SCLERODERMA ASSOCIATION OF B.

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Oral Health and Scleroderma

June Awareness Month

12

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A Word from Our President

ROSANNE QUEEN President, Scleroderma Association of B.C.

With flowers in bloom, it can only mean one thing — the June Awareness Campaign is just around the corner!

I'm thrilled to share that our "Moving to Cure Scleroderma" events are in full swing once again.

This year, **Kenny** and his band **17West** will be performing at KinVillage in Tsawwassen, and we're proud again to be hosting our annual **Scleroderma Ride for Research**.

Our virtual events continue to bring communities together — whether you're walking, running, biking, or taking part in a backyard yoga class, we invite you to participate however you can. Rally your friends and family, show your support, and help us raise crucial funds for scleroderma research in B.C. and across Canada.

And don't forget to share your photos on social media — every post helps spread awareness.

Did you know? You can now set up monthly donations to support ongoing research! Together, we can make a difference.

A heartfelt thank you to Scleroderma Quebec for their ongoing work in publishing up-to-date, informative articles. You can find one of these within — and even more articles inside past issues — check out our website under the Resources tab in the Scleroderma Resource Hub.

Speaking of our website, we're constantly improving it to help you easily find the information you need. Instead of searching Dr. Google, visit us at **sclerodermabc.ca** for trustworthy, helpful resources.

P.S. If this bulletin — like the Fall edition — arrives a bit late, rest assured: it's never too late to donate. And check back often for updates on this June's Moving to Cure Scleroderma campaign results!





This June we're Moving, Grooving, and Riding for a Cure!

Join us throughout June 2025 as we come together to raise awareness and funds for scleroderma research through three exciting community-driven events. Whether you're dancing the night away, getting active in your own neighborhood, or cycling through scenic Vancouver, there's a way for everyone to get involved and make a difference.

With the participation of you: BC's patients, families, and friends, we are once again excited to come together in a sea-of-blue t-shirts and support each other as we live with this rare disease, providing us the opportunity to connect over a shared cause; showcasing our enduring warrior spirit while raising funds to support research.

Explore all 3 of our events and find your way to support hope, progress, and a future without scleroderma.

It's time again for *Moving to Cure Scleroderma...* please join us this June for all the fun!

JUNE IS SCLERODERMA AWARENESS MONTH!

GROOVE TO CURE SCLERODERMA KINVILLAGE, TSAWWASSEN

SATURDAY, MAY 31, 2025

Doors open at 7:00 PM | Event ends at 11:30 PM



Get ready to dance the night away to live 80s hits performed by your favourite local dance band, 17 West! It's going to be a high-energy evening full of music, fun, and community spirit.

- Cash Bar: Enjoy Beer, Wine, Non-Alcoholic Beer, and soft drinks.
- **Raffle Prizes & 50/50 Draws:** Bring some cash and take a chance on great prizes—all while supporting an important cause.

All net proceeds go toward vital research into Scleroderma, a rare and chronic autoimmune disease. Your participation helps make a real difference.

MOVING TO CURE SCLERODERMA ANYWHERE YOU ARE

ANY DAY IN JUNE 2025

Your time, your pace!

Join us this June for our virtual event, Moving to Cure Scleroderma! Wherever you live, pick a day, wear blue, and get moving—walk, run, bike, dance, stretch—whatever gets you active and raises awareness..

- Why We Move: We move for hope. Hope for earlier diagnosis, better treatment, and ultimately, a cure for scleroderma—a rare and chronic autoimmune disease that affects thousands across Canada.
- Where Your Donations Go: 100% of the funds raised support scleroderma research in BC and across Canada.

Your steps, your strength, and your support bring us closer to a cure. So get active, spread the word, and help us keep the momentum going!

SCLERODERMA RIDE FOR RESEARCH STANLEY PARK

SUNDAY, JUNE 15, 2025 9:00 AM Start



Join us for the Scleroderma Ride for Research, a meaningful way to spend Father's Day while making a real impact. Whether you ride, walk, or just hang out, you're helping us raise awareness and critical funds for scleroderma research.

Choose Your Challenge:

- 30 km Ride to UBC
- 10 km Ride around the Stanley Park Seawall
- 10 km Walk around the Stanley Park Seawall
- Or just Sit & Chill—your presence makes a difference!

