



# SCLERODERMA ASSOCIATION of B.C.

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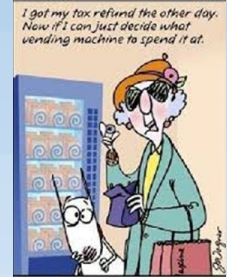
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## Issue 1 **SCLERODATA** 2020

### ***In This Issue:***

- Highlights
- Good to Know
- Interesting Reading



## ***Highlights***



### ***June is Scleroderma Awareness Month!***

As in past years, enthusiastic leaders in different parts of the province make plans to host group activities in support of fundraising for scleroderma research and to promote greater awareness of the disease. However, due to the COVID-19 health regulations and our concern for the health of all those involved, these plans now have to be changed.

### ***Introducing the 1<sup>st</sup> Virtual June Event for SABC!***

Previously planned events for this year have been replaced by a **month-long virtual campaign** to support fundraising and to promote awareness of scleroderma. Supporters who would have gathered together in-person at scheduled events in June, and anyone else for that matter, will now be able to participate online in this virtual event.

Like other virtual events, this is an opportunity to participate and connect with others in a shared cause without having to be in the same location. We won't be physically together in large groups but we can still support this province-wide campaign, which **starts on June 1<sup>st</sup> and ends on June 29<sup>th</sup>, World Scleroderma Day.**

All funds raised will support research in BC and in other parts of Canada and receipts will be issued for all donations.

(See the next page for details on how to participate)


# Highlights cont'd

## ***We welcome your participation in this virtual event!***

There are many ways to participate. There is no specific 'walk' requirement, although walking may be a choice for many. Using social distancing, you may choose to go for a walk or run, a bike ride, hold a virtual or socially distanced family activity or do some relaxed stretching at home. Your options are endless, and the choice is yours to be as energetic, adventurous or creative as you want to be.

We encourage participants to capture their experience with **photos or videos**, which can be shared online. Photos and videos, with accompanying information, such as location, possibly first names of people featured and other details or comments, may be sent by email to SABC's Alex MacDonald at [alexandria.cmacdonald@gmail.com](mailto:alexandria.cmacdonald@gmail.com). A slideshow or YouTube of these submissions will be created to demonstrate how we all came together in the month of June to promote awareness and raise funds in support of scleroderma research. We also encourage you to share your participation through Facebook (don't forget to tag us: Scleroderma Association of B.C.).

### ***How to Participate - Joining and Supporting the June Virtual Campaign***

Instructions for **participation** and for **making donations** are available by going directly to the SABC website, [sclerodermaabc.ca](http://sclerodermaabc.ca) home page and clicking on the **CLICK HERE** beside the  This brings up the options for participating and donating.

Overall Walk/Ride Support: Use the **Donate Now** button!

Specific Team Support: Scroll down and click on a Fundraising Team or an Individual Fundraiser. Don't see a team for your specific BC region? Choose the Walking for a Cure - Anywhere in BC Team! Use the **Donate to Team** or **Donate to Me** buttons!

Join a Team Support: If you've selected a Team, scroll down and click on **Join this Team** button to help with fundraising efforts then forward the link to the people that care about you.

If you have questions regarding participation, please contact SABC's Yvonne Alexander at [yvonnea@shaw.ca](mailto:yvonnea@shaw.ca)



*Rosanne Queen, promoting scleroderma awareness*

*while watching icebergs in Newfoundland last year.*

**SCLERODERMA**

*Awareness breeds compassion,  
which leads to funding,  
which leads to a cure!*



## Good to Know

### ***SABC Conference and AGM – a virtual affair - October 3, 2020***

With our focus on scleroderma awareness events being held in June, the SABC conference and Annual General Meeting will be held in October again this year. It is scheduled to be held on **Saturday, October 3, 2020 as a virtual event**. The impact of the COVID-19 pandemic has resulted in it being changed from an in-person event to a virtual affair. It will be available online as a webcast or video conferencing service of some kind, and will include the AGM and speakers on a variety of topics. Your SABC team is working on arrangements and will provide more information later - keep your eye on our website!

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### ***SABC Newsletters and Magazines***



This is the first issue of the *Sclerodata* newsletter since last August, and many of our readers have probably been wondering about this apparent lack of communication. Traditionally, issues of *Sclerodata* were produced three or four times a year, usually a 10-page newsletter featuring reports, news and tips of interest to scleroderma patients. It was sent to our readers online or as mailed printed copies, as well as being available on our SABC website, [sclerodermabc.ca](http://sclerodermabc.ca)

The recent production of a magazine, *The Bulletin*, is a major change in SABC communications. The new magazine, and the new SABC website, are the result of collaborative efforts by the provincial scleroderma support organizations in British Columbia, Quebec and Manitoba. Quebec has been instrumental in this process, as was discussed in articles in *Sclerodata*, Issues 1 & 2 last year.

You have received two issues of *The Bulletin* so far, in April and November of last year. The content of those two magazines included much of what would have otherwise been presented by way of *Sclerodata* newsletter issues. The third issue of *The Bulletin* is prepared but printing has been delayed due to COVID-19 controls. If you know of any person or medical office that wants to be on the mailing list to receive *The Bulletin*, please contact Rosanne Queen at 604-984-9425.

The *Sclerodata* newsletter will continue to be issued but the frequency and format will be adjusted to partner with *The Bulletin* magazine in maintaining SABC communications.

