SCLERODERMA ASSOCIATION of B.C.

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Issue 3 SCLERODATA 2018

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Take Action for Pulmonary Arterial Hypertension

Scleroderma Canada and the Pulmonary Hypertension Association of Canada (PHA) continue to work collaboratively on a campaign of advocacy for access to treatments for patients living with pulmonary arterial hypertension (PAH), including systemic scleroderma associated PAH (Ssc-PAH). One of the drugs approved for PAH treatment is Actelion Pharmaceuticals' product, Uptravi (selexipag). It is approved by Health Canada and is recommended for public funding, however British Columbia is the only province that has not approved public funding for the use of Uptravi. Thus, the appeal for your support, as presented below.

SABC advocates for the scleroderma community across the province and is committed to promoting disease awareness and improving the quality of life for all patients, including those with SSc-PAH. Through advocacy, we aim to raise public awareness and rally support around the issues affecting the scleroderma community to ensure our voice is heard and needs are met by government decision-makers. One of these issues is ensuring that our community has publicly funded access to all new and existing treatments—including treatments for those in BC who are living with SSc-PAH. Lend your voice and visit www.takeactionPAH.ca to take action!

Over 85% of Canadians now have publicly funded access to Uptravi.
But PAH patients living in British Columbia do not.

Lend your voice to PHA Canada and Scleroderma Canada to help ensure equal access to PAH treatments for **all Canadians**.

Help us advocate!

www.takeactionPAH.ca #TakeActionPAH

June AGM & Conference Highlights

Your 2018/2019 SABC Board of Directors

At the AGM, SABC President Rosanne Queen reminded us that it is the passion, commitment and caring of the members of our board that find the time to allow SABC to operate and grow and thanked the 2017/2018 board members and other volunteers throughout the province who continue to bring public awareness to scleroderma.

SABC's 2018/2019 Directors of the Board were confirmed as: Tiasha Burch (secretary), Grant Dustin (member), Michele Gervais (vice president), Dianne McPhee (member), Neil Mackie (member), Melissa Patton (member), David Queen (treasurer), Michael Queen (member), Pat Thomasson (member), Veronika Boyeva (member) and Rosanne Queen (president).

Retiring from the Board, after many years of service, is Bob Buzza (pictured here with his sister Joan).

New SABC 'First Responder'

Joan Kelly, one of the founders of the Scleroderma Association of B.C., is stepping down from her position as the SABC contact person. Among her varied roles in the Association, Joan became known as the friendly, helpful person who answered the telephone calls and responded to correspondence. We thank Joan for her many years of dedication and valuable service.

Dianne McPhee, one of our Board Directors for many years, will take over the responsibilities formerly carried out by Joan Kelly. Dianne offers this introduction.

Hello everyone:

In my new role, I will man the phone lines and all SABC email inquiries. I will do my best to fill Joan's shoes (a very hard task to do). Our new local phone line is 604-371-1005, our toll free and email address have stayed the same at 1-888-940-9343, and scleroderma@telus.net. I will do my best to promptly respond to your inquiries and direct you to the right person if I'm unable to answer your question!

In the next few months we will be trying to update all our member contact information, so it is very much appreciated if you could send me any recent changes to your current email address, mailing address and phone number. If you know of someone who is a new patient and who would like to receive our *Sclerodata* newsletter by email please don't hesitate to forward SABC's contact information to them.

Thank you

Dianne McPhee

Note: During this transition from Joan to Dianne, Dianne's email responses are appearing, unfortunately, as a message from 'Dianne McPhee' (instead of SABC). Please bear with us (as we work with Telus to correct) and do not immediately delete Dianne's response when you don't recognize her name. Please note the email's subject line to recognize it as Dianne's response.

Change to SABC membership fees! (But we still need your support)

The Scleroderma Association of BC's focus has always been to support ALL individuals affected by scleroderma. We have never wanted the cost of SABC membership to prevent anyone from accessing the services that we provide. With this goal in mind, we have decided to formally discontinue membership fees, as approved at the AGM in June. Since membership in SABC is no longer tied to payment of fees, a 'member' is anyone on our contact list (and we welcome new members and their contact information!).

This membership fee change will benefit everyone as all will be considered members and able to access the support they need. The SABC however, still needs funds to maintain its service as an effective scleroderma support organization. In place of the previous annual membership fee, we are now encouraging members to make an annual donation to the Association. Members will receive a tax receipt for their donation.

