2024
AGM & CONFERENCE

The Scleroderma Association of B.C.'s 40th Annual General Meeting and Conference Program.

6650 Southoaks Crescent, Burnaby BC.
Allan Emmott Centre
Saturday, October 26th 2024
10:00 AM - 5:30 PM

Scleroderma
Association B.C.

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	Dr. Joseph Pellizzari Presenting - UPHEAVAL, CONNECTION & MEANING-MAKING: Reflections on Coping with Scleroderma
12:15 PM	Lunch
1:20 PM	Lihong Yang Memorial Scholarship Award(s) Presented by Songsen Duan
1:30 PM	Dr. John Swiston & Lisa Kolkman Presenting - Pulmonary Hypertension in Scleroderma
2:30 PM	Break
2:50 PM	Dr. Sarvee Moosavi Presenting - Scleroderma & the Gut
4:00 PM	Closing Remarks Rosanne Queen, SABC President
4:15 PM	Social Hour Celebrate 40 years of the SABC

Conference Adjournment

A message from the
SABC PRESIDENT

I am delighted to extend a warm welcome to all of you this year.

SABC's 40th anniversary is a celebration led by an incredible “Scleroderma Warrior,” Joan Kelly. In 1982, Joan was joined by two other individuals diagnosed with this rare disease, brought together by the same doctor. By 1984, their group had grown to five members, who decided to launch a program through doctors to identify more patients and establish a provincial support system. Their initial personal cash pooling resulted in $17, and in 1985, they achieved registration as a charity.

In researching SABC’s history, Bob Buzza provided me with a box containing every Sclerodata newsletter since Spring 1986. It's been a long time since I’ve seen anything typewritten. It's truly amazing to see how they connected and organized events before the days of computers and social media.

It’s remarkable that an all-volunteer registered charity has raised over $1 million for research while staying true to its mission statement for 40 years. This achievement is a testament to the incredible people who have passionately stepped up to help others.

Thank you to all those who participated in another successful June Awarness.

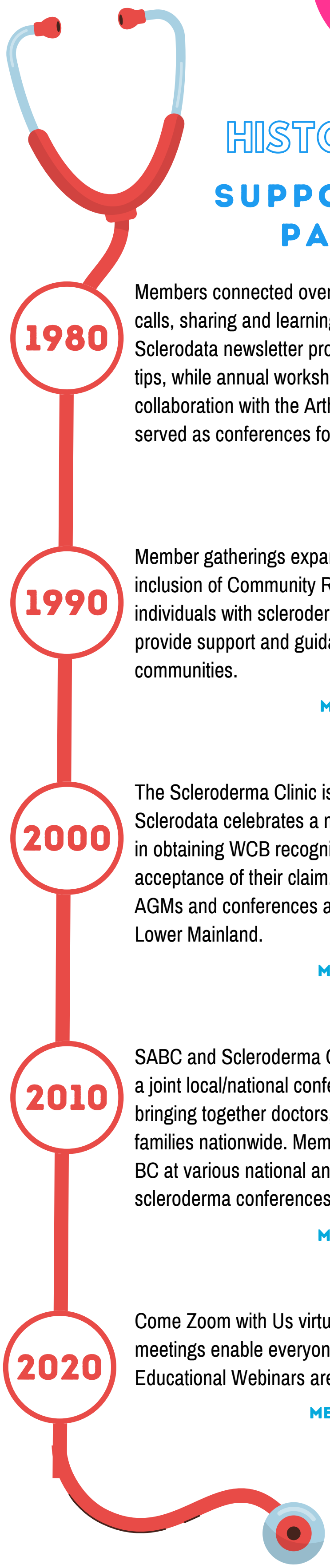
I feel honoured to be a part of this incredible community. Together, we can continue to make a difference in the lives of those affected by scleroderma.

Warm Regards,

Rosanne Queen

Rosanne Queen
SABC President

HISTORY OF
SUPPORTING PATIENTS



1980

Members connected over coffee or phone calls, sharing and learning. The semi-annual Sclerodata newsletter provided updates and tips, while annual workshops, in collaboration with the Arthritis Society, served as conferences for the community.

