

## 2025 AGM & CONFERENCE

The Scleroderma Association of B.C.'s 41st Annual General Meeting and Conference Program.

Holiday Inn Express Vancouver-Metrotown 4405 Central Blvd, Burnaby, BC V5H 4M3 Saturday, October 25th 2025 10:00 AM - 5:30 PM





## Today's **Agenda**

#### Registration

**10:00 AM** Doors Open - Registration Begins

#### AGM

**10:30 AM** Welcome and Opening Remarks

Rosanne Queen, SABC President

Business of the AGM, Reports, Election of Board of Directors

David Queen, SABC Board Member

11:00 AM Vanessa Cook

Presenting:

Nourishing Diets & Scleroderma: FOUNDATIONS OF NUTRITION &

**INTEGRATIVE CARE** 

**12:15 PM** Lunch

1:20 PM Lihong Yang Memorial Scholarship

Award(s)

1:30 PM Vanessa Cook

Presenting:

Nourishing Diets & Scleroderma:

**GUT HEALTH & PRACTICAL STRATEGIES** 

2:30 PM Break

2:50 PM Dr. Maggie Larché, MRCP(UK), PhD

Presenting:

Current Research in Systemic Sclerosis:

A CANADIAN PERSPECTIVE

4:00 PM Closing Remarks

Rosanne Queen, SABC President

4:15 PM Social Hour

Celebrate 41 years of the SABC

**Conference Adjournment** 

# 41<sup>ST</sup> SABC

(May 2024 to April 30<sup>th</sup> 2025)

#### **FORWARD**

Our 40<sup>th</sup> Annual General Meeting & Conference was a huge success as it was the first "all in-person" conference since Covid with more than 85 in attendance. Those listed as Directors were elected by acclamation. New to the board are: Emily Wang, Sara Blais, Cecille Soriano and Emilio Chiarizia. SABC thanked and acknowledged Helen Hsaio & Beth Miller for their work on the Board.

#### SABC RESEARCH PROGRAM

Work on the SABC-sponsored Research Program continues with the aim of identifying biomarkers specific to people who have pulmonary fibrosis caused by systemic sclerosis. This research program is creating a firm foundation for intensive research to control lung and skin damage in patients with scleroderma and lung damage in patients with Idiopathic Pulmonary Fibrosis (IPF). Being able to distinguish between pulmonary fibrosis that is idiopathic (of various or unknown origin) or the result of scleroderma, will allow medical professionals to provide patients with an accurate diagnosis.

Identifying reliable biomarkers also provides an opportunity to develop a functional cure; an ongoing treatment that corrects and prevents the disease from continuing to damage the affected organs (in this case, lungs).

To read the quarterly updates on this research, visit our website: www.scleroderma bc.ca under the "Research" tab.

#### FINANCIAL REPORT

For fiscal year 2024-25 (May 1, 2024, to April 30, 2025), revenue consisted of \$140,294.19 with expenditures of \$144,666.36 for a net decrease of \$4,372.17 to end of fiscal year. The largest disbursement included a research contribution of \$98,214.25 to St. Paul's Foundation for their ongoing research work.

The Joan Kelly Endowment investment fund established last year has increased in value from \$393,189 to \$446,928.78 with an additional \$10,000 contribution along with interest, dividends and increased equity value. The interest and dividends accumulated provide an annual investment income that is distributed later in this fiscal year for further research projects such as the St. Paul's Foundation work.

The Lihong Memorial Scholarship fund was established two years ago for educational support for medical students who are focusing their studies in or pursuing research in arthritis (rheumatology), heart (cardiology), lung (pulmonology) or kidney (nephrology) - all areas of scleroderma involvement. Two \$1000 scholarships were awarded at last years AGM and Conference.

The Joan Kelly Community fund was established to provide financial assistance for patients of scleroderma who may need help as part of the challenges of living with scleroderma. The fund has \$1,849.20 at the end of April.

As of April 30, 2024, SABC had \$595,360.63 in total cash and investments (including amounts from Operating, Endowment, Community and Scholarship funds).

