



SCLERODERMA ASSOCIATION of B.C.

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Issue 1 **SCLERODATA** 2022

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- Good to Know: Forums, Meet Ups, Events, October Conference
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Highlights

June is Scleroderma Awareness Month!

With the participation of patients, their families and friends, each June we raise awareness of scleroderma and funds for research. We come together as a province and support the ground-breaking research in B.C. and elsewhere in Canada and continue to promote awareness about living with this rare disease.

This year our **live events** provide us with the long-awaited opportunity to participate in-person and in the same location, connect with others over a shared cause.



Please join us this June for all the fun as we Move to Cure Scleroderma!

For more details on the schedule of the walks and to register online, please visit sclerodermabc.ca See You There!

Not able to be at any of the in-person organized walks? No problem!

Wherever you are in B.C. please click on **[Anywhere in BC](#)** and help raise funds for research. With the support of you, our families and community, we can all make the June events truly special. **As usual, 100% of funds raised will support research in B.C. and in other parts of Canada and receipts will be issued for all donations.**

KAMLOOPS

SUNDAY, JUNE 5TH / WALK, RIVERSIDE PARK - 100 Lorne St, Kamloops, BC V2C 1V9

KAMLOOPS is excited to host our first in-person walk on June 5th! Our goal this year is to create awareness for scleroderma and raise money for critical research in B.C. We look forward to collaborating and connecting with our wonderful community. Together, we are better.

JEN BECKETT - KAMLOOPS



Highlights cont'd

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

VICTORIA



SUNDAY, JUNE 12TH / WALK, WEST SHORE PARK - 1767 Island Hwy, Victoria, BC V9B 1J1

We are looking forward to seeing everyone in-person at our Victoria "Moving to Cure Scleroderma" 2022 Walk on June 12th. It's been a difficult few years to fundraise for our cause so we are excited to join together again and set some new goals to raise awareness and funds for research for scleroderma. My family and friends are gathering around to make this the best event yet, and we warmly welcome you to join us and help spread the word about this debilitating disease. **Thanks for your support!**

LINDA BARNES - VICTORIA

I have been able to participate in these events for the last few years and each time I am surprised at how much love and support is received from friends and family. I look forward to joining this year's walk in Victoria for scleroderma awareness.

JACKIE ALEXANDER - CAMPBELL RIVER

VANCOUVER

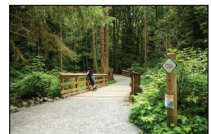


SUNDAY, JUNE 19TH / BIKE RIDE/WALK, STANLEY PARK - Vancouver, BC V6G 1Z4

David and I came up with the idea of starting a ride to raise awareness and funds for research on our way home from a two-month cycle tour of Ireland. We could not have imagined the impact that has come from the people that have joined us over the years and the generous donations that contribute directly to scleroderma research. We are all making a difference and are looking forward to really getting together this year to celebrate our 11th year.

ROSANNE & DAVID QUEEN - VANCOUVER

SURREY



SUNDAY, JUNE 26TH /WALK, TYNEHEAD PARK - Surrey, BC V4N 2E2

We are excited for our first "Moving to Cure Scleroderma" in the Lower Mainland. We invite everyone to help us raise money for research for scleroderma.

CHELSEY FITZPATRICK-LINDSAY - COQUITLAM

KELLY GRANT - CHILLIWACK

VALEMOUNT & ANYWHERE IN B.C.

ALL OF JUNE / 'VIRTUALLY' MOVING

Hey B.C., would you like to participate in the Province-Wide "Moving to Cure Scleroderma" virtual campaign?

Simply go to: [All of BC](#) and click on [Donate To This Team](#). Then engage in an activity of your choice, in a location of your choice! You can walk, bike, run, do yoga, kayak or any activity you enjoy. It's your choice to be as energetic, adventurous or creative as you can be!!



Please capture your "Moving to Cure Scleroderma" in pictures or videos, including your location and email to:

valerie.doyon@alumni.ubc.ca

I am so excited about this virtual walk!!! Let us see how many family members and friends we can get to participate across British Columbia in "Moving to Cure Scleroderma".