Why We Ride: Founded in 2012 by David and Rosanne Queen, the Scleroderma Ride for Research has a simple but powerful mission: to raise awareness and fund critical research. Why? Because research gives us hope hope for earlier diagnosis, hope to slow the progression of this disease, and hope for an eventual cure.

You Can Help: Your participation and support help power the research that changes lives.

Bring your bike, your sneakers, or just your heart—and let's ride for a future without scleroderma.

VIRTUAL MOVING TO CURE SCLERODERMA ALL OF JUNE

"Go out or stay in, put on your blue shirt and participate in any activity you enjoy. Invite your family, friends, co-workers or your community to go for a walk, a run, dancing, kayaking or joining a class... whatever activity that makes you feel good! Please visit SABC's website to make a donation, join an existing team, or create your own team. Let's see a "Wave of Blue" across BC and Canada to raise awareness and find a cure for Scleroderma".

TERESSA COLOSIMO, VALEMOUNT

JUNE IS SCLERODERMA AWARENESS MONTH!



June 1st, across Canada, starts Scleroderma Awareness Month which involves raising awareness of scleroderma and much needed funds for research.

The yearly campaign ends on June 29th, World Scleroderma Day.



For more details on the schedule of the events and to register on-line, please visit

* The Scleroderma Association of B.C. will accept donations before (on-line) or during these events. You will receive a receipt for the full amount of your donation. This fundraising campaign is part of the walks organized in June for scleroderma.





A big Thank-You to all the event coordinators who welcome you to join them and support us all this June.

We are excited to see everyone in Tsawwassen, Vancouver and Anywhere in BC!

With the support of you, our families and community, we can all make this June's events truly special. If you're interested in fundraising in your community this June, please contact the SABC.

 Not able to attend any of the June events? No problem!
Wherever you are in B.C. please visit sclerodermabc.ca and help raise funds for research.
100% of funds raised supports scleroderma research here in B.C. and across Canada.

ORAL HEALTH AND SCLERODERMA

Christine Brunet, D.M.D. – Retired Dentist

Christine Brunet is a retired dentist who contributed her clinical expertise to the development of this educational sheet.



Every human being should enjoy oral health that is good enough to allow them to eat, drink or speak every day of their life. However, scleroderma often interferes with these essential actions, either directly by disrupting the physiological function of the oral space, or indirectly by significantly hindering hygiene methods. Fortunately, most people living with scleroderma will not experience the full range of these problems, and the severity of symptoms will vary from person to person.

This text is not intended to be scientific or exhaustive. Its goal is to address the main known concepts to better understand how a disease like scleroderma can affect the function of this unique part of the body: the mouth.

Let us explore how scleroderma influences oral health and the various approaches that can help improve quality of life for many people who may face these challenges.

And let us also emphasize the importance of consulting a dental professional regularly as soon as the first symptoms of scleroderma appear, in order to prevent or limit the progression of oral complications described below.

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ORAL HEALTH AND SCLERODERMA

MICROSTOMIA

Reduced mouth opening and loss of facial elasticity

The skin of the face loses elasticity, and mouth opening can become significantly restricted. This leads to difficulties with speaking and eating, especially as the tongue may lose mobility and the lingual frenulum, a thin membrane connecting the tongue to the floor of the mouth, may become fibrotic and limit movement. Basic hygiene routines become harder to carry out, and dental visits may be uncomfortable or even impossible to perform properly, particularly in the back areas of the mouth.

Facial skin thickening may also cause the teeth to shift due to the pressure applied to them. It can also worsen dryness in the mouth because of an inability to close the lips and achieve a proper seal, leaving the mouth slightly open at all times.

Clearly informing your dentist about your scleroderma diagnosis allows care to be properly adapted to your needs, whether it involves the duration of the procedures, a more comfortable position, the choice of instruments, or the type of restoration if needed, to make treatment easier and more comfortable.

STRATEGIES FOR IMPROVEMENT

Numerous studies show that positive results can be achieved through daily stretching exercises of the mouth using fingers or tongue depressors. These exercises need to be performed several times a day to yield meaningful improvements. Physical therapy, kinesiology and occupational therapy can also offer relevant exercises and techniques. In more severe cases, hyaluronidase injections may be used to soften the skin, along with autologous fat grafts taken from the patient, or IPL treatment, a technique using intense pulsed light.





