

SCLERODERMA ASSOCIATION OF B.C.

The Bulletin

Fall-Winter 2021-2022 | Volume 3 Number 2



Scleroderma Medications Guide

Lihong's
Story

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Contact :

Scleroderma Association of B.C.

PO Box 16155 Lynn Valley
North Vancouver BC V7J 3H2
Phone: 604-371-1005
Email: info@sclerodermabc.ca
www.sclerodermabc.ca

SCLERODERMA ASSOCIATION OF B.C.

Board of Directors

Rosanne Queen, President
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Jeff Gammon, Administrative Director/Secretary
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Board Members

Tiasha Burch
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The Bulletin Team

Michele Gervais
Tiasha Burch

Graphic Designer

Antonella Battisti - GrafistaDesign

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Board of Directors



Rosanne Queen
President
604-984-9425
rq.sabc@telus.net



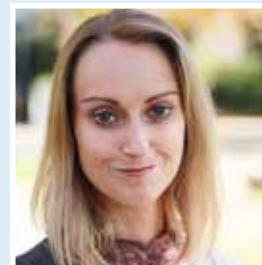
Michele Gervais
Vice President
604-761-7782
gordmich17@gmail.com



Jeff Gammon
Adm. Director/Secretary
604-809-6939
info@sclerodermabc.ca



Patrick Livolsi
Treasurer
778-791-7834
treasurer@sclerodermabc.ca



Tiasha Burch
Board Member
778-984-3745
burchtiasha@gmail.com



Valerie Doyon
Board Member
250-202-9449
valerie.doyon@alumni.ubc.ca



Chelsea Fitzpatrick-Lindsay
Board Member
778-288-2936
cjofitz@hotmail.com



Jessica Jun
Board Member
778-887-0523
jessjun@student.ubc.ca



Grace Kim
Board Member
778-926-0118
ggkim@student.ubc.ca



Beth Miller
Board Member
604-815-8740
bethmiller@telus.net

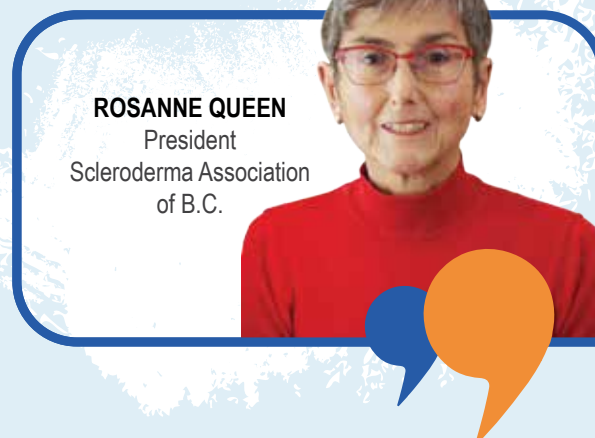


David Queen
Board Member
604-984-9425
dq.sabc@telus.net

Published under the aegis of the Scleroderma Association of B.C. The opinions expressed in this magazine are not necessarily those of the organization. The information contained therein is intended to provide readers with a general guide to health and should not replace the advice of a physician.

A Word from Our President

I'm hoping, despite the ongoing Covid restrictions this summer, some SABC members were able to get out into the sunshine and safely visit with family and friends. As we all know, one of the biggest challenges during these unusual times is staying connected.



SABC COMMUNITY CONNECTIONS

During our northern B.C. road trip this September David and I managed to connect with a few "scleroderma" friends, for some backyard chats. We do what we can, while still being safe. I feel however we are getting closer to the light at the end of the restrictions tunnel. Why? The Vancouver Park Board sent me an email inviting me to book the picnic site in Stanley Park for the June 2022 Scleroderma Ride for Research! Keep an eye out for all our June is Scleroderma Month events across the province where we raise awareness and funds for needed research.

This past June we had another wonderful awareness and fund-raising campaign Moving to Cure Scleroderma thanks to those SABC team captains and members who participated. It is inspiring to see every year, more and more scleroderma patients and their friends and families helping us spread the word across the province and country. Looking forward to what we can achieve together next year!



HEALTH CARE COMMUNITY CONNECTIONS

For many years now the Scleroderma Association of B.C. has built a strong relationship with the St. Paul's Foundation with our continuous support for research and operations of the Scleroderma Clinic at St. Paul's Hospital. In May, David and I were invited to represent SABC at the ground-breaking celebration for the new St. Paul's Hospital. For a small non-profit association, it is with great pride that SABC is recognized for our contributions to date of over \$600,000 which has been raised for the SABC Research Project and other endeavours.

