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SABC

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SCLERODATA

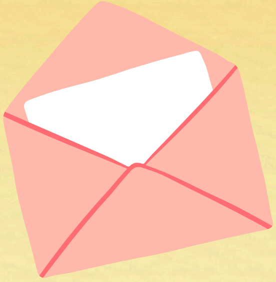
Help Us Make a Difference for the Pulmonary Hypertension and Scleroderma Community

Scleroderma Association B.C.

People living with scleroderma face unique challenges. For some, those challenges include developing pulmonary arterial hypertension (PAH) - a progressive and life-threatening condition. Timely diagnosis and access to new treatments can make all the difference, but too often, patients face delays that can cost them their health and quality of life. That's why we're proud to support PHA Canada's Time Matters PAH campaign - an advocacy initiative pushing for timely access to sotatercept, a breakthrough treatment that offers hope to PAH patients, including those in our scleroderma community.

Here's how you can help and it's simple!
- Take 2 minutes to send a pre-written letter to your provincial health minister. Once you click on the link, scroll down and click on the blue box, "send a letter", type in your name and address and then hit "send your letter" at the bottom of the page. It automatically fills in the rest for you.
- Share this with your family and friends to amplify your impact.

Every voice matters - not just those living with scleroderma! By speaking up - you, your family and friends are helping pulmonary arterial hypertension and scleroderma patients access this new treatment to improve their day to day lives.



Take action now by sending a letter at: www.phacanada.ca/advocate. Together, we can ensure timely access to life-changing treatment for PAH and scleroderma patients in Canada.

2025'S VIRTUAL SUPPORT & CONNECTION MEETINGS: COME ZOOM WITH US

SABC Community Support Groups

COME ZOOM WITH US

The Scleroderma Association of B.C. strongly believes in the merits of support groups. Support group meetings create an environment conducive to discussion by providing a safe place where people affected by the disease, their families, friends and caregivers can give and receive practical and emotional support.

Currently, SABC is offering virtual support (Come Zoom With Us) meetings featuring various topics for discussion on Wednesdays, 7:00 – 8:00pm PST.

Keep an eye on your inbox and social notifications for the Come Zoom With Us Time to Register reminders. People with Scleroderma, family, supporters, and caregivers are ALL welcome to attend!

Wednesday, May 14, 2025 | 7-8pm PT
Stretch and Feel Good with Teressa
Join our special guest, Teressa for a guided gentle stretch and feel-good class. The class will start with a guided breathing exercise then move gently from the top of your head to the bottom of your toes and finish with savasana. People with Scleroderma, family, supporters, and caregivers are ALL welcome to attend! Teressa will give you different options throughout the class to help you find your own movement.

Daily stretching will help strengthen muscles, help with range of motion to prevent, or slow down the loss of motion in joints. Stretching our bodies will leave you feeling awake and centered for the day ahead. For this class it will help if you have on hand: a yoga mat; blocks; pillows; a blanket; strap or scarf; water.
To **register** for this session please email Teressa at pattess72@hotmail.ca After registering, a waiver will be sent to you for insurance purposes and a zoom link.

Wednesday, July 2, 2025 | 7-8pm PT
Celebrate Summer!
Join us for an evening session to check-in, share, and chat. People with Scleroderma, family, supporters, and caregivers are ALL welcome to attend!

Here's the link to register: **Celebrate Summer!** After registering you will receive a confirmation email containing information on how to join the meeting.

JUNE AWARENESS EVENTS 2025

June is Scleroderma Awareness Month across Canada and the United States with June 29th as World Scleroderma Awareness Day. This special time is dedicated to educating and raising public awareness about this little-known and often misunderstood orphan disease and stress the critical importance of funding research to find a cure and support quality of life for people living with scleroderma. As one of our objectives is to encourage as many people as possible to learn more about this disease which affects over 20,000 Canadians, the SABC holds awareness and fundraising events throughout the province with our "Moving to Cure Scleroderma" campaign.

