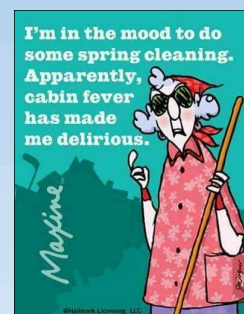


Issue 1 **SCLERODATA** 2021

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- Highlights: Annual June Awareness & Fundraising Campaign
- Good to Know: SABC Conference & AGM, Medical Travel
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Highlights

June is Scleroderma Awareness Month with our 2nd Annual Virtual Event!

For the second year in a row we are planning our **month-long virtual campaign** to fundraise and promote awareness of scleroderma. Virtual events are an opportunity to participate and connect with others over a shared cause without having to be in the same location. We won't be physically together in large groups but we can still support this province-wide campaign, which **starts on June 1st and ends on June 29th, World Scleroderma Day.**

As usual, 100% of funds raised will support research in BC and in other parts of Canada and receipts will be issued for all donations.

This Year's Theme: Moving to Cure Scleroderma!

Join one of our teams, fundraising while engaging in an activity of your choice. Or simply support a team by donating online. Continue to practice social distancing while walking, hiking, bicycling, running, holding a virtual family activity or doing relaxed stretching at home. Your options are endless, and the choice is yours to be as energetic, adventurous, or creative as you want to be!



Read the next page for the many ways you, your family, community and supporters can participate!

Highlights cont'd



We encourage participants to capture their 'moving' experience with **photos or videos**, which can be shared online. The fun continues after the event when we share how we participated. The SABC will create a slideshow that includes your "Moving to Cure Scleroderma". Check out these recent June 'movers' who inspire and encourage us all to participate!



Please remember to take pictures or videos then include your location and any other details you would like to provide and email them to SABC's: Valerie Doyon at valerie.doyon@alumni.ubc.ca. We want to demonstrate how we all came together in the month of June to raise awareness and funds to support scleroderma research.



We also encourage you to tag SABC on Facebook at @ScleroAssnBC, Twitter or Instagram @sclerodermabc using the hashtag #Move4Sclero2021.

We Welcome Your Participation!

Instructions for participation and for making donations are available by going directly to the SABC website, sclerodermabc.ca, then to [Moving to Cure Scleroderma](#)

1. **MAKE A DONATION** to one of our teams or a particular participant

Every dollar received enters us into a draw to receive \$20,000. Your donation could be the one that makes a big difference!

2. **JOIN THE FUNDRAISING EFFORTS** by joining one of our teams



Questions Regarding Participation?

Contact SABC's David Queen at dq.sabc@telus.net

With the support of you, our families, friends and community, we can make this event truly special and we can really make a difference!

FOR MORE DETAILS PLEASE VISIT: sclerodermabc.ca

Good to Know

Save The Date: SABC AGM & Conference – October 2, 2021

With our focus on scleroderma awareness events being held in June, the SABC Annual General Meeting & Conference will be held in October again this year.

It is scheduled to be held on **Saturday, October 2, 2021** and again, as a **virtual event**. Similar to last year, it will be conducted online as a webcast/video conferencing service and will include the AGM then informative presentations on a variety of topics.

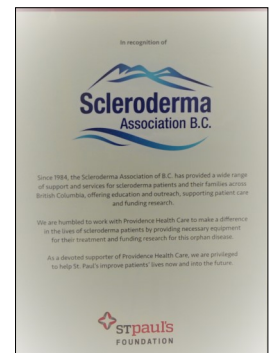
Your SABC team is working on arrangements and will provide more information later - Keep an eye on our website for details regarding the program and how to participate.

SABC Honored at St. Paul's Hospital

SABC has recently been recognized by the St. Paul's Foundation for the many years of financial support of the Scleroderma Clinic. Your donations have contributed to over \$600,000 raised for the SABC Research Project, other programs and specialized equipment.

This lovely plaque has been installed in the Lung Centre's patient waiting room, located on the 8th floor of the Providence Building.