*"I used to be indecisive. Now I'm not so sure."*

# Good to Know Cont'd



## **Scleroderma Patient-centered Intervention Network (SPIN)**

The Scleroderma Patient-centered Intervention Network (SPIN) recently announced the launch of their new **SPIN-Hand toolkit**, the latest development from their new SPIN-SHARE platform and SPIN-SHARE toolkits.

The SPIN-Hand toolkit provides exercises to improve hand function with sections to help you develop a personalized program, set goals, and track your progress. Instructional videos demonstrate how to perform each exercise properly with pictures to illustrate common mistakes.

**SPIN-SHARE** is a central hub where you can access all the online SPIN toolkits as they become available. See this website for instructions on how to access **SPIN-SHARE** and the **SPIN-HAND Toolkit**: [Login or Register](#)

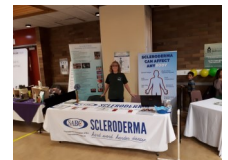
More information about the SPIN organization and its programs is available on their website, [SPIN](#)

We are pleased to note that the Director of SPIN, Dr. Brett Thombs, was honoured by induction into the Royal Society of Canada last November. Congratulations!

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## **2019 Kelowna Wellness Fair**

Angie Reglin, SABC's Kelowna community representative set up an information table at Parkinson Recreation Center on Sunday, November 3, 2019 right by the main entrance, allowing SABC much exposure as everyone who walked in, walked by her table first!



The day was a great success in getting information about scleroderma out to the public. Many people stopped by and asked questions and took away informational pamphlets. Not surprisingly, very few of the hundreds of people who attended had actually heard of scleroderma, never mind being able to say it!

SABC would like to thank Angie and scleroderma patient Gary Groff and his wife Linda who sat with Angie at the information table for 3 hours. Angie certainly appreciated Gary being there to share his story with many visitors who came to the table, helping to promote awareness and education about scleroderma. Angie was also glad to have this opportunity to get better acquainted with Gary and Linda.

The Wellness Fair is on the calendar for this year and we are hoping it will be possible for it to take place! Angie is looking forward again to being part of Kelowna's support for scleroderma awareness in 2020.

# Interesting Reading



## COVID-19

In these trying times of adjusting to the changes brought on by the pandemic, the Scleroderma Association of B.C. would like to send you and your family its wishes for safety and good health.

There are many sources of information related to COVID-19, including guidelines for coping with its impact on individuals and society. Presented here are references to some of the government sources as well as some information specifically related to **scleroderma interests in the context of COVID-19**.

### Scleroderma and Covid-19

A video forum, *Scleroderma & COVID-19: 'A Conversation with the Experts'* was held on March 21, 2020. The video forum was hosted by **SPIN** (Scleroderma Patient-centered Intervention Network), in support of its goal to develop, test and disseminate tools to support people living with scleroderma. Sponsorship for the production came from the Scleroderma Society of Ontario, Scleroderma Canada, the Scleroderma Foundation, and the Scleroderma Research Foundation. (read more about SPIN below)

- the video forum and accompanying questions and answers are presented here, courtesy of Sclerodermie Quebec: [Scleroderma and COVID-19](#)

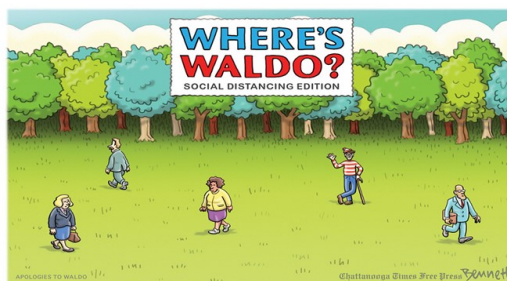
The video only is also available on YouTube via the SABC website: [SABC Videos](#)

### Government of Canada

On June 5, 2020 the Prime Minister announced support coming to help Canadians with disabilities deal with extra expenses during the pandemic.

This proposed support includes a special one-time, tax-free payment (\$600) to individuals who are certificate holders of the **Disability Tax Credit** as of June 1, 2020.

See the details here: [Proposed Disability Tax Credit](#)



# Interesting Reading Cont'd



## Government of British Columbia

In early April the BC government announced that, due to COVID-19, new emergency measures were being put in place to ensure that people on income or disability assistance and low-income seniors, do not encounter additional barriers. Those eligible will automatically receive a \$300 supplement on their cheques issued in April, May, and June.

More information is available on this website: [Disability Supplement](#)

The BC Minister of Social Development and Poverty Reduction, Shane Simpson, noted that for those who might not have internet access, more information is available by calling 1-866-866-0800.

## Mental Health

If you or someone you know would like emotional support to deal with a feeling, issue or concern or if you are looking for information on mental health resources or services, **call 310-6789 (no area code needed) any time of the day or night** or visit these websites:

- Virtual mental health supports: [Virtual Supports Covid-19](#)
- Coping with stress, anxiety and substance abuse during COVID-19, from the Mental Health Commission of Canada: [Coping with Stress](#)
- Tips for supporting your mental health through the COVID-19 pandemic, from BC Mental Health and Substance Use Services: [Mental Health Support](#)
- Conversations about mental well-being. The **WE** Charity presents a series of podcasts to help us challenge the way we think and talk about mental well-being. Featuring intimate and soul-lifting interviews and conversations, the WE Well-being podcast series is an open-minded discussion that boosts grit and busts stigma around mental health. Hosted by Madame Sophie Grégoire Trudeau: [WE Conversations](#)

*"Why is it called "after dark" when it really is "after light"?"*

## SABC Board of Directors 2019 / 2020

President	Rosanne Queen	604-984-9425	rq.sabc@telus.net
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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).