TSAWWASSEN - Groove to Cure Scleroderma

L📍 Location: KinVillage, Tsawwassen
📅 Date: Saturday, May 31, 2025
🕖 Time: Doors open at 7:00 PM | Event ends at 11:30 PM
👤 Coordinator: Kenny Reid
🍷 Cash Bar: Enjoy Beer, Wine, Non-Alcoholic Beer, and Soft Drinks
🎟️ Raffle Prizes & 50/50 Draws: Bring some cash and take a chance on great prizes—all while supporting an important cause.

VANCOUVER - Scleroderma Ride for Research

📍 Location: Stanley Park, Vancouver, BC V6G 1Z4
📅 Date: Sunday, June 15, 2025
🕘 Time: 9:00 AM Start
👤 Coordinators: Rosanne & David Queen (North Vancouver)
🚲 Choose Your Challenge: 30 km Ride to UBC OR 10 km Ride or Walk around the Stanley Park Seawall
🧺 Or Just Sit & Chill: Your presence makes a difference!

ANYWHERE IN B.C. - Moving to Cure Scleroderma

ALL OF JUNE / VIRTUAL MOVING
VIRTUAL COORDINATOR: TERESSA COLOSIMO – VALEMOUNT & NORTHERN RURAL COMMUNITIES
Keep checking SABC's website for detailed info and how you can participate.

A BIG Thank-You to the Event Coordinators! Let's support them and each other by showing up! ♻️

SUPPORT SABC AT YOUR NEAREST RETURN-IT EXPRESS!

Did you know you can continue to and easily raise money for SABC all year by using the Return-It Express? All you do is put your cans, bottles etc. in a clear bag, then get a label at the kiosk by entering 604 371 1005. It will print a Scleroderma Association of B.C. label for you to put on the bag… and then your done!
Find your nearest Return-It Express location HERE.

SABC’S ANNUAL AGM & CONFERENCE

Exciting follow-up to last Fall’s conference is the addition of another SABC Board Member! Please join the SABC in welcoming Sara Blais to the Board of Directors.

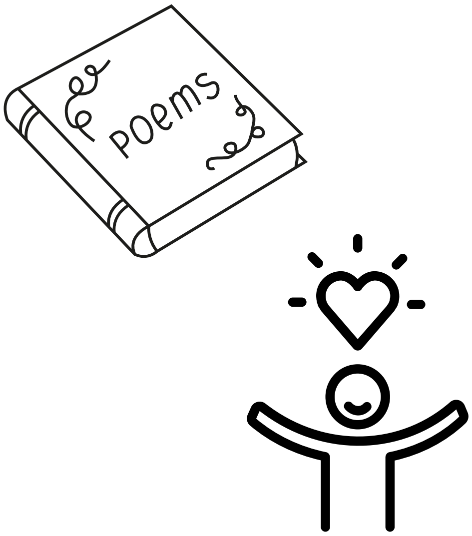
Sara is a second-year medical student at the University of British Columbia. Before medical school, she studied neurobiology and psychology at the University of Victoria. She joined the Scleroderma Association of BC Board to raise awareness about scleroderma and enhance public understanding of its impact. With an interest in the intersection of dermatology, psychiatry, and rheumatology, she hopes to contribute to advocacy efforts and increase awareness of scleroderma.

This year’s AGM & Conference will be hosted on Saturday, October 25th, 2025 as an in-person event in beautiful Burnaby, located at Holiday Inn Express Metrotown. Keep an eye on your inbox and our website for details on parking and accommodations coming soon!

As usual, the agenda for the day will include the usual social and informative sessions starting with the Annual General Meeting, followed by speaker presentations. Please keep checking SABC’s website often for updates regarding the day and how to attend.

Life Is

Life is an opportunity, benefit from it.
Life is beauty, admire it.
Life is bliss, taste it.
Life is a dream, realize it.
Life is a challenge, meet it.
Life is a duty, complete it.
Life is a game, play it.
Life is a promise, fulfill it.
Life is sorrow, overcome it.
Life is a song, sing it.
Life is a struggle, accept it.
Life is a tragedy, confront it.
Life is an adventure, dare it.
Life is luck, make it.
Life is too precious, do not destroy it.
Life is life, fight for it.



by Mother Theresa

KEEP MOVING AND NEVER GIVE UP

By Teressa Colosimo, SABC's Valemount and Northern Rural Communities Rep, January 2025

Hi, I would like to introduce myself to new and old members of SABC. My name is Teressa, and I am currently SABC's Community Representative for Valemount and Northern Rural Communities.

