

# Scleroderma Association of B.C. 2024 AGM & Conference

## *40th Annual General Meeting – October 26, 2024*

### Agenda:

1. October 2023 AGM Minutes
2. May 2023 to September 30, 2024, Board of Directors Report - Highlights
3. May 1, 2023, to April 30, 2024, Financial Report
4. Election of 2024 – 2025 SABC Board of Directors
5. New Business
6. Adjournment

### **1. MINUTES OF THE 39TH ANNUAL GENERAL MEETING – October 21st, 2023**

The meeting was called to order at 9:04 am.

#### **Approval of Agenda**

Motion to approve agenda: Dianne McPhee / Aryn Rajan. Motion carried, unopposed.

#### **Approval of minutes of October 2022 AGM**

Motion to approve last year's minutes: Aryn Rajan / Susan Goss. Motion carried, unopposed.

#### **Presentation of SABC Directors Report**

David Queen presented highlights of SABC activities during the past year.

- The SABC Research Project is continuing with the research being done by our team through the St. Paul's Foundation. The research team has had two peer reviewed papers published, showing that the work matters. Quarterly updates are included on our website.
- June was scleroderma awareness month, with SABC having events across the province to raise awareness and research funds. A total donation of \$102,723.09 was presented to the St. Paul's Foundation specifically for the SABC Research Project.
- Other research funding was provided to the SABC Research Program, SPIN and Canadian Scleroderma Research Group (for stem cell research).
- We hosted 3 educational webinars and are available on our website.
- We have continued to publish our semi-annual magazine "*The Bulletin*" and patient newsletter "*Sclerodata*". Our other communication methods include our website and social media that are active year long.
- The President has included her perspective of the year and recognizes the contribution that everyone has made over the year to make this organization the continued success that it is.

Motion to accept Directors Report: Aryn Rajan / Susan Goss. Motion carried, unopposed.

### **Presentation of Financial Report**

Treasurer Patrick Livolsi presented the Financial Report for the period May 1, 2022 to April 30, 2023.

Motion to accept Financial Report: Jackie Alexander / Kathryn O'Neil. Motion carried, unopposed.

### **Election of 2023 / 2024 SABC Board of Directors**

David Queen introduced new nominees as well as the current Board members who wish to continue for the coming year. The new nominees are Amir Pourghadiri, Kenny Reid and Helen Hsiao. The Board members who wish to continue serving in their positions on the SABC Board are Michele Gervais, Patrick Livolsi, Beth Miller, Kelly Grant, David Queen, Rosanne Queen, Aryn Rajan and Chelsea Fitzpatrick-Lindsay.

David thanked the medical students for their service on the Board and called for approval of the new slate. There were no additional nominees presented.

Motion to accept the slate as presented: Rosanne Queen / Susan Goss. Motion carried, unopposed.

### **New Business**

None.

### **Adjournment**

Motion to adjourn: Kathryn O'Neil / Jackie Alexander. Motion carried.

## **2. 40th SABC DIRECTORS REPORT (May 2023 to April 30, 2024)**

### **Forward**

Our 39th Annual General Meeting & Conference was conducted both in person and on-line via Zoom on October 21, 2023. Those listed as Directors were elected by acclamation. Kenny Reid, Amir Pourghadiri and Helen Hsiao joined our board. SABC thanked and acknowledged all the work that Jessica Jun, Valerie Doyon and Grace Kim have done for SABC over the years. Guest speakers included Lauren Wolfe, Elaine Furst and Dr. Daniel Furst.

### **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](http://www.scleroderma.bc.ca) under the “Research” tab.

## **Financial Report**

For fiscal year 2023-2024 (May 1, 2023, to April 30, 2024), revenue consisted of \$269,376.26 with expenditures of \$227,220.59 for a net increase of \$42,155.67. The largest disbursement included a research contribution of \$194,489 to St. Paul’s Foundation for their ongoing research work.

The Joan Kelly Endowment investment fund established last year has increased in value from \$379,000 to \$393,189 from an additional \$10,000 contribution along with interest and dividends. The interest and dividends accumulated provide an annual investment income that will be distributed later this fiscal year for further research projects such as the St. Paul’s Foundation.

The Lihong Memorial Scholarship fund which was established last year 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. The fund had \$865 at the end of April after 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 \$3,578.68 at the end of April.

As of April 30, 2024, SABC had \$554,886.63 in total cash and investments (including amounts from Operating, Endowment, Community and Scholarship funds).

## **Raising Funds & Awareness**

**2023 Moving to Cure Scleroderma:** Total funds raised this June was \$100,714.25. A cheque for \$91,714.25 was presented to the St. Paul’s Foundation to support the SABC Research Program and \$10,000.00 was presented to Dr. Hyein Kim through Arthritis Research Canada to support her Nailfold Capillaroscopy Research Project.

Three teams participated in June 2024, helping us surpass our goal: Scleroderma Ride for Research – Vancouver \$56,884.44, Moving to Cure – Anywhere in BC \$15,065.00 and Kenny’s Groove for Scleroderma – Delta/Ladner \$14,198.01. The addition of interest dollars accrued via the Joan Kelly Memorial Research Fund of \$14,266.80 bumped us up to the grand total of \$100,714.25 for research!

