SCLERODERMA ASSOCIATION of B.C.

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Issue 1 SCLERODATA *2023*

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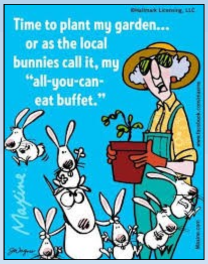

Highlights

How Can You Support June Awareness 2023?

June is Scleroderma Awareness Month across Canada and the United States with June 29th as World Scleroderma Awareness Day. This special time is dedicated to educate and raise public awareness about this little-known and often misunderstood orphan disease and stress the critical importance of funding research to find a cure and support quality of life for people living with scleroderma. As one of our objectives is to encourage as many people as possible to learn more about this disease which affects over 20,000 Canadians, the SABC holds awareness and fundraising events throughout the province with our "***Moving to Cure Scleroderma***" campaign.

It's so easy to be a part of this years campaign!

Moving to Cure SCLERODERMA

Donate

Just want to make a donation and not join us for a walk?

click the donate link below

Register

If you want to attend one of the physical events.

After registering you will receive a confirmation email with a link to join the team to fundraise and/or donate to this event.

Fundraise

If you want to fundraise for the virtual event.

click the fundraise link below

Click **DONATE NOW** to support

Click **REGISTER** to choose your walk

Click **FUNDRAISE** to create your own personal fundraising page

100% of funds raised support research in B.C. and Canada with receipts issued for all donations!

Highlights cont'd

A BIG Thank-You to the Walk Coordinators! Support them and us all by showing up at the walks!

SURREY

SUNDAY, JUNE 4TH /WALK, TYNEHEAD PARK - Surrey, BC V4N 2E2

We are excited to welcome everyone to our second "Moving to Cure Scleroderma" 5 km walk! Our goals are to create awareness for scleroderma and raise money for critical research. Please join us at 9 am at Tynehead Park's Serpentine Fields Entrance. Let's get moving for a cure for scleroderma!

WALK COORDINATORS: CHELSEY FITZPATRICK-LINDSAY - COQUITLAM & KELLY GRANT - CHILLIWACK

VICTORIA

SUNDAY, JUNE 11TH / WALK, WEST SHORE PARK - 1767 Island Hwy, Victoria, BC V9B 1J1

We are excited to host this 6th Annual Scleroderma Walk. We are looking forward to more friends and family joining in to raise awareness and funds for research for this little understood disease. There will be a choice of a 2 or 5 km walk as well as refreshments and a silent auction of exciting prizes. Please save the date and we would love to see your smiling faces at 9 am at West Shore Parks and Recreation's Picnic Shelter.

WALK COORDINATOR: LINDA BARNES - VICTORIA

VANCOUVER

SUNDAY, JUNE 18TH / BIKE RIDE/WALK, STANLEY PARK - Vancouver, BC V6G 1Z4

David and I are now hosting our 12th *"Scleroderma Bike Ride/Walk for Research".* Each year we are amazed at the continued support we receive from people joining us and helping raise research dollars. The SABC Research Project team is deeply committed to helping those living with scleroderma and we are deeply committed to supporting them.

RIDE/WALK COORDINATORS: ROSANNE & DAVID QUEEN - NORTH VANCOUVER

ANYWHERE IN B.C.

ALL OF JUNE / VIRTUAL MOVING

Come on out and participate in SABC's virtual *"Moving to Cure Scleroderma".* No matter where you live in BC, pick a day in June, wear your blue and show us your favorite activity. *What is a virtual event?* Engage in an activity of your choice, in a location of your choice! You can walk, bike, run or run a marathon, do yoga, kayak or any activity you enjoy. It's your choice so be as energetic, adventurous or creative as you can be!! Let's get our family, friends, co-workers and even your community involved in spreading awareness and most of all having fun.

