

SCLERODERMA ASSOCIATION OF B.C.

# The Bulletin

FALL-WINTER 2023-2024 | VOLUME 5 NUMBER 2



**Accepting the  
diagnosis of  
Scleroderma**

**Natural Health  
Products**



**Managing Anxiety  
and Stress**



# Summary

- 3 A Word from Our President
- 4 2023 Moving to Cure Scleroderma
- 6 AGM and Conference Highlights
- 8 Testimonial from Aryn Rajan
- 9 Natural Health Products
- 12 Accepting the Diagnosis of Scleroderma
- 15 Managing Anxiety and Stress
- 20 Community Contact Representatives

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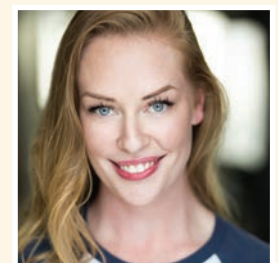
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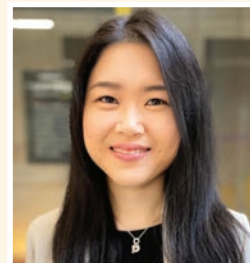
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## A Word from Our President

**As the winter season approaches and the festive spirit of Christmas fills the air, it's astonishing to reflect on the incredible year we've had at SABC.**

Our commitment to raising awareness and funding research has remained unwavering since the inception of SABC. The "Moving to Cure Scleroderma" campaign was nothing short of amazing, and I extend my heartfelt gratitude to the dedicated walk organizers, volunteers, participants, and generous donors. Your unwavering support is the driving force behind our mission, and we couldn't have done it without you. **A special thank you goes to the Rajan family for their extraordinary \$100,000 donation to the SABC Research Program. Your generosity is truly remarkable.**

Together, we are forging ahead, pushing the boundaries of knowledge, and paving the path toward groundbreaking, life-changing treatments.

In this bulletin, you'll find educational resources that delve into managing anxiety and stress. As we embrace the winter season and navigate the "new normal" of *Covid, flu, and respiratory syncytial virus (RSV)*, it's natural for stress levels to rise. If you ever feel the need to talk to someone, I strongly encourage you to reach out to one of our community representatives or join our "Come Zoom with Us" meetings.

Many of our community reps are trained through a partnership with the **Scleroderma Patient-Centered Intervention Network (SPIN)**. The "Come Zoom with Us" meetings provide a platform for individuals with scleroderma to break the loneliness of isolation, seek answers to their questions about the disease and their well-being, and ultimately enhance their quality of life.

These meetings serve as a haven where people affected by scleroderma can come together, sharing their experiences, gathering valuable information, and providing mutual support. It's a safe, nurturing space where participants can openly express their concerns, seek guidance, and thrive in a positive atmosphere.

**I look forward to "seeing" you on Zoom, where we can connect, learn, and grow together.**

As we approach the holiday season, I wish you and your loved ones a joyous and safe celebration. May the warmth of the season fill your hearts with happiness and hope.



*A Huge Thank You to*



The realization and mailing costs of a magazine are important elements of the budget of a charitable organization such as ours.

For this reason, we want to emphasize the generous gesture of our partner, Janssen Canada which, thanks to an educational grant, made production, printing and distribution of this Fall-Winter Bulletin possible.



## 2023 Moving to Cure Scleroderma



June 1<sup>st</sup>, across Canada, starts Scleroderma Awareness Month which involves raising awareness and much needed funds for research. The yearly campaign ends on June 29<sup>th</sup>, World Scleroderma Day.

B.C. scleroderma patients, their families and friends again did their part this June by raising over \$180,000 for research.

*We raised*  
**\$180,000**  
**for research**  
*Thank You!*

### JUNE 18 SCLERODERMA RIDE FOR RESEARCH

Our 12<sup>th</sup> Scleroderma Ride for Research was once again successful. We had over 75 join us to celebrate raising awareness and the very necessary research monies to make a difference for those of us living with scleroderma. Our group cycled, walked or just joined us for our potluck lunch. Our team raised over \$146,000 and I couldn't have done it without everyone's help. After 12 years of organizing this event, I am always so humbled to see how family, friends, people that we worked with continue to support our passion. There are so many great organizations asking for donations but because SABC puts 100% of their donation to research, our donors have said that is what makes a difference in continuing to support us.

**ROSANNE & DAVID QUEEN**



### JUNE 4 SURREY WALK

We had a fantastic Surrey Walk on June 4<sup>th</sup>! It was a great day for connecting with people living with scleroderma, friends, family, and supporters. Over 50 people came together for the 5 km walk in the sunshine. We were joined by Dr. Kevin Keen who gave us an update on the progress of the SABC research program at St. Paul's that our donations support. Because of the help and generous support of our team we raised \$9,797.00 to help patient driven research for scleroderma. Thank you to everyone who helped make this walk a success!