#### 41ST SABC

### **DIRECTORS REPORT**

Continued

#### **RAISING RESEARCH FUNDS & AWARENESS**

#### 2025 MOVING TO CURE SCLERODERMA

Total funds raised this June was \$72,583.05. Three events contributed to this amount, two of which surpassed last year's fund-raising efforts: Scleroderma Ride for Research - \$36,085.25, Groove to Cure Scleroderma -\$18,675.00 and Moving to Cure - Anywhere in BC - \$17,822.80. The addition of interest dollars accrued via the Joan Kelly Memorial Research Fund of \$19,626.58 bumped us up to the grand total of \$92,209.63 raised for research! A cheque for this total was presented to the St. Paul's Foundation to support the SABC Research Program.

#### SUPPORT & EDUCATION

This year, we hosted eight **"Come Zoom with Us" support meetings**, covering topics such as Redefining Appearance & Make-up Tips, Advocacy, Managing Scleroderma & Sjögren's, Scleroderma Resources, Stretch & Feel Good Yoga, and general check-ins.

We also offered three Educational Webinars:

- · Mental Health & Scleroderma Dr. Danielle Smith
- · Dental Care & Scleroderma Dr. Leslie Laing
- Scleroderma 101 Dr. Janet Pope

Teressa Colosimo, an SABC Community Representative, continues to lead Chair and Easy Flow Yoga classes, tailored for those with Scleroderma.

#### COMMUNICATIONS

We produced our semi-annual magazine, The Bulletin, in November 2024 and May 2025 with grants from both Janssen and Boehringer Ingelheim. These magazines are mailed to our members, donors and rheumatologists.

As well, we shared member-specific news and tips within the February 2025 newsletter, Sclerodata.

Like all websites, they are ever-changing. We are pleased to share that the major changes to our website have been completed and now it's so much easier to find our up-to-date content.

Since our 2022 audit, SABC's online presence has grown dramatically. In November 2022, we averaged fewer than 30 monthly organic sessions. By August 2024, that number had climbed to 500 monthly organic sessions and 600 monthly organic searches — a 1,500%+ increase.

We increased our presence on social media in 2024 and 2025 with Instagram, X, and Facebook.

Across all platforms (May 2024 to April 2025):

- Our Posts reached 87,122 people and made 66,946 impressions.
- Average post engagement increased from 8.63% to 13.38%.
- 423 new followers were gained

## A message from the

### **SABC PRESIDENT**

As we celebrate our 41st AGM & Conference, what I feel most strongly is a deep sense of community. Today is about bringing together members and families who are willing to share their journeys, knowing they will be met with understanding and support. It's about learning something new, or being reminded of what we already know, as we walk this path together.

This past year has once again been incredible filled with education webinars, support group meetings on Zoom and simple but meaningful moments like gathering for coffee.

June Awareness was another great success and I want to sincerely thank everyone who participated. Whether you donated, fundraised, or simply shared information about scleroderma, each action helps us raise awareness.

SABC would not be celebrating 41 years continuing Joan Kelly's legacy without the dedication and compassion of countless board members who have volunteered their time. As we all know, there is no "I" in team. Looking ahead, I hope that you, a family member, or a friend might consider joining the board. I would like to thank Michele, Patrick and David for their many years of being on our board and welcome, Rita, Jorge and Clara.

I've had the honour of serving on the board for 14 years, 10 of those as President. It has been a truly rewarding experience. I know I will be leaving SABC in the hands of a strong team who will bring new ideas while continuing what Joan and the five founding women began. David and I will continue leading the Scleroderma Ride for Research, and I will always remain a part of this incredible organization.

Thank you for supporting the SABC. Together, we are stronger.