In this Bulletin, Sclérodémie Québec has once again graciously shared their latest educational sheet, this one on scleroderma medications. Scleroderma Quebec created this guide in collaboration with health professionals for both those living with scleroderma and their doctors. Watch for it also being available on the SABC website; search "Articles and Publications".

In talking to my own pharmacist, she said it was so important for scleroderma patients to let their doctors and pharmacists know if in addition to their prescribed medications, they also take natural or over-the-counter products. When I asked her why, she had three reasons: 1) These natural products may interact with each other, 2) they may interact with your prescribed medications by harmfully affecting (increasing or decreasing) the pharmaceutical ingredient and 3) if you just started a new prescribed medication and are feeling better (or worse) but at the same time have been taking a natural or over-the-counter product, you won't know which one is working (or not working).

I'm looking forward to the 2021/2022 year and working with the SABC Board to support scleroderma patients, raising awareness and to continue to support research.



In March of 2019, I was diagnosed with systemic diffuse scleroderma. I remember feeling broken down at that time, both emotionally and physically. My life became overrun by this disease!



My name is Lihong Yang, I live in Richmond B.C. and this is the story of my journey with hematopoietic (hee-MA-toh-poy-EH-tik) stem cell transplant (HSCT, for short) to treat my scleroderma. Hematopoietic stem cells are immature cells found in your body's blood and bone marrow. These cells can develop into all types of blood cells including white blood cells, red blood cells and platelets.

In March of 2019, I was diagnosed with systemic diffuse scleroderma. Questions I asked myself were: How do I face my uncertain future? How long can I live? When will be the time to say goodbye to my family and friends, and the job I love? I remember feeling broken down at that time, both emotionally and physically. My life became overrun by this disease.

I took the medication Methotrexate® for 3 months but it did not work for me. The stiffness and pain in my joints and muscles were getting worse. As my lungs were also getting worse, the doctor then suggested I try mycophenolate mofetil (CellCept®) to slow down the lung progression. After I had taken this medication for more than 3 months, it seemed to be working, as the skin on my hands became softer and thinner. In the meantime, my acid reflux was getting worse and worse. I had to sit or walk to stay up until midnight before I could sleep. My swallowing was becoming a very serious issue too.

I had to remind myself that there is always hope when we think positively. I joined the SABC's June fundraising program. When I read patient stories and see the people who are fighting the same disease, I am inspired.

Testimony

In January 2020 I had an appointment at the Scleroderma Clinic at St. Paul's Hospital. The doctor asked me about my health history and I told him before I got this disease, I was very healthy. I had joined the Vancouver Sun Run 4 times, did a lot of hiking and I don't smoke or drink. The doctor said I was still young and although my lung CT showed lung involvement, my kidneys and heart were ok. He said this disease was developing so aggressively and suggested I think about doing HSCT.

Following the doctor's suggestions, I did some of my own research and decided to do the stem cell transplant. Despite him telling me of the possible bad results with HSCT, I knew I had to be brave to fight this disease. I tried to only think of the good results.

Because of the COVID-19 pandemic, the starting of the stem cell transplant process was delayed half a year. When I did go to the Tom Baker Cancer Centre in Calgary for the HSCT pre-tests, the doctor told me that now my heart was involved and I no longer qualified for the transplant. I was so disappointed. I expressed my strong desire to go ahead with the transplant because I think this is the only chance to possibly improve my quality of life. When I was back home, the doctor called me. He had discussed my situation with the heart specialist. It was decided that my heart was in an early stage of involvement and if I really did want to do it, he would do it for me, but I had to accept an even higher rate of risk of mortality.



On February 9th the doctor put my stem cells back into my body. They marked that day as my new birthday. My life had been renewed and I was so excited! But the worst was not over yet. Five days later my white cell count dropped down to zero and my red blood cell and blood platelet counts dropped to very low. I did not have any energy except to lie down on the hospital bed. Nurses helped me to the bathroom. I did not want to eat anything. The doctor and nurses encouraged me to keep going.