I was diagnosed with Scleroderma in November 2011. After being diagnosed, I found myself depressed, anxious and lost. I felt like I had no control over my life. There were a lot of changes I had to make; it was hard letting go of my old life and excepting my new life. I have always been active and enjoyed practicing yoga before I was diagnosed with Scleroderma. But after a while going to classes, I found myself feeling self-conscious wearing my gloves or getting out of breath or just not moving the way I used to move. Feeling frustrated, I started not showing up for classes. Thank goodness for online classes, which kept me motivated and helped so much with my mental health.

In 2023, I had the privilege of joining a zoom yoga session with Lori Pierce and her special team. She touched my heart, I sat there and cried after her session. I thought, what an amazing woman, sharing her love for yoga and the diversity yoga has with our bodies. You could feel her passion and her joy for yoga. With Lori and her team showing the sustainability and diversity of yoga, it made me feel I must share as well.

Long story short, I was walking with my friend and was sharing my experience during the yoga zoom session and how Lori had inspired me to teach. But how? With living here in Valemount and being not too crazy about an online teaching program. My friend mentioned she had seen an advertisement for a yoga teacher training course in Prince George B.C. I sent an email, and I was accepted into the program within that week. Wow this was meant to be!! I had two wonderful teachers and they both taught me so much about myself and the diversity of my body. After 6 months of traveling and so much studying, I was certified in October 2023 as a 200-hour Yoga and Movement Teacher.

Through this past year, I have been taking zoom classes with Scleroderma for Yoga and learning different ways to practice yoga safely. Our bodies are so special, and we all move in a different way. Also, coming up this year, I will be taking a teacher training course for Yoga for Scleroderma and Arthritis. Soooo excited, I cannot wait to share that with everyone.

SABC has made my dreams come true. I am teaching yoga virtually to you in the comfort of your own home, throughout Canada. There are 3 classes: Chair, Stretch & Feel Good and Gentle Flow. I guide and move you safely through a peaceful and healing practice that you can enjoy throughout your life.

Yoga has allowed me to learn so much more about myself and I am still learning. Yoga has helped me settled my brain and has helped me to listen to my body. By honoring my body through movement or just saying to myself it is ok just to lie here still and listen to my heartbeat.

This is the wonderful thing about yoga, it is like a never-ending story, it keeps you wanting more. Finding what works for you, and makes you smile from ear to ear.

Yoga has changed my life so much and I want to share my passion with you.

Virtual Yoga Classes

Tuesdays: Chair Yoga | Time: 11:00 am PT
Mondays: Stretch & Feel Good Yoga | Time: 6:30 pm PT
Thursdays: Gentle Flow Yoga | Time: 6:30 pm PT

All classes include meditation, breathing techniques, and performing yoga postures. Each class is 45 minutes to an hour. To register and for more information please email Teressa at pattess72@hotmail.ca or call at 250-566-3165. At that time, Teressa will send the waiver and zoom registration to get started!

Diet Rest Exercise Attitude Medication Socialization

By Nora Sundby-Slamp, SABC member, September 1989

When I was first stricken
This disease made me mad,
The hardest part was coping
Not knowing what I had.

Then I remembered a phrase
“Believe in the magic of DREAMS”
So I turned pain into promise
I was rewarded, so it seems.

My first step was proper Diet
Chocolate and coffee were out,
Then how much better I felt
Of that I’ve no doubt.

I had to learn to get Rest
Even when I felt up to going,
And not to get over-tired
Became well worth knowing.

I had to work even harder
To develop and Exercise plan,
I spend hours at physio
To stay as flexible as I can.

But the change in my Attitude
Became my strongest asset,
For I’m positive in life
You should give as good as you get.

Through Medication and loving care
My scleroderma's in remission for today,
I try to live a daily program
So in good health I can stay.

Above all, I love people
Socialization comes easy for me,
If I can help one other person
That's where I want to be.

Just remember to think positive
DREAM the most for each day,
And don't dwell on your ills
Smell more flowers along the way.

