SCLERODERMA ASSOCIATION OF B.C.

The Bulletin

Fall-Winter 2019-2020 | Volume 1 Number 2

When the Diagnosis is Received

JACKIE'S STORY

SPIN-SHARE

The Experience of Informal Caregivers

Summary

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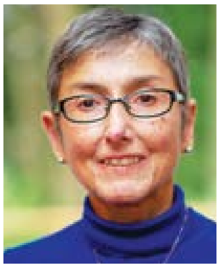

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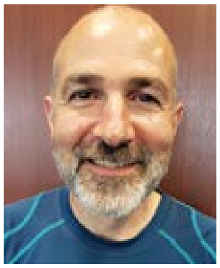

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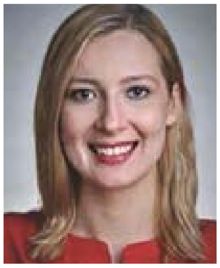

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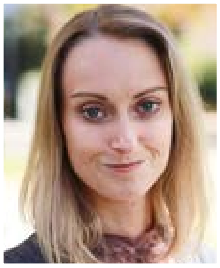

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Celebrating 35 years

With this year being our 35th year as an association, I feel honored to be a part of such a great organization.

When Joan Kelly, one of the founders of our association, was told 37 years ago she had scleroderma, like everyone else diagnosed she said she was, in her words, "gob smacked". At the time her only resource for information was the library. All she found was "frightening medical jargon and she could be dead within 5-7 years." Can you imagine today, having that very little info on such a rare and horrible disease? Thinking you are the only one! Joan found four other women and they decided to support one another and founded our association, SABC. The mission statement has not changed since then.

- Supporting scleroderma patients by promoting patient outreach and education
- Raising public awareness and developing informational tools for the general public and stakeholders in the medical community
- Encourage and support leading edge research in British Columbia and Canada

June Scleroderma Awareness

June is International Scleroderma Awareness Month. SABC did our part as our members organized and participated in four events across the province. There was media coverage in local newspapers and radio. Every time someone supports one of these events there are more people that become scleroderma-aware; after all that is the point. Have a look on page 8.

This year there was a group of women in Kamloops who reached out to their community, Valemount had their 3rd walk, Victoria had their 2nd walk and the Scleroderma Ride for Research had its 8th year in Vancouver. What is so incredible, but not surprising, is that each year the events succeed in raising awareness and raising funds for research. This June's fundraising topped $70,000, all going to research; primarily the BC Research Project. How do we make such a difference? People care!

Dr. Google

Access to medical information has come a long way since SABC was first formed. Today, you can Google anything to find out more than you need to know. This is the same for scleroderma. The internet is filled with information; but what is reliable, what is not accurate and what is downright harmful? How does one decide?

SABC works hard to provide information that is reliable and accurate. Our annual conference is a perfect example of sharing information with our community enabling us to learn from trusted sources. See page 9. We have been working with Sclérodermie Quebec and Scleroderma Manitoba to produce consistent websites that inform you of current research direct from those doing the research, and information from the three provinces and nationally. As we know, systemic scleroderma manifests differently with everyone. SABC's goal is to continue to reach out and give people hope!

Personal

Having been the President for the last four years, what I hear the most of is how wonderful it is to talk to someone who has this disease; to know they are not alone. I have also learned that scleroderma patients are one of the most positive group of people I've ever met.

David and I have been doing our Scleroderma Ride for Research for 8 years now. I know that research dollars are patient driven and I'm a patient that is driven. We all know that everyone is being asked by every charitable organization for help. For me, personally, the very first time I asked my family, friends and everyone I knew for help to support us, it was hard. Then each year, it has become easier to ask. It is amazing how many people care about you; just ask for their support and you will be surprised!

ROSANNE QUEEN
President

JACKIE ALEXANDER'S STORY

In the fall of 1998 at the age of 25 and newly married, I delivered our first baby, a healthy beautiful girl. Not long after her birth, I noticed my hands would swell when out walking or exercising and occasionally turn blue. I was concerned so I went to the doctor and received my initial diagnosis - Raynaud's phenomenon. I was told that Raynaud's was not uncommon, which I found interesting but not too worrisome. A couple of years later, while on vacation in Mexico, I noticed that the nice dark tan I usually get included a shiny tightness on my chest that I had never seen before. As soon as we returned home I went to my family doctor who took one look at me and immediately referred me to a rheumatologist, who gave me the scary diagnosis of diffuse scleroderma.