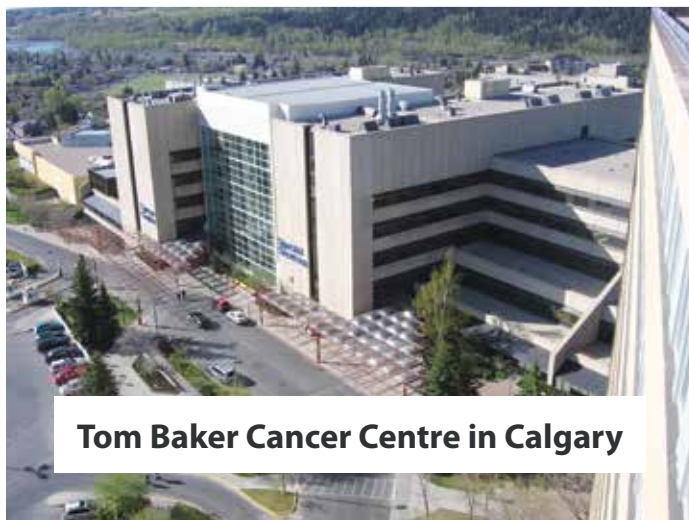
After those worst days, I started to feel better day by day. I was recovering slowly, thanks to my medical team. They made me feel like a family member. On February 28th I was discharged from the hospital, but not yet to home. I still needed to be regularly checked by the hospital's doctor. I stayed in Calgary two more months until May 1, 2021.

Back in Richmond now I walk 7000 steps every day. I am very grateful I can do this exercise again. Some of my skin has become softer, and my knees can bend more. I can walk up and down stairs. I don't have heartburn. I feel much better.

I know everybody has a different life with scleroderma. For my life, I have to stay positive and active.

I am so grateful that I had the stem cell transplant. I thank my family and friends for their support and I thank you for reading my story.

Lihong



Tom Baker Cancer Centre in Calgary

On January 5, 2021, my husband drove me back to Calgary. On January 20th, my stem cells were collected in the hospital and my long hospital stay started on February 3rd. I did not have much more time to think while I received two days of radiation treatments. These two days I was okay. I could walk and I could eat. Then I had three days of chemotherapy. During this treatment I was tired, sometimes felt dizzy and nauseous. I had little appetite.

AGM and Conference Highlights

Fifty-five (55) patients and their supporters registered for this year's 37th Annual General Meeting & Conference (2nd virtual) on Saturday October 2nd, 2021.

AGM HIGHLIGHTS

Director's Report provided a recap of last fiscal year's activities (May 2020 through September 2021)

SUPPORTING RESEARCH

Work on the SABC-sponsored Research Program continues with the aim of identifying biomarkers specific to people who have pulmonary fibrosis caused by systemic sclerosis. This research program is creating a firm foundation for intensive research to control lung and skin damage in patients with scleroderma and lung damage in patients with idiopathic (of various or unknown origin) pulmonary fibrosis (IPF). Being able to distinguish between pulmonary fibrosis that is idiopathic or the result of scleroderma will allow medical professionals to provide patients with an accurate diagnosis. Identifying reliable biomarkers also provides an opportunity to develop a functional cure; an ongoing treatment that corrects and prevents the disease from continuing to damage the affected organs (in this case, lungs).

In July 2020 a \$43,000 cheque was virtually presented to the St. Paul's Foundation for the SABC Research Program and **this July \$65,191.10 was presented.**



To support ongoing scleroderma research in Canada, \$5,000 was donated from SABC to the Canadian Scleroderma Research Group (CSRG), \$1,000 to SPIN and \$1,000 to CHUM, the Scleroderma Research Chair in Montreal in 2020. Again in 2021, SABC showed their support of SPIN by donating \$5,000 and of CHUM by donating \$10,000 for research equipment.

For updates on this and other research SABC supports, visit the website: sclerodermabc.ca/sabc-research-project



WELCOMING NEW 2021-2022 SABC BOARD MEMBER



CHELSEA FITZPARICK- LINDSAY

**COO & VP of
Operations at Park
Insurance.**

**Chelsea first met
SABC president
Rosanne Queen
when she was 5 years
old! She is driven
to advocate, raise
funds and make a
difference.**

AGM and Conference Highlights

RAISING AWARENESS HIGHLIGHTS

JUNE 2020 MOVE FOR SCLERODERMA VIRTUAL CAMPAIGN:

Funds for research were raised by five teams across the province.

JANUARY 2021 WOUND CARE & SCLERODERMA, KEEPING YOU IN THE KNOW VIRTUAL SEMINAR:

Thirty-eight attended Lauren Wolfe, RN of VGH's WOCN Department educational presentation.

