SCLERODERMA MANITOBA

The Bulletin

FALL-WINTER 2025-2026 | VOLUME 7 NUMBER 2

Education Event

New Research Plan

SPIN

Table of Contents

Contact :
Scleroderma Manitoba
16 Carlington Crescent
Oak Bluff , MB R4G 0C5
204-510-2855
sclerodermamb@gmail.com
www.sclerodermamanitoba.com

SCLERODERMA MANITOBA
Board Executive
Ademola Salami, President
Arthura Phan, Treasurer
Dolores Krahn, Secretary

Members-At-Large
Rachel Akpaloo
Linda Cassell
Manu Jagdeo
Jo-Ann Lapointe McKenzie
Debbie Robitaille

Medical Advisor
Dr. David Robinson

Graphic Designer
Antonella Battisti - GrafistaDesign

ISSN 2562-5772

A Huge Thank You to

Boehringer Ingelheim

We would like to emphasize the generous gesture of our partner, Boehringer Ingelheim, who made possible, thanks to an educational grant, the production of this Fall-Winter 2024-2025 edition of the Bulletin.

Board of Directors

Ademola Salami
President

Arthura Phan
Treasurer

Dolores Krahn
Secretary

Rachel Akpaloo
Member-At-Large

Linda Cassell
Member-At-Large

Manu Jagdeo
Member-At-Large

Jo-Ann Lapointe McKenzie
Member-At-Large

Debbie Robitaille
Member-At-Large

WE HAVE BOARD VACANCIES TO FILL

Vice-President

The term for our Board positions are 3 years for Member at Large Fundraising. The Vice-President is a term of 3 years followed by a 3 year term as President.

Please talk with your family and friends in your networks about membership on our board. It is not necessary to be living with scleroderma to be eligible for these positions and in fact it may be better as those of us living with this disease manage a challenging chronic illness on a daily basis along with fatigue. If a board position is beyond your energy level, consider volunteering for one of our committees.

For additional information please contact us at:
sclerodermamb@gmail.com

President's Message

As the seasons shift and fall turns to winter, we are reminded of the importance of warmth, connection, and support. Shorter days and colder temperatures often encourage us to slow down and look inward, making this a meaningful time to reflect on the strength and resilience of our scleroderma community.

The fall and winter months can bring added challenges for those living with scleroderma. Managing symptoms in colder weather, navigating the holiday season, and maintaining both physical and emotional well-being can feel overwhelming at times. It is during these months that our community becomes especially important. Through shared experiences, educational opportunities, and compassionate support, we continue to ensure that no one faces scleroderma alone.

I am continually inspired by the dedication of our members, volunteers, healthcare partners, and supporters. Your commitment allows Scleroderma Manitoba to provide resources, raise awareness, and advocate for improved care and research. Every conversation, event, and act of kindness helps strengthen our collective voice.

As we move through the winter season, **I encourage you to prioritize self-care, stay connected with one another, and reach out for support when needed.** Whether it is attending a support group, participating in an educational session, or simply checking in with a fellow member, these connections make a meaningful difference.

A snippet into our activities for 2025 shows we have worked hard in the year, we had three support group meetings in February, May and November covering basic scleroderma issues and allowing patients to share their stories and learnings and allowing each other to take lessons that help us in managing ourselves. I want to thank Debbie, Linda and their team for putting these together and hope we will be able to continue in this trajectory in 2026.

We had **two fundraising activities in the year i.e. 50/50 raffle draw and Holiday Spirit Raffle**. Jo Ann, Dolores and Rachel worked very hard to make these successful. **We would like to thank Robert Schellenberg for huge donations** from his charity event as well as other charity events held which donated to our organization. We are grateful for all your contributions and look forward for much more.

ADEMOLA SALAMI
President
Scleroderma Manitoba

Our AGM and education event held in September 2025 with two doctors - **Dr Shane Cameron and Dr Anastasiya Muntyanu** delivering invaluable presentations on *"Understanding current and upcoming treatments for Scleroderma"* and "*Systemic Sclerosis: Pathogenesis, Diagnosis and Management"* respectively. Other activities of the AGM also went very well, and we would like to **appreciate Merck Canada and Boehringer Ingelheim Canada limited who have continually supported us in ensuring a successful event.** I would like to thank Arthura and Manu and every board member for their support in 2025.