I wondered, "What is scleroderma?" Like most newly diagnosed people, I went on the internet to research the disease. Perhaps not the best idea! There was fear, panic, and sadness. I had no idea what this disease would do to my body or how long I was going to live. I saw the effects this horrible disease had on many people and thought to myself, "Is all of this going to happen to me?" All this info only escalated my fears. I soon realized I had to stop going online, refocus, find trusted information, and develop a positive support system.

I was 28 and our daughter was almost 3. What did this diagnosis mean for me and my family? I worried about our little girl, my husband and my dream of adding one more baby to our family. Since I am an only child, I have always wanted two children, thinking that they could experience life together and always be there for each other. On my next visit with the specialist we discussed this dream. Since I hadn't started treatment for my scleroderma, my husband and I decided I was healthy enough to try for another baby before my disease worsened. In the winter of 2002 while being closely monitored by my doctors, I delivered our second healthy, beautiful girl. Finally, my first born had a sister. My family felt complete!

The next several years passed with as much normalcy as I could hope for. I maintained a home and raised our girls while my husband worked. Although my body was changing and my energy was lacking some days, I was still able to enjoy my family, friends and work. When I was diagnosed I had been a hairdresser which was a super fun job. I met and worked with a lot of very cool people that I am still friends with today. Eventually my hands weren't able to perform like they once did so I had to change careers. I spent the next years working as an Aboriginal Education Assistant in elementary, middle and high school classrooms. What a wonderful opportunity! It was and still is my dream job. I am grateful that I was a part of a team that had such a great impact on our youth.

Presently my life looks a lot different. Scleroderma has attacked my lungs. I also experience many symptoms: telangiectasia on my face and chest which I try to hide with makeup, Raynaud's, tightened skin, finger ulcers that can hurt like crazy, reflux that limits when and what I can eat, fatigue and aches and pains. Unfortunately, due to my lung fibrosis, I am being assessed for a lung transplant and no longer able to work. I take a handful of medicine daily and I exercise to try to stay as healthy and strong as possible. I go to the Scleroderma Clinic at St. Paul's Hospital in Vancouver for my routine checkups and tests. It's also where I connected with people that work with me and genuinely care about my health and future.

Some days are harder than others. Sometimes I have to listen to my body and just stay in bed all day. I do the best I can with what I have. My worries about my family have shifted. One day I may not be able to contribute to the daily chores. My husband is wonderfully supportive, but I know it is difficult for him to have a wife that has health issues and limitations. I am thankful that I have seen our girls grow up through their school years. I now hope to see them marry and, hopefully, one day there will be grandchildren to spoil.

For a long time I was silent about my disease, just living with it the best I could, but no longer. I spread the word about scleroderma. I talk to family and friends about the challenges I face and allow them to help me on my bad days. I educate myself about this disease and I do what I can to promote awareness. I don't know what the future holds but I do know I have a wonderful supportive family and great friends that will help me through it. I try hard to find something to enjoy and to be thankful for - every day!

The *SPIN-SHARE*

THE EXPERIENCE OF INFORMAL CAREGIVERS: SPIN-CARE SUPPORTING CAREGIVERS

Caring for a loved one with scleroderma can be a rewarding experience. Sometimes though, it can involve frequent visits to the hospital, missed work days, overwhelming exhaustion, and even a looming sense of responsibility and worry that can carry over into all aspects of your life.

Taking on the role of an informal caregiver for somebody with scleroderma means you share an important relationship with someone living with the disease. You know that scleroderma doesn't only strike those who live with the disease, but their friends and families as well. The experience of illness changes the ways that we experience day-to-day events. Although greater empathy and feelings of closeness can come from supporting your loved one, taking on this role also comes with less desirable consequences. Feelings of burden, anxiety, and fear are common among caregivers to a loved one with scleroderma, as is the need for supportive services. Unfortunately, there are no organized services to support people caring for a loved one with scleroderma. The Scleroderma Patient-Centered Intervention Network (SPIN) team is working to address this problem.