MEMBER COUNT: 27

1990

Member gatherings expanded with the inclusion of Community Representatives, individuals with scleroderma volunteering to provide support and guidance in their local communities.

MEMBER COUNT: 270

2000

The Scleroderma Clinic is established.[1] Sclerodata celebrates a member's success in obtaining WCB recognition and acceptance of their claim.[2] Annual local AGMs and conferences are held in the Lower Mainland.

MEMBER COUNT: 400

2010

SABC and Scleroderma Canada co-hosted a joint local/national conference in Burnaby, bringing together doctors, patients, and families nationwide. Members represented BC at various national and international scleroderma conferences

MEMBER COUNT: 800

2020

Come Zoom with Us virtual support group meetings enable everyone in BC to attend. Educational Webinars are also hosted online.

MEMBER COUNT: 1000

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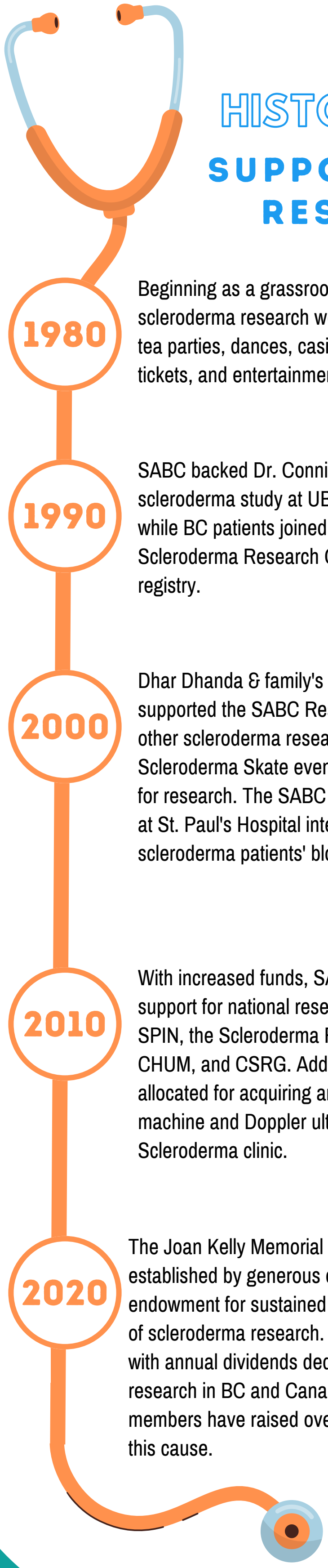
[1] The BC Scleroderma Clinic, a collaboration between SABC and Research Centre at St. Paul’s Hospital, was the sole clinic of its kind in Western Canada, offering specialized care for patients across the province. This initiative created the potential to greatly improve the quality of life for scleroderma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

[2] 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 success! I will be forever grateful and appreciative to the SABC”.

Meet our
Presenters



HISTORY OF
SUPPORTING RESEARCH

1980

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

1990

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.

2000

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.

2010

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.

2020

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.

Dr. Joseph Pellizzari

Ph.D, C.Psych

Presenting

UPHEAVAL, CONNECTION & MEANING-MAKING: Reflections on Coping with Scleroderma

Dr. Joseph Pellizzari received his Ph.D. in Clinical Psychology in 2000 from the University of Western Ontario. He has always worked in the broad area of health psychology. As a hospital-based psychologist for over 25 years, he has worked in a variety of settings such as acute medical/surgical wards and in a number of medical specialties. Presently, he splits his clinical and academic work between the Mental Health and Addiction Program and Palliative Medicine at St. Joseph's Healthcare Hamilton. His academic appointment is with McMaster University, Department of Psychiatry and Behavioural Neurosciences.