APRIL 2021 SCLERODERMA & MEDICAL CANNABIS VIRTUAL SEMINAR:

Twenty-five attended Fonda Betts and Caroline MacCallum, MD of Greenleaf's Medical Clinic educational presentation.



Video recordings of the educational presentations are available on SABC's website at www.sclerodermabc.ca



JUNE 2021 "MOVING TO CURE SCLERODERMA" VIRTUAL CAMPAIGN:

Funds for research were raised by eight teams across the province.

CONFERENCE HIGHLIGHTS

SPIN UPDATE – PROGRAMS FOR PATIENTS, CARE GIVERS AND MEMBER ORGANIZATIONS



Brett Thombs, PhD, a professor in the Faculty of Medicine, McGill University, a Senior Investigator at Lady Davis Institute for Medical Research and the Jewish General Hospital in Montreal has focussed his research career on developing strategies to improve quality of life and to reduce disability among people living with scleroderma. He is the Founder and Director of the Scleroderma

Patient-centered Intervention Network, or SPIN. SPIN maintains an ongoing cohort of more than 2,000 people with scleroderma who are recruited from almost 50 sites in seven countries and conducts trials of programs to support different aspects of coping with scleroderma and then makes these programs available free-of-charge.



Video recordings of the conference presentations are available on SABC's website at www.sclerodermabc.ca



LUNG TRANSPLANT 101 – THE PROCESS WITH PERSONAL EXPERIENCE



Jennifer Wilson, MD, FRCPC, a general respirologist with a focus in lung transplant medicine, **Mandeep Dhindsa, RN**, a post lung transplant coordinator working at the solid organ transplant at VGH and SABC members, lung transplant recipients and patient panelists **Beth Miller, Cecille Soriano and Kathryn O'Neil** explained the steps involved from transplant eligibility deter-

mination through the surgery of lung transplantation to the post-transplant care regime. Each panelist shared their personal challenges and triumphs with each step of the process.

SOCIAL TIME

The conference concluded with an opportunity for attendees to stay online and virtually meet using Zoom's break-out rooms. SABC members look forward to saying hello to one another and to talk about various topics of interest.

2021

Moving to Cure Scleroderma

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

B.C. scleroderma patients, their families and friends again did their part this June by raising over \$65,000 for research.

Eight teams spread across our province participated in this successful virtual event:

VANCOUVER – SCLERODERMA RIDE FOR RESEARCH	\$38,815
ANYWHERE IN B.C.	\$6,071.10
KAMLOOPS	\$4,880
VICTORIA	\$3,200
TEAM PRINCE RUPERT	\$4,360
SEA TO SKY	\$3,550
VALEMOUNT	\$2,810
CAMPBELL RIVER	\$1,555





Heartfelt thanks to all the team captains who led the fundraising efforts and to especially the caring donors who not only supported the campaign but who truly 'Moved' to Cure Scleroderma this June. Check out the video on SABC's website, sclerodermabc.ca, set to the music of Nicole Edwards and capturing everyone moving to spread awareness and raise funds to support scleroderma research.

All monies raised directly supports the SABC Research Program.



Moving to Cure
Scleroderma
\$65,191.10
Thank You!



SCLERODERMA MEDICATIONS GUIDE

Scleroderma Quebec™

Collaborators:

Dr. Jean-Luc Senécal, MD, FRCPC, MCRA

Dr. Sabrina Hoa, MD, MSc, FRCPC

Ai-Minh Van, pharmacist, PeBC



November 2021

Symptoms and treatments

Published in this edition of the bulletin:

- ▶ Raynaud's Phenomenon
- ▶ Pulmonary Fibrosis/Interstitial Lung Disease
- ▶ Pulmonary Arterial Hypertension
- ▶ Joint & Tendon Pain

To consult the full version of the Scleroderma Medications Guide, visit our website at sclerodermabc.ca.

- ▶ Gastrointestinal Symptoms
- ▶ Renal Crisis/New Onset Hypertension
- ▶ Skin Fibrosis
- ▶ Sjögren's Syndrome
- ▶ Localized Scleroderma
- ▶ Skin Itching (Pruritus)/Dryness

Although there isn't a cure for scleroderma, there are effective treatment options that can help alleviate symptoms and slow down disease progression. Current prescription and over-the-counter medication are designed to treat scleroderma by targeting:

- ▶ Inflammation
- ▶ Autoimmunity
- ▶ Vascular disease
- ▶ Tissue fibrosis

As a medical doctor or health care professional caring for persons with scleroderma, it is important to ensure patients understand the nature of the medications they may be prescribed and how they work to help control disease symptoms from progressing. Patient knowledge is powerful, as it reduces fear and increases compliance, resulting in a higher percentage of successful treatment.