As a first step, SPIN team members did a review of research describing the effects of support services, including therapy, support groups, and educational sessions that have been developed for caregivers of people with a rare disease. The SPIN team then held a series of focus groups with caregivers of people with scleroderma from Canada and the United States, which allowed us to develop a better understanding of the caregiving experience specific to scleroderma. Based on these focus groups, the SPIN team created an online survey to further explore the caregiving experience. More than 200 informal caregivers from Canada, the United States, Europe, and Australia completed the survey and provided information related to caregiver burden, quality of life, and emotional wellbeing. Survey responses revealed that caregivers' most difficult challenges relate to their care recipient's emotional struggles, changes in relationship dynamics, and balancing caregiving and other responsibilities. Additionally, having services that provide information about the disease soon after diagnosis were found to be of high-priority. The SPIN team plans to work to develop an internet-based resource to help address some of the challenges encountered by informal caregivers of people living with scleroderma.

SPIN's international team is led by Dr. Brett Thombs of McGill University and the Lady Davis Institute for Medical Research of the Jewish General Hospital in Montreal. Other members of the team include Danielle Rice, a PhD student at McGill University; Mara Cañedo Ayala and Andrea Carboni Jiménez, undergraduate students at McGill University; Dr. Mariët Hagedoorn of University Medical Center Groningen, the Netherlands; and Dr. Vanessa Malcarne of San Diego State University in the USA. The team also benefits from a Caregiver Advisory Board formed by caregivers from Canada (Judi McDonald, Mathieu Ross, Terry Stacey) and the USA (Marcia Greiten, Christy McCaffery, John Michalski, Lisa Spinney, Linda Tarantino).

We would like to express our deepest gratitude to caregivers who have participated in this important research. Your support in our research is appreciated as we move this exciting work forward!

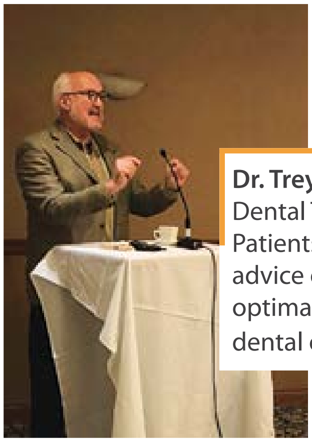
DANIELLE RICE,
ANDREA CARBONI JIMÉNEZ,
MARA CAÑEDO AYALA,
AND BRETT D. THOMBS
on behalf of the SPIN team

SABC AGM & Conference Highlights

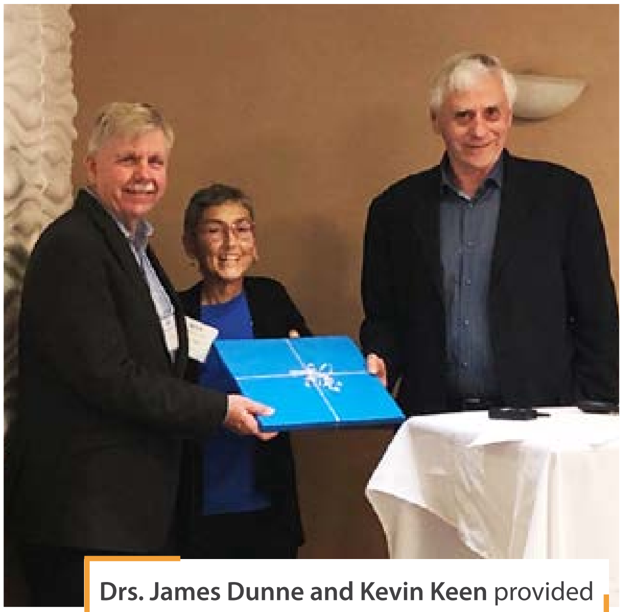
On Saturday October 5th in a conference room at the POCO Inn and Suites, 74 attendees began the day with the Annual General Meeting, followed by conference presentations on a variety of topics by excellent speakers. The day concluded with a Tai Chi demonstration and an opportunity for both scleroderma patients and their supporters to discuss via separate group sessions, topics of common interest.

Dr. Mark Harrison and Tiasha Burch introduced and provided an update to their research study, Identifying Patient's Preferences When Considering Stem Cell Transplant as a Treatment Option for Scleroderma.