This season, we are excited to continue building connections through our programs and activities. From educational opportunities to social gatherings, our goal remains the same: ***to ensure that no one affected by scleroderma feels isolated or unheard. We are deeply grateful to our volunteers, healthcare partners, donors, and members who make this work possible.***

As we move through the winter season, I encourage you to prioritize self-care, stay connected with one another, and reach out for support when needed. Whether it is attending a support group, participating in an educational session, or simply checking in with a fellow member, these connections make a meaningful difference.

Thank you for being part of Scleroderma Manitoba. ***Together, we will continue to build a community grounded in understanding, compassion, and hope—no matter the season.***

Connections:
Support Group

THE POWER OF SUPPORT GROUPS

We offer regular patient support activities that are designed to build community, create connections, and provide support to those living with scleroderma. These events are free! We believe that the ability to self-manage our disease increases our self-esteem and confidence so that we can achieve specific goals.

The meetings are held via Zoom to allow people from across the province to participate, but this year we will have an in-person meeting. Some of our meetings are educational and some are about supporting each other as we live our best lives in spite of scleroderma.

We hope you will consider joining a future Scleroderma Manitoba Support Group. **Patients, families, caregivers, friends, medical professionals and health care providers are all welcome!** For information on upcoming groups, visit sclerodermamanitoba.com, email us at **sclerodermamb@gmail.com** or look for info on Facebook.

November 22, 2025 meeting "Open Discussion Forum" was held over Zoom.

This was another opportunity to share (or just listen) to others living with the same challenges. We were able to recommend Doctors that we liked as well as exchange other ideas.

Our next meeting on February 21, 2026 "Exercise and Scleroderma" will be held on Zoom.

Dr. Amanda Wurz is a Behavior Change Researcher and an Assistant Professor at the University of the Fraser Valley in B.C. She partners with individuals who have lived experience with chronic and clinical conditions to co-design and evaluate physical activity interventions. Through pragmatic trials conducted across Canada, Dr. Wurz explores how to help more people engage in physical activity and how it can improve health and quality of life.

Dr. Wurz will conduct an interactive session with the option to engage in physical activity, tailoring activity to meet individual needs, highlighting how even small changes can lead to meaningful improvements in well being.

We are also planning a **Spring 2026** "In Person" meeting. *Details to be determined.*

If there is a topic you are interested in, please contact Debbie via email at **drobit@hotmail.ca** or by phone or text at **204 396-2336**

Check out this list of links to sites that you may find helpful and interesting:

The Scleroderma Patient-centered Intervention Network (SPIN): **www.spinsclero.com**

Scleroderma Quebec: sclerodermie.ca/en/

Scleroderma Association of British Columbia: sclerodermabc.ca

ScleroCare: sclerocare.ca

The National Scleroderma Foundation: scleroderma.org

Scleroderma News: sclerodermanews.com/

Stuff that Works: stuffthatworks.health/scleroderma/symptoms

Scleroderma Australia: sclerodermaaustralia.com.au

General Meeting and Education Event

DR. SHANE CAMERON

Understanding current and upcoming treatments for scleroderma

Dr. Cameron has returned from his Fellowship at John Hopkins in Baltimore, Maryland. He began his presentation by acknowledging the support he received from Scleroderma Manitoba. He then shared some information about the rheumatology centre, the type of training he underwent including collaborations with other specialists. He reviewed the current treatments for scleroderma and the different classifications of medication. Dr. Cameron emphasized the importance of looking at the whole picture to find solutions that work. He highlighted all the research underway to find more targeted treatments for this disease including stem cell and car-T treatment. He was able to explain these in a clear and understandable way. His full video presentation is on our website.

DR. ANASTASIYA MUNTYANU

Systemic Sclerosis: Pathogensis, Diagnosis and Management

Dr. Muntyanu shared with us that her interest in scleroderma is connected to a family member who lives with the disease. Autoimmune diseases have been rising over time. The skin is the largest organ and is in constant exposure to the climate. She reviewed the basic types of scleroderma using a number of photographs. She described the treatment approaches used by dermatologists including injections for calcinosis and microstomia. She also shared with us the highlights of her PhD work studying the environmental influences that lead to autoimmune diseases like systemic sclerosis. You can watch her presentation on our website.

Mark your calendar!

Our Annual General Meeting and Education Event will be held on:

Saturday, September 12, 2026

We will be meeting once again in the Tamarack Room of the Qualico Family Centre at 330 Assiniboine Park Drive *(in the Assiniboine Park next to the Duck pond and across from the English Garden)*in Assiniboine Park in Winnipeg

We will announce the presentations once the details have been confirmed.