VIRTUAL COORDINATOR: TERESSA COLOSIMO – VALEMOUNT & NORTHERN RURAL COMMUNITIES

And please DON'T FORGET to email your "MOVING TO CURE SCLERODERMA" blue t-shirt photos to Chelsea at: chelsea@sclerodermabc.ca

Highlights cont'd

SABC's First Endowment: The Joan Kelly Memorial Research Fund

As we all know there is limited financial support from governments and institutions for research into finding cures for rare diseases such as ours. Despite this reality, SABC members have taken it upon themselves to donate, over the last 30 years, to Scleroderma research here in B.C. and across Canada to the tune of $1,000,000.00. Now is the time to take our support for Scleroderma research to the next level by setting up an endowment to fund future research.

What is an endowment? An endowment is simply a pot of money (called the capital), held in an interest-accruing account or fund. How it works is that any contributions (cash or assets) made to the endowment are invested and in our case, the earnings from the investments (called the income) will be used to fund future research. Contributions to the capital will always be earning income to fund Scleroderma research. It is the gift that keeps on giving. What is also great about an endowment is it helps make funding for research more consistent helping us predict how much the endowment will earn every year so we can better plan for multi-year research projects we want to support.

Endowments provide peace of mind. We get to select where and how the capital is continually invested, resulting in an annual income earned which is used as a source of funding for the long-term financial support of scleroderma research. Endowments come with rules as well. SABC has established a Terms of Reference document describing the use of the income to ensure it remains consistent with SABC's vision regarding supporting scleroderma research and patient care. The income generated can only be provided for research purposes where the research is intended to improve the treatment, care or support of patients coping with scleroderma. As per SABC's research grant application process, funding is determined based on assessment of research proposals and the amount withdrawn from the endowment limited to the income earned in the previous SABC fiscal year. The Terms of Reference is available for review by all donors.

Why name this research endowment after Joan? Joan Kelly was a true Scleroderma warrior who co-founded SABC with a mission to provide outreach and peer support, raise awareness and encourage research. Joan reached out to rheumatologists to let their patients know of the SABC, created BC-based printed material, held support group meetings and created a phone tree for peer support. She became the friendly voice answering the help line, editing newsletters, sending birthday cards to members and thank you cards to donors, visiting the hospital and organizing annual meetings and fundraisers. As for the connection to research, Joan played a key role in advocating for the creation and equipping of the Scleroderma Clinic at St. Paul's Hospital and supported the efforts of the SABC Research Program and their work to find a cure.

The *Joan Kelly Memorial Research Fund* has already been given a generous initial boost by a few Scleroderma warriors gifting over $370,000.00. To continue the endowment's growth (and its subsequent interest earnings), any size of gifts of cash and/or assets can be directed to the Joan Kelly Memorial Research Fund, by simply selecting it when donating via SABC's website or by specifically documenting it in your financial and estate plans.

Joan touched hundreds of lives as she devoted herself to SABC members for 30 years, but she would be the first to say that her life was touched by theirs. Now, as the all-volunteer registered charity SABC approaches 40 years, its mission remains steadfast. Education and outreach remain vital. Research progresses but there is still no cure.

The endowment fund reflects Joan's history of giving her all for scleroderma patients: who she was and her lasting memory truly is, the gift to us all, that keeps on giving.

Good to Know

SABC Community Support Groups

COME ZOOM WITH US

Virtual Community Support & Connection Meetings

The Scleroderma Association of B.C. strongly believes in the merits of support groups. Support group meetings create an environment conducive to discussion by providing a safe place where people affected by the disease, their families, friends and caregivers can give and receive practical and emotional support. Currently, SABC is offering virtual support meetings...**We Invite You to Come Zoom With Us!**

These (almost) monthly meetings feature various topics for discussion:
Days: Wednesdays
Time: 7:00 – 8:00pm Vancouver time

Upcoming Dates:
Wednesday May 17 – Informal update of the SABC Research Program with Dr. Jim Dunne and Kevin Keen
Wednesday July 5 – Let's Wrap It Up for Summer

Click Here for more information and to register!
Questions or suggestions about our Support Group meetings? Please email sabcbeth@gmail.com

Missed previous meetings? No worries! If you would like information about the resources provided during those meetings, please email Beth or Kelly at sabcbeth@gmail.com or thekellygrant@gmail.com

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Scleroderma Association B.C.

