Scleroderma Association of B.C.

38th Annual General Meeting – Oct 22, 2022

Agenda:

1. October 2021 AGM Minutes
2. May 2021 to September 30, 2022, Board of Directors Report - Highlights
3. May 1, 2021, to April 30, 2022, Financial Report
4. Election of 2022 – 2023 SABC Board of Directors
5. New Business
6. Adjournment

1. MINUTES OF THE 37TH ANNUAL GENERAL MEETING – October 2nd, 2021

Board Members Present: Rosanne Queen, David Queen, Patrick Livolsi, Tiasha Burch, Jeff Gammon, Michele Gervais, Beth Miller, Grace Kim, Jessica Jun, Valerie Doyon

Introductions and Opening Remarks 9:00 AM

The Scleroderma Association of B.C.'s standing president, Rosanne Queen called the meeting to commence and welcomed attendees to the 37th AGM and Conference. She acknowledged the challenges of COVID-19 to our community but was grateful to be able to safely come together online today. Tiasha welcomed and thanked everyone for joining. She began by taking participants through how to work Zoom for the AGM. Tiasha directed people how to participate in the election of the board and clarified that Presenters will be recorded and made accessible for later use, but the AGM portion will not be recorded. David welcomed everyone and acknowledged his role as MC for the AGM. He requested everyone take a look at the materials provided on the SABC website or the registration email. He also thanked the standing Board for their work this last year.

Adoption of Agenda

Motion moved to adopt the agenda for today by Tiasha Burch. Seconded by Beth Miller. Approved, all in favour, motion carried.

Adoption of 2020 Minutes

Motion moved to adopt the minutes from the 2020 AGM by Dianne McPhee. Doreen Lassam seconded this motion. Approved, all in favour, motion carried.

Board of Directors Report - Highlights

The SABC has continued work on our Research Program with the aim of identifying biomarkers specific to people with pulmonary fibrosis caused by systemic sclerosis. Identifying reliable biomarkers provides an opportunity to develop a functional cure. For those interested in more information a full update is on our website.

Our 2021 Virtual June Awareness campaign raised $65,366.10 through the dedicated work of 8 teams across the province, and our President Roseanne Queen presented a cheque to the SABC Research Program at St. Paul's Hospital Foundation for $64,191.10. We once again showed our support of SPIN with a $5,000 donation, and of CHUM with a $10,000 donation for research equipment.

This year also saw the SABC establish a connection with Global BC for an awareness campaign across television stations, social media and editorial coverage. We thank Global BC for their in-kind donation to help promote our awareness and fundraising campaign.

2021 saw the first iteration of the SABC promoting virtual seminars, including one on wound care and one on medical cannabis. Video for the Wound Care Seminar can be found on our website and YouTube channel.

Our team has continued to produce our semi-annual magazine, *The Bulletin*, which is sent to members, donors, and doctors around the province. We have made updates to our website and are happy to have increased our social media presence this past year thanks to the younger members of our Board.

The Synergy of Three has continued to develop a strong, collaborative relationship with Sclérodermie Quebec and Scleroderma Manitoba. This has allowed us to improve our website, *The Bulletin*, and to facilitate a sharing of ideas.

Patrick Livolsi motioned to accept the Directors Report. Tiasha Burch seconded this motion. Approved, all in favour, motion carried.

Financial Report

Patrick Livolsi reviewed the Financial Report summary as presented in the 2021 AGM program. The greatest expense has continued to be donations given by the SABC, primarily made to the SABC partnered Genome Research Project through St. Paul's Hospital.

SABC's revenue consisted of $111,826.16 (in part due to a large estate donation) with our expenditures reaching $70,352.93 for a net increase of $41,473.23. The SABC has $123,650.94 in total cash and investments as of August 20, 2021. Further donations given by the SABC to research initiatives will be undertaken throughout the remainder of the fiscal year (May 1, 2021, to April 30, 2022).

Financial report adopted by Cecille Soriano, seconded by Doreen Lassam. Approved, all in favour, motion carried.

Election of the Board of Directors

Pat Thomasson has retired her position on the Board. The floor was opened to nominees for new members.

Board of Directors for 2021-2022

Re-elected: Rosanne Queen – President, Michele Gervais – Vice President, Tiasha Burch, David Queen,

Patrick Livolsi - Treasurer, Jeff Gammon - Secretary, Grace Kim, Jessica Jun, Beth Miller and

Valerie Doyon.

New Nominees: Chelsea Fitzpatrick.

Motion to adopt the nominees for 2021-2022 made by David Queen, seconded by Jeff Gammon. Approved, all in favour, motion carried.

Motion to adjourn the meeting made by David Queen, seconded by Valerie Doyon.

With no additional business, the 2021 AGM was adjourned at 9:25 AM.