Our AGM will present our Annual Report and elect new Board members. If you or someone you know would be interested we will have the following positions to fill:

VICE-PRESIDENT ROLE:
Assumes the role of the chair of the board if the president is absent or is unable or refuses to act. The term of Office is three years followed by three years as past president.

MEMBER AT LARGE FUND RAISING:
Create & operationalize the plan for the annual fundraising activity by proposing fundraising activities; exploring opportunities for grants and donations; preparing grant applications; developing messaging around different facets of fund-raising; ensuring/developing mechanism for donations; monitoring fundraising efforts to be sure that ethical practices are in place, that donors are acknowledged appropriately, and that fundraising efforts are cost-effective.

Thank You

your generosity changes lives!

We are deeply grateful for your continued support. Because of your generosity we can keep delivering vital services across Manitoba — from enabling province-wide support group meetings via our annual Zoom subscription to providing meeting space for our board and committees. Your donations also fund research and clinical partnerships (including with the University of Manitoba's Section of Rheumatology and SPIN — the Scleroderma Patient Intervention Network) and help provide essential equipment to people living with scleroderma. Every gift, large or small, brings us closer to our shared goal of better care and quality of life.

Thank you for believing in our work and for helping build a brighter future together.

Cigars Under the Stars

event held by Thomas Hinds Tobacconist

Thank you

Pictured here is **Robert Schellenberg**, owner of ***Thomas Hinds Tobacconist***, presenting a cheque to **Scleroderma Manitoba President, Ademola Salami** and **Past-President Jo-Ann Lapointe McKenzie.** These funds were raised at the second annual ***"Cigars under the Stars"*** event. The June 2025 event was held at the Glendale golf and Country Club which is located on the north bank of the Assiniboine River. Robert has been a huge support to our organization over the past few years and co-sponsored our November Awareness "Holiday Spirits Raffle". Thank you to Robert for his ongoing commitment to helping us achieve our mission. Robert does this work as a tribute to his mother who lives with scleroderma.

PROFILE SCLERODERMA PATIENT

Kimberly Watkinson

I was born and raised in Winnipeg and still reside here. My true love is lake time in the Canadian shield. My husband Doug and I have two beautiful children and our lives are happily centred around family and friends.

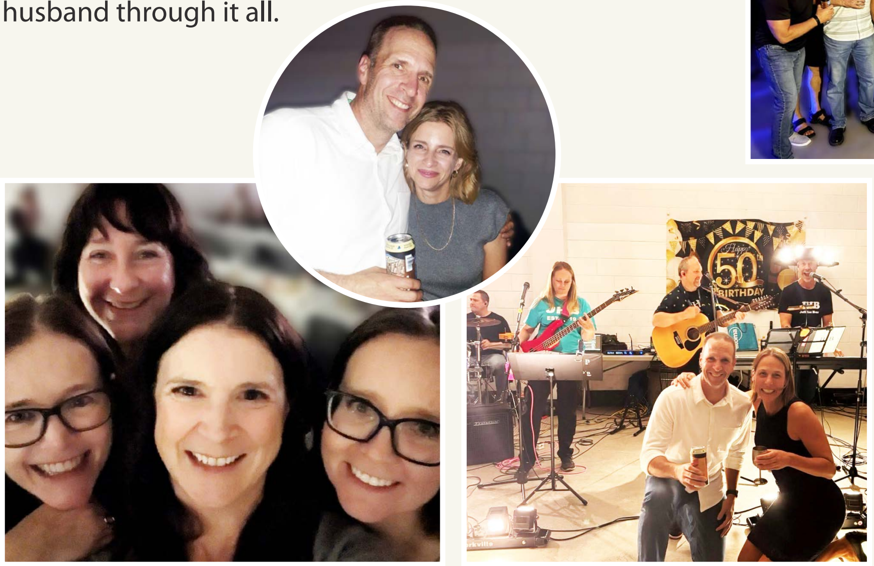
I was diagnosed with diffuse scleroderma 15 years ago around the time my daughter turned one. It was a very scary time with an unpredictable disease course ahead. The hardest part for me was the fear of mortality and not being present to watch my children grow up. I desperately wanted to be an active role model for my kids.

Getting diagnosed with a grim disease hasn't been all bad. I already had a zest for life but it has given me even more appreciation. Over time I've learned better ways to manage my disease and overcome limitations by modifying activities so I can continue to enjoy them. I live every day feeling grateful my disease remains stable. I've been able to stay fit, work, and even travel with a supportive husband through it all.