Toothbrushes with small heads or designed for children, or electric toothbrushes with rotating heads and larger handles, can help improve access to back teeth. Interdental brushes and oral irrigators, such as Waterpik, may also be considered. If subtle dental shifting causes discomfort when chewing or muscle pain, the dentist can perform minor adjustments by carefully grinding the teeth that no longer fit together properly.

More frequent dental visits, ideally every three months, are highly recommended to detect and prevent issues before they arise and require longer or more demanding treatments. In addition, when cleanings are done more often, they are much quicker. 0

ORAL HEALTH AND SCLERODERMA

XEROSTOMIA

Dry mouth caused by reduced saliva flow

Many people with scleroderma experience xerostomia. Fibrosis can affect the salivary glands, but in some cases, it is Sjögren's syndrome, a chronic, systemic autoimmune condition, that is responsible. Both lead to similar effects: an irreversible reduction in saliva flow, resulting in a dry mouth.

Saliva lubricates the mouth, helping with speech and swallowing. It cleans food debris and contains substances that neutralize the acid produced by oral bacteria and that help remineralize tooth enamel. It also contains components that help control the number of microbes and viruses in the mouth.

Reduced saliva flow clearly increases the risk of tooth decay and enamel erosion, mainly due to the heightened acidity in the mouth. Dryness also affects the comfort and fit of removable prostheses. Xerostomia can also disturb the oral microbial balance, leading to candidiasis, fungal infections caused by microscopic yeast, especially under prostheses or in the corners of the lips, where they trigger painful inflammation known as angular cheilitis.



STRATEGIES FOR IMPROVEMENT

To help compensate for reduced saliva flow, it is recommended to:

- Drink small amounts of water frequently.
- ▶ Keep indoor humidity between 40% and 50%.
- Avoid smoking, alcohol, salty or spicy foods.
- Use sugar-free candies or chewing gum to stimulate saliva production.

Saliva substitutes, lubricants, and saliva stimulants are available over the counter, such as lozenges, or by prescription, such as pilocarpine.

For more information, refer to the sheet titled "Sjögren's Syndrome Associated with Systemic Scleroderma".

To reduce the risk of cavities, it is advised to:

- Avoid sticky or sugary foods, soda, fruit juices, wine, coffee and tea.
- Maintain good dental hygiene, including brushing and flossing.
- Remove dental prostheses before bedtime and brush the sides of the teeth that serve as anchors.

In case of candidiasis, dentists can prescribe antifungal creams, which are usually effective. For more persistent cases, oral medication may be used.

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ORAL HEALTH AND SCLERODERMA

TOOTH DECAY

Tooth decay is the most widespread infectious disease in the world. According to the World Health Organization, nearly all adults have had cavities. It is rare to find someone who has never had one. People living with scleroderma who also experience microstomia, xerostomia, gastroesophageal reflux, or reduced manual dexterity are especially at risk.

When the mouth opening is limited and hand movements are difficult, brushing and flossing become extremely challenging.

Xerostomia is an aggravating factor for the development of new tooth decay because it reduces the beneficial effects of saliva. Saliva normally helps clear food particles from teeth, neutralizes acid, and strengthens enamel.

Gastroesophageal reflux, or GERD, increases the presence of acid in the mouth. This further raises the risk of cavities and contributes to enamel erosion.

STRATEGIES FOR IMPROVEMENT

Dental plaque must be removed regularly. It contains salivary proteins, food debris, and many bacteria that turn sugars into acid. This includes natural sugars such as those found in honey, maple syrup, or fruit. The acid then attacks the enamel, eventually creating a cavity, and can also irritate the gums. Reducing sugar intake, whether from foods or drinks, helps protect teeth. Bacteria make no distinction. They use all forms of sugar to produce acid.

People who are at higher risk of cavities or who experience frequent tooth decay would certainly benefit from fluoride. This natural element strengthens enamel and helps reduce the number of bacteria that produce acid. Its antimicrobial and protective action makes the enamel more resistant to acid attacks.

