

## Scleroderma Association of B.C. 2023 AGM & Conference

### *39<sup>th</sup> Annual General Meeting – October 21, 2023*

#### Agenda:

1. October 2022 AGM Minutes
2. May 2022 to September 30, 2023, Board of Directors Report - Highlights
3. May 1, 2022, to April 30, 2023, Financial Report
4. Election of 2023 – 2024 SABC Board of Directors
5. New Business
6. Adjournment

### **1. MINUTES OF THE 38<sup>TH</sup> ANNUAL GENERAL MEETING – October 22<sup>nd</sup>, 2022**

Meeting called to order at 9:00am

#### **Approval of Agenda**

Moved Chelsea Fitzpatrick/Patrick Livolsi, motion carried unopposed

#### **Approval of October 2021 AGM Minutes**

Moved Marie Mackie/Beth Miller, motion carried unopposed

#### **Approval of 38<sup>th</sup> Board of Directors Report - May 2021 to September 30, 2022 (submitted by President Rosanne Queen)**

Moved Doreen Lassam/Rosanne Queen, motion carried unopposed

#### **Approval of 38<sup>th</sup> Financial Report – May 1 2021 to April 30, 2022 (presented by Treasurer Patrick Livolsi)**

Moved Doreen Lassam/Rosanne Queen, motion carried unopposed

#### **Appointment of 2022/2023 SABC Board of Directors**

Introduction of new Board Members Kelly Grant and Aryn Rajan

Reintroduction of current serving Board Members – President Rosanne Queen, Vice-President Michele Gervais, Treasurer Patrick Livolsi, Secretary Beth Miller, Valerie Doyon, Chelsea Fitzpatrick-Lindsay, Jessica Jun, Grace Kim, David Queen

Goodbye and sincerest thanks to departing Board Members Tiasha Burch and Jeff Gammon

#### **New Business**

None

#### **Adjournment**

Moved Aryn Rajan/Chelsea Fitzpatrick, carried

Meeting adjourned 9:25am

## 2. 39<sup>th</sup> SABC DIRECTORS REPORT (May 2022 to April 30, 2023)

### Forward

Our 38<sup>th</sup> Annual General Meeting & Conference was conducted on-line last year via Zoom on October 22, 2022. Those listed as Directors were elected by acclamation. Kelly Grant and Aryn Rajan joined our board and SABC thanked and acknowledged all the work that Tiasha Burch and Jeff Gammon have done for SABC over the years. Guest speakers included Dr. Wilson and Mandeep Dhindsa of the BC Lung Transplant Program along with recipients Kathryn O'Neil, Beth Miller and Cecille Soriano. Brett Thombs gave us an update on SPIN.

### SABC Research Project

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/research/sabc-research-program/>

### Financial Report

For fiscal year 2022-2023 (May 1, 2022, to April 30, 2023), revenue consisted of \$517,491.36 with expenditures of \$148,932.53 for a net increase of \$368,558.83. Major disbursements included a research contribution of \$107,723.09 to St. Paul's Foundation, \$10,000 for the Canadian Scleroderma Research Group – Stem Cell Research and \$5000 for Scleroderma Patient-centered Intervention Network (SPIN).

In an effort of providing more stable long-term funding for scleroderma research, a new endowment fund (Joan Kelly Endowment) was also established this year. The fund was seeded with \$372,000 from three dedicated donations from revenue. All future annual revenue from investment of the fund will be distributed to scleroderma research projects in the following year.

Two other funds were also established this year. The Lihong Memorial Scholarship fund was established 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 \$2,865 at the end of April. 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 had \$3,858.68 at the end of April.

As of April 30, 2023, SABC had \$499,974.45 in total cash and investments (including amounts from Operating, Endowment, Community and Scholarship funds).

### Raising Funds & Awareness

**2022 Moving to Cure Scleroderma:** A cheque for \$102,723.09 was presented to the St. Paul's Foundation to support the SABC Research Program. Five teams participated in June 2022, helping us surpass our goal: Scleroderma Ride for Research – Vancouver \$65,723.50, Moving to Cure Anywhere in BC - \$9,370, Kamloops - \$7,700.49 Victoria - \$11,402.20 and Surrey - \$8,466.90.

In 2022 we had the following sponsors: Global BC, Park Insurance, Save on Foods, C-Lovers, Out of the Blue Designs, MPERO 4 Entertainment & Pratt Pharmacy

SABC members Valerie Doyon and Chelsea Fitzpatrick created a fantastic YouTube video showing the support we received across the province.

In addition, SABC donated to the following: \$5,000 to the St. Paul's Foundation – SABC Research Project, \$5,000 to the Jewish General Hospital Foundation -Lady Davis Institute – SPIN, and \$10,000 to the Canadian Scleroderma Research Group – Stem Cell Research.

### **Educational Days**

SABC also hosted 3 successful educational webinars: September 13, 2022 Pain Management with Dr. Micah Burns of ChangePain Clinic - Vancouver, January 21, 2023 Yoga for Scleroderma and April 5, 2023 Calcinosis and Hand Restrictions with Dr. Justyn Lufty.

These webinars have been recorded and can be found in our website. Under the events tab <https://sclerodermabc.ca/resources/videos/?t=webinars>.

### **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, Twitter (X), and Facebook.

### **President's comments**

Once again, 2022/23 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 this June.

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 the walk organizers, volunteers and all those who participated in this June's "Moving to Cure Scleroderma". You all made 2023 our most successful fundraising year, yet.