**CHELSEA FITZPATRICK-LINDSAY AND KELLY GRANT**



## 2023 Moving to Cure Scleroderma

Four teams across our province participated in this June's event. Our heartfelt thanks to all the team captains who organized the in-person and virtual events and especially to our caring donors who supported this June's campaign.

Check out the video at [sclerodermabc.ca](https://sclerodermabc.ca) which captures everyone moving to spread awareness and raise funds to support scleroderma research. All monies raised directly supports research in B.C. and Canada.



### JUNE 11 VICTORIA

Victoria's sixth annual Scleroderma Walk took place on a bright and sunny morning at West Shore Parks and Recreation. With coffee and treats donated by Tim Hortons, over 70 participants, patients and volunteers mingled and reconnected and listened to Dr. James Dunne talk about the importance of funding for furthering research into Scleroderma. The cheerful crowd walked the 2.5 km or 5 km route according to their preferences and gathered after to bid on a table full of donated Silent Auction items.

Thanks to West Shore Parks and Recreation Board for donating the venue, Tim Hortons, Soul Sisters for their support and route marshalling, and all the donors of auction items.

This year we raised \$9,794 and over \$47,000 since we started our Victoria Walk.

Thank you everyone! See you all next year!

LINDA BARNES

### ALL OF JUNE, ANYWHERE IN B.C.

"Moving to Cure Scleroderma" virtually was another successful year raising more than \$19,000. A big heartfelt shout out to all the amazing Scleroderma Warriors, family and friends who get out every year, spread awareness and raise funds for research to find a cure for Scleroderma. Thank you to: *Jennifer Beckett (Jen's Conquer the Lake Scleroderma Run)*, *Michelle Kennedy*, *Sandra Hapke*, *Kenny Reid (Walk with Kenny)* and *Teressa Colosimo (Move with Teressa)*.

TERESSA COLOSIMO





## AGM and Conference Highlights

**Sixty-two patients and their supporters registered for this Fall's 39<sup>th</sup> Annual General Meeting & Conference (in-person and virtual) on Saturday, October 21, 2023.**



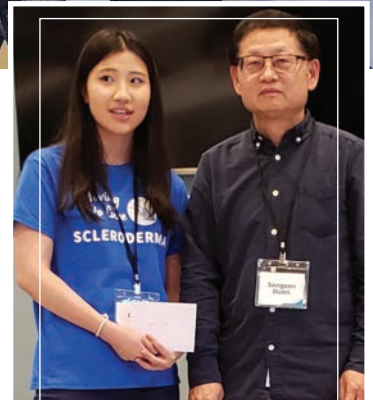
### AGM HIGHLIGHTS

- Reviewed a recap of last fiscal year's activities (May 2022 to September 2023)
- Sincerely thanked our three retiring SABC Board Members and welcomed the new 2023-2024 Members:

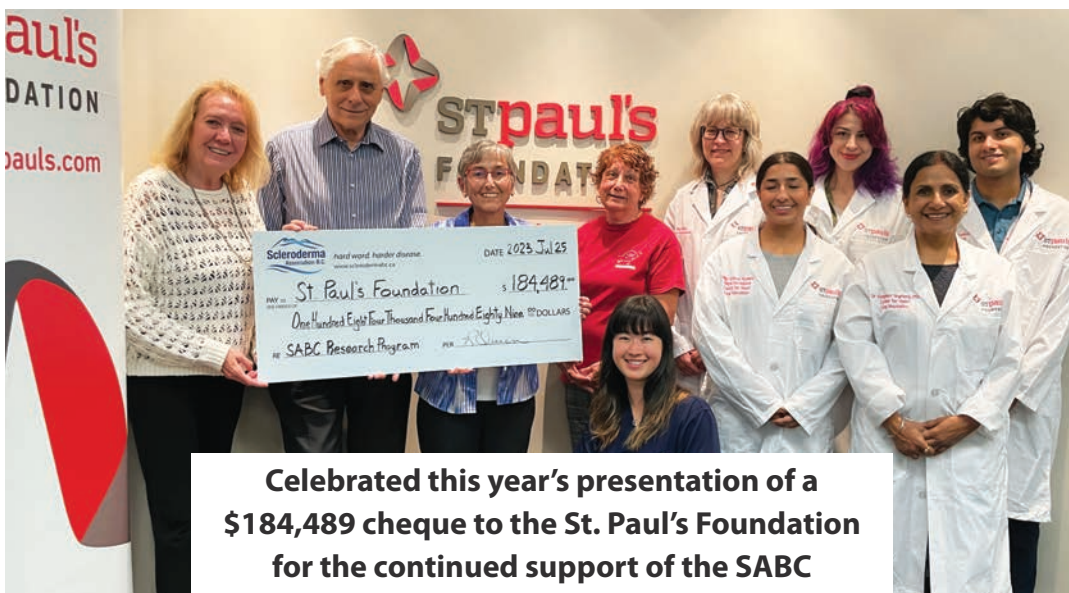
**Amir Pourghadiri** - is a third-year medical student at the University of British Columbia (UBC).