The following guide includes a list of drugs commonly prescribed by doctors in Canada to treat patients with scleroderma. The list is provided for informational purposes only, and is not to be taken as an endorsement of any drug by Scleroderma Association of B.C.

Many of these drugs are prescribed by doctors, but have not been proven useful and should be used only with caution and supervision. It is important to consider, that not every medication is appropriate for every patient. The treating physician, who is familiar with the patient's medical history, health status and disease progression, will be able to determine the most appropriate treatment options.

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.

CALCIUM CHANNEL BLOCKERS

- NIFEDIPINE (ADALAT[®])
- AMLODOPINE (NORVASC[®])
- DILTIAZEM (CARDIZEM[®])
- FELODIPINE (PLENDIL[®])

Action - Relax blood vessels

Side Effects

Flushing, headache, dizziness, constipation, low blood pressure, swelling in the legs, palpitations.

PHOSPHODIESTERASE TYPE 5 INHIBITORS

- SILDENAFIL (REVATIO[®])

Action - Relax blood vessels

Side Effects

Headache, flushing, indigestion, nose bleed, vision abnormalities, nasal congestion, diarrhea, insomnia.

- TADALAFIL (ADCIRCA[®])

Action - Relax blood vessels

Side Effects

Headache, myalgia, flushing, indigestion, nausea, nasal congestion.

ANGIOTENSIN II RECEPTOR ANTAGONISTS

- LOSARTAN (COZAAR[®])

Action - Block constriction of blood vessels

Side Effects

Headache, respiratory tract infection, dizziness, tiredness, dry cough.



TOPICAL NITRATES

- NITROGLYCERIN OINTMENT

Action - Relax blood vessels

Side Effects

Flushing, headache, dizziness, low blood pressure, palpitations, reflux.

PROSTAGLANDIN DERIVATIVES

- EPOPROSTENOL (FLOLAN[®], CARIPUL[®])
- TREPROSTINIL (REMODULIN[®])

Actions - Relax blood vessels

Used for severe, refractory or complicated Raynaud's

Side Effects

See section of Pulmonary Arterial Hypertension page 13.

ALPHA-ADRENERGIC BLOCKERS

- PRAZOSINE (MINIPRESS[®])

Action - Relax blood vessels

Side Effects

Dizziness, headache, drowsiness, tiredness, light-headedness, palpitations, nausea.

OTHER

- PENTOXIFYLLINE

Action - Unclear

Side Effects

Nausea, dizziness, headache, vomiting.

PULMONARY FIBROSIS/ INTERSTITIAL LUNG DISEASE

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.



IMMUNOSUPPRESSANTS

- MYCOPHENOLATE MOFETIL (CELLCEPT®)

- MYCOPHENOLATE SODIUM (MYFORTIC®)

Action - Suppress immune response; anti-fibrotic effect

Side Effects

Abdominal pain, diarrhea, nausea, vomiting, decreased appetite, headache, increased susceptibility to infections, anemia.

- CYCLOPHOSPHAMIDE (PROCYTOX®)

Action - Suppress immune response

Side Effects

Hair loss, decreased appetite, bladder inflammation, bone marrow damage, nausea, diarrhea, vomiting, mouth ulcers, increased susceptibility to infections, increased cancer risk.

- RITUXIMAB (RITUXAN®, RIXIMYO®, RUXIENCE®, TRUXIMA®, RIABNI®)

Action - Suppress immune response

Side Effects

Infusion reaction, cardiac arrhythmias, skin rash, increased susceptibility to infections.

- TOCILIZUMAB (ACTEMRA®)

Action - Suppress immune response

Side Effects

Infusion or injection site reaction, GI perforation, dyslipidemia, elevated liver enzymes.

- AZATHIOPRINE (IMURAN®)

Action - Suppress immune response

Side Effects

Nausea, vomiting, diarrhea, decreased appetite, increased susceptibility to infections, pancreatitis, increased cancer risk, anemia.