Save The Date: SABC AGM & Conference

Saturday October 21st

The SABC Annual General Meeting & Conference is scheduled to be held on **Saturday, October 21, 2023** as...WAIT FOR IT...an actual **live**, **in-person event**. We are super excited to once again host this social and informative event; this year in beautiful Burnaby!

As per usual, it will include the Annual General Meeting portion first followed by presentations by speakers with scleroderma expertise on a variety of topics. Your SABC events team is working on arrangements and will email more information later. Please keep checking SABC's website often for updates regarding the program and how to register.

The event will **also be on-line** for those unable to travel to the venue and/or who prefer to participate in the comfort of their living room.

If the cost of things lately is wreaking havoc on your household budget making attending this year's AGM & Conference feel financially out of reach, please do contact the SABC to inquire about available funds specifically set aside to help scleroderma patients connect with one another and the SABC; thanks in no small part to the donations made in memory of Joan Kelly, supporting her legacy of patient support, scleroderma awareness and in honour of all she did and continues to do for SABC members.

Interesting Reading

We Got Published!

We all know the SABC research team at St. Paul's has been diligently working at analyzing our blood and skin samples and generating data that fall into individual research projects under the giant umbrella of the **SABC Research Program**. For ease of reference we'll give the projects within the program abbreviated names that describe their specific targets of study: micro (mi) RNAs, auto-antibodies (proteins produced by the body's immune system directed against other proteins), cytokines (small proteins important in cell signalling), metabolites (intermediate products of the body's metabolism), nuclear DNA, and long non-coding (lnc), circular (circ), and messenger (m) RNAs.

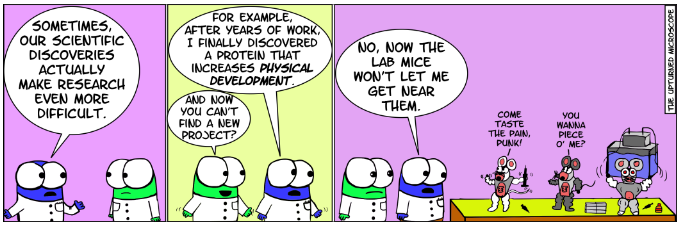
And the hard work is paying off as the team and we SABC members are celebrating our first research publication in the journal *Scientific Reports.* On 24 April 2023 the journal published an article submitted by the research team on the differences in certain proteins called cytokines in people with either systemic scleroderma or interstitial lung disease, or both.

The levels of 87 cytokines in blood plasma were compared with those of healthy individuals. No substantial association was found for any of the cytokines with changes in lung capacity over time, but four cytokines were found to be markedly different in patients compared to healthy individuals. One cytokine associated with ageing was increased two-fold in all patient groups. Another cytokine associated with tissue inflammation was increased eight-fold but only in patients with interstitial lung disease and was not increased in healthy individuals or patients with scleroderma with no lung involvement. A third cytokine associated with blood clotting was decreased in all patient groups compared to healthy individuals. Another cytokine was increased two-fold only in patients with the limited cutaneous form of scleroderma compared to healthy individuals. This fourth cytokine is associated with immune-cell migration into tissue and the promotion of fibrosis and may be a marker of milder forms of scleroderma.

These results suggest there may be common and different reasons why people develop pulmonary fibrosis and is a starting point for future research into the reasons.

Congratulations to the researchers and article authors Boyang Zheng, Kevin Keen, Marvin Fritzler, Chris Ryerson, Pearce Wilcox, Beth Whalen, Basak Sahin, Iris Yao and Jim Dunne. The full text of the research article Circulating cytokine levels in systemic sclerosis related interstitial lung disease and idiopathic pulmonary fibrosis is available at https://rdcu.be/daAJ5 .

We look forward to hearing more updates regarding the projects listed above at this year's AGM & Conference in October.