The Scleroderma Patient-centered Intervention Network (SPIN)

Many people with inflammatory rheumatic diseases live with persistent pain, but important differences exist between diseases in how pain is considered in research and clinical management. While pain research is a key focus in many rheumatic diseases, it remains largely overlooked in scleroderma.

For the Scleroderma Patient-centered Intervention Network (SPIN), patient engagement is at the forefront of all research studies. The SPIN-PAIN project aims to develop a survey to assess pain in scleroderma by identifying pain sources, available management services, and barriers to care. In 2024, the SPIN team conducted discussion groups in English and French with people living with scleroderma from around the world to refine the pain survey. In January 2025, we sent the final pain survey to the SPIN Cohort and have collected over 400 responses so far!

In the next couple of months, we will be working on analyzing the data and publishing the results. Stay tuned for meaningful insights on pain in scleroderma!

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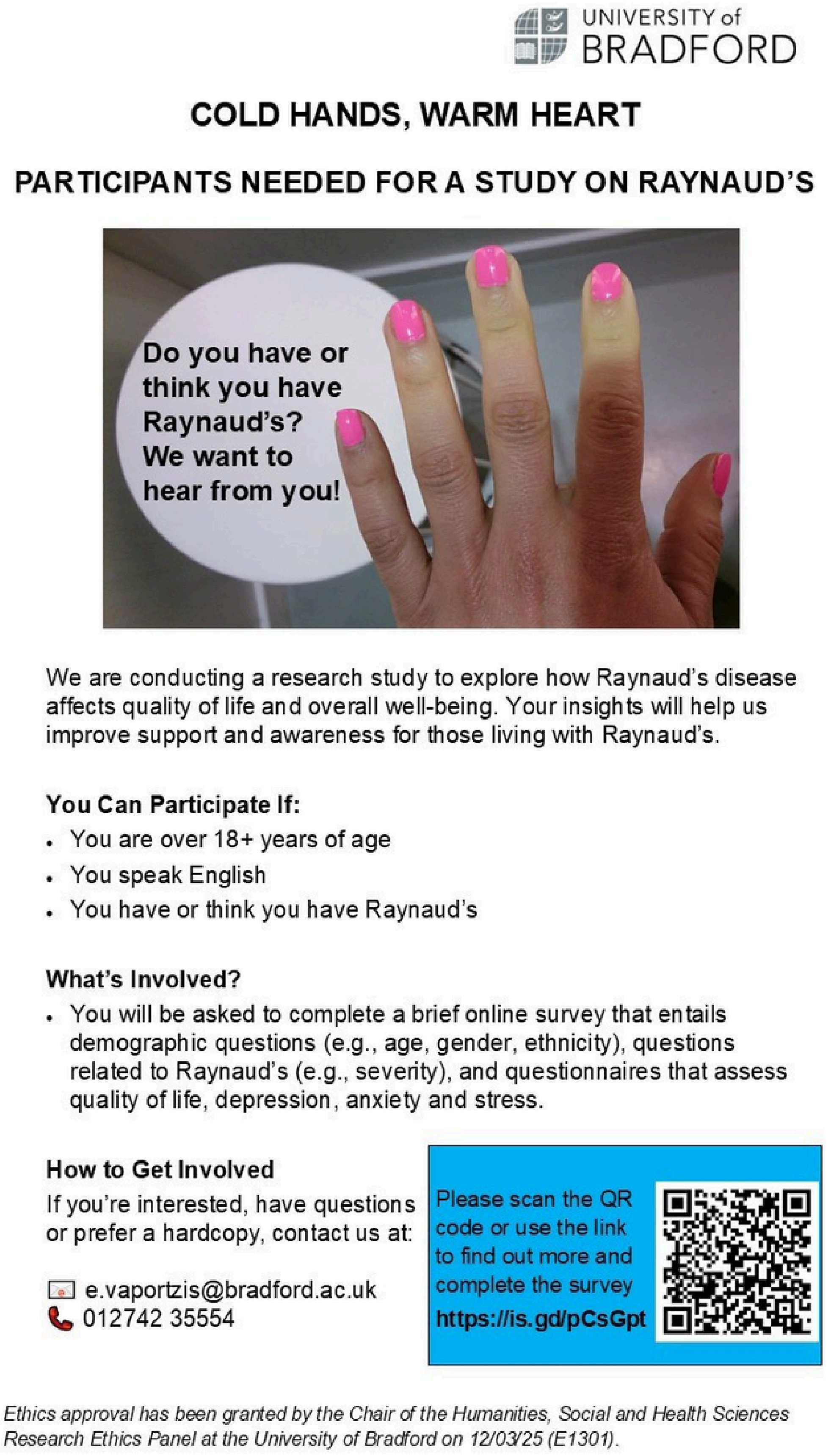
Raynaud Study Recruitment