Dr. Sarvee Moosavi explained the many GI issues experienced by scleroderma patients, describing diagnostic testing and treatments commonly used in her esophageal motility laboratory and practice at St. Paul's hospital.



Dr. Trey Petty presented his topic of Dental Treatment for Scleroderma Patients, providing invaluable patient advice on the best methods to ensure optimal oral care at home and at dental office visits.



Drs. James Dunne and Kevin Keen provided their annual update for the SABC-sponsored Scleroderma Research Genome Project.

Video recording of the speaker presentations will be available on SABC's website at **www.sclerodermabc.ca**

These two awards were established and are sustained by Dr. Dhar Dhanda, his wife Harv and their two daughters Kiran and Meera. The awards were created in 2008 in memory of Dhar's mother, Gurmej Kaur Dhanda, who passed away in 2000 from the effects of scleroderma.

The Gurmej Kaur Dhanda Memorial Scleroderma Community Service Award was presented to Dianne McPhee. Dianne is a scleroderma patient and has been part of the Scleroderma Association of BC since 1993. She has been on the Board of Directors for many years and has served in various leadership roles and in 2017 initiated the very successful practice of inviting UBC students to attend our annual conference.

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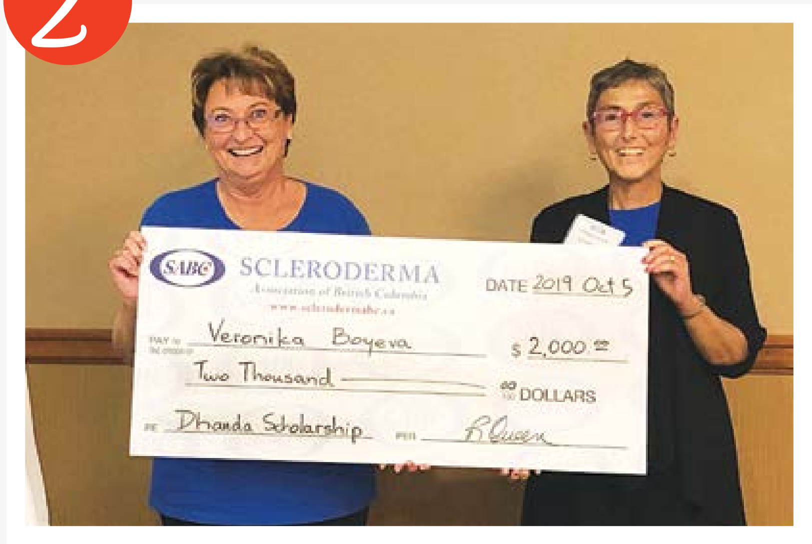

The Gurmej Kaur Dhanda Memorial Scholarship Award was presented to UBC fourth year medical student **Veronika Boyeva**. Veronika originally attended SABC's AGM as a first year student and eventually went on to become a member on the SABC Board of Directors, now beginning her second year with the board. Veronika was unable to attend, and Dianne McPhee accepted the award on her behalf.

Eight medical student guests joined us this year from UBC again with enthusiastic participation in the day's program, including mutually beneficial interaction with scleroderma patients.

Results of June Scleroderma Awareness Month

All around the province we raised Scleroderma Awareness and

OVER $75K FOR RESEARCH

NORTH VANCOUVER

Scotiabank Community Day Hot Dog Lunch – May 31 Lonsdale Branch

Residents of the North Shore contributed to and joined SABC for the afternoon, raising $6000 for scleroderma research. Thank you to all who attended, Assistant Manager Susanne Kingshott and her team at the Lonsdale Branch and to Nicole and Anroe of O'Canadawg.

VANCOUVER

Ride for Research – June 16 Stanley Park

The 8th annual bike ride/walk organized by Rosanne and David Queen was attended by over 90 supporters and raised $52,851 for the SABC research project. Thank you to all cyclists, walkers, organizers, Park Insurance and Open Road Audi Boundary for a great day.

2019 events

VICTORIA

Walk for Scleroderma Research – June 23 West Shore Parks

The 2nd annual Victoria walk organized by Linda Barnes spread awareness and raised money for research. Nearly 100 supporters of scleroderma patients donated, walked, volunteered and cheered raising $11,408. Thank you to Tim Horton's, West Shore Parks and Recreation, CFAX radio, the organizing committee and families and friends who travelled from all over the Island, promoting scleroderma awareness as a vital part of finding a cure.