**Kenny Reid** - is committed to giving back to help other "*Scleroderma Warriors*" and those going through Lung Transplant.

**Helen Hsiao** - is a second-year medical student at UBC.



Presented the **inaugural Lihong Yang Memorial Scholarship Award** to UBC medical students **Grace Kim** and **Jessica Jun** (*in absentia*).



**Celebrated this year's presentation of a \$184,489 cheque to the St. Paul's Foundation for the continued support of the SABC Research Program**



Conference presentation information will be available at [www.sclerodermabc.ca](http://www.sclerodermabc.ca)

# AGM and Conference Highlights

## CONFERENCE HIGHLIGHTS

Obtained valuable tips from the three scleroderma-specific health care professionals



### TREATMENTS FOR SCLERODERMA DR. DANIEL FURST

The keynote speaker received rousing applause to his first statement: ***"Scleroderma is a treatable disease"***. The complexities of scleroderma, as a disease of immunology, were emphasized. The variations and changes in the way scleroderma affects patients can make the work of diagnosing and treating it a very challenging task, indeed.

The various medications that are used in the treatment of scleroderma were reviewed, noting the outcomes of their use and pointing out differences in their applications and effectiveness. The medications discussed are available in B.C., with special authority approval needed first from Pharmacare and/or the manufacturer in some cases.

**Take away tips:** One of the complexities in treating scleroderma is that a patient's genetic background can have an effect on the extent to which the disease impacts the patient. So, understanding the genetic background of the patient is helpful in determining the best 'personalized' treatment, that is, getting the right medication for the right patient.



### UNDERSTANDING SCLERODERMA WOUNDS & DRESSING APPLICATION WORKSHOP LAUREN WOLFE

The afternoon focused on wounds and skin conditions that are common among scleroderma patients like digital ulcers, calcinosis, and tight skin. Characteristics

of wound healing and treatment were explained, noting also that healing for the scleroderma patient can be complicated by the skin being thicker.

The workshop offered hands-on experience with samples of some of the bandages and wound dressings that are used for these issues. Various treatments and dressings were explained, with specific information about medications and proper wound care.

**Take away tips:** Patients should seek help with a wound, sooner rather than later. Wound care might need to involve specialized services, such as those of a rheumatologist, a wound care specialist, an occupational therapist or a plastic surgeon.

***Did you know? Wound care is free within the B.C. health care system. There is a wound care clinic at Vancouver General Hospital's Gordon and Leslie Diamond Health Care Centre.***



### HOW TO TRAIN YOUR DOCTOR ELAINE FURST

The effectiveness of a Patient-Doctor relationship depends upon many factors, such as trust, communication, respect and understanding. An effective relationship is one of a partnership where both the doctor and the patient share in the responsibility for the patient's care.

As in any partnership, the success of the patient-doctor relationship starts with two people getting to know each other, understanding the expectations of each other and the extent to which such expectations are being met. The doctor needs to be aware of the characteristics and conditions that define the patient, such as their level of medical knowledge, anxiety level and comfort with communication. Similarly, the patient needs to understand the doctor's qualities and characteristics, such as the doctor's knowledge of their particular illness, experience and teaching/explaining skills.

**Take away tips:** If a patient feels that there is a need to 'train' the doctor to improve the relationship, the following suggestions were offered:

- provide information from reliable sources to help educate your doctor(s);
- be clear in expressing your concerns regarding treatments and effects of treatments;
- ask for additional help if your concerns give rise to further questions;
- take notes at appointments and prepare clear, organized questions or concerns for next time.



### SUMMARY OF SABC RESEARCH ACTIVITIES DR. JIM DUNNE AND DR. KEVIN KEEN

The day ended with a recap of activities completed and exciting discoveries noted for the SABC Research Program.



## Testimony



*My name is Amyn*

**The diagnosis was a bit of a challenge.** I first started having issues with Raynaud's in October 2019 and then lung issues which got progressively worse. Of course, Covid hit in early 2020 and so when I had issues with breathing and coughing, every doctor made me do a Covid test before they would even look at me. Getting an appointment with a respirologist was impossible. My family doctor finally got me in to see a Vascular Specialist in April 2021 who then passed me on to a Rheumatologist, who then got me to a Respirologist. Once they all realized this was serious, things moved much faster. I was diagnosed with Diffuse Systemic Sclerosis (Scleroderma) in June 2021. From first symptoms to an actual diagnosis, it took 20 months! They found I had skin thickening, Raynaud's, GERD, and ILD (interstitial lung disease). My lungs were at about 50% capacity, I was losing weight and declining fast.

**This was not a gut punch but rather a body blow.** I had always been healthy; I don't drink, I don't smoke, I exercise regularly and eat well (ok, so I have a penchant for Coca Cola and Big Macs but I did this in moderation). The diagnosis was a true existential crisis for me. My kids were 15 and 13 at the time and I was terrified of what happens if I die. Yes, I tried to keep calm on the outside, but inside I was terrified. I have always been a planner and forward thinker and considered all the possibilities and in this case, a lot of the possibilities led to me dying. Not good. The demons in my head kept harping on about "what if I die?"