2. 38th SABC DIRECTORS' REPORT (May 2021 to September 30, 2022)

Research

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: https://sclerodermabc.ca/sabc-research-project/

Financial Report

For fiscal year 2021- 2022 (May 1, 2021, to April 30, 2022), revenue consisted of $123,595.67 with expenditures of $111,326.78 for a net increase of $12,268.89. Major disbursements included research contributions of $80,191.10 to St. Paul's Foundation and $5,000 to the Scleroderma Patient-centered Intervention Network (SPIN). SABC had $131,415.62 in total cash and investments at the end of April 2022.

Following this year's successful 2022 Moving to Cure Scleroderma ride/walk fundraiser which raised over $100,000, SABC also contributed funding of $102,723.09 to St. Paul's Foundation for further scleroderma research. As of August 16, 2022, SABC currently has $128,850.18 in total cash and investments. Further contributions to scleroderma research initiatives will be assessed through the remainder of the fiscal year.

Fundraising & Raising Awareness

2021 Moving to Cure Scleroderma virtual campaign: A cheque for $65,191.10 was presented to St. Paul's Foundation to support the SABC Research Project. Nine teams participated in June 2021, helping us surpass our goal: Scleroderma Ride for Research – Vancouver $38,815, Moving to Cure Anywhere in BC - $6,021.10, Kamloops - $4,880, Prince Rupert - $4,360, Sea to Sky - $3,550, Victoria - $3,200, Valemount - $2,810, Campbell River - $1,555.

SABC members Valerie Doyon & Alex MacDonald created a fantastic YouTube video showing the support we received across the province. This video was set to the music of Nicole Edwards, also one of our members.

In addition, SABC donated the following: $15,000 to St. Paul's Foundation – SABC Research project, $5,000 to Jewish General Hospital Foundation – SPIN, and $10,000 for research equipment to Centre de Recherche du CHUM.

2022 Moving to Cure Scleroderma campaign: A cheque for $102,723.09 was presented to St. Paul's Foundation to once again support the SABC Research Project. It was so good to see everyone in person this June. We had five teams participate: Scleroderma Ride for Research – Vancouver $65,723.50, Moving to Cure Scleroderma - Victoria $11,402.20, Province Wide (virtual) $9.370.00, Surrey (first walk) $8,466.90, Kamloops (first walk) $7,760.49.

Valerie Doyon created another fantastic YouTube video showing the support we received across the province. This video was again set to the music of Nicole Edwards.

This year we had the following sponsors: Global BC, Park Insurance, Save on Foods, C-Lovers, Out of the Blue Designs, MPERO 4 Entertainment & Pratt Pharmacy

Educational Days

In May 2021 Beth Miller conducted an interview with Dr. Brett Thombs to talk about the SPIN organization. In November our community reps facilitated their first virtual Support Group meeting. They discussed Raynaud's Phenomenon and Difficulties in Swallowing. It was a successful event where patients shared their concerns and their tips on dealing with these issues.

In December Valerie Doyon created the first two of the eventual five podcasts where she interviews a Doctor and a Patient regarding various topics related to scleroderma to get both their points of view. These podcasts will also be available to medical students. The first two topics were Sclerodactyly and Raynaud's Phenomenon.

On February 15, 2022, SABC held a virtual meeting on Mental Health and Scleroderma: An Emotional Journey, presented by Dr. Elain Roth.

Valerie completed the remaining three podcasts on The Role of Surgery, Interstitial Lung Disease and Gastrointestinal Manifestations of Systemic Sclerosis. All podcasts are available on our website.

On May 10th, the SABC had another virtual support group meeting. The topic was on Gastrointestinal issues and on June 7th the SABC had a virtual Social Meeting.

Communications

We continue to produce our semi-annual magazine, *The Bulletin*, with grants from both Janssen and Boehringer Ingelheim. These magazines were not only sent to our members but to our donors, rheumatologists, hospitals, and family clinics around the province.

As well, we continue to share member-specific news and tips twice a year with the newsletter, *Sclerodata*.

Like all websites, they are ever-changing. We will be updating our website this year so we can continue to provide up to date information regarding scleroderma and upcoming events.

We continue to increase our presence on social media with Instagram, Twitter, and Facebook.

Synergy of Three – SABC partnership with Scleroderma Manitoba & Sclérodermie Quebec

The Synergy of Three continues to be a strong and collaborative relationship to the benefit of the three organizations. The semi-annual magazine, *The Bulletin*, is developed through the combined efforts of staff at Sclérodermie Quebec and volunteers in Manitoba and British Columbia. The three websites are continuing to improve with input from those in each organization to create a better platform for people to get information. We continue to share ideas on how to be the best that we can be for the patients and their families.

President's comments

Once again, 2022 has been an interesting year. Although Covid still lurks among us, I have to say it was certainly wonderful, with our safety measures in place, to successfully conduct the June Awareness ride and walks in person.