VALEMOUNT

Scleroderma Walk in the Park for Research – June 29 Centennial Park

The 3rd annual walk for scleroderma organized by Teressa Colosimo had a turnout of over 60 supporters of family, friends and members of the community and raised $4780.10. Thanks to those who walked, contributed to the bake sale, donated items for the raffle and Tim Horton's.

KAMLOOPS

June Awareness On-Line Campaign

New this year Jen Beckett, Vickie Gray and Darla Martin decided to raise awareness and money for scleroderma research in the month of June. They collected funds and thank their families, friends and community in raising $1,910.

"Two and a half years ago compassion, empathy and kindness brought three Kamloops girls together. We were fighting the same battle individually and knew little about this tough, rare disease. The common links among us were compassionate pharmacists who kind-heartedly brought us together. We are forever grateful to them and our community! Our lives have been enriched through the support we offer one another. We often hear and experience how challenging this disease is but the real comfort lies in knowing that we are not alone. We are amazing women who together can make a difference in our community and put scleroderma on the Kamloops map! Although we have scleroderma, it does not define us. In fact, it has created a bond that fills our hearts with gratitude. Thank you to SABC for the support and help in bringing people together, decreasing social isolation in a disease that can be so scary. Together we are better. Next year we are passionate about organizing a walk for scleroderma in June!" - Jen

WHEN THE DIAGNOSIS IS RECEIVED

For a certain time, we suspect that something is wrong. Sometimes weeks, months pass, with several medical visits before being steered to the right specialist. Finally, we have a diagnosis!

Relief, but also shock.

It's hard to describe our feelings when we learn that we have a serious disease. Reactions can resemble those of mourning: shock, denial, anger, frustration, anxiety. To have those emotions is perfectly human.

The surprise and stress sometimes prevent us from fully comprehending the information the specialist gives us. This disease is totally unknown. We don't even know what questions to ask and what to expect. We leave the doctor's office confused, in shock. We know the name of the disease, systemic sclerosis, but we are unsure of exactly what it is.

THE SEARCH FOR INFORMATION

Internet

The first reflex is to use a search engine, hoping to find answers. We type "scleroderma" and hundreds of sites are listed… a lot of information, many images and we fear the worst. This uselessly increases our anxiety. Beware, it is of the utmost importance to use caution, as the disease affects different people in different ways. Many will never experience some of the symptoms. As with any disease, some cases are more severe. Luckily, it is a low percentage.

Website of Scleroderma Association of B.C.

www.sclerodermabc.ca was created specifically for people affected by scleroderma, for and by health professionals, rheumatologists, doctors, researchers, nurses and the patients themselves. This important source of information, updated on a regular basis, contains an array of pages to answer your questions. A wide range of symptoms and complications are related to scleroderma and this site explains them in easy to understand terms.

Contact person

Thanks to the website of Scleroderma Association of B.C., you can contact someone for help. People who have been afflicted by scleroderma, sometimes for years, can help calm your anxiety, answer many of your questions, and share tips on how to cope with daily tasks. Breaking the feeling of isolation is key to better manage the stress caused by having an orphan disease. Speaking to other people who have scleroderma helps to alleviate the fears that come with the diagnosis, and reassures us that our life is not over.

SUPPORT

Scleroderma Association of B.C.

Founded in 1984, our association promotes outreach and education to raise public awareness. We develop information tools for the general public and stakeholders in the medical community. We also encourage and support leading edge research in British Columbia and Canada.

Family and friends

We strongly encourage the families and friends of scleroderma sufferers to seek as much information as possible, to better understand the limitations and challenges their loved one faces every day. The caregiver's role is very important: accompaniment and, even more so, support. During a visit to the doctor's office, the patient is often nervous, which may prevent him or her from fully understanding the doctor's information.

- It is crucial that the patient be accompanied.
- Accept that you will not always have the correct positive answer.
- If you offer your support, make sure you are available at the proper moments.
- We don't always know what to say or do, but we can always say: I don't know what to say but I love you and I am here for you.