The SABC was also invited to celebrate the 'breaking of ground' for the new St. Paul's Hospital. Rosanne and David were at the new site to see first hand the exciting future of patient care and research ahead.



Good to Know cont'd

Financial Assistance for Travel and Accommodation for Scleroderma Patients Requiring Medical Treatment

By Angie Reglin, our Kelowna Community Contact Representative



Is there financial aid for travel and living expenses for scleroderma patients needing medical treatment? A good question! And one that was prompted by a phone call from my rheumatologist's office asking if there was some sort of financial aid available for a scleroderma patient needing to travel for medical reasons. I had no clue.

Finding the answer to this question started me on an interesting and informative journey. I made several phone calls and sent out emails to people and organizations that I thought might be helpful with this type of request or at the very least, offer suggestions as to who to contact.

When might a patient require such assistance? A good example is when a scleroderma patient is being considered for stem cell therapy and the financial burden of receiving the treatment is playing a role in the decision-making process of whether or not to go ahead with it.

Here is what I learned and hope it is helpful for our readers:

1. Hope Air – 1-877-346-4673, www.hopeair.ca

Hope Air offers financial assistance for the costs of travel and accommodation. They are teamed up with many organizations and individuals who donate time, money, flights and places to stay. Hope Air recently announced the Radisson Hotel Group will provide free accommodation for patients who must travel for medical care far from home.



The requirements and other information:

- * Eligibility: The treatment must be covered by your provincial Medical Services Plan based on a gross income criteria
- * No self-referrals. The treatment must be recommended by a doctor
- * Anyone can apply for the assistance: patient, family member, social worker, etc. A spouse or family member may also be eligible for assistance if their presence is medically necessary as per the doctor
- * The initial response back from Hope Air can take anywhere from a few hours to a few days. Rush requests can be accommodated.

Good to Know cont'd

2. Scleroderma Association of B.C. (SABC) 604-371-1005 www.sclerodermabc.ca

Triggered by my request for information, the SABC's Board of Directors met and agreed there was indeed a need and desire to help patients financially to obtain the required medical treatment. After much discussion regarding what this assistance could look like, the Board concluded they would look at each patient's needs on an individual basis. Patients requiring assistance are asked to please contact SABC President, Rosanne Queen.

3. Scleroderma Canada www.scleroderma.ca

Scleroderma Canada does not currently offer financial assistance for patients. However, my (and others) email has 'sparked' an interest in creating a bursary patients can apply for, for financial assistance on a case-by-case basis. This is exciting and hopeful for the future.

4. Disability Alliance BC (DABC) 604-872-1278 www.disabilityalliancebc.org

DABC does not offer financial assistance for patients. They help patients to apply for disability benefits.

5. Scleroderma Patient Intervention Network (SPIN) www.spinsclero.com

SPIN also does not offer financial assistance to patients. They do fund scleroderma research projects and offer for free, patient tools.

Angie

Be an advocate for your own health

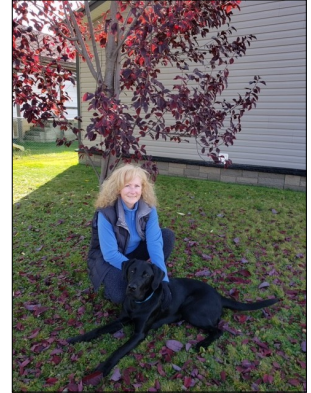


Interesting Reading

Nutrition and Scleroderma

By Teresa Colosimo, our Valemount Area Community Contact Representative

Having scleroderma is exhausting! There is so much going on in our bodies from Raynaud's, GI involvement, swollen hands and feet, arthritis and rheumatoid arthritis, Sjogren's, hypertension, renal failure, pulmonary fibrosis, thick skin over limbs and trunk, itching, telangiectasias, calcinosis, ulcers, polymyositis, myopathy, nerve involvement, fibromyalgia, lupus and many more symptoms.