TERESSA COLOSIMO – VALEMOUNT & NORTHERN RURAL COMMUNITIES

Good to Know

Collaborating for a Cure: A Patient Forum

The Scleroderma Research Foundation (SRF) would like to invite people living with scleroderma and those who care about them to join them for an on-line, half-day, first-ever patient forum called [Collaborating for a Cure: the SRF Patient Forum](#).

Leaders from the scleroderma scientific and medical community will present educational sessions on symptom management and new developments in research. The forum will also include live Q&A with presenters, interactive activities to win prizes, and more.

This virtual event will be held on **Wednesday, June 1st, 9:00 am PDT**. There is no charge to participate, so don't miss out on this opportunity to learn more about scleroderma and the latest research efforts to address this complex disease by registering today [here](#).



SABC Support Group Meet Up Come Zoom With Us!



Next Meet Up is Tuesday June 7, 2022 @ 7pm

In May:

On Tuesday May 10, we held a support group meeting via Zoom. Our focus was **Let's Chat About Gastro**. Our wonderful facilitators Suzanne Gavin and Kelly Grant showed the group two very informative video clips from Dr. Elizabeth Volkmann (UCLA Rheumatology) and we were all given the opportunity to share our struggles and successes around food and digestion.

In June:

We'd like to keep the support group momentum going, so we have planned our next meet up for Tuesday June 7th at 7pm. Our focus this time will be on getting to know one another and building community. Please join us by clicking on the link below to register for the session. All are welcome, including those of us living with scleroderma, their caregivers and friends.

Come Zoom With Us! [Click Here to Register in Advance](#) for this Meet Up. After registering, you will receive a confirmation email containing information about joining the meeting.

Bring your favourite beverage and let's get to know each other.

Together we can build a supportive scleroderma community!

Good to Know cont'd

Hacking Wounds: A Research & Innovation Event

Mark your calendars! St. Paul's is seeking the participation of patients with chronic conditions that cause wounds!

On **September 22-23**, Providence Research in partnership with St. Paul's Foundation is hosting its second Skunkworks event. This unique two-day mixing of minds will bring together multi-disciplinary teams from Providence Health Care and our partner organizations to work collaboratively on innovative solutions related to wounds (prevention and care).

Patients and family caregivers with experience in wounds are a critical component of the teams and are invited to participate in the event. The event will be **in-person** at a downtown Vancouver hotel.

Interested in what this event looks like "in action"? check out these links: [Video link](#) and [The recap story](#)

Registration will open soon. For more details visit www.providencehealth.ca/skunkworks or email skunkworks@providencehealth.bc.ca



Save The Date: SABC AGM & Conference – October 22nd



The SABC Annual General Meeting & Conference is scheduled to be held on **Saturday, October 22, 2022** as a **virtual event**. As the Fall is the start of respiratory virus season, the SABC thought we'd continue to be cautious this year.

Similar to previous years, it will be conducted online as a webcast / video conferencing zoom service and will include the AGM then informative presentations by speakers with scleroderma expertise on a variety of topics.

Your SABC team is working on arrangements and will email more information later. Check [SABC's website](#) often for updates regarding the program and how to participate!

Is My Prescription Covered?

Good Question!

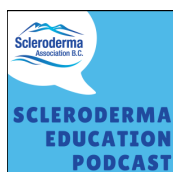
The Canadian Skin Patient Alliance (CSPA) has a new tool, an interactive drug coverage finder, to help you determine if you have coverage for the prescription you have received. Click on CSPA's link to [Is my prescription covered?](#) to find out how the tool works.



Good to Know cont'd

Educational Podcasts

SABC is pleased to announce that **Episode #4: Interstitial Lung Disease** of The Scleroderma Education Podcast has been published! The podcasts offer the opportunity to learn about the various facets of Scleroderma from the perspectives of both patients and healthcare providers.

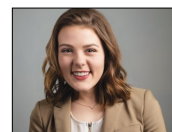


In episode 4, we dive into SSc-associated interstitial lung disease. We go through screening, clinical presentation, investigations, and treatments. We also discuss how to differentiate it from pulmonary arterial hypertension. Guests: Jen Beckett and Dr. Chris Ryerson. Hosted by: Valerie Doyon, UBC Medical Student

Check out the Home Page of the [SABC website](#) for previous and future videos in the series.

