates/times for the virtual luncheon will be posted on our website and links to join sent out to all members via MailChimp email.

New SABC 'Essential Service' Patient Liaison

Pat Thomasson, a SABC Board Member has taken over patient (and their supporters) communication responsibilities formerly carried out by Dianne McPhee. Thank you Dianne for being such an important link to all SABC members for the past years. Below is a message from Pat:

Hello from Surrey!

I'm excited to take over from Dianne and answer all your phone and email inquiries.

You can reach me at 604-371-1005 and/or email address info@sclerodermabc.ca. If I don't pick up or reply to your email right away, rest assured I'll respond to your inquiries as quickly as I can and if I'm not able to answer your question, I will direct you to the right person!

As SABC is constantly updating our member contact information, please be reminded to email me any recent changes to your current email address, mailing address and phone number.

*If you know of someone who is a new patient and who would like to receive our *Sclerodata* newsletter by email please don't hesitate to forward the above SABC contact information to them.*

Thank you, Pat



Good to Know cont'd

SABC to be Honored at St. Paul's Hospital

At your next visit to the St. Paul's Scleroderma Clinic, keep an eye out for a SABC commemorative plaque! The St. Paul's Foundation have announced they want to publicly thank all of us SABC members for our financial support over the many years.



From 2000 to the present, SABC has donated \$653,846 for research and for the purchase of an ultra sound machine in 2010

- From 2000 to 2008, \$233,229 was raised in no small part to the Dhanda family's fundraising efforts in memory of their mother, Gurmej Kaur Dhanda.
- From 2010 to the present, an additional \$420,617 has been donated specifically to research including SABC's own research project. The Scleroderma Ride for Research raised \$304,028 of this with an additional \$116,589 raised from other sources like the June walks and generous donations throughout the year

Congratulations SABC! Please help us spread the word on social media of this imminent recognition!

Shout Out to 'Published' SABC Members

As you may recall, SABC board member, Tiasha Burch and member Dr. Mark Harrison have been working with a team of researchers at UBC to understand what scleroderma patients' preferences are when considering stem cell transplant as a treatment option. You, dear reader, may have been among the many individuals that completed a survey for this study!



This summer, the research team successfully published an academic article, along with a commentary written by Tiasha, in *The Patient*. **Congratulations Tiasha and Mark!**

SABC plans on hosting a Zoom webinar in the new year to provide members with more information about the results of this project so please check your email for this MailChimp invite.

Speaking of Upcoming Zoom Webinars...Caring for Our Skin

SABC is in the planning stages of securing a speaker from The Skin Care Centre in Vancouver to speak on a topic of interest specific to wound care. Scleroderma patients have digital ulcers and other kinds of scleroderma skin-related wounds they deal with on a daily basis.

Questions we would like answers to, for example, are: Why do wounds appear? What types of wounds are there and how do we treat them? What are the best practices for daily/weekly care routines? How do we best avoid wounds in the first place? What are some of the wound resources out there for patients?

An important topic for sure.

Again, stay tuned for another MailChimp invite in your email inbox!



Interesting Reading

Keeping Informed is as Easy as Click, Click, Click!



Disability Alliance BC (DABC) Rolls Out Their Access RDSP Program

The Registered Disability Savings Plan (RDSP) is a powerful way for eligible people with disabilities to save for their long-term financial security. It also enables people receiving social assistance to protect assets and income. In August 2016, DABC started operating **Access RDSP** in partnership with Plan Institute and the BC Aboriginal Network on Disability Society (BCANDS). **Access RDSP's** goal is simple: to increase the number of British Columbians who have an RDSP.

Through this partnership, DABC advocates provide direct service by:

- Helping people who are eligible for the RDSP to apply for the Disability Tax Credit (DTC), a prerequisite for the RDSP. To make applying easier, Access RDSP has created an interactive tax credit tool.
- Going to the bank or credit union to help individuals open an RDSP
- Connecting individuals who have the DTC to Plan Institute or BCANDS who will help people open an RDSP.

Click on this [Planning for the Future](#) to learn more.