WHAT TO DO IMMEDIATELY

PERSONAL

- **Take stock of what you know and what you want to know.**
- **Make a list of questions for the nurse or resource person. Don't worry about forgetting some, you can always call them later.**
- **Talk to a loved one, provide them with information, pamphlets, etc.**
- **Avoid stress, get enough rest, sleep more, ask for help with difficult tasks.**

TECHNICAL

- **If you have heartburn, acid reflux, raise the head of your bed about 6 inches. You can buy blocks for this purpose in big box stores.**
- **Avoid eating 2 hours before going to bed. Your evening meal should be light and eaten early.**
- **Reduce your caffeine intake and quit smoking, which will reduce the effects of Raynaud's Phenomenon.**
- **Keep active, exercise lightly.**
- **Protect yourself from the cold: dress warmly and pay special attention to your hands and feet.**
- **Make an appointment with your family doctor to inform him or her of this new diagnosis, and ensure a proper follow-up.**
- **If you must stop working, take steps with your doctor and disability insurance.**

Tips that do the Trick for stress-free shopping

By **WAI YIU KWOK, OCCUPATIONAL THERAPIST,** Constance-Lethbridge Rehabilitation Centre

Can I find a parking space near the store's entrance?

Will I be able to lift and carry heavy items?

Will the frozen aisle section trigger a Raynaud's reaction?

Do you recognize yourself in these questions? Then running errands is probably very difficult for you. In fact, scleroderma can cause physical limitations that make this task difficult to accomplish. However, strategies are available to make shopping easier and more pleasant. Let's explore them together!

CHOOSE THE BEST TIME: Run your errands at times and on days when your energy level is at its peak. If possible, go at the shops' least busy hours (for example, going to the grocery store at 1 p.m. on a Sunday is never a good idea), to have more space in the aisles and avoid long lines at the register.

ASK FOR HELP: There are usually clerks available to help you while shopping. You only need to ask! Otherwise, you can ask a family member or a friend to accompany you, and to help you if needed.

USE A SHOPPING CART: A shopping cart can make it easier to transport bags. In addition, if you have stairs to climb, a six-wheel cart can be very useful.

USE A BACKPACK: You can also carry your purchases in a backpack for a better weight distribution on both shoulders. This allows for a better spine posture. You also avoid carrying your bags in your hands, which are often affected by scleroderma.

CAR SERVICE: Most major grocery stores offer car service. Some will take the shopping cart to your car and help you load, while others allow you to drive to a pick-up door where they load your bags for you.

DELIVERY SERVICE: You can do your shopping in person and have your groceries delivered to your home, usually for a small fee. It is well worth it.

CARRY GLOVES OR MITTENS IN YOUR BAG: If you are affected by Raynaud's phenomenon, carry a pair of gloves or mittens, and wear them when shopping in the frozen food section to protect your hands. Use anti-slip gloves to have a better grip on the product you handle. Same thing for your feet: avoid sandals and wear warmer socks if your Raynaud's is acting up.

USE A FOUR-WHEEL SCOOTER:
Many stores have one or two four-wheel scooters (including a basket) available at the main entrance. Don't hesitate to use them. Even if you have no problem walking, think of your energy level.

SHOP ONLINE: To avoid going from store to store to find the items you need or to compare prices, choose to shop online. No need to go anywhere, and you can take breaks as needed. The stores' websites usually indicate if the item is in stock, and at which location.

ONLINE ORDER: Once your virtual basket is full, why not order it online? You can now do all of your grocery shopping, including meat and produce, online. You often have the choice between getting it delivered to your home, or to go and pick it up at the store. Online grocery shopping is very helpful, especially for heavier items such as cat litter and extra-large cleaning products.

PARKING PERMIT: Do you have difficulty walking and would like to park closer to the shops or grocery store? Talk to your health specialists about your eligibility for a reduced-mobility parking permit. To find out more, please visit **permits@sparc.bc.ca**

REQUEST FOR ADAPTED TRANSPORT: Although not often available in small towns, adapted transportation may be available if you live in a larger city. Talk to your health specialists to determine availability, and your eligibility, for this service in your area.