4. Interstitial Lung Disease with Dr. Chris Ryerson and Jen
3. The Role of Surgery in Scleroderma with Dr. Erin Brown and Kelly
2. Raynaud's Phenomenon with Dr. Hyein Kim and Angie
1. Sclerodactyly with Dr. Jan Dutz and Rosanne

Thank you to SABC Board Member and UBC Medical Student Valerie Doyon for these wonderfully informative educational interviews.



COVID Reminder

A reminder for those of us with scleroderma. At the first sign of mild symptoms or a positive COVID test, contact 1-888-268-4319 or the emergency department of your nearest hospital. **You may be eligible for treatment but it must be taken within 5 days of the start of symptoms.**



Have a list of **ALL** your medications. Tell them you have scleroderma and any lung complications such as interstitial lung disease (ILD), pulmonary hypertension (PH), or pulmonary arterial hypertension (PAH). Tell them any immune-system suppressants you have been prescribed, such as azathioprine, cyclophosphamide, hydroxychloroquine (Plaquenil), infliximab (Remicade), methotrexate, mycophenolate, tacrolimus, or tocilizumab (Actemra). This is not a full list so please discuss the drugs that you are on with the medical professionals.

If you can, contact your primary care doctor or the Rapid Access Clinic at VGH, ASAP. Those with PAH may want to contact the PAH clinic.

For more info, visit [the BCCDC](#) for information on the treatments available.

Interesting Reading

Yet Another SPIN Trial Published

SPIN's Vaccination Experiences and Perceptions trial is the first study to detail experiences and perceptions of the COVID-19 vaccination in the scleroderma community



I'm very happy to share with you that SPIN's study on vaccination experiences among SPIN Cohort participants has been published in Lancet Rheumatology. This is the first large study on the topic in scleroderma and a really important study for our community.

Congratulations to SPIN and their colleagues from Cornell – Jessica Gordon, Kim Lakin (Showalter), and Robert Spiera, who conceived of the idea for the study and led the authorship and to other SPIN contributors, including, in particular, to the dedicated SPIN COVID-19 Patient Advisory Team. Stay tuned, as the author group is preparing a follow-up survey!

Click to find the article here: [Systemic Sclerosis and COVID-19 Vaccines: A SPIN Cohort Study](#)

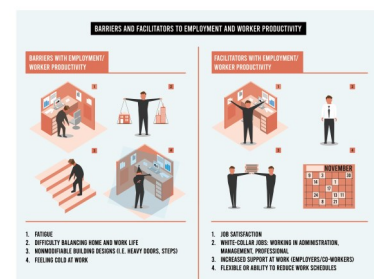
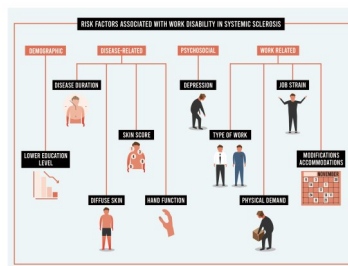
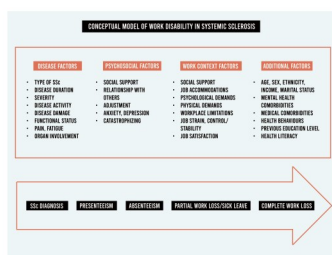
The Toronto Scleroderma Program's Publication



And here is an interesting study the SABC helped fund back in 2019: \$5,000 from the Gurmej Kaur Dhanda Scleroderma Research Award was donated to the Toronto Scleroderma Program to support research projects conducted there.

Work by Dr. Sindhu Johnson's student, Jennifer Lee, on 'Employment Outcomes in Scleroderma' has been selected by the publishing journal Best Practice & Research Clinical Rheumatology Volume 35, Issue 3, September 2021, to be featured on a promotional basis.

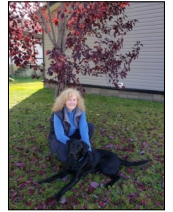
Please follow this link to read the article: [Employment outcomes in systemic sclerosis - ScienceDirect](#)



From our Members

Nutrition: One of the most discussed topics in Scleroderma

Am I eating enough? How can I gain weight?



By Teresa Colosimo, SABC's Valemount & Northern Rural Communities Community Contact Representative

It's hard!! We are always juggling with the feelings of being full, constipation, being bloated, nausea, diarrhea or just feeling miserable. It's not fun dealing with one of the most important things: fueling your body. I find myself struggling with this daily.