Fluoride is available in many forms. It is helpful to speak with your dental team to choose the best options for your situation.



There are high-fluoride toothpastes available, such as Colgate PreviDent Booster Plus, which contains 5000 ppm fluoride and is safe for regular use. Fluoride gels applied at night using trays may also be recommended. Topical creams containing calcium, phosphate, and fluoride, such as MI Paste Plus, can be useful for people with low saliva flow. Fluoride varnish applied professionally at the dental office, as is done with children, is also well suited for adults at high risk of cavities. In addition, the occlusal or chewing surface of molars can be sealed to block bacteria from settling in grooves and to make cleaning easier.

Daily exercises to maintain or increase mouth opening and hand mobility are valuable. They make oral hygiene easier to perform at home.

These exercises are described in the educational sheet "The Scleroderma Patient-centered Intervention Network (SPIN) and the SPIN-HAND Program."

Toothbrushes with adapted handles or electric toothbrushes can improve grip for those with limited dexterity. Floss holders and interdental brushes are also practical tools to replace regular flossing when needed.

ORAL HEALTH AND SCLERODERMA

PERIODONTAL DISEASE Gingivitis and periodontitis worsened by scleroderma

The periodontium refers to the set of tissues that support the teeth, namely the bone, the periodontal ligament, and the gum. The root is firmly anchored in the jawbone, covered with a protective layer called cementum, and held in place by small fibers that form the periodontal ligament. The gum acts as a protective tissue over the bone. Many adults suffer from periodontal disease, which often leads to tooth loss due to the gradual destruction of these supporting tissues by bacteria. A tooth may appear completely normal, with no decay or visible wear, but without a solid anchor in the bone, its stability and longterm survival are compromised.

Scleroderma can increase the severity of periodontal disease through fibrosis of the oral mucosa and frena, creating tension on the gums and thereby increasing gingival recession, that is, receding gums. In addition, microstomia and reduced manual dexterity greatly complicate the hygiene techniques essential for eliminating the bacteria responsible for gum inflammation, known as gingivitis, as well as the possible damage to the supporting structures of the teeth, known as periodontitis. Furthermore, reduced saliva flow worsens the situation, since its cleansing and bacterial-regulating roles are compromised.

STRATEGIES FOR IMPROVEMENT

The simplest and most effective way to prevent periodontal disease is to remove dental plaque loaded with bacteria before they produce enough toxins and acid to first damage the gums, then reach deeper areas and cause bone resorption, meaning a progressive loss of the bone that supports the teeth.



Therefore, with each brushing, it is important to pay close attention to the gumline by gently massaging this area using a soft-bristled toothbrush. The same applies to dental floss, which should be adapted to the curved surface of the tooth to dislodge bacteria hidden beneath the gum. Floss can be gently inserted under the gum without risk.

Your dental hygienist is without a doubt the best person to teach you these techniques. Your hygienist or your dentist is also the one who can effectively remove tartar deposits, which are made up of hardened or calcified dental plaque, using specialized instruments, as this cannot be done with a toothbrush. Tartar also harbors a large number of bacteria that can cause irreversible damage to the periodontium. It is therefore essential to remove these deposits regularly to avoid progressive deterioration that could lead to tooth loss. 0

ORAL HEALTH AND SCLERODERMA

GASTROESOPHAGEAL REFLUX DISEASE (GERD) Oral acidity and tooth enamel erosion

GERD, which is common among adults, is even more frequent in people living with scleroderma. The esophagus, the tube that connects the mouth to the stomach, may have weak or ineffective contractions, and the lower esophageal sphincter, which is the valve that separates the esophagus from the stomach, may become deficient and fail to close properly. This results in the backflow of stomach acid and bile into the esophagus, sometimes reaching the mouth.

The acid produced by the stomach has a very low pH, between 1 and 3, whereas a neutral pH, like that of most drinking water, is 7. This extreme level of acidity makes it particularly aggressive or damaging to tooth enamel. When saliva production is also reduced, a condition known as hyposialia, this acidity becomes even more harmful.

Unfortunately, lost enamel does not regenerate naturally. Once it is damaged, it can only be restored through dental treatments.