- CYCLOSPORINE (NEORAL®, SANDIMMUNE®)

Action - Suppress immune response

Side Effects

Tremor, hypertension, hirsutism, renal failure, headache, nausea, vomiting, infections.

ANTI-FIBROTIC DRUGS

- NINTEDANIB (OFEV®)

Action - Blocks the activity of fibroblasts which contribute to tissue fibrosis

Side Effects

Diarrhea, nausea, vomiting, abdominal pain, decreased appetite, weight loss, elevated liver enzymes, bleeding.



PULMONARY ARTERIAL HYPERTENSION

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.

Patients diagnosed with pulmonary arterial hypertension should be referred to a pulmonary hypertension center for experienced evaluation and management of this serious scleroderma complication.

ENDOTHELIN RECEPTOR ANTAGONISTS

- AMBRISENTAN (VOLIBRIS®)

Action - Act on blood vessels

Side Effects

Peripheral edema, headache, decreased hemoglobin, nasal stuffiness, palpitations.

- BOSENTAN (TRACLEER®)

Action - Act on blood vessels

Side Effects

Headache, nasal stuffiness, flushing, liver function abnormality, pulmonary edema, low blood pressure.

- MACITENTAN (OPSUMIT®)

Action - Act on blood vessels

Side Effects

Nasal stuffiness, headache, anemia, bronchitis, sore throat.

PROSTAGLANDIN DERIVATIVES

- EPOPROSTENOL (FLOLAN®, CARIPUL®)

Action - Act on blood vessels, inhibit platelet aggregation

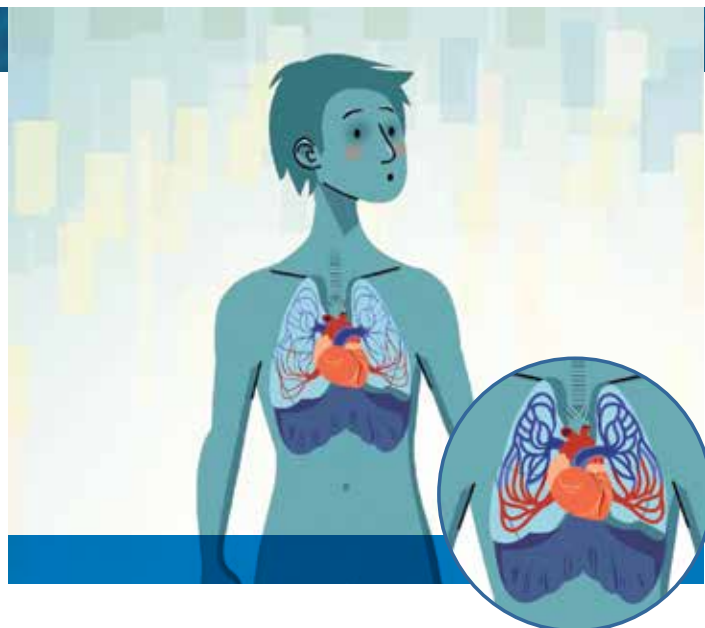
Side Effects

Headache, dizziness, flushing, jaw pain, diarrhea, bone pain, potential serious infection associated with central line catheter in the chest wall.

- TREPROSTINIL (REMODULIN®)

Side Effects

Pain at infusion site, headache, cough, diarrhea, nausea, flushing, jaw pain, skin rash, edema.



SOLUBLE GUANYLATE CYCLASE STIMULATOR

- RIOCIGUAT (ADEMPAS®)

Action - Act on blood vessels

Side Effects

Headache, dizziness, nausea, diarrhea, edema, low blood pressure, palpitations, bleeding.

PHOSPHODIESTERASE TYPE 5 (PDE5) INHIBITOR

- SILDENAFIL (REVATIO®)

Action - Act on blood vessels

Side Effects

Headache, flushing, dyspepsia, nosebleeds, vision change, nasal stuffiness, diarrhea, insomnia.

- TADALAFIL (ADCIRCA®)

Action - Act on blood vessels

Side Effects

Headache, muscle pain, flushing, stomach upset, nausea, respiratory tract infection, nasal stuffiness.

COMBINATION OF TREATMENTS

- MACITENTAN AND TADALAFIL (OPSYNVI®)

Actions and side effects - See sections on individual drugs above.

JOINT AND TENDON PAIN

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.