Like I said, I have always been a planner and forward thinker so upon diagnosis, **I started researching and learning everything I could about Scleroderma.** I realized it is a very challenging disease to deal with as it presents in so many different ways and affects so many parts of the body. Also, since the disease is rare, most rheumatologists have not seen very many cases (if any). As such, I hunted down one of the world's top rheumatologists who specializes in Scleroderma (he edited a book used to teach other doctors about the disease so he must know a thing or two). I found out that **Dr. Daniel Furst** also takes patients and made my way to the US to consult with him. **His first words to me were "Scleroderma Can Be Treated".** I liked him already. Working with my local doctors, Dr. Furst took a more aggressive treatment approach and while I still have Scleroderma, my lungs are now at about 60% and my mRSS is 0 (yes, zero according to Dr. Furst). I still have Raynaud's, GERD, ILD, fatigue, and Peyronie's (yes, the disease affects everything), but I am generally stable and feeling good.

**Battling the demons in my head.** When we talk about chronic disease, everyone tends to focus on the physical aspects of the disease. What they tend to forget about is the mental impact. I am a deeply religious person and generally very optimistic in my approach to life. However, the body blow of the Scleroderma diagnosis really hit me hard mentally. While I try to hide what I feel and be strong for those around me, I have days when I just feel like hiding away and crying. Prior to Scleroderma, I had confidence that things would work out well in life. Now I wonder about the plans for growing old with my wife. I often wonder if I will see my kids graduate from college or will I be around to play with my grandchildren. I don't really mind dying, eventually all of us will, but there are just so many things I want to share and do with my family. Scleroderma introduced this great uncertainty – these demons in my head. Always wondering, always questioning, is everything ok? What if? Crazy thoughts. I just wish the demons would go away and life could go back to what it was before.

Many times, I have to remind myself that I am still alive, and I am doing everything possible to fight this terrible disease. I have to keep on living life to the fullest knowing that I have to constantly take all these crazy meds and keep taking tests to ensure all is well. Oh, well. Life happens. I will keep battling the demons in my head while I work to raise money to help find a cure.



# NATURAL HEALTH PRODUCTS

Amélie Granger-Pouliot, Pharm. D.



## WHAT IS A NATURAL HEALTH PRODUCT?

They are natural substances used to restore or maintain good health. Natural products are often made from plants, but can also be from microorganisms or animal and marine sources.



## WHAT INDICATES THAT IT IS A NATURAL HEALTH PRODUCT?

Natural health products evaluated by Health Canada all have an NPN (i.e., Natural Product Number), or in the case of homeopathic remedies, a DIN-HM. The NPN is an eight-digit number which means that it has been licensed by Health Canada. By having an NPN or a DIN-HM, Health Canada is indicating that the product is authorized for sale in Canada and that it is safe and effective when used according to label directions. If there is no NPN or DIN-HM, it means that there is no control over the product and no evidence of effectiveness and/or safety has been demonstrated. Similarly, for prescription drugs a DIN is assigned to each drug, which is a Drug Identification Number. This DIN is an eight-digit number assigned by Health Canada before it is marketed in Canada. Thus the NPN and the DIN-HM are subject to regulations similar to the DIN, but they are specific to natural health products and homeopathic medicines.



### NATURAL HEALTH PRODUCTS

## WHAT DOES AN NPN OR A DIN-HM LOOK LIKE?

### IS A NATURAL HEALTH PRODUCT ALWAYS SAFE?

Although it is generally safe to use, it is not without risk. Just because a product is called "natural" does not mean it is "harmless"! Natural health products, like prescription drugs, can have side effects and may even be toxic if not taken at the recommended dose. In fact, 12% of Canadians who use natural health products have reported experiencing adverse reactions to these products!

In addition, natural health and homeopathic products may not be suitable for some people with health problems, or they may interact with prescription drugs. These interactions may result in a decrease, cancellation or increase in the therapeutic effects of prescription drugs.

For example, echinacea is a natural product that is not recommended for scleroderma patients. Indeed, echinacea has, among other properties, that of stimulating the immune system. As a result, all diseases considered "autoimmune", including scleroderma, may potentially interact with echinacea. Thus, this product can exacerbate the symptoms of autoimmune disease by stimulating the immune system.

Another example of a product to be used with caution in people living with scleroderma is melatonin. Although melatonin can lower nighttime blood pressure in people with essential hypertension, it may paradoxically interact with the antihypertensive drug nifedipine. This pharmacodynamic interaction may lead to an increase in blood pressure. Therefore, melatonin may interact with several medications that scleroderma patients may be taking, including anti-inflammatory drugs and immunosuppressants. In addition, its drowsy effect may compound the sedative effects of narcotic pain medications. For all these reasons, scleroderma patients should be very careful before taking melatonin.