Copy the link below into your browser to quickly and easily donate online today! (Donations may also be made by cheque and mailed to PO Box 16155 Lynn Valley, North Vancouver, BC V7J 3H2)

https://www.canadahelps.org/en/charities/scleroderma-association-of-bc/#donate_now

How Your Donations Are Used

When you support the Scleroderma Association of BC, you are helping to achieve the goals of our organization, namely to promote patient outreach and support, to increase awareness and understanding of the disease and to support research being done right here in BC and elsewhere in Canada. Your donations support:

- Research being done in our province and nationally. Let's keep the research rolling! Learn more about this exciting research on our website at www.sclerodermabc.ca
- The annual Scleroderma Association of BC conference, where members can receive updates on research and socialize with fellow members.
- On-going practical and emotional support for those living with scleroderma - whether a member is newly diagnosed or facing a change in symptoms and/or other scleroderma issues - the Association's volunteers frequently provide support at challenging times.
- Promoting awareness and education, as well as covering basic administration expenses. The Association is proudly staffed entirely by volunteers meaning that administration costs are kept very low, but we still need to buy stamps :)

For more information on how your donations help all of us living with Scleroderma, please contact Rosanne at rq.sabc@telus.net or 604-984-9425

Don't forget! You can ALSO help by forwarding the above link to your friends and family to help spread awareness about scleroderma and to help support research into finding a cure.

June AGM & Conference Highlights Continued….

Social events, Speakers Extraordinaire, UBC Students and so much more!

The Friday evening reception provided a good pre-conference opportunity for folks to have a relaxed visit with friends and to make new acquaintances in the scleroderma community. Saturday sessions began with the Annual General Meeting, followed by presentations on a variety of topics by excellent speakers. The program concluded with group sessions that generated much discussion on topics of common interest.

Fran Schooley spoke on patient advocacy and scleroderma and lung patient support systems at St. Paul's Hospital. Her message was all about scleroderma patients getting better access to education and new modalities of treatment and creating a better learning environment for physicians (resulting in more accurate diagnosis for scleroderma patients).

Leah Chang, presented Pain BC's free self-management tool. Her live learning session encouraged audience engagement, a spirit of inquiry, and made information and resources accessible and relevant.

Dr. Elaine Dupuis, spoke of skin issues in scleroderma, discussing current themes of skin and systemic sclerosis. A Question & Answer format yielded helpful information.

Dr. Murray Baron, provided a worldwide research update on scleroderma and stem cell research developments, including collaborative work in Canada to develop a national protocol for selection, treatment and after-care of scleroderma patients who might access stem cell therapy. This would hopefully contribute significantly to nation-wide research of patient outcomes and to international literature on stem cell therapy for scleroderma patients.

Our student guests from UBC were an important part of our conference again this year. This initiative started last year with 11 UBC students in health profession studies attending our conference to learn about scleroderma and scleroderma patients. This year 12 students in health profession studies at UBC attended our conference, again with enthusiastic participation in the day's program, including mutually beneficial interaction with scleroderma patients.

The annual awards sponsored by the Dhanda family were a special feature of the conference program. We are very grateful for the continuing generosity of the Dhanda family in providing these annual awards. Members of the Dhanda family conveyed their regrets that they were unable to attend our conference this year to present the awards in person.

Gurmej Kaur Dhanda Memorial Scleroderma Community Service Award

The Gurmej Kaur Dhanda Memorial Scleroderma Community Service Award was presented to Bob Buzza. Bob is retiring this year from his role as a Director with the SABC Board. Over the course of the 34-year existence of the SABC, Bob has contributed in many ways to make it a successful organization, including having served in every executive capacity. We extend our sincere thanks to Bob for his dedication and leadership in helping to make the Scleroderma Association of BC an effective, important service to the scleroderma community in British Columbia and beyond. Bob was completely surprised – and very pleased – to be named the recipient of this award. Congratulations Bob!

Gurmej Kaur Dhanda Memorial Scleroderma Scholarship Award

The Gurmej Kaur Dhanda Memorial Scleroderma Scholarship Award was presented to UBC medical student Alice Mai. Alice Mai is a 1st year rheumatology fellow at UBC. She was raised in Vancouver and has done all of her medical training here. Alice plans on practicing in the Lower Mainland after she finishes her fellowship program. She has been working with Dr. Antonio Avina on his registry studies, and hopes to complete her project with him on overall and cause-specific mortality in scleroderma in the coming year. Congratulations Alice!

June - Scleroderma Awareness Month

June 1st— Annual ScotiaBank Community "Hot Dog Day" in **North Vancouver**. Thanks to all those who joined us in raising $3,000 and thanks to Scotiabank for matching it to make $6,000 for research at St. Paul's. A big thank you to James, Assistant Manager & his gang at 1357 Lonsdale, Nicole & Anroe of O'Canadawg and the residents of the North Shore.