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COLD HANDS, WARM HEART

PARTICIPANTS NEEDED FOR A STUDY ON RAYNAUD’S

Do you have or think you have Raynaud’s? We want to hear from you!

We are conducting a research study to explore how Raynaud’s disease affects quality of life and overall well-being. Your insights will help us improve support and awareness for those living with Raynaud’s.

You Can Participate If:

- You are over 18+ years of age
- You speak English
- You have or think you have Raynaud’s

What’s Involved?

- You will be asked to complete a brief online survey that entails demographic questions (e.g., age, gender, ethnicity), questions related to Raynaud’s (e.g., severity), and questionnaires that assess quality of life, depression, anxiety and stress.

How to Get Involved

If you’re interested, have questions or prefer a hardcopy, contact us at:

✉ e.vaportzis@bradford.ac.uk
☎ 012742 35554

Please scan the QR code or use the link to find out more and complete the survey
https://is.gd/pCsGpt

Ethics approval has been granted by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 12/03/25 (E1301).

SABC Founders Bob Buzza & Donna Gervais

By Michele Gervais, SABC's VP, February 2025

Bob Buzza, April 1932 - January 2025 and Donna Gervais, July 1936 – February 2025

It's almost like they planned it. So, we are celebrating them here together. And by the way, neither are 'resting' in Heaven, they are most certainly dancing. You could say the SABC runs in both families. Bob became involved in the world of scleroderma when his sister Joan was diagnosed in the early 80's and Bob was at her side when Joan co-founded the SABC. Donna was diagnosed in 1983. After meeting Bob, Joan and the rest of the SABC Board in the early nineties, Donna hosted and ran a monthly support group out of her home in White Rock. Donna's husband John became the SABC's treasurer.

In recognition of his role in co-founding the Scleroderma Society of Canada in 1999 and work as scientific liaison with the Canadian Scleroderma Research Group (CSRG) and co-authoring a number of studies; Bob was awarded an honorary doctorate by the CSRG. Donna received the Gurmej Kaur Dhanda Community Service Award, acknowledging her generous hospitality and support for patients for many years. Bob was especially proud of supporting the inception and growth of the Scleroderma Clinic at St. Paul's, the SABC Research Program and the now international Scleroderma Patient-Centered Intervention Network (SPIN), seeking a cure for this rare disease.

Donna was grateful for all the donations her family and friends gave over the years at both the Scleroderma Skates and June Awareness Ride for Research annual events, supporting her to raise funds for research. Donna and Bob shared many a good laugh and time at provincial and national scleroderma conferences they attended, and their families continue to hold the same fondness for each other. Bob's obituary describes him as a storyteller, waltz king, calligrapher, world traveler, pancake maker, scrabble demon, master pumpkin carver, golfer, bowler, bocce player and table tennis wizard. Donna's describes her as loved, cherished, enthusiastic, humorous, entertaining, caring, an inspiration and always welcoming with 'happy hour' snacks. Bob and Donna were clearly the hub, heart and soul of their families, families SABC was fortunate to be a part of.

Community Contact Representatives

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Chilliwack	Kelly Grant	604-378-1806	sabckelly@gmail.com
Creston	Betty Kuny	250-428-8875	rkuny@telus.net
Kelowna	Angie Reglin	250-860-5700	angiereglin@gmail.com
Kamloops	Jen Beckett	250-574-3151	jenniferbecketts@hotmail.com
Maple Ridge	*Seeking Representative*		
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Nelson	Sylvia Reimer	250-551-0973	reim1syl@gmail.com
New Westminster	*Seeking Representative*		
Prince George	*Seeking Representative*		
Squamish	*Seeking Representative*		
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Disclaimer

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