*Rosanne*

### 3. FINANCIAL REPORT

2022 May 01 – 2023 April 30

#### BALANCE SHEET (APR 30)

##### Scotiabank

Operating	\$17,798.63
Research	\$977.72
Technology	\$0.05
High Int Savings	\$200,000.00
GIC Investment	\$250,000.00
GIC Research and Technology	\$31,198.05
<b>TOTAL</b>	<b>\$499,974.45</b>

#### PROFIT & LOSS (OPERATING)

##### INCOME

Conference	\$0.00
Dues	\$0.00
Interest	\$792.57
General	\$44,934.65
Research	\$69,570.60
Ride for Research	\$7,800.00
Walk – BC Virtual	\$2,450.00
Walk – Victoria	\$3,186.00
Walk - Kamloops	\$2,583.88
Walk - Surrey	\$2,803.50
Other Revenue	\$4,646.48
Lihong Scholarship Fund	\$2,865.00
Kelly Community Fund	\$3,858.68
Kelly Endowment Fund	\$372,000.00
<b>Total</b>	<b>\$517,491.36</b>

##### EXPENSES

Bank Charges	\$25.25
Events	\$875.00
Fundraising	\$0.00
Grants	\$15,000.00
Office	\$8,079.28
Other	\$3,206.53
Promotion	\$13,485.61
Qualified Donations	\$107,723.09
Scholarship	\$0.00
Professional	\$537.77
Travel	\$0.00

**\$148,932.53**

**Net \$368,558.83 (Profit)**

#### 4. ELECTION OF 2023 – 2024 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.

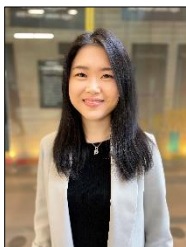
##### NEW NOMINEES (PRE AGM)



**Amir Pourghadiri** is a third-year medical student at the University of British Columbia (UBC). Amir holds a Master of Science degree from UBC where he studied the mechanisms of burn and wound healing, and the application of collagen hydrogels in reducing hypertrophic scars in patients with burn injuries. Amir has been actively involved in both basic and clinical research since 2015, with experiences in autoimmune and chronic skin diseases. Amir's dedication to the medical community goes beyond his research endeavors. He takes great joy in mentoring undergraduate students who aspire to pursue a career in medicine. In addition, he actively contributes to the Peer Mentoring in UBC Medical Education club, where he teaches current medical students about common case presentations on the medicine ward. When not engaged in academic pursuits, he enjoys exploring BC and fly-fishing in new lakes and streams across Canada. Amir is very excited to join our team and advocate for patients with scleroderma.



**Kenny Reid** was diagnosed with Systemic Scleroderma in 2020, which quickly developed into extreme lung fibrosis (Interstitial Lung Disease), which eventually required a Double Lung Transplant in Aug 2022. The journey to recovery was long after an initial 3 month stay in hospital, but now Kenny is in good health. He is committed to giving back to help other "Scleroderma Warriors" and those going through Lung Transplant. He is committed to do all he can, to assist in finding a cure for this terrible disease. Kenny moved to the Vancouver area from Scotland 20 years ago with his wife Alison and son Lewis. His background is in Sales and Marketing, having worked for over 30 years in the Office Interiors Industry associated with office furniture innovators Herman Miller. He has strong communication and strategy skills, and a positivity to drive to succeed in whatever he puts his mind to. His hobbies include Golf, Soccer, Snooker and Music, and was lead singer in an 80's cover band playing gigs across the lower mainland. Kenny is currently volunteering in conjunction with VGH staff (Doctors and Nurses), to help Lung Transplant patients in their recovery, providing tips and goal setting from his own personal experience, that will help their recovery be as smooth as possible.



**Helen Hsiao** is a second-year medical student at the University of British Columbia (UBC). She completed a Bachelor of Science in Microbiology and Immunology but wrote her undergraduate thesis on the underlying neural networks of 3 different cognitive functions. As someone who has been diagnosed with a skin condition herself, Helen is very interested in learning about other skin diseases and supporting people living with these diseases. Hence, she has volunteered for organizations that promote awareness for skin cancer, acne, and dermatology education across Canada. Besides her interest in dermatology, Helen is also actively involved at her school, spearheading the production of the UBC Medical Journal as Co-Editor in Chief, and serving as a student representative on the UBC Faculty of Medicine student affairs committee. In her free time, Helen enjoys running, dancing, drawing, reading, and doing yoga. She loves anything art-related, especially film and design, which is why she enjoys creating videos and graphic designs for clubs and side projects. Helen is beyond excited to join the Scleroderma Association of BC Board and looks forward to supporting SABC's initiatives to advance knowledge and care for people living with scleroderma.

## NEW NOMINEES (DURING AGM)

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## RETURNING DIRECTOR NOMINEES



Michele Gervais (Vice President)



Patrick Livolsi (Treasurer)



Beth Miller (Secretary)



Kelly Grant



David Queen



Rosanne Queen (President)

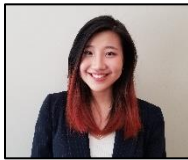


Aryn Rajan



Chelsea Fitzpatrick-Lyndsay

## SAYING GOODBYE & SINCERIST THANKS



Grace Kim



Valerie Doyon



Jessica Jun

## 5. NEW BUSINESS

## 6. ADJOURNMENT