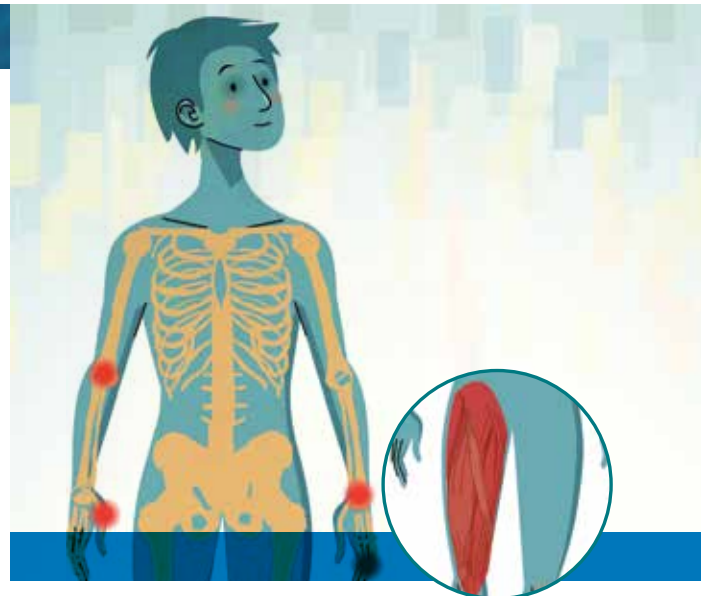
NON-STEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS)

- DICLOFENAC (VOLTAREN®)
- DICLOFENAC & MISOPROSTOL (ARTHROTEC®)
- DICLOFENAC SODIUM (VOLTAREN®)
- FLURBIPROFEN (ANSAID®)
- IBUPROFEN (MOTRIN®, ADVIL®)
- KETOPROFEN
- KETOROLAC (TORADOL®)
- MELOXICAM (MOBICOX®)
- NABUMETON (RELAFEN®)
- NAPROXEN (NAPROSYN®, ANAPROX®, ALEVEV®)
- OXAPROZIN
- PIROXICAM
- SULINDAC

Action - Suppress inflammation

Side Effects

Abdominal pain and cramping, gastric irritation and stomach ulcers, high blood pressure, impaired kidney function, bleeding and bruising, cardiovascular disease, increased liver enzymes.



COX-2 INHIBITORS

- CELECOXIB (CELEBREX®)

Action - Suppress inflammation

Side Effects

Abdominal pain and cramping, gastric irritation and stomach ulcers, high blood pressure, impaired kidney function, bleeding and bruising, cardiovascular disease, increased liver enzymes.

ANTALGICS

- ACETAMINOPHEN (TYLENOL®)

Action - Relieve pain

Side Effects

Anemia, skin rash, metabolic disorder.

Overdosage manifestations include: nausea, vomiting, elevated liver enzymes, jaundice, hepatic impairment, renal toxicity.

- TRAMADOL (ULTRAM®)

Side Effects

Nausea, dizziness, headache, drowsiness, constipation, vomiting, flushing, itching.



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.

VANCOUVER

**We are seeking a
volunteer representative.**

Please contact Rosanne Queen
at **604-984-9425**

or by email at
rq.sabc@telus.net

Campbell River

Jackie Alexander
250-830-7287
jackie.alex97@gmail.com

Chilliwack

Kelly Grant
604-378-1806
thekellygrant@gmail.com

Creston

Betty Kuny
250-428-8875
rkuny@telus.net

Kamloops

Jen Beckett
250-574-3151
jenniferbecketts@hotmail.com

Kelowna

Angie Reglin
250-860-5700
angiereglin@gmail.com

Nanaimo

Linda Allen
llallen.52.14@gmail.com

Penticton

Barb Creighton
250-770-7836
mischief2@shaw.ca

Quesnel

Leah McAnena
250-925-0281
almcanena@hotmail.com

Squamish

Beth Miller
604-815-8740
SABCBeth@gmail.com

Valemount & Northern Rural Communities

Teresa Colosimo
250-566-3165
pattess72@hotmail.ca

Vernon

Lisa VanDyk
250-542-5231
sannicolaswest@icloud.com

Victoria

Susan Goss
250-479-8586
susangoss@shaw.ca

Williams Lake

Cecelia Jaeger
250-392-3656
cecejaeger@gmail.com

Yellowknife

Helen White
867-873-5785
hwhite@theedge.ca

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 Inc. which, thanks to an educational grant,
made production, printing and distribution of this Fall Bulletin possible.

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.