6th Systemic Sclerosis World E-Congress

The FESCA – the Federation of European Scleroderma Associations, has been offering our community, since July, a ‘virtual’ world congress experience. They have been recording congress speakers and we will have access to the presentations until December 20th. Registration is free and we can view as many sessions as we like. Check out this link to register and learn about [what is happening with scleroderma globally](#).



Scleroderma Canada Virtual Conference, October 5 - 9, 2020

Scleroderma Canada (SC) offered, in their conference, a variety of topics, featuring interesting speakers providing information helpful to patients and others in the scleroderma community.

Presentations are being uploaded to YouTube at [Virtual Conference](#).



Grant Dustin, SABC member and previous *Sclerodata* editor, attended several program sessions and stated:

“The presentations illustrated the growth of knowledge about the disease and the progress in treatments available to scleroderma patients. For example, Dr. Ahmad pointed out that successful stem cell transplantation can extend the life of the patient but it's important to recognize that this treatment is a long process, with risks, and it is not a cure. Dr. Harper spoke about some of the new drugs available for scleroderma-associated ILD or PAH and Dr. Volkmann presented practical information on the topic of nutrition for scleroderma patients.” **Thank you, Grant!**

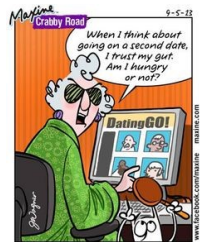
Interesting Reading con't

Keeping Informed is as Easy as Click, Click, Click!

Learning to Love Our Friend: The Gut

Presented as part of the Scleroderma Foundation's fall patient education series, this presentation focuses on scientifically based kindness strategies to befriend the gut by enhancing food tolerance and augmenting nutrition; while considering prevention and management strategies to reduce scleroderma related GI symptoms and complications.

Click here: [Learning to Love Our Friend: The Gut](#)



A review of this YouTube video was conducted by Board Member, Beth Miller:

“Dr. Saketkoo clicks through her slides at a very fast rate, so I found myself pausing and rewinding the video. She is very relatable and passionate about the topic. She speaks about the brain<—>gut connection and outlines the digestive system explaining the various issues that can impact each part. She emphasizes the importance of movement, and also talked about breathing, the diaphragm, and singing or humming with names of some organizations who have online singing groups!” **Thanks, Beth!**

Managing your Pulmonary Fibrosis During the COVID-19 Pandemic

If you happen to have missed the Canadian Pulmonary Fibrosis Foundation's (CPFF) webinar on pulmonary fibrosis and COVID-19, featuring Dr. Marin Kolb, Sarah Goodwin and Sharon Lee, it has been posted on YouTube here: [PF and COVID](#)



(And Now for Something Completely Different...) Member Engagement

A Guessing Game

It looks like the 80s or maybe even the 90s? Can you recognize, provide the names of and any interesting anecdotes for, these past SABC Board Members?



Send your best guesses to info@sclerodermabc.ca with the subject line: Guessing Game. Correct guesses will receive a 'gift package' in the mail!

The winners, the names of the below and any interesting anecdotes will be published in the next *Sclerodata*!



SABC Board of Directors 2019 / 2020

President	Rosanne Queen	604-984-9425	rq.sabc@telus.net
Vice President	Michele Gervais	604-761-7782	gordmich17@gmail.com
Secretary	Jeff Gammon	604-809-6939	jeff.t.gammon@gmail.com
Treasurer	Patrick Livolsi	778-791-7834	treasurer@sclerodermabc.ca
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Board member	Tiasha Burch	778-984-3745	burchtiasha@gmail.com
Board member	Beth Miller	604-815-8740	SABCBeth@gmail.com
Board member	Grace Kim	778-926-0118	ggkim@student.ubc.ca
Board member	Valerie Doyon	250-202-9449	valerie.doyon@alumni.ubc.ca
Board member	Jessica Jun	778-887-0523	jessjun@student.ubc.ca
Patient Liaison	Pat Thomasson	604-591-3033	pthomasson2001@shaw.ca

Community Contact Representatives

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Nelson	<i>Seeking Representative</i>		
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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).