STRATEGIES FOR IMPROVEMENT

THERE ARE SEVERAL PROVEN TECHNIQUES TO HELP REDUCE GERD:

- Keep the head of the bed raised to prevent acid from rising during sleep.
- Avoid eating during the three hours before going to bed.
- Limit or avoid caffeine, alcohol, fatty foods, chocolate, and acidic drinks.
- Drink water regularly or rinse the mouth frequently.
- Avoid sugary foods and drinks, since oral bacteria turn them into acid.

For more information, refer to the educational sheet titled "*The Digestive System and Systemic Scleroderma*."

In more serious cases, antacids or medications such as proton pump inhibitors may be prescribed to reduce stomach acid production.

It is also recommended to use fluoride in all its forms. This includes toothpaste, fluoride varnish, gels, and topical creams. Fluoride helps protect enamel by making it more resistant to acid and supporting remineralization.

The amount of enamel already lost cannot be naturally restored. Severely eroded areas may eventually require dental restorations, such as fillings, crowns, or inlays. However, if the remaining enamel becomes stronger and more resistant to acid, further damage can be significantly reduced.

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ORAL HEALTH AND SCLERODERMA

TMJ AND FACIAL PAIN

Temporomandibular Joint and muscle or nerve pain

The temporomandibular joint, or TMJ, connects the lower jaw to the skull. It is located on each side of the face, just in front of the ears. This joint is complex and allows a wide range of motion, which often makes it prone to discomfort.

Scleroderma can affect this joint just as it affects other joints in the body. Muscle fibrosis, reduced blood flow, and shifting of the teeth caused by tightening of the facial skin can all contribute to joint pain. Bruxism, which refers to involuntary grinding as well as clenching of the teeth, is a common cause of TMJ discomfort. In addition, when the teeth no longer fit together properly, this can increase the strain on the joint. Pain in the jaw and facial muscles can be especially bothersome, since this area is constantly engaged in eating, speaking, swallowing, and even smiling.

In some cases, people report sharp, intense, and brief nerve pain. This usually involves the trigeminal nerve, which has several branches across the face, and generally affects only one side of the face. These neuralgic pains can be triggered by chewing or even by a light touch on certain areas of the face.

Bone resorption, referring to damage affecting the bone, has been observed at the attachment points of the jaw muscles, particularly at the posterior angle of the lower jaw and in the region of the condyles, located near the ears. These bone changes are usually asymptomatic and are often discovered incidentally during X-rays.



STRATEGIES FOR IMPROVEMENT

The dentist may carry out selective grinding of misaligned teeth to restore balanced contact and reduce tension or sensitivity. Night guards, also known as occlusal splints, are often worn at night to relieve TMJ pain and protect the teeth from wear. In some cases, anti-inflammatory medication or muscle relaxants may be recommended.

It is advisable to avoid chewing gum and to limit hard or sticky foods to reduce strain on this already sensitive joint. Taking small bites and avoiding always chewing on the same side are also good habits to adopt.

Applying warm, moist compresses to painful areas may also help relieve discomfort, especially during more intense episodes.

In cases of trigeminal neuralgia or bone resorption, which are more complex and less common situations, the dentist may recommend a consultation in oral medicine.



Testimony — Jorge Antunes



Family Matters. I'm married to the most amazing woman, Clara, who keeps me going every day and supports me in everything that I do. Clara and I are both trail runners and love all things outdoors that we share with our dogs. We have three children (Kristen, Ryan and Jordan) and a granddaughter (Grace). I was born in Portugal and immigrated to Canada as an infant in 1968. I am fortunate to have a good career as a Professional Engineer with great thanks to my parents Jose and Lucilia, who taught me the benefits of hard work, kindness and perseverance.

Health Matters. In late 2022 I had been suffering from carpal tunnel syndrome and decided to have a release surgery on my right hand in April of 2023. Additionally, I had been having swelling in my legs and ankles along with some noticeable unexplainable changes in my blood work. During the surgery recovery period, the fingers in my right hand started to show curvature and I had noticeable tightening in the tendons of my fingers. This condition became progressively worse and while my hand fully healed from the surgery, I began to lose a great deal of functionality in all my fingers. I sought answers but was unable to find out the cause. As time progressed in 2023 the problems in my right hand started to occur

in my left hand leaving that hand progressively worse. By early 2024, my condition spread to my feet and lower legs. I was forced to give up my running and was finding it difficult walking and going up and down stairs.