CANNABIS ESSENTIALS

Cannabis is a plant that can be used for its array of medicinal properties through various methods of administration. Now that cannabis can legally be purchased over the counter in Canada, many people are curious about its potential as a medical option for treating symptoms related to scleroderma. Before purchasing cannabis products, it is strongly advised to speak with your doctors for their opinion, determination of your eligibility, and a prescription if appropriate. Though representatives at dispensaries might be knowledgeable about the plant's medicinal properties, they are not medical experts, nor do they know your current medical situation like your doctor.

The pharmacologically active molecules in cannabis are called cannabinoids. More than 70 cannabinoids are produced in the plant but the two best understood are tetrahydrocannabinol (THC) and cannabidiol (CBD).

THC is the primary psychoactive compound responsible for producing euphoric and psychotropic effects. Cannabis with higher THC content can act as an analgesic (reduces pain), antiemetic (reduces nausea), appetite stimulant, muscle relaxant, bronchodilator, and anti-inflammatory.

CBD has little to no psychotropic properties and is especially known for its medicinal properties. It has been attributed as analgesic, anti-inflammatory, antipsychotic, antispasmodic, and anti-anxiety. It is thought to affect THC absorption and minimize unpleasant psychoactive effects such as anxiety or paranoia. Though it is generally found in smaller quantities than THC, this varies depending on the strain of cannabis consumed.

There are about 100 different strains of cannabis but most of these come from one of two cannabis families: Cannabis Indica and Cannabis Sativa. Each strain will offer different quantities of CBD and THC but generally, Indica strains have higher CBD content whereas Sativa strains have higher THC content. Indica-dominant strains tend to have a more physical effect, which can be sedative and pain reducing whereas Sativa-dominant strains tend to have greater psychological effects, which can be stimulating and euphoric.

The effects experienced from any strain are dependent on the user, ingestion method, and dosage. It is necessary to start with a trial period of any cannabis product to ensure that the potential benefits are maximized while minimizing unwanted side-effects. Most important is to start gradually using low doses based on what is prescribed by your doctor. He/she will adjust the dosage or type of product prescribed based on how cannabis interacts within your body. As with any new medication, it is a good idea to keep a logbook to support your physician in this process.

Methods of administration include smoking, vaporizing (inhalation of heated vapours), direct consumption (available in pills), edibles (cannabis infused fats or oils), and tinctures or oils (cannabis extracts).

Cautions

Some of the side effects of cannabis use can be counter indicative for scleroderma patients. Cessation and avoidance of smoking is already advisable to SSc patients to minimize the potential for the disease to affect the respiratory system. Though vaporizing is intended to minimize the harms associated with smoking, emerging research suggests that it may also contribute to respiratory conditions.

Consumption of cannabis using any technique can cause temporary increase in heart rate and decrease in blood pressure. Scleroderma patients with heart complications or undergoing dialysis treatments are at higher risk of experiencing dizziness and orthostatic hypotension when using cannabis. It can also cause short term physical or mental impairment including anxiety and paranoia. Cannabis should not be combined with alcohol or other depressants as it can amplify effects including nausea and vomiting.

As with any medication, it is important to discuss cannabis use with your doctor as it can have adverse interactions with other medications and may not be a suitable alternate to other medications.

Cannabis products can have serious consequences, including death of children and animals. Please ensure that cannabis products are stored safely.

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www.canada.ca/en/health-canada/services/drugs-medication/cannabis/health-effects.html

The Société québécoise du cannabis: sqdc.ca/en-CA/

Arthritis society/medicinal cannabis brochure: arthritis.ca/getmedia/1148862d-d223-4a78-9b06-483532041d2c/Medical-Cannabis-Brochure-2018-EN-WR.pdf

The Canadian Consortium for the Investigation of Cannabinoids: https://ccic.net/

CONNECT WITH THE SCLERODERMA COMMUNITY IN YOUR AREA!

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

VANCOUVER

We are seeking a volunteer representative.

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WINTER AT LAST!

Tricks and tips

A large number of people living with scleroderma fear winter. To make these colder months easier to live with, download Dr. France Joyal's booklet *Winter at last!* After reading it, you might start saying *I love winter!*

WINTER AT LAST!

is available on the website of Scleroderma Association of B.C. at **www.sclerodermabc.ca**, section ***Articles and Publications***.

You can also get it by contacting Scleroderma Association of B.C.

by email: **info@sclerodermabc.ca**
or by phone: 1-888-940-9343.

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