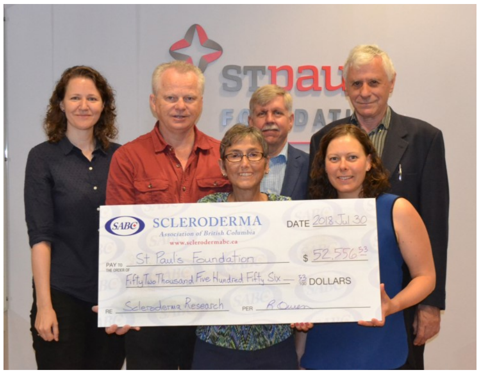
June 24—1st Annual Walk in Victoria. Linda Barnes and helpers organized this successful new event in **Victoria**, raising over $11,000 for scleroderma research. Linda was featured on a TV interview and the local newspaper covered the event in a front page story. There were approximately 90 in attendance, including some folks from up island. Congratulations on your success with the event and many thanks to all organizers and supporters!

June 30—2nd Annual Walk in **Valemount.** Teressa had more than 45 people join her, raising over $2000 to go towards the St. Paul's Research Project. Congratulations to Teressa Colosimo and fellow organizers, and many thanks to all supporters!

June 17—7th Annual Scleroderma Ride For Re-search in **Vancouver**. Thanks to your support, we raised over $40,000! The group of 77 who came out to ride (long & short), walk and tend the home fires preparing the potluck lunch all have smiling faces in preparation of spreading awareness and having fun. 4 dogs, with their blue bandannas, joined the walkers. SABC thanks Rosanne and David Queen and their helpers for organizing the event again this year, and Rosanne extends her sincere thanks to all the supporters who make it such a success.

Across Canada

2018 Walk, Run, Ride events raised a total of over $400,000 for scleroderma awareness, education and research.



SABC SCLERODERMA
Association of British Columbia
www.sclerodermabc.ca
DATE 2018 Jul 30
PAY TO THE ORDER OF St Paul's Foundation $ 52,556.53
Fifty Two Thousand Five Hundred Fifty Six — 53/100 DOLLARS
RE Scleroderma Research PER R Queen

News and Announcements

Renal/Scleroderma Book Update

Sales of Priscilla Stanbury's inspiring book *Warriors and Heroes of a Different Kind: Battling Kidney Failure* are exceeding expectations. Over 200 have already been purchased on line. Over 70 have been purchased directly from the author. The book was featured at the recent Scleroderma Canada Conference in Calgary. Combined with anticipated results from media outreach efforts this fall, further significant sales are likely. Sales have already occurred in Canada, the US and UK, Europe and India. Purchasers include not only renal and scleroderma patients and their loved ones but also nurses and medical specialists and technicians as well as the general public. The book is an award finalist in the non-fiction category of The Canadian Book Club Awards.
To date media outreach has resulted in a forthcoming Podcast sponsored by Canada's Podcast and an article in the winter edition of the national renal publication *Spice It Up.*

Feedback has been very positive. One terminally ill elderly man afflicted with a serious, paralyzing stroke and no hope for a kidney transplant had decided to forego further dialysis. After meeting with Priscilla and reading her book, he changed his mind. Priscilla continues to cope with hospital-based dialysis nightly three times a week for eight hours as well as severe neuropathic pain, Raynaud's disease symptoms, and deteriorating mobility. Writing the book, which is a rich mix of personal renal and scleroderma patient stories and current medical information, has been a huge challenge. Doing so has been cathartic and fulfilling for her and inspiring to many.

To purchase an autographed book for only $15.00 directly from Priscilla call 604 739 4057 or email pstanbur@capilanou.ca. It can also be purchased for $17.02 CDN by citing the title at Amazon.ca. All net proceeds from sales are being divided between scleroderma and renal research with the administrative support of the St. Paul's Hospital Foundation.

November Christmas Lunch

The Scleroderma Association of BC will be holding its **annual Holiday lunch on Sunday, November 25, 11:30 to 1:30 at Boston Pizza in Columbia Square Plaza, New Westminster (1045 Columbia Street)**

We invite and encourage all members to join us for this annual tradition to toast the holiday season, meet some new faces and simply enjoy the company of others, learning and sharing information as a member of the scleroderma community!

If you are joining us, please RSVP to Dianne at telephone 604-371-1005 or email scleroderma@ telus.net.