My condition didn't seem to make sense compared to simpler health problems. Finally, I was fortunate to be referred by my family doctor to a rheumatologist who began to investigate the causes of my symptoms. She immediately noticed and commented that I was likely dealing with an autoimmune response. She ordered a lot of blood tests. I have never seen a lab requisition with so many check marks. All the while, my mobility and condition were worsening. There were no definitive answers.

Then came my in-person visit in May 2024. My rheumatologist asked me a simple question... "Have you noticed anything new with your symptoms lately?" I said, "I have noticed the weirdest thing starting about three weeks ago. The skin on my arms is so tight and it feels like someone put a tourniquet on my skin and is tightening it." She immediately examined my skin, and she said "I know what you have... you have Scleroderma!! We need to start to treat you right away." We immediately began a treatment

Testimony — Jorge Antunes

program of various immunosuppressant drugs and started investigating the status of the disease in my body.

That day began a whirlwind of specialist doctor visits, CT scans, MRI's, lab tests and a lot of other tests I have never heard of. This had a big impact on my own mental health and the anxiety of dealing with a disease with no cure. It seemed like every week was filled with a new fear, worry, medical visit or questions with no immediate answer. We began to suffer from what we called "medical fatigue". Those months were spent at hospitals, specialist appointments and taking many new medications. Clara was my rock, I could not have gotten through those weeks and months without her strength, her being by my side, and keeping me motivated and moving forward.

Taking Matters into Our Own Hands. We decided that we needed to take our life back. Every time I received a call about an upcoming test or appointment, we wouldn't just take the first available date or time; instead, we would ask for dates that allowed us to double up visits and minimize disruption to our lives. We set a limit and refused to talk or consider medical things on our weekends. By this time, the medications were starting to work, and the swelling and pain was leaving my legs. I could start running again. This all played a part in releasing my stress and improving my mental health. I started training again and it was making me feel so much better.

Despite struggling with my health in January 2024, Clara and I both signed up for the Javelina Jundred 100 km trail race in Scottsdale, AZ, scheduled for October 2024. Even with my undiagnosed health problems at the time, I was hopeful that I could run. After my health stabilized in the late summer, I was able to train again with the help of my coach Hilary, and we set a realistic goal. The 100 km was out, but we agreed on one loop (36 km). I couldn't have done the training without Clara pushing me every weekend to put in the miles! I talked with my doctors and told them I wanted to race. I wanted to prove to myself that I could overcome my condition. Their advice to me was to listen to my body and not to overexert myself and risk a setback in my health progress. Fast forward to October 26, 2024 and I'm at the Javelina Jundred start line with my two best running buddies, Clara and Jen to give it everything we had in the desert. It was an amazing time, and I wouldn't trade it for anything.

Every Minute (or Mile) Matters. The official race roster recorded a DNF (Did Not Finish) at Rattlesnake Ranch with a running time of 5:27:38, covering 27.52 km. This is the hardest run I have ever done in my life. I had never run that distance in my life, this was a PB (Personal Best) for me. It was no joke; the temperature was over 40 degrees Celsius out there. The smart choice was to protect myself, so I pulled out of the race! I was feeling great at the time but I did not want to hurt myself. I had promised everyone that I wouldn't do anything to risk my health, and I didn't!

One of my favorite memories is the lone park bench in the middle of the desert. How did it get there? Who hikes 20 km in the desert to get there? How long can you even sit there? So many questions... I took every step as though this was the last time I may ever be there. I enjoyed every moment.

I am happy to say that my multitude of tests is currently showing that my medications are working well and that my Scleroderma has stabilized. I continue to run and train and improve my health every day. I try to stay positive and live every day to the fullest. I really want to thank my doctors for all their hard work in finding a path to keeping me healthy. Thanks to Clara, her mom Gizella and my entire family for keeping me motivated and positive. We cannot change what happened in the past, but we can choose to live the best life every day and be thankful for what we have.

By the way, Clara and I are signed up for the 2025 Javelina Jundred in October. I plan to do my best to finish the full 100 km this time!!

Forge Antunes

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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