Rosanne Queen SABC President

Losanne Queen

HISTORYOF SUPPORTING **PATIENTS** Members connected over coffee or phone calls, sharing and learning. The semi-annual 1980 Sclerodata newsletter provided updates and tips, while annual workshops, in collaboration with the Arthritis Society, served as conferences for the community. **MEMBER COUNT: 27** Member gatherings expanded with the inclusion of Community Representatives, 1990 individuals with scleroderma volunteering to provide support and guidance in their local communities. **MEMBER COUNT: 270** The Scleroderma Clinic is established. 1 Sclerodata celebrates a member's success 2000 in obtaining WCB recognition and acceptance of their claim.2 Annual local AGMs and conferences are held in the Lower Mainland. **MEMBER COUNT: 400** SABC and Scleroderma Canada co-hosted a joint local/national conference in Burnaby, 2010 bringing together doctors, patients, and families nationwide. Members represented BC at various national and international scleroderma conferences **MEMBER COUNT: 800** Come Zoom with Us virtual support group meetings enable everyone in BC to attend. 2020 Educational Webinars are also hosted online. **MEMBER COUNT: 1000** 

The BC Scleroderma Clinic, a collaboration between SABC and Research Centre at St. Paul's Hospital, was the sole clinic of its kind in Western Canada, offering specialized care for patients across the province. This initiative created the potential to greatly improve the quality of life for scleroderma patients in the region, addressing a significant healthcare need. It is now a combined clinic with rehumatologists and respirologists for patients diagnosed with scleroderma and interstitial lung disease

SABC member Nobby Breen, a painter, and his employer convinced the Worker's Compensation Board that scleroderma was a work-related, occupational hazard, resulting in the WCB accepting his claim and providing full compensation benefits. From SABC member Kelly Mauro, "It's impossible for me to put it into a few sentences. I can only simplify it with, if it hadn't been for Nobby Breen coming forward to Joan Kelly with his story, and then Joan having the amazing ability and foresight to communicate and understand how much sharing his story would impact not only my husband Rino and our family, but many more over the years, encouraging us to come together to help others having their claims accepted. I can't express how much the Sclerodata meant to so many patients and families. Patient outreach is at the core of what makes support groups and networking a successful will be forever grateful and our previously to the SABC".

## PRE AGM New Nominees



Karli Soriano

Secretary

Karli is a project and event coordinator at an engineering company on the North Shore. Her older sister Cecille was diagnosed with Scleroderma at the age of 19; she has witnessed both the negative effects of this illness on her sister's health but also the powerful result of her resiliency and perseverance. As Cecille steps into her new role as President of the Scleroderma Association of BC, Karli is very excited to step into the role of Secretary as a way to get more

involved, join the community, and further support her sister. Karli's interests include weightlifting, spoken word poetry, playing instruments, and singing with her sister.



## **Jorge Antunas**

**Board Member** 

After receiving his scleroderma diagnosis in May 2024, was confronted with the overwhelming reality of a rare and incurable autoimmune disease. In his search for answers he discovered the Scleroderma Association of BC (SABC), an organization whose valuable outreach and resources guided him as he navigated his new health journey. This experience ignited a commitment within Jorge to give back and ensure that others who receive a similar diagnosis find the same support and guidance he did. Professionally, Jorge brings over 35 years of

experience as a Professional Engineer, with a career defined by complex problem-solving, strategic budget management, and collaborative leadership. His ability to unite diverse stakeholders—from Engineers and contractors to clients—around a shared vision is a skill he now wants to apply to help SABC. Jorge views his health journey as the most challenging project of his life. With the same determination that shaped his Engineering career, he is now focused on raising awareness, advancing research, and strengthening the voice of the scleroderma community across British Columbia and Western Canada. His mission is clear: to help improve the daily lives of those affected and contribute to the search for a cure.



**Clara Edvi** 

**Board Member** 

After her husband Jorge's diagnosis with scleroderma last year, experienced firsthand the overwhelming and isolating nature of the disease. Finding her way to the Scleroderma Association of BC's monthly meetings proved to be a turning point, offering a compassionate and supportive community that helped her, and Jorge feel less alone. This experience has ignited a fierce commitment within Clara to join the Board and ensure others receive the same lifeline of support that was extended to her family. Professionally, Clara's background in

wellness and fitness provides a unique perspective. As an account manager for the sportswear brand On and a Pilates instructor, she understands how to motivate individuals and build supportive communities. Her extensive experience in marketing and event planning, combined with her leadership as a "Right to Run" volunteer ambassador for On, directly aligns with the Board's strategic goals of expanding public awareness and fundraising capacity. A dedicated ultramarathon runner, Clara embodies the resilience and determination that drives the scleroderma community. She is committed to leveraging her skills and networks to build a stronger, more visible association for all British Columbians affected by this condition.