A final example is probiotics. Immunosuppressants such as cyclophosphamide or azathioprine may often be necessary to help control the symptoms of the disease in scleroderma patients. However, probiotics are not recommended for this immunosuppressed population because although probiotics are considered "good" bacteria, they can be harmful or even dangerous to someone who is immunosuppressed.

Therefore, even with natural health products, one must be very vigilant and only a pharmacist can check for these numerous potentially harmful interactions.



### NATURAL HEALTH PRODUCTS

## HOW TO REDUCE THE RISKS?

**ALWAYS** consult a doctor or pharmacist before choosing a product, even if it is a natural or homeopathic product, just as you would consult a health care professional for a prescription drug. This precaution is even more important for people who are taking multiple medications, to ensure that there are no interactions with them.

Furthermore, it is preferable to use natural health products for a short period of time (less than 3 months), as the effects of long-term use are often unknown because there are very few long-term studies on the subject.

### IN SUMMARY:

In short, there is still a lack of clinical studies and research on natural health products and homeopathic remedies. Therefore, great caution must be exercised. It is difficult to say with certainty whether a natural health product will interact with prescription drugs, and one should be aware of this risk. Always talk to your doctor and pharmacist when taking a natural or homeopathic product to make sure it is safe and effective.



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# ACCEPTING THE DIAGNOSIS OF SCLERODERMA

**Stephanie Baril, ps.ed.**  
Psychoeducator



Accepting the diagnosis of scleroderma is a unique experience for each person. Some adapt quickly, while others require more time to assimilate the information. Certain people are upset by the news while others can feel a sense of relief, putting a name on their symptoms and reducing their feeling of uncertainty<sup>(1)</sup>.

## TOWARDS ACCEPTANCE

Someone who has difficulty accepting their diagnosis may need to grieve for their previous life before being able to adapt and accept their new reality. This process may include progressions and regressions. It is not necessarily linear<sup>(2)</sup> and it varies from one person to the other, depending on their interpretation of their situation and their ability to bounce back<sup>(1)</sup>. Regardless of the path taken, it is important to respect the person's pace.

### STATE OF SHOCK

Upon the confirmation of the diagnosis of scleroderma, the person may feel shocked<sup>(2)</sup>. Various physiological reactions may occur, such as an apparent insensitivity to the news, a ringing in the ears, blurred eyes, a cold sensation, a feeling of heaviness, uncontrollable laughter, a feeling of paralysis, etc.

### DENIAL

The person may experience denial towards the news, refusing the diagnosis, and adopting behaviours to protect themselves<sup>(2)(3)</sup>. For example, they may seek a second medical opinion, distract themselves with other activities, or suppress their emotions.

# Educational Sheets

## ACCEPTING THE DIAGNOSIS OF SCLERODERMA

### A WHIRLWIND OF EMOTIONS

The person may feel various emotions, which can change in nature or intensity, and may leave and resurface at times<sup>(2)</sup>. They may feel helpless towards the situation, not knowing how to proceed with the confirmation of scleroderma<sup>(3)</sup>. They may tend to have more negative interpretations of certain situations and may seek to isolate themselves.

By gradually accepting the situation, the person can experience their emotions with less intensity, better understand their situation, and continue their path toward acceptance.

### ACCEPTANCE AND ADAPTATION

Finally, acceptance occurs when the person accepts their current situation<sup>(3)</sup>, including the reality of scleroderma. They let go of elements beyond their control (like the presence of the illness) and focus on the things within their control (like decisions and actions).

## SUGGESTIONS

Here are concrete actions that a person can take during their process of acceptance of scleroderma.

### INFORMATION

Because scleroderma is a little-known disease, a person is likely to have many questions and concerns when the diagnosis is confirmed. They can therefore develop their knowledge on this subject<sup>(1)</sup>. They can learn about scleroderma, its forms, symptoms, and causes. They can also learn more about the different treatments available. They can obtain information from their doctor, specialized professionals on this subject, or the SABC website.

### HEALTHY LIFESTYLE

Responding to basic physiological needs (e.g., eating, sleeping, etc.) is essential for the body to function optimally<sup>(4)</sup>. Therefore, a person should try to ensure that these primary needs are met. In doing so, they can facilitate their acceptance process by avoiding additional challenges, such as difficulty regulating stress<sup>(5)</sup>, fatigue, difficulty concentrating, etc



In practical terms, a person could:

- ▶ Eat at regular hours and have balanced meals. However, they must follow their doctor's medical recommendations.
- ▶ Sleep at regular hours and maintain a sleeping routine.
- ▶ Practice physical activity according to their interests and capabilities (e.g., walking, sitting outside, taking in the fresh air, etc.).
- ▶ Try to maintain a daily routine by continuing their regular activities<sup>(2)</sup>.