Being on the SABC Board keeps me very busy but it is so rewarding because we have such a wonderful community. I want to thank our Board members for their hard work and for making our association such a success. I would also like to thank the walk organizers and volunteers who made this year our most successful fundraising year.

Tiasha Bruch and Jeff Gammon have been on the Board for several years. Tiasha has played many roles but is best known for helping us become more 'tech capable' and you'll recognize her smiling face today and from all our previous virtual offerings. Jeff stepped into the role of Secretary when we needed it most and diligently kept our paperwork complete. Unfortunately for us but fortunately for them they are moving away and starting another chapter in their lives together. We wish them luck and thank them for all they have done for SABC and our community.

Rosanne

3. FINANCIAL REPORT

2021 May 01 – 2022 April 30

BALANCE SHEET	**APR 30 2022**	**MAY 1 2021**
Scotiabank		
Operating	$96,735.87	$88,032.71
Research	$4,272.74	$903.34
Technology	$0.05	$0.05
Research GIC	$20,165.41	$20,035.90
Technology GIC	$10,241.55	$10,175.23
TOTAL	***$131,415.62***	***$119,147.23***

PROFIT & LOSS (OPERATING)

INCOME		**EXPENSES**	
Conference	$0.00	Bank Charges	*$22.50*
Dues	$0.00	Events	*$675.00*
General	*$31,132.33*	Grants	*$6,000.00*
Interest	*$196.48*	Office	*$4,409.41*
Research	*$6,821.20*	Other	$3,266.65
Ride for Research	$11,250.00	Professional Fees	$732.26
Walk – BC Virtual	$51,897.16	Promotion	$*16,029.86*
Walk - Victoria	$192.50	Donations	$80,191.10
Other Revenue	$22,106.00		
Total	**$123,595.67**		**$111,326.78**

Net $12,268.89 (Profit)

4. ELECTION OF 2022 – 2023 SABC BOARD of DIRECTORS

Nominees to serve as Directors of the SABC Board follow. There will be a call for further nominees at the AGM. SABC by-laws require the election of a President, Vice-President, Secretary and Treasurer and one or more other persons as Directors.

NEW NOMINEES (PRE AGM)

Kelly Grant was diagnosed with Scleroderma in 2006. She went to her first SABC Conference the next year and has attended almost every conference since. The SABC community provides much needed support and education for Kelly as she deals with the daily challenges of coping with this rare incurable disease. She became a Community Contact for Chilliwack in 2019. She completed the SPIN*/SSLED** Support Leadership training in 2021 and participates in the SPIN/SSLED Support Group Leadership meetings. In 2022 she helped organize and facilitate SABC Virtual Patient Support Group Meetings. She co-organized the first Lower Mainland Moving to Cure Scleroderma in Surrey, BC this past June. In 2021 Kelly retired after 34 years of teaching. She knew this was the time for her to help others with this disease. Her strengths are communication, collaboration, organization, and problem solving. She is highly adaptable and compassionate. She now has time and energy to support the scleroderma community and SABC. Her passions are patient support through outreach and education, raising awareness, and fighting for a cure by encouraging and supporting research.

*SPIN= Scleroderma Patient Intervention Network
*SSLED= Scleroderma Support Group Leader Education Program

Amyn Rajan was diagnosed with Systemic Scleroderma on June 3, 2021. Although it was a terrible diagnosis, it was a relief to learn what had been causing his various health issues which had started almost 2 years previously. He immediately scoured the internet for everything he could learn about Scleroderma and set out to find the best doctors and treatment. One year later, his condition is much improved and largely stable. In the meantime, he has committed himself to helping others and to contribute to research into Scleroderma. As further background, Amyn is a serial entrepreneur, having started his first company, Orbital Technologies in 1997. Since then, he has been involved in additional companies including Simba Technologies, Bit Quill Technologies, and Revela Systems. He has extensive experience in strategy and sales as well as leading various winning teams. On the philanthropic side, he has a passion for supporting women in technology and has been a strong supporter of various endeavours at SFU, UBC, and UVIC.

NEW NOMINEES (DURING AGM)

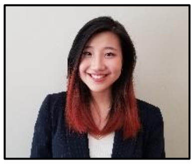
____
____
____
____
____
____
____
____

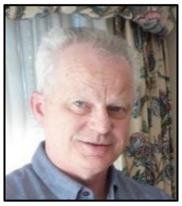
RETURNING DIRECTOR NOMINEES


Michele Gervais (Vice President)


Patrick Livolsi (Treasurer)


Beth Miller (Secretary)


Grace Kim


David Queen


Rosanne Queen (President)


Jessica Jun


Valerie Doyon

5. NEW BUSINESS
6. ADJOURNMENT