Dr. Sarvee Moosavi

MD, FRCPC, MEd. (Candidate)

Presenting

Scleroderma & The Gut

Dr. Sarvee Moosavi is a Clinical Assistant Professor in Gastroenterology at Vancouver General Hospital. She practices in all areas of general Gastroenterology and Hepatology. In addition, she sees complex referrals from all around the province for disorders of gut-brain interaction (formerly known as functional GI disorders), as well as neurogastroenterology and GI motility disorders.

She is the founder of the only gastroenterology motility lab in the province of British Columbia with access to both esophageal and anorectal manometry, where she personally performs high-quality tests assessing gastrointestinal function, including esophageal and anorectal manometry, pH monitoring, and esophageal planimetry (EndoFLIP). She has first authored several articles in highly reputable journals, as well as the "Atlas of High-Resolution Manometry and pH Monitoring".

She has presented at international and national conferences on various topics on disorders of gut-brain interaction and esophageal motility disorders. She is fluent in both English & Farsi.

Meet our Presenters Continued....

Dr. John Swiston

MD, FRCPC, MPH.

Co-Presenting

Pulmonary Hypertension in Scleroderma

Dr. John Swiston is an associate professor in the Faculty of Medicine at the University of British Columbia. He is in the respiratory division at Vancouver General Hospital, is the medical director of the UBC Pulmonary Hypertension Program at VGH, the medical director of the Pulmonary Hypertension Association of Canada and a member of the Canadian Thoracic Society Pulmonary Vascular Disease Committee. Dr. Swiston's clinical and research interests focus on pulmonary hypertension and pulmonary vascular diseases. Dr. John Swiston completed a BSc in Biochemistry in 1993 and an MSc in Biochemistry and Molecular Biology in 1995, both at the University of Calgary. He received his MD in 2000 from the University of Alberta. His Internal Medicine residency and subsequent fellowship in Respirology were completed in 2005 at UBC .Through the UBC Clinical Investigator Program he went on to further clinical and research training in pulmonary hypertension at the University of Toronto in the Toronto General Hospital Pulmonary Hypertension Program as well as completing a Masters Degree in Public Health from the Harvard School of Public Health in Boston. Dr Swiston's clinical and research interests focus on pulmonary hypertension and pulmonary vascular diseases.

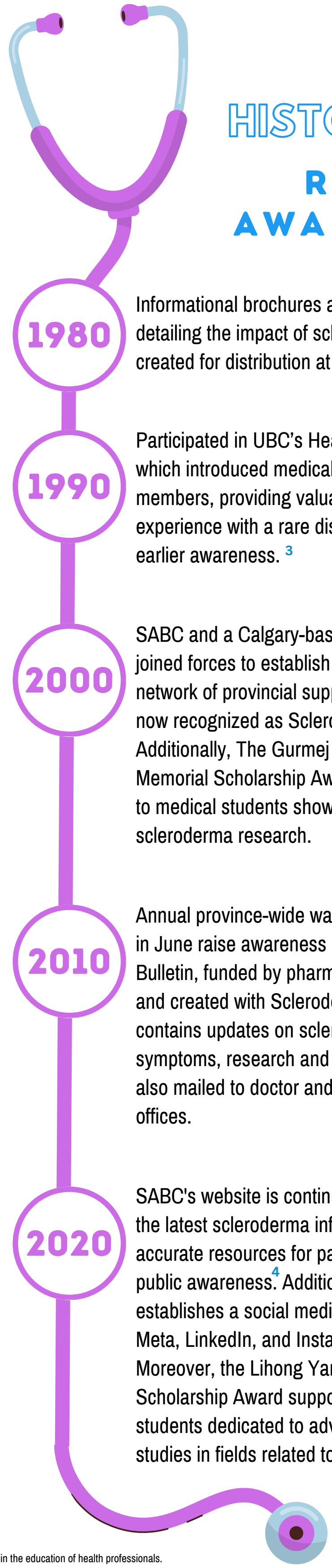
Lisa Kolkman

NP (F)