## ENJOYABLE ACTIVITIES

To clear their mind, a person can focus on activities they enjoy<sup>(2)</sup><sup>(5)</sup>. These may include current or new activities, which can be done individually or with others. The choice of activities varies from one person to another depending on their interests, abilities, schedule, etc. Examples include music, art, social activities, cooking, exercising, etc.



# Educational Sheets

## ACCEPTING THE DIAGNOSIS OF SCLERODERMA

### SOCIALIZATION

When a person receives confirmation of the diagnosis, they may feel isolated. To help them get through this period, they can talk about it with others and seek support. For example, they can speak with their family and friends, contact helplines, speak with a professional, and/or participate in a support group. These suggestions could help break their isolation, help them feel more supported, and lower their level of stress <sup>(6)(7)</sup>.

### EMOTIONAL RECOGNITION AND ACCEPTANCE

Each person follows a unique path to accepting their diagnosis and may experience various emotions. By acknowledging and accepting these emotions they can then allow themselves to express rather than repress them and this can help to regulate emotions <sup>(2)</sup>. For example, a person becomes anxious while learning about their diagnosis. They allow themselves to express this emotion, which helps them to reduce its intensity. They are then more opened to address it by seeking help, and trying treatments recommended by professionals, etc.



### IN CONCLUSION

In summary, confirmation of the diagnosis of scleroderma may require a process of acceptance. We encourage the person to progress at their own pace, practice self-care, and seek support.

If a person has concerns during their acceptance process, they can seek professional help by calling the Health Link BC's 811 number, request professional follow-up or participate in a SABC support group. SABC support group info: [sclerodermabc.ca](https://sclerodermabc.ca).



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# MANAGING ANXIETY AND STRESS

Stephanie Baril, ps.ed.  
Psychoeducator

Everyone experiences anxiety and stress, this includes people with scleroderma. This article aims to demystify these two terms, to understand them, and to learn coping strategies.

## STRESS OR ANXIETY?

The terms anxiety and stress are often mixed up and used interchangeably. Even though they have similarities, they also have differences.

Anxiety is a healthy, normal, and universal emotion. It protects us, it is essential for survival and it allows us to adapt to situations<sup>(1)(2)</sup>. It is present when we anticipate a potential threat and varies depending on our interpretation of the situation.

Stress is the body's physiological reaction to an actual or potential threat. Like anxiety, it is healthy, normal, universal, and has a protective function. When our brain detects a threat, several mechanisms are triggered, and we present various physiological reactions (increased heart rate, sweating, etc.). These reactions allow us to react to the threat, by fighting, fleeing or freezing<sup>(2)</sup>.

In short, anxiety is the emotion we feel in the face of potential danger and stress is our body's reaction to it. For example, we feel anxious in our doctor's waiting room, anticipating the start of the appointment. Our stress response activates to prepare us to react to the situation; our heartbeat increases, our breathing accelerates, and our pupils dilate.



## MANAGING ANXIETY AND STRESS

### ADVANTAGES AND DISADVANTAGES

Anxiety and stress often carry negative labels, but they also have benefits. In the short term and in small doses, they can stimulate us to perform better, motivate us, increase our creativity, improve our concentration<sup>(3)(4)</sup>, help us plan, and project us into the future to analyze a situation<sup>(1)</sup>. They become problematic when they are long-lasting and in large doses, which can tire us, decrease our concentration, change our mood, etc.

### STRESS TRIGGERS

Regardless of age, life experiences or characteristics, we all share the same stress triggers. However, how our response is expressed may vary depending on our interpretation of a situation.

There are four universal stress triggers<sup>(5)</sup>. A single trigger is enough to activate stress, but there is an additive effect. The more triggers there are, the more stressed we can feel.

#### THE TRIGGERS

- ▶ **Low Control:** When we feel like we have little or no control over a situation (e.g., feeling like we have no control over the progression of the disease / feeling that we are losing control over our body).
- ▶ **Unpredictability:** When something completely unexpected happens or we can't predict something (e.g., learning that we have scleroderma / being unsure if the treatments will alleviate our symptoms).
- ▶ **Novelty:** When we face something that we have never experienced before (e.g., knowing little information about the disease, its causes, its symptoms / not knowing how to navigate the medical world).
- ▶ **Threatened Ego:** When we feel that our skills or ego are being tested or that someone doubts our abilities (e.g., thinking that we will have difficulty living with the disease / having difficulty performing some daily tasks).

### SOME COPING STRATEGIES

Having a better understanding of anxiety and stress, we can now focus on concrete ways to regulate them.

#### MEETING BASIC NEEDS

Properly meeting our physiological needs, such as sleeping or eating, can be a helpful tool for regulating emotions. In fact, a person can experience various side effects if they are hungry or tired, such as they may have aches, mood changes, etc.<sup>(6)</sup>. Thus, if their basic physiological needs are met, a person may be more available to regulate their anxiety and may experience fewer side effects related to an unmet physiological need.