I have always had an interest in nutrition, especially how it might influence or help control our scleroderma symptoms we experience and if eating whole nutrients and well-balanced meals along with exercise could make a difference in symptom control. Last year I completed my Diploma in Nutrition Counseling and I am so excited to have this opportunity to talk with you about nutrition. The courses I took included Nutritional Counseling, Nutritional Sciences, Anatomy and Physiology, Vegetarian Nutrition, Nutrition: Studies and Applications, Natural Health Fundamentals and Sports and Fitness Nutrition.

As we've all experienced, dietary changes do not always affect us positively. For me, a change to my diet started with the desire to 'fix me' from always being tired, struggling to get motivated, losing my breath while going up stairs and yes, from being a little overweight. I tried different diets from very restricted calorie intake, to eating vegetarian and then to the FODMAP diet. However changes to my diet typically ended with me being miserable, hungry, bloated, constipated, having diarrhea and being extremely tired. We have all been there, it is very frustrating.

I've learned that we may have no control over our symptoms, but we can control what we put into our bodies. Throughout the last couple of years, I have been really struggling with GERD and trying to eat nutritious meals. But just this in itself was not at all working for me.

Diet plays a major role in controlling acid reflux symptoms. There are plenty of GERD-friendly foods you can eat every day. The goal is to create a meal plan that consists of eating a variety of healthy foods such as lean proteins, complex carbohydrates, and fruits and vegetables. Alkaline foods have a higher pH that can help offset strong stomach acid. Watery foods dilute and weaken stomach acids. Fibrous foods can decrease stomach and gut mobility and delay gastric emptying which increases reflux.

Interesting Reading cont'd

Here are some examples of foods to try:

- Healthy fiber foods like 100% whole wheat, brown rice, oatmeal, couscous, berries, apples and pears (helps food motility)
- Alkaline foods like sweet potatoes, carrots, beets, bananas, melons, nuts and cauliflower
- Watery foods like celery, cucumber, lettuce, low fat milk, coconut water, herbal teas, lemon water with honey (helps neutralize stomach acid) and ginger tea (ginger is a digestive aid, it eases irritation in the digestive tract)

Some of us with GERD struggle with anemia. Here is a yummy bread recipe I tweaked. My family just loves it and it is so good for you; high in easily digestible fiber and iron.

Oatmeal Bread

1 pkg. dry yeast
½ cup warm water
1 ½ cup large flake oats
½ cup molasses
1 tbsp salt
2 tbsp margarine
2 cups of boiling water
5-6 cups of 40/60 baker's flour blend or whole wheat



1. Dissolve yeast in water with a bit of sugar.
2. In a large bowl (I use my kitchen aid) combine oats, molasses, salt and margarine. Pour in boiling water and mix well. When mixture is cooled to lukewarm stir in yeast.
3. Stir in flour. Then turn on floured surface and knead.
4. Place in a greased bowl. Cover and let rise until double. Punch down. Shape into loaves and place into greased bread pans. Let rise again. Bake at 350F for 30-40 minutes. Cool on rack, brushing loaves with margarine for a soft crust.



I am personally researching scleroderma and GERD diets and I am still learning. There is so much more to know about scleroderma and special diets, especially for us who struggle with GERD and there is not enough information out there. GERD is extremely hard to grasp in how it relates to our complex digestive system.

Interesting Reading cont'd

I have so many questions. Like how you can eat anything and everything and then BOOM our body decides yeah, I do not like that anymore! We are all so different. 'GERD triggers' will vary for all of us. One healthy lifestyle may work for me but not for you. I wish there was a one-size-fits-all answer I could give you, but you know your body the best and what works or doesn't work for you.



I would love to hear from you. Everything and anything from what works in your day-to-day diet to what doesn't work for you. If you would like, please email me at: taccnc2020@outlook.com and I will send you a short questionnaire to fill out. Also, if you like to discuss more about nutrition and/or how I might be able to help you achieve your health goals through nutrition, support, knowledge, and experience, please do reach out.

Keep your eye out for future health-related articles from Teresa in the *Sclerodata*!

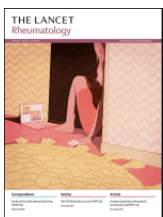


SPIN-CHAT Trial Published!