Co-Presenting

Pulmonary Hypertension in Scleroderma

Lisa spent 13 years working as a registered nurse on inpatient units throughout Canada and the United States. Her training and certifications as an RN focused on neurology, neurosurgery, trauma and intensive care. She completed her Masters of Nursing in 2012 at the University of British Columbia. Lisa joined the Pulmonary Hypertension Clinic as a nurse practitioner in 2012. Lisa is the manager of the prostacyclin program for the province of BC and Yukon Territory. She developed and coordinates the genetic testing program for Familial PH, Idiopathic PAH and Pulmonary Veno-Occlusive Disease. She is a member of the Canadian Pulmonary Hypertension Registry Steering Committee and is responsible for overseeing the clinic's database. She has been a member of the Canadian Pulmonary Hypertension Professional Network since its inception and has been a repeat member of the executive. She is a regular contributor to the efforts of PHA Canada, the national patient advocacy association.



HISTORY OF RAISING AWARENESS

1980 Informational brochures and pamphlets detailing the impact of scleroderma were created for distribution at events.

1990 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]

2000 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.

2010 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 offices.

2020 SABC's website is continually updated with the latest scleroderma information, offering accurate resources for patients and boosting public awareness.[4] 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.

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[3] 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.

[4] 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

Moving to Cure
SCLERODERMA

TOTAL RAISED:
$101,715.25

In June 2024 throughout BC, the scleroderma community moved together to raise awareness and fund research initiatives towards finding 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.

Visit our Facebook page for photos of June Awareness from 2012-2024

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.

Thank you to our sponsors

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Meet our **Researchers**

Dr. James Dunne

MB, FRCP (C)

James V. Dunne, MB, FRCP(C), is currently on staff at St. Paul's Hospital and Vancouver General Hospital in British Columbia, Canada. He is a Clinical Assistant Professor for the University of British Columbia's Department of Medicine, and specializes in rheumatology.

Scleroderma and fibromyalgia are also among Dr. Dunne's clinical interests; he is a contributor to the book The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners. He has also been published in the journal Arthritis & Rheumatology, and other peer-reviewed journals. Dr. Dunne has the unique distinction of studying in four countries: Ireland, England, the United States (fellowship), and Canada.

Dr. Kevin Keen

Ph.D.

Kevin J. Keen, Ph.D., is a Professor in the Department of Mathematics and Statistics at The University of Northern British Columbia and an Affiliate Professor in the Department of Medicine at The University of British Columbia (UBC). He is also an Associate Member of the Centre for Heart Lung Innovation at UBC and St. Paul's Hospital. Dr. Keen has held visiting appointments with the Netherlands Institute for Health Sciences (Erasmus University, Rotterdam) and the Faculty of Medicine at Leiden University. He has published more than thirty peer-reviewed articles in journals, two book chapters, and two editions of a textbook on statistical graphics.

Dr. Keen's research involves the development of novel statistical techniques and cutting-edge computer software for the analysis of multivariate data in the study of complex diseases. He is the co-author of articles on lung and skin involvement in scleroderma. Dr. Keen is accredited as a Professional Statistician (P.Stat.) by both the Statistical Society of Canada and the American Statistical Association (ASA) and is a Fellow of the Royal Statistical Society.

Dr. Hyein Kim

MD, MPH, FRCPC

Dr. Hyein Kim is a staff rheumatologist at St. Paul's Hospital and Vancouver General Hospital (Mary Pack Arthritis Centre). She is a Clinical Assistant Professor in the Department of Medicine at the University of British Columbia (UBC).

She practices general Rheumatology in Vancouver, but has a special interest in systemic sclerosis and works at the Scleroderma Clinic at the VCH Mary Pack Arthritis Centre and the Scleroderma-Interstitial Lung Disease Clinic at St. Paul's Hospital.

She obtained her Undergraduate Medicine degree at UBC, followed by an Internal Medicine Residency at the University of Western Ontario. She completed her Masters of Public Health at Harvard School of Public Health. She returned to Vancouver for Rheumatology fellowship.