Rita Jin
Board Member

Rita is currently a second-year medical student at UBC with prior work experience in non-profit organizations and medical research. SABC plays an important role in supporting patients with scleroderma and their family, ranging from various advocacy efforts to fundraising and research. As a student passionate about medical research and patient advocacy, Rita is grateful to have the opportunity to contribute to these efforts and learn from patients lived experiences.

## Meet our Presenters



### Dr. Maggie Larché MRCP(UK), PhD

Presenting

#### Current Research in Systemic Sclerosis: A Canadian Perspective

Dr. Maggie Larché is a Professor of Medicine and Division Head of Rheumatology at the University of Calgary, as well as Director of the Canadian Scleroderma Research Group. Her presentation explores current research opportunities for patients across Canada, highlights emerging avenues in systemic sclerosis research, and encourages patient participation in advancing knowledge and care.

Originally from the UK, Dr. Larché has over 18 years of clinical and research experience in Canada, with a focus on scleroderma, early inflammatory arthritis, and personalized biomarkers in autoimmune disease.



Vanessa Cook
Naturopathic Medical Intern
Presenting

## Nourishing Diets & Scleroderma: Part 1: Foundations of Nutrition & Integrative Care Part 2: Gut Health & Practical Strategies

This two-part session explores the role of nutrition and integrative care in supporting those living with scleroderma. Session one focuses on holistic approaches to chronic disease management, the impact of diet on symptoms and overall health, and recognizing food sensitivities. Session two delves into gut health, the microbiome's role in immunity and cognition, and practical, evidence-based tools for daily symptom management.

Vanessa Cook is a Naturopathic Medical Intern based in Toronto whose personal journey with scleroderma inspires her work. As Chair of Patient Support for Scleroderma Canada and a researcher with SPIN (Scleroderma Patient-centered Intervention Network), she is dedicated to advancing patient-centered care and improving quality of life for those affected by scleroderma.



Beginning as a grassroots effort, funds for scleroderma research were raised through tea parties, dances, casino days, raffle tickets, and entertainment book sales.

SABC backed Dr. Connie Wong's scleroderma study at UBC with over \$90,000, while BC patients joined the Canadian Scleroderma Research Group (CSRG) registry.

Dhar Dhanda & family's annual gala supported the SABC Research Project and other scleroderma research in BC, The Scleroderma Skate events also raised funds for research. The SABC Research Program at St. Paul's Hospital intensified its study of scleroderma patients' blood and skin.

With increased funds, SABC expanded support for national research initiatives at SPIN, the Scleroderma Research Chair at CHUM, and CSRG. Additionally, funds were allocated for acquiring an ultrasound machine and Doppler ultrasound for the Scleroderma clinic.

The Joan Kelly Memorial Research Fund, established by generous donors, creates an endowment for sustained financial backing of scleroderma research. Capital is invested, with annual dividends dedicated to funding research in BC and Canada. SABC members have raised over \$1.5M to date for this cause.

2020

1980

1990

2000

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## **Lihong Yang**

#### **Memorial Scholarship Award**

Lihong Yang's battle with scleroderma was a courageous journey, made possible by a hematopoietic stem cell transplant (HSCT). These unsung heroes, found in our blood and bone marrow, played a crucial role in her fight.

In 2019, Lihong faced the daunting diagnosis of systemic diffuse scleroderma. Uncertainty loomed as she grappled with questions about her future, her loved ones, and her job. Both emotionally and physically, she felt broken.

Treatment attempts with Methotrexate® and mycophenolate mofeti (CellCept®) brought challenges like worsening acid reflux. Yet, amid the struggle, she joined the SABC's June fundraising program.

In 2020, Lihong consulted the Scleroderma Clinic, where HSCT was proposed as a lifeline. Despite the pandemic and complications involving her heart, her determination remained unshaken.