Once again, our sponsors helped us advertise and spread awareness for this June’s Campaign: Global BC, Park Insurance, Save on Foods, C-Lovers, Out of the Blue Designs, MPERO 4 Entertainment & Pratt Pharmacy.

SABC board member Chelsea Fitzpatrick created a fantastic YouTube video showing the support we received across the province.

In addition, SABC donated to the following scleroderma-focused research: \$5000.00 to SPIN at the Jewish General Hospital Foundation, Lady Davis Institute and \$10,000.00 to Stem Cell Research at the Canadian Scleroderma Research Group.

### **Educational Days**

SABC held an educational webinar on Raynaud’s and Ulcers with Dr. Hyein Kim and hosted seven (7) “Come Zoom with Us” meetings which featured topics of a SABC Research Program update with Dr. Dunne & Dr. Keene, Advocacy & Scleroderma, Let’s Chat about Gastro Part 1 (upper GI) and Managing Systemic Sclerosis: Shared Tips and Tricks. Two social meet & greets were also added in for good measure!

These webinars have been recorded and can be found on our website, under the events tab <https://sclerodermabc.ca/resurces/videos/?t=webinars>.

SABC member Teresa Colosimo started virtual yoga classes geared to those living with scleroderma. She is holding both Chair and Easy Flow Yoga classes once a week.

### **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 donors and rheumatologists.

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 are pleased to share that the major changes to our website have been done and now it’s so much easier to find our up-to-date content.

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

### **President’s comments**

Once again, 2023/24 has been another interesting year.

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 continuing to make our association such a success.

I would also like to thank all those that participated in “Moving to Cure Scleroderma” for not only raising money for research but helping us raise awareness.

*Rosanne Queen*

### 3. FINANCIAL REPORT – BALANCE SHEET

**2023 May 01 – 2024 April 30**

**End of Fiscal Year**

#### **Accounts**

**Scotia - Operating \$5,761.71**

**CIBC - Operating \$22,239.64**

**CIBC GIC FLX (4.55%) – Feb 2025 \$100,734.13**

**CIBC GIC FLX (4.4%) – Mar 2025 \$20,068.54**

**CIBC IE – Joan Kelly Endowment Fund Total \$396,082.61**

*GIC 1 YR (5.28%) – Feb 2025 \$20,000.00*

*GIC 2 YR (4.99%) – Mar 2026 \$20,000.00*

*GIC 3 YR (4.78%) – Mar 2027 \$20,000.00*

*GIC 5 YR (4.47%) – Feb 2029 \$72,000.00*

*GIC FLX (4.55%) - Mar 2025 \$13,864.00*

*Equity Investments \$249,815.81*

*Cash from Dividends \$402.80*

**TOTAL \$544,886.63**

## profit & Loss (Operating)

### INCOME EXPENSES

Conference \$935.90 Bank Charges \$354.04

June Awareness \$191,431.87 Events \$7,258.99

General \$18,574.11 Fundraising \$226.10

Research \$14,356.39 Grants \$0.00

Walk – Victoria Reg \$1,415.50 Office \$5,865.68

Walk – Surrey Reg \$1,587.00 Other \$2,534.00

Other Revenue \$17,254.13 Promotion \$6,588.56

Kelly Endowment \$10,000.00 Qualified Donations \$194,489.00

Interest \$13,337.36 Scholarship \$2,000.00

Sales \$180.00 Professional \$7,904.22

Groove to Cure \$304.00 Travel \$0.00

**Total \$269,376.26 \$227,220.59**

**Net \$42,155.67 (Profit)**

### 4. ELECTION OF 2024 – 2025 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)

**Emilie Wang** is currently a second-year medical student at UBC Vancouver. Prior to entering medical school, she studied environmental health at UBC through Integrated Sciences. She joined the Scleroderma Association of BC Board because she is passionate about knowledge translation and health literacy, and she hopes to bring more awareness to this chronic condition and further research in the fields of rheumatology and dermatology.

**Emilio Chiarizia** was diagnosed with Scleroderma in 2024. He is a small business owner and is apt in decision making and wearing of many different hats in his day-to-day business affairs which has also moved onto many volunteer roles. Emilio is an avid cyclist, golfer and yoga

participant. His proudest time has been a member of the Ride 2 Survive for ten years (a one day, 400 km ride from Kelowna to Delta in support of Canadian Cancer Society) where they were the largest independent fundraiser, raising over 12 million dollars for the Society with no administrative costs. Emilio's strengths are strong communication skills, experience in fundraising and events, as well as having a large network of business and personal associates.

NEW NOMINEES (DURING AGM)

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RETURNING DIRECTOR NOMINEES

Rosanne Queen, President  
Michelle Gervais, Vice President  
David Queen, Secretary  
Patrick Livosj, Treasurer  
Chelsea Fitzpatrick  
Aryn Rajan  
Amir Pourghadiri  
Kenny Reid  
Kelly Grant

5. NEW BUSINESS

6. ADJOURNMENT