Scleroderma Canada Bi-Annual Conference Highlights

Calgary, September 19-22

SABC Board Members Michele Gervais, Grant Dustin and Melissa Patton travelled to Calgary to attend two days of pre-conference Scleroderma Canada Board meetings on September 19th and 20th, during which we discussed and helped prioritize Scleroderma Canada's (SC) 2018/2019 primary initiatives (special events, projects, national campaigns) in support of Patient Advocacy & Scleroderma Awareness and Patient & Community Education.

We ended the meetings with AGM approval of a new SC Board structure which, in addition to the existing members, now includes four chairpersons overseeing committees working on budgeted projects within the four pillars: Advocacy, Research, Education and Patient Care. These chairs will also be responsible for providing updates and communicating project statuses to the Board.

Two more SABC Board Members (Dianne McPhee and Neil Mackie) and others from BC joined the fun on Friday and Saturday for the conference. The packed agenda featured these highlights: an expert panel discussion, the City of Calgary's inaugural Scleroderma Awareness Walk to the Bow River and excellent presentations on topics ranging from help for the newly diagnosed to exciting new treatments being researched. These educational sessions, on a variety of topics (too many to list!), were of interest to scleroderma patients, their caregivers and healthcare providers. Opening and closing keynote speakers provided inspirational messages of living well with scleroderma in the present and messages of hope for the future. Selected speaker sessions were recorded and will be available for on-line viewing once posted to the SC website. Keep your eye on www.scleroderma.ca for these postings. Join us as we look forward to making new acquaintances and seeing old friends at the next Scleroderma Canada conference in 2020 in Niagara Falls!

Neil Mackie, Marie Mackie, Grant Dustin, Michele Gervais, Kevin Keene, Donna Gervais, Heather Durfeld, Dianne McPhee, Jen Beckett

St. Paul's Pulmonary Fibrosis Support Group

The next support group meeting will be on **October 23, 2018**. Meetings are held at St. Paul's Hospital, 1081 Burrard Street, Vancouver. All meetings are in Dining Room 1 – Fourth Floor Providence Wing – Beside the Cafeteria. Meetings run from 1:00 to 4:00 pm. All patients with pulmonary fibrosis of any kind or level of severity, caregivers and significant others are welcome to attend. The other meeting date remaining for 2018 is scheduled for **December 11**.

The support group meetings offer an opportunity to meet and mix with other patients and to hear a presentation from a guest speaker, with time for questions. The meetings are hosted by **Fran Schooley, who is** the clinic coordinator for the Scleroderma Lung Clinic, which is part of the Pacific Lung Health Centre at St. Paul's Hospital. Information about the Pacific Lung Health Centre and the Scleroderma Lung Clinic may be found on their website, http://pacificlung.ca/scleroderma-lung-clinic.

Information about the clinic and support group meetings may be found on the SABC website or by contacting Fran Schooley at 604.806.8818 Extension 2, or email fschooley@providencehealth.bc.ca.

SABC Board of Directors 2018 / 2019

President	Rosanne Queen	604-984-9425	rq.sabc@telus.net
Vice President	Michele Gervais	604-761-7782	gordmich@telus.net
Secretary	Tiasha Burch	778-984-3745	burchtiasha@gmail.com
Treasurer	David Queen	604-984-9425	dq.sabc@telus.net
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Board member	Veronika Boyeva	778- 994-6490	veronikaboyeva@gmail.com
Board member	Neil Mackie	604-999-8729	neilmack@telus.net
SABC Contact	Dianne McPhee	604–513-5875	diannemcphee@shaw.ca
Board member	Pat Thomasson	604-591-3033	pthomasson2001@shaw.ca

Community Contact Representatives

Campbell River	Sharon Watson	250-923-6171	s.watson@telus.net
Creston	Betty Kuny	250-428-8875	rkuny@telus.net
Kelowna	Angie Reglin	250-860-5700	angiereglin@gmail.com
Kamloops co-reps	Jen Beckett	250-574-3151	jenniferbecketts@hotmail.com
Kamloops co-reps	Darla Martin	250-554-4636	lmartin7@telus.net
Maple Ridge	*Seeking Representative*		
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New Westminster	*Seeking Representative*		
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Disclaimer

The Scleroderma Association of B.C. does not endorse any drug, treatment, or dietary material presented in this newsletter. Always discuss alternative medical options with your doctor before including them in your treatment plan. Although we aim to keep you informed and engaged, the opinions shared through this newsletter are not those of the Scleroderma Association of B.C. and are intended to spark discussion.

Sclerodata may still be received in print form but may also be received as an email attachment (just send us your email address if we don't have it yet).