Interesting Reading cont'd

SPIN's 2023 Progress Report

The Scleroderma Patient-centered Intervention Network (SPIN) is one of the many organizations your research donation dollars support. This international organization is special as it is comprised of not only researchers and health care providers but also of people actually living with scleroderma. This patient inclusion and engagement supports SPIN's mission: to work with people living with scleroderma to identify their needs and prioritize research in the areas most important to them, as well as to develop, test and distribute programs that improve their quality of life. The dedication of people living with scleroderma to advancing research is a key factor in SPIN's success.

Speaking of international, it is interesting to note that SPIN's cohort (group of research participants) was established in 2013 and now is made up of over 1400 patients in 7 countries. Its longevity is possible thanks to the incredible work of over 90 researchers and clinicians, in 49 treatment centers around the world. Thanks to the efforts of all SPIN's collaborators, experts, patients, and partner organizations, SPIN has been able to publish numerous studies from the analysis of its cohort data.

Besides the research studies and what we are probably most familiar with is SPIN's scleroderma-specific patient programs. Some of the programs to date we already follow are:

SPIN-HAND SPIN-SELF SPIN-SSLED SPIN-CHAT

Some of the future patient programs in the works are:

SPIN-COACH SPIN-COPE SPIN-PACE

With many exciting ongoing projects and more to come.

Within the Progress Report SPIN expresses its deepest gratitude to patient partner organizations such as the SABC, whose support over the years has enabled the development and/or completion of several SPIN projects.

SPIN looks forward to continuing their work to fill the gaps in scleroderma knowledge, advancing research and producing patient-friendly resources to improve patient quality of life. Please see the SPIN website for further information regarding all their projects and programs for scleroderma patients, their families and friends.

WHY DO THE FINGERS REFUSE TO AGREE WITH THE THUMBS?

THIS IS BECAUSE THE THUMBS CAN BE OPPOSABLE.

From our Members

Don’t Forget Those All Important Cancer Screening Tests!

Mammography, colonoscopy, PSA, PAP…the list goes on. We know its yet another appointment to get a referral for, wait for the call back, write on the calendar, book off the ½ day, find parking, change into the gown and bear with the uncomfortability of being poked and prodded for the requisite amount of time. But we do walk out of there thinking, phew, glad I got it done and its over for another year or two.

Our rheumatologists and GPs do recommend we get these age and sex-appropriate cancer screening tests. Often, especially when a scleroderma patient is newly diagnosed, we focus on the disease and forget the routine care but let’s please learn from Rosanne’s experience below and her determination in advocating for herself.

“In 2018, I attended the 5th Systemic Sclerosis World Congress in Bordeaux, France with my husband David. We listened to several speakers discuss scleroderma, but the one thing that stood out to me was the repeated emphasis on cancer screening, and I quote "Check for cancer, check for cancer, check for cancer!”. I took this advice to heart and continued getting annual mammograms, except for 2020 when the pandemic hit. When I went back for my mammogram in 2022, I was informed that, since I turned 65, I only needed to come in every two years. However, I knew I was at higher risk of cancer due to my scleroderma, so I requested a referral from my family doctor to get an annual mammogram. It turned out to be the right decision, as they found something suspicious during my mammogram that required further examination.

My worst fear was confirmed after the biopsy - it was cancer. However, the great news was it was caught early, it was estrogen-produced, and it was treatable. It was still a shock to learn I had cancer, but since I was told 26 years ago that I had only five years to live due to scleroderma, I took on a positive attitude and believed it to be treatable. I knew I had to take things one step at a time and stay positive.

At the beginning of the lumpectomy surgery, I politely told the nurse she was not to put the IV in my hand. I had been advised in previous procedures to ask they call an IV nurse and use the machine that helps locate veins. She appreciated my suggestion, and the IV was instead inserted with minimal discomfort in my lower arm. During the surgery, a lymph node was also removed for testing and thankfully it came back negative for cancer.