Meet the
SABC Board of Directors

President
Rosanne Queen

Vice President
Michele Gervais

Secretary
David Queen

Treasurer
Patrick Livolsi

Board Member
Kelly Grant

Board Member
Chelsea Fitzpatrick

Board Member
Kenny Reid

Board Member
Amir Pourghadiri

Board Member
Amyn Rajan

Welcome to the Board

Board Member
Emilie Wang

Board Member
Emilio Chiarizia

We are seeking dedicated community representatives and new board members to join us in October 2025.
Scan the QR Code to find out more.

Thank You For Your Service

Helen Hsiao

Beth Miller

We're sincerely grateful for the contributions made by our outgoing directors. Wishing you all the best in your next season of life!

Sclerodata & The Bulletin

The Bulletin, a semi-annual magazine, keeps members up-to-date on developments & events taking place within SABC.

It covers a broad range of topics, from how to meet the needs of those impacted by the disease, to new advances in scleroderma research, or the latest medical treatments and care options. It also includes moving testimonies from scleroderma patients as well as many other articles of interest.

Sclerodata provides you with relevant and timely scleroderma news, advice, SABC updates and more!

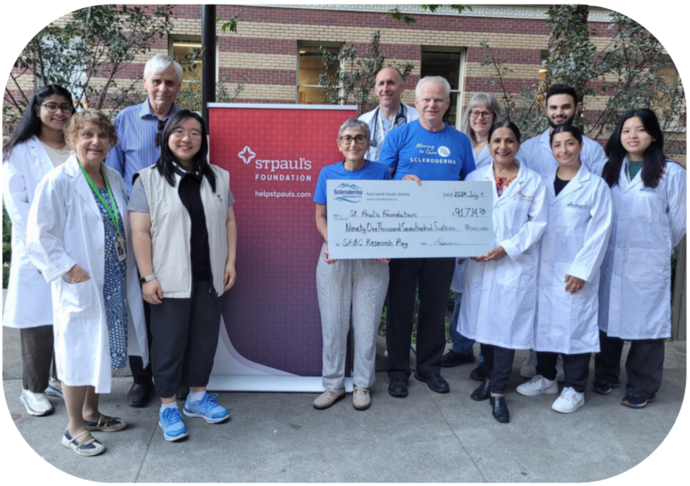
To receive SABC's digital Sclerodata and the Bulletin magazine please email your name, address, email address, and phone number to info@sclerodermabc.ca or call 1-604-371-1005.

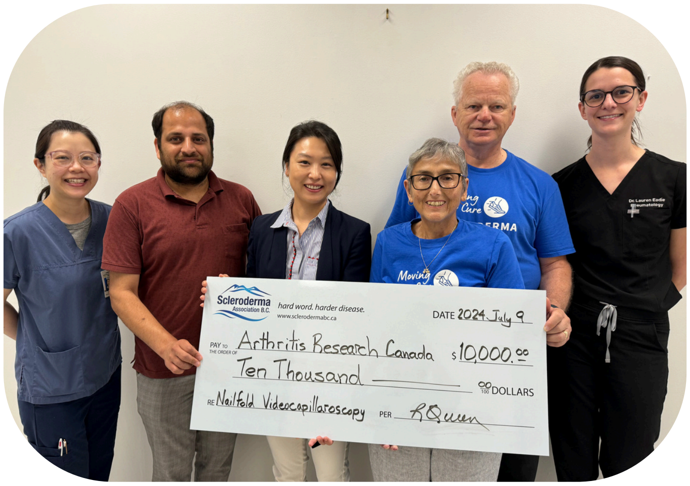
Our Commitment to Research

SABC encourages and supports SSc research in BC & across Canada. We fund and co-lead the SABC Research Program which is a Genome Research Study and began recruiting people with SSc in 2017.

This research program is creating a firm foundation to intensive research to control lung and skin damage to people living with SSc. SABC has raised over $600,000 since the inception of this project.

Overall, SABC has raised more than $1,000,000 for research in Canada.





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!

EDUCATIONAL WEBINARS

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!

Scleroderma
Association B.C.

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