Thanks to the overwhelming support of SPIN's SPIN-CHAT (COVID-19 Home-isolation Activities Together) Program during the early stages of the pandemic last year, SPIN was able to obtain grants from the Canadian Institutes of Health Research for the program.

As a result, SPIN provided support to almost 200 people with scleroderma during the initial stages of the pandemic. The videoconference groups ran for 4 weeks (3 sessions a week). Each of the groups was expertly moderated by a trained SPIN-SSLED group leader, along with professional educators who provided tips for coping in a variety of ways, including mental health strategies, ways to stay physically active and engaged, and tips on healthy information management and staying connected.

The results of the evaluation of the program show that it was effective in reducing anxiety, and the trial's report was accepted into the medical journal *The Lancet Rheumatology* for publication! This is one of the world's top journals, and the fact that it was accepted highlights the tremendous effort on behalf of so many people in the global scleroderma community to make this possible. To put this in perspective, to date, this trial will be only the second high-quality intervention trial on COVID-19 mental health support in any setting around the world to publish results.



It wasn't easy for SPIN to get it off the ground, and they couldn't have done it without all our support. Congratulations SPIN!

[Click here to read the published article!](#) Effects of a Multi-faceted Education and Support Program on Anxiety Symptoms among People with Systemic Sclerosis with at Least Mild Anxiety during COVID-19: A Two-Arm Parallel Partially Nested Randomised Controlled Trial

From our Members

Esophageal Dilation

By Angie Reglin, our Kelowna Community Contact Representative



I want to share with you my first ever experience with esophageal dilation. What is **Esophageal Dilation**? Esophageal dilation is a procedure that allows your doctor to **dilate**, or stretch, a narrowed area of your **esophagus** or swallowing tube.

What I can tell you all is that I was scared at the beginning of this new change with my body, especially the not eating, losing weight and lack of energy. I actually thought this may be the beginning of the end but it has turned out to be only the beginning of a new phase of this disease.

Initially I was contemplating not having the dilation done, out of fear of the unknown. But then I spoke with Rosanne Queen and it was nice talking to someone who spoke the same language even though she had never had the procedure done. I also spoke to two other scleroderma patients that actually had this dilation done. I spoke to many of you in my community who just listened and encouraged me. Talking to Rosanne, the other patients and my community peers helped tremendously and the support was invaluable. So thank you all.

On January 26th, the procedure went well with no complications. I had some pain in my chest for a couple of days, and it actually hurt to swallow which was new. However by Friday, I was swallowing without pain, and my chest no longer hurt. By Saturday, I was feeling great and I was eating again, although cautiously. By Sunday, I was eating more than I had in 5 weeks with no complications, or heartburn. Annnddd.... the biggest difference I noticed is I was hungry again! When the esophagus wasn't functioning properly, I wasn't hungry and I had to consciously make sure I ate or drank something nutritious every couple of hours.



I feel good. I am putting the weight back on and I started to exercise again as the energy returned because I was eating again. Crazy how the normal cycle works!

The valuable lesson learned here was not to be afraid to reach out to another patient when your disease changes, or you are just having an awful day. Talking to someone else who understands is such a blessing.

Thank you all again for allowing me to be part of your journey and for you being a part of mine.

Angie

Be an advocate for your own health

From our Members

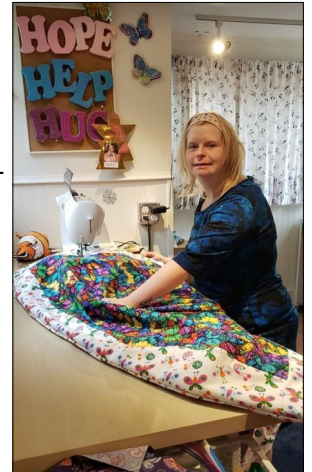
Angel's Blankets

SABC members Cheryl Magnussen and her daughter Angel are two of the smiling faces we all look forward to seeing on our zoom calls. We feel so fortunate, with the help of technology, to be able to welcome these two from Port Alberni into our hearts and homes. During one of these calls we learned about the heart-warming work Angel does, with the support of her team, to make children's lives a lot brighter during trying times. When asked, Cheryl kindly agreed to share Angel's story with us for this issue of the *Sclerodata*.