Now I have a two-month waiting period for the next steps in this process. I’ve learned that radiation might not be an option for me due to my rheumatoid arthritis and fibrosis. I'll be starting my hormone therapy. It has been a lot to take in, but I know I have to stay strong.

I am grateful for the fantastic technician who did the mammogram and caught the cancer, as well as for the compassionate and gentle care I received from the nurses, radiologist, oncologist, and surgeon. The support of my family and friends made the most frightening news more bearable, and I am grateful for them.

The lesson I learned from this experience is that regular cancer screenings are critical. We need to make sure to add them to our regular check-ups and not skip ANY appointments. Catching abnormal results early from annual PAP tests, mammograms, and prostate checks can make all the difference in the world for successful treatment. We need to be our own advocates and take care of ourselves.”

By Rosanne Queen, SABC President and determined advocate

From our Members cont'd

Caregiver's Corner: Home Care Support Experience

We have a light-hearted saying in our family…'it's not the Christmas holiday unless your Mother's in the hospital!' because every winter Mom comes down with her annual respiratory infection and is admitted to the Peace Arch Acute Care Unit. We had a lovely reprieve during Covid but this January the tell-tale increased wheezing began and we thought we knew what to expect. This time, however, it was different: maybe because she's 3 years older or maybe due to this particularly nasty strain of virus but it was clear this pneumonia was not clearing up anytime soon.

Mom has had a written die-at-home plan complete with all the signed government-required forms for a couple of years now (with help from an End-of-Life Consultant) and all her doctors are aware of her wishes. She is very adamant that there will be no hospital death and her plan clearly states where, how and who she wants around when its time. So when Mom opted not to have the recommended but potentially painful lung tube surgically placed and left in on the side of her chest (in the hopes it would continue to slowly drain some of the fluid off her lung), we began the discussion with the hospital doctor of allowing her to be discharged to her home. The doctor stated "Donna can get better or worse here or at home; its really her choice." All Mom heard was she didn't have to be in the hospital anymore if she didn't want to.

Within 24 hours, her hospital bedside was a whirlwind of Fraser Health home healthcare professional introductions, assessments and goodie bags filled with comfort products and detailed instructions. I was filling a notebook with contact info, future dates and times of scheduled home assessments from palliative nurses, occupational therapists, home care support workers, respiratory technicians, equipment supply companies, etc. I ran to the red cross to pick up a mobility chair. I ran to her house to redecorate her bedroom to allow for the hospital bed delivery and set-up and then to the store to buy the special bedsheets. I ran to the pharmacy to pick up a bucket of discharge medications and personal care supplies they told me we'd need.

I have to admit it was chaos for the first 3 days at home. It was hard to get use to the comings and goings of all these new people in our life. But then it became, how I described it to family and friends checking-in, as kind of peaceful and magical. We fell into a routine of care and knew what and who to expect when. The palliative team provided a wonderful thick binder with contact info and everything you'd ever want to know about looking after someone at home. Mom was sleeping well, something she's not done for years, which meant we were all sleeping well. We moved the bird feeders to her bedroom window for entertainment. We had visitors (thank you for the muffins and cookies!), great chats at tea time and life slowed down to a wonderful pace.

Of course the story doesn't end here. It should come as no surprise to those of you who know my Mom, that there is no holding her down for long. She graduated from the mobility chair to the walker within a week and was off the home oxygen in a month. She is off all the discharge meds and back to her usual meds and, due to her increased mobility, has been designated by Fraser Home Health as no longer palliative. Although her home care visits have been suspended, we will continue to have access to the palliative nurse hotline, giving us that sense of security. Her recent chest x-ray was clear. Her PFT score was the same as her last one, 6 months ago.

When Mom and I look back at this home care support experience we are sure her turn around is in no small part due to the exceptional care she received from everyone at Fraser Health Home Care. We are forever grateful for all the support we received.

Both of us will see you at the walks this June!

By Michele Gervais, SABC Board Member and determined caregiver

SABC Board of Directors 2022 /2023

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