#### ROUTINES AND ACTIVITIES

To concentrate on the positives and lower their stress<sup>(3)</sup>, a person can maintain their regular routine and complete their daily tasks. They can also participate in enjoyable projects, alone or with others<sup>(7)</sup>. These activities can vary from one person to another, depending on their interests, capabilities, etc.

In addition, spending time outdoors and observing nature can decrease stress<sup>(8)</sup>. So, getting fresh air can be part of a healthy routine.

#### GETTING TO KNOW ONESELF

A person with scleroderma may experience anxiety and stress toward their situation. Therefore, they can start by having a better understanding of their stress triggers. Here are some examples:

- ▶ **Low Control:** "I feel like I have no control over the disease."
- ▶ **Unpredictability:** "I just learned that the change in the color of my skin's fingertips is related to Raynaud's phenomenon."
- ▶ **Novelty:** "I don't know how to navigate the medical world. What do I do?"
- ▶ **Threatened Ego:** "I feel discouraged because I need help with certain tasks that I could do independently beforehand."

# Educational Sheets

## MANAGING ANXIETY AND STRESS

Once they have a better understanding of their triggers, a person can then find ways to address them and reduce their impact. Here are some examples:

- ▶ **Low Control:** The person can talk to their doctor to explore ways to manage their symptoms.
- ▶ **Unpredictability:** They can learn more about the various symptoms of scleroderma and become more familiar with warning signs.
- ▶ **Novelty:** With their doctor, they can discuss which steps to take to receive a medical follow-up adapted to their needs.
- ▶ **Threatened Ego:** They can share their challenges with their loved ones to clarify their needs. They can maintain or perform tasks that they can complete.

In summary, several options exist and vary from one person to another. Nevertheless, a good starting point to reduce stress is to inform ourselves<sup>(3)</sup>. In fact, by developing our knowledge, the stressful effect of novelty and unpredictability decreases, which increases our sense of control over the situation.

### SOCIALIZATION

Socialization can help to decrease feelings of isolation and anxiety. Creating social connections, especially in the presence of stress triggers, can help a person feel more empathy, connect with others, and increase their sense of security<sup>(4)</sup>. Simply being in the presence of others can help reduce feelings of isolation<sup>(4)(8)</sup>.

It is also possible to seek specialized help related to scleroderma in a support group. Although people may be hesitant to participate, it can have several benefits. In fact, a person can develop a better understanding of the illness and ask questions. By discussing with others and learning about their experiences, they can normalize their suffering and learn that they are not alone in overcoming challenges<sup>(4)</sup>. They can even support others by talking about their experiences and sharing their knowledge. Helping others and practicing empathy can help reduce anxiety and stress.

### BREATHING

Breathing exercises can be a useful strategy because they can help curb a stress response, decrease anxiety and improve mood<sup>(3)(9)</sup>. Several breathing techniques exist, including singing. The majority recommend deep breathing to counteract a stress response.

Some studies show that listening to classical music helps reduce stress<sup>(3)</sup>. A person tends to synchronize their breathing with a musical rhythm. A gentle rhythm, like classical music, can help reduce stress hormones.

### MINDFULNESS

Several studies demonstrate the benefits of meditation and mindfulness on general health and on the reduction of anxiety<sup>(10)(11)(12)</sup>. In short, these techniques consist of focusing one's attention to regain mental calm and positive emotions<sup>(10)</sup>. To accomplish this, a person concentrates on the present moment by focusing on their breathing. They can then observe their emotions, physical sensations, and thoughts, identify them and let them pass on their own. The person tries to accept them by adopting a non-judgmental attitude rather than trying to modify or react to them.

### PLANNING AND TIME MANAGEMENT

Planning and time management can be effective in decreasing anxiety and stress<sup>(5)</sup>. They can be applied in various moments of everyday life. For example, a person with scleroderma may have several medical appointments, which may require some planning (e.g., planning transportation, knowing their route to the appointment, bringing documents, etc.). Therefore, they can plan their schedule and get ready ahead of time to reduce their anxiety for the meeting. Also, if they feel overwhelmed, they can ask for help or delegate tasks to others.

### PERSONAL LIMITS

A person may have varying levels of energy, depending on their condition or symptoms, and may experience changes in their abilities, depending on their treatments or the progression of the disease. They can learn to prioritize and refuse certain activities if they require rest. Therefore, listening to the body and enforcing limits can be good ways to regulate anxiety and stress<sup>(5)</sup>.



## MANAGING ANXIETY AND STRESS

### IN CONCLUSION

It is important to specify that the tools presented in this article are suggestions to regulate anxiety and stress. These do not replace, in any way, a consultation with a professional. Moreover, some people may have certain physical or medical restrictions; they are strongly encouraged to follow their doctor's recommendations.

Although anxiety and stress have a protective function and ensure our survival, it is always possible to seek professional help if concerns arise or persist. A person can contact a mental health organization in their region, call the Health Link BC's 811 number, request professional follow-up or participate in a SABC support group. SABC support group info: [sclerodermabc.ca](https://sclerodermabc.ca).