Here are some strategies to help you eat nutritionally:

It is important to consider the quantity, quality and even timing of the foods you eat. There are some **great Apps** that can help you track your calories, fats, carbohydrates, proteins, vitamins, and minerals. We can put these Apps on our phones, tablets, or computer. They are quite simple to use and important tools for us when we are struggling with food intake. The Apps provide an easy way to track what we are putting into our bodies, and they even let us know what we are *not* incorporating in our diets. Some App examples are: MyFitnessPal, Samsung health, Nutrition counter, Super tracker, or MyPlate calorie counter

Another good tool is a little more old school: writing a **daily food journal**. A journal can track all you've eaten at mealtime and how you feel after each meal. You'll find it so interesting when you look at your journal at the end of week and identify what foods contributed to feeling well-fueled. Also, the journal is a great resource to show your family or GI doctor.

Am I getting enough nutrients? There are weeks I am eating only potatoes, chips, crackers, and soup. I know I am not getting enough nutrients and on days like that, I **supplement**. Luckily, there are so many different supplements out there that can provide you with your daily intake .

We are all so different with Scleroderma and our GI symptoms and you might be trying to gain weight. **Here are some strategies for gaining weight healthfully:**

Consume energy and nutrient dense foods like avocado, fatty fish, nuts and nut butter, and oils (olive, avocado and flaxseed). Also consider adding protein powders to your smoothies, morning oatmeal or drinks.

Don't skip meals. Overnight our bodies expend the stored glycogen creating energy to pump our hearts, expand our lungs and basically keep us alive. It is important to replenish this energy used overnight with a balanced breakfast. Skipping breakfast extends the body's fasting period, causing us to rely more heavily on the energy stored in fat and muscle tissue.

Eat frequently. Aim to eat every 2-3 hours. This will help you achieve your overall daily calorie needs while consistently refueling the energy used for daily function and physical activity. Consume 3 to 5 balanced meals with snacks in between. Include whole grains, lean protein, fruits, vegetables, healthy fats, and dairy with each meal. When snacking, pair a quality carbohydrate such as whole grains, fruit, or vegetables with a protein. In doing this, the carbohydrates can restore energy and the proteins can help rebuild muscle tissue. Some snack examples are: an apple with peanut butter, carrot sticks with hummus, crackers with cheese, a peanut butter and jam sandwich, trail mix or fruit and yogurt.

Drink healthy calories. Consuming nutrient packed, calorie-containing drinks can help you reach your healthy weight gain goals or give you calorie intake on days where food is not your friend. A good meal replacement drink should have between 20-30 grams of protein, 10 grams of fiber, healthy fats (omega-3s), a wide variety of vitamins and minerals and enough calories to keep you satiated (around 200-400). Some drink examples are: Protein shakes like Soylent, Vega All in One nutritional shake, Rumble super shake, Slimfast advanced nutrition, Precision Nutrition all-natural whey protein, Boost or Kirkland Signature complete nutrition shake.

From our Members cont'd

Below is a little chart providing estimates of calorie needs per day by age, gender and physical activity:

Gender	Age	Sedentary	Moderately Active	Active
<u>Female</u>	19-30	1800-2000	2000-2200	2400
	31-50	1800	2000	2200
	51-65	1600	1800	2000-2200
<u>Male</u>	19-30	2400-2600	2600-2800	3000
	31-50	2200-2400	2400-2600	2800-3000
	51-65	2000-2200	2400	2600-2800

And food intake amounts for adults by calorie:

Calorie needs	1600	2000	2400	2800	3200
Daily food group amounts					

Fruits	1.5 cups	2 cups	2 cups	2.5 cups	2.5 cups
Vegetables	2 cups	2.5 cups	3 cups	3.5 cups	4 cups
Grains	5 oz	6 oz	8 oz	10 oz	10 oz

** one ounce of grains is equivalent to: 1 slice of bread, 1 oz of ready-to-eat cereal or 1/2 cup of raw rice, pasta or cereal. Half of the total amount of grains should be whole grains.