Hugginz by Angel Foundation (HBAF) was created by Angel Magnussen when she was 16-years-old in December 2012 as a way for her to help the seriously ill and hurting children she saw, on multiple occasions, lying beside her in the ICU at BC Children's Hospital. Angel's plan was to sew blankets of love to wrap each child in so they would feel loved and comforted and brave as they undergo the scariest of treatments and situations. Angel lives with Down syndrome and autism spectrum disorder as well as multiple medical issues. Angel knows the inside of a hospital quite well, having gone through many surgeries and medical tests. She has witnessed, and experienced, the anxiety and fear that medical procedures can cause a child. In 2017 HBAF became a registered Canadian charity.

When families wish to apply for Angel to sew their child a Hugginz blanket they reach out to us through our Facebook page or through our website www.hugginzbyangel.com and complete an on-line application or request. We ask them to provide us with a list of 10 different things their child absolutely loves or adores, such as tv or movie characters, Disney characters, superheroes, animals, sports, colors, etc. Angel then uses this information to design a very special one-of-a-kind blanket for that child. She wants each blanket to contain the child's favorite things, things that bring them comfort.

All the work done by Angel and her team is voluntary. When the blanket is nearly complete, Angel then quilts a large heart into each corner and in the middle of the blanket, places a special Love Pocket. The purpose of the Love Pocket is to give the child a special place to place their teddy bear or dolly, safe and secure, for when they go into surgery or while they sleep. Each Love Pocket has a beautiful angel stitched into its center, crafted by Angel's 94-year-old grandmother, Marge Mikulic, who hand cuts each angel with a set of wings. Angel chooses the perfect angel and wing set to sew onto the pocket. A Hugginz blanket is truly 'a work of heart'.



From our Members cont'd

To date, Angel has sewn and shipped over 1700 love-filled blankets to seriously ill, traumatized and medically fragile children across Canada. Below is only one of the many stories of families who have received a blanket sewn by Angel over the last year.

Two beautiful young girls passed away last September, one after a 4-year-long battle with brain cancer, the other child was a miracle baby who wasn't expected to even see her first birthday. Amazingly she had 6 beautiful years with her family before her irreparable heart stopped beating. Both children received a Hugginz blanket when they were younger. We have watched these children fight their hardest again and again and both their families be their absolute bravest. Angel is now in the midst of making memorial Hugginz blankets for each of these families. These special memorial blankets will display, on the front, multiple photographs of each child and their families. We find these memorial blankets bring so much comfort and love to the grieving families.

When a family has a child who is medically fragile, palliative or has a severe disability their family can often become isolated from family and friends. They feel alone in their struggles and their child's medical team is often the only people they get to talk to in a day. Friends and even family can shy away, caring yet unsure as to how to help. We strive to be a charity that is there for these families during their times of darkness, that listens to their stories, that celebrates their child and sends love to their child.

We have seen far too many Hugginz Kids pass away over the past 8 years. These losses have been painful to us as well, as we have become close to so many of these families as we tried to emotionally support them as their child and family endure the hardest of times. We do feel so comforted though to know that the families have felt the love and care that we extend to them. Some of these children have been wrapped in their Hugginz blanket while they've gained their wings. Their blankets have graced their caskets. We have sobbed alongside these families feeling their pain and loss, albeit from a distance. We remember their children and celebrate them. They were here and their lives mattered greatly.

I, Cheryl, am the CEO of HBAF as well as Angel's primary caregiver. I am also proud to say that although I'm fighting scleroderma, myositis and a rare immunodeficiency disorder, I am still able to support Angel to help other families. This is what keeps me going strong. Helping these families through their toughest days helps me to realize the strength I have within me and to see the many, many blessings we have in our lives. We are truly grateful for being given the opportunity to be there for these families.

Sincerely,
Cheryl and Angel



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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).