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# HOW SCLERODERMA CAN AFFECT THE HUMAN BODY

The symptoms of scleroderma vary greatly from person to person, so that patients will not necessarily develop all the complications of the disease. The symptoms of the disease may be visible, as is the case when the skin is affected, or the symptoms may be invisible, as when internal organs are affected.

## SYMPTOMS AND MANIFESTATIONS OF SCLERODERMA

### SKIN HARDENING

Thickening and loss of elasticity of the skin on different parts of the body. Hence the name «scleroderma», which means hard skin.

### PULMONARY FIBROSIS

A potentially serious complication where normal lung tissue is gradually replaced by scarred fibrotic tissue, making it difficult to breathe and deliver needed oxygen to the body.

Pulmonary fibrosis causes shortness of breath and also sometimes a dry cough.

### RENAL CRISIS

A renal crisis, which is due to an acute obstruction of arterioles and capillaries in the kidneys, leads to a sudden and sharp increase in arterial blood pressure. The symptoms are those of a hypertensive crisis: new and severe headaches, marked shortness of breath (left heart failure), and even epileptic seizures (convulsions). This is a very serious complication which requires urgent medical attention. Often during a scleroderma renal crisis, the kidneys stop functioning and dialysis (filtering the blood to avoid uremia) is then needed.

### BLOOD VESSELS

The narrowing of the arteries, small blood vessels, and capillaries, can lead to many complications, including the development of pulmonary arterial hypertension (PAH), digital ulcers, and other conditions.

### PULMONARY ARTERIAL HYPERTENSION (PAH)

Increased pressure in the pulmonary arteries due to the narrowing of small arteries in the lungs. Blood flow to the lungs is significantly restricted, making the heart work harder to pump blood through the lungs.

As arterial blood pressure rises in the pulmonary arteries, small pulmonary vessels slowly become clogged (a process which may take several years). This occurs through fibrosis of the small vessels, eventually leading to thrombosis, and the blood can no longer reach all parts of the lungs. Thus, it becomes more difficult for the lungs to supply enough oxygen to the body.

Sustained high blood pressure in the arteries of the lungs puts a strain on the heart, making it more difficult to circulate the blood through the lungs. Over time, this can eventually lead to congestive heart failure, particularly the right side, what is referred to as right heart failure (RHF). Right heart failure is indicative of significant PAH and is a serious complication of scleroderma.

PAH results in one or more of the following symptoms:

- Shortness of breath on exertion and at rest
- Palpitations (heart rhythm disorder)
- Fatigue
- Chest pain • Dizziness
- Temporary loss of consciousness (syncope)
- Swelling of the ankles and legs

### SCLERODERMA FACES

Hollow eyes, pinched nose, thin pursed lips, mask-like face, small puckered mouth (microstomia), and peri-oral folds. Thinning lips and facial muscle atrophy can make the teeth appear more prominent.

### EYES

Dry eyes caused by a decrease in tear production.

### TELANGIECTASIA

Small dilated capillaries visible on the face and hands, sometimes referred to as «spider veins».

### RAYNAUD'S PHENOMENON

Raynaud's is present in up to 95% of people with scleroderma. Whitening of fingers and/or toes triggered by cold or severe stress. The whiteness phase can be followed by a blue phase and then a red phase.

### SCLERODACTYLY

The skin of the fingers, which have become infiltrated with collagen (fibrosis), may look full and sausage-like. Functional loss or decreased range of motion.

### CALCINOSIS

Calcium deposits under the skin that may require antibiotics to cure occasional infections and sometimes surgery to drain calcium deposits and relieve pain.

### DIGITAL ULCERS

Ulcers occur on the fingertips or on the top of the fingers. They are painful and difficult to heal. In the most severe cases, it can lead to necrosis and amputation may be needed.

### SKIN PIGMENTATION

Dark or pale spots occurring in one-third of patients.

### DIGESTIVE SYSTEM

Gastrointestinal disorders affect the vast majority of patients. Gastric reflux is a common symptom that manifests itself by a burning sensation radiating up to the throat after meals and may cause inflammation of the lining of the esophagus (esophagitis reflux) if left untreated.

### MUSCLE AND JOINT PAINS

Joint pain is common. It is caused by inflammation of the joints and tendons, which quite often leads to joint swelling and stiffness that can become quite debilitating.

Muscular pain (myalgia) can be intermittent or continuous. It can also be associated with muscle weakness (myositis). Symptoms include difficulty in climbing stairs, lifting objects and getting up, and also difficulty swallowing.

**SCLERODERMA ASSOCIATION OF B.C.**  
**info@sclerodermabc.ca / 604-371-1005**  
**www.sclerodermabc.ca**

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# Community Contact Representatives

## CONNECT WITH THE SCLERODERMA COMMUNITY IN YOUR AREA!

Give us a call, send us an email, and meet other people living with scleroderma.

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