Protein foods	5 oz	5.5 oz	6.5 oz	7 oz	10 oz
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** one ounce of protein is equivalent to: 1 egg, 1 tbsp peanut butter, 1/4 cup cooked dry beans or 1/2 oz of nuts or seeds. Meat, poultry, or fish should be lean.

Dairy	3 cups	3 cups	3 cups	3 cups	3 cups
Oils	5 tsp	6 tsp	7 tsp	8 tsp	11 tsp
Maximum SoFAS limit	121	258	330	395	596

**Limit your calories from solid fats and added sugars (SoFAs) to these amounts per day.

I am personally researching Scleroderma and GERD diets. I find there is not enough information out there and I would love to hear from you. From what works in your day-to-day diet and what doesn't. If you would like, you can email me at tacnc2020@outlook.com and I will send you a short questionnaire you can fill out.

Also, if you like to discuss more about nutrition, I can help you achieve your health goals through nutrition, support, knowledge, and experience. I am a **Nutritional Coach**. I provide health and wellness services to individuals to make good decisions to support their well-being. I am NOT a registered Dietician or a Medical Doctor. As, such, I do not provide medical nutritional services, diagnose, and treat disease. Rather, I educate individuals on the benefits of a healthy lifestyle to improve their quality of life.

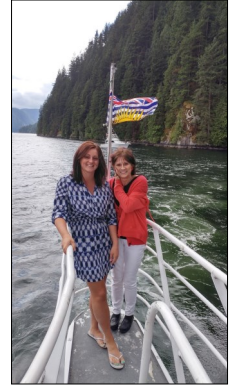


From our Members cont'd

Sandra's FUNdrive for SABC

By Sandra Hapke, SABC Member

A few years ago, our family had never heard of scleroderma and it wasn't until my mom, Margitta, was diagnosed and we started doing our own research online that we began to understand what this was. It opened a whole new chapter in our lives. My mom is the strongest person I know, she is my best friend - and having seen the change in her and watch her struggle everyday to deal with this new challenge has been so difficult for us all.



The reason I wanted to fundraise was to help bring awareness of Scleroderma in the hopes of one day, finding a cure. Still today, when I mention it to people, they haven't a clue about it. My Mom truly is a Scleroderma Warrior and I hope that getting the word out there will remind people to be kind, as you never know what someone might be struggling with.

Value Village offers a great fundraising opportunity called FUNdrive. I simply signed-up with my information noting the **SABC is the organization I wanted to fundraise for.** Then I told as many people as I could about it and they donated their gently used household items and clothing (stuff you normally donate anyways) to me. I collected all the donations and sorted them into boxes or bags and then arranged a time and date to deliver them to the Value Village. At my appointment they weighed all the donated goods and sent money directly to the SABC. Easy-peasy!

From Value Village's FUNdrive website:

Step 1: Sign up by filling out the online form

Step 2: Promote by spreading the word and collecting items from your community, family and friends.

Step 3: Earn money by Value Village buying those items and paying your non-profit directly, helping them reach their fundraising goals.

A HUGE THANK-YOU FROM ALL SABC MEMBERS, SANDRA!

Follow-up: Success with the Disability Tax Credit!

By Michele Gervais, SABC Board Member and determined caregiver



Recall in the winter edition of the *Sclerodata* I was contending with a large pile of scleroderma-related receipts contained in a file folder labeled *Medical Expenses*. The hope was that some, if not all, could be used as deductions on my Mother's 2021 tax return. After completing CRA's 16 page Form T2201 Disability Tax Credit Certificate and submitting it via the tax accountant...I left you holding your breath in suspense at:

Step 7: Wait anywhere from 2-4 months to get a Notice of Determination mailed directly to you from the CRA. This notice informs you of the CRA's decision whether or not to even grant you the disability tax credit (DTC).

The wait is over and the multi-step process was worth the effort.

Step 8: A belated Xmas gift! The Notice of Determination was mailed on January 7th stating Mom's eligibility for the DTC. And bonus, it says any fee the Dr. charged to complete the Form T2201 is also an eligible deduction!

Step 9: Her 2021 tax return (line 97) shows the disability tax credit in addition to the final tally of all those receipts. (In reality, you only get a percentage of the receipts total as a credit (line 113), but we'll take what we can get).

Step 10: And again, we'll have to store that file folder for the required 7 years in case of audit.

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Disclaimer

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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).