On January 5, 2021, her transplant journey began, marked by radiation, chemotherapy, and stem cell transplantation. While the road was tough, her spirit remained strong.

Following the transplant, she faced challenges but gradually improved, resuming physical activities and finding relief from heartburn. Unfortunately, her improvements did not hold for a long time. Lihong Yang lost her courageous battle with scleroderma. Her story is a testament to her strength and resilience in the face of adversity, and her memory will continue to inspire us all.

Lihong lost her battle to scleroderma on January 4, 2023. Her husband Songsen will continue to honour her memory with the Lihong Yang Memorial Scholarship Award.



Informational brochures and pamphlets detailing the impact of scleroderma were created for distribution at events.

Participated in UBC's Health Sciences Fair which introduced medical students to patient members, providing valuable hands-on experience with a rare disease, leading to earlier awareness. 3

SABC and a Calgary-based support group joined forces to establish the national network of provincial support organizations, now recognized as Scleroderma Canada. Additionally, The Gurmej Kaur Dhanda Memorial Scholarship Award was presented to medical students showing dedication to scleroderma research.

Annual province-wide walks and bike rides in June raise awareness and funds. The Bulletin, funded by pharmaceutical grants and created with Sclerodermie Quebec, contains updates on scleroderma symptoms, research and SABC events. It is also mailed to doctor and rheumatologist

SABC's website is continually updated with the latest scleroderma information, offering accurate resources for patients and boosting public awareness. Additionally, SABC establishes a social media presence on Meta, LinkedIn, and Instagram platforms. Moreover, the Lihong Yang Memorial Scholarship Award supports two medical students dedicated to advancing their studies in fields related to scleroderma.

<sup>3</sup> The Health Sciences Fair evolved into a society of volunteers called PIE, Patients in Education. The purpose of PIE was to provide opportunities for patients and community organizations to have a voice in the education of health professionals SABC made a small annual donation to PIE and had representatives on the organizing committee.

<sup>4</sup> Over 25 Information Sheets have been produced and placed on the website providing explanations, beneficial insights and current, credible information on the various aspects and symptoms of systemic sclerosis or scleroderma



# TOTAL RAISED: \$92,209.63

## In 2025, we moved, grooved, and rode for a cure!

Congratulations for all of the efforts from our donors, walk & concert organizers, volunteers, and those individuals who raised awareness by Moving to Cure Scleroderma.

















### Meet our 2025-2026

## **SABC Board of Directors**



Cecille Soriano
President



Kelly Grant
Co-Vice President



Chelsea Fitzpatrick
Co-Vice President



Amyn Rajan Treasurer



Karli Soriano Secretary



Emilio Chiarizia Board Member



**Kenny Reid**Board Member



Amir Pourghadiri
Board Member



**Emilie Wang**Board Member



**Sara Blais**Board Member



**Rita Jin** Board Member



Jorge Antunes
Board Member



**Clara Edvi** Board Member

## Thank You For Your Service

We're sincerely grateful for the contributions made by our outgoing directors.

Wishing you all the best in your next season of life!



Rosanne Queen
President



Michele Gervais
Vice-President



David Queen Secretary



Patrick Livolsi Treasurer

### Come Zoom with us

and find your community

The SPIN Network is based in Montreal

SPIN = Scleroderma Patient Intervention Network SSLED = Scleroderma Support Group Leader Education program



Support groups are facilitated by a team of scleroderma patients from across BC who have all completed the SPIN-SSLED program.

The Scleroderma Association of B.C. strongly believes in the merits of support groups. Support group meetings create an environment conducive to discussions by providing a safe place where people affected by the disease and their caregivers can give and receive practical and emotional support. Currently, SABC is offering virtual support meetings, we invite you to Come Zoom With Us!



Questions or suggestions about our Support Groups & Educational Webinars?

Please email sabckelly@gmail.com

There is much to learn about this complicated disease. SABC hosts educational webinars led by experts to help inform people living with scleroderma with the latest advancements and learnings.



#### Return-It Express Program

You can continue to raise money for SABC all year by using 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!





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