Since my diagnosis, it has been a goal of mine to make it to 50 and celebrate with a big party. I reached that milestone birthday this fall. Our close friend Jon Kell was also turning 50 and wanted a big party, so we decided to host a celebratory social together and raise funds for scleroderma at the same time!

The social was a fun night and a special way to celebrate with so many who have been part of our lives. It was a great feeling to be supporting a worthy cause dear to us!

Thanks to our families, friends old and new, the JHB band, coworkers and teammates that came out to the social, as well as the overwhelming support through support ticket donations, we raised $6,300, with all proceeds split between Scleroderma Manitoba and Scleroderma Canada.



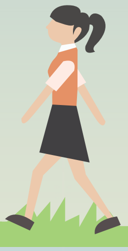
Facts about
Exercising with Scleroderma

1 in 2

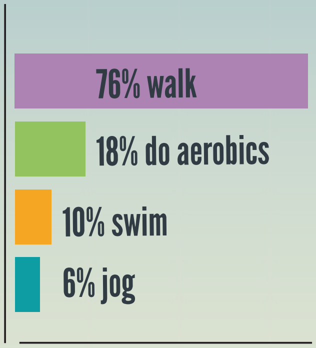
people with scleroderma are physically active, with an average of

4.7

hours of exercise per week



Among patients who exercise,



As with other chronic diseases, people with scleroderma who exercise report **lower** levels of ...

anxiety & depression

fatigue & sleep disturbance

pain & overall disability

People who exercise also report **greater** ability to participate in social roles and activities.

Source: Marleine Azar et al. (2018) Exercise habits and factors associated with exercise in systemic sclerosis: a Scleroderma Patient-centered Intervention Network (SPIN) cohort study, *Disability and Rehabilitation*, 40:17, 1997-2003. *Please contact SPIN for the full-text article.*

✉ spingeneral@gmail.com
☎ 1-800-370-5099 (US & Canada)
01-86-26-53-61 (France)

www.spinsclero.com
/spinsclero
/spinsclero

Coping with Scleroderma

Common strategies for patients, from patients

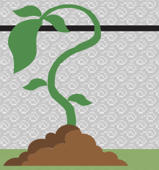
In three focus group sessions, SPIN asked 22 individuals with scleroderma how they cope with having a chronic illness.

> “If you’re nervous during appointments bring a friend or family member for that second set of ears.”

Problem-Solving

- Seeking support from a psychologist or health professional
- Gathering information about the disease through local or national patient organizations, the Internet, and information sessions (practise asking questions!)
- Using organizational strategies, like making lists

> "For me, it’s writing it down and actually seeing what needs to be done ... taking that small problem, tackling it and then taking the next small problem and tackling it."



Dealing with Emotions

- Asking for support from family and friends
- Attending support groups
- Keeping busy with other activities
- Practising relaxation techniques, such as meditation exercises and yoga

Focusing on Meaning

- Finding positives in your situation and focusing on what's most important in life
- Accepting symptoms when they can't be changed
- Letting yourself grieve; being forgiving and kind to yourself
- Taking it one day at a time

> "Two steps forward, one step backwards ... I used to really beat myself up when I was having a bad day. And I don’t think we should. I think we’re entitled to have a really bad day and not dwell on it. Because I found 100% that to every bad day I had, the next day is always without exception a better day. It’s not perfect but it’s a better day."

Source: Stephanie T. Gumuchian, Sandra Peláez, Vanessa C. Delisle, Marie-Eve Carrier, Lisa R. Jewett, Ghassan El-Baalbaki, Catherine Fortune, Marie Hudson, Annett Körner, Linda Kwakkenbos, Susan J. Bartlett & Brett D. Thombs (2017): Understanding coping strategies among people living with scleroderma: a focus group study, Disability and Rehabilitation. *Please contact SPIN for the full-text article.*

SPIN

spingeneral@gmail.com
1-800-370-5099 (US & Canada)
01-86-26-53-61 (France)

www.spinsclero.com
/spinsclero
/spinsclero

SCLERODERMA & RESILIENCE:

HOW DOES SCLERODERMA IMPACT MENTAL HEALTH?

Little is known about resilience and mental health experiences of scleroderma patients. We took a look at what factors affect resilience and mental health and how scleroderma patients are impacted by them.

What is resilience?

Positive adjustment or the ability to preserve mental wellbeing in adverse circumstances.

Why does it matter?

People who exhibit resilient coping report less mental health concerns & higher quality of life. Studying resilience is important to improve mental health care and coping strategies for those with scleroderma.

WHO DID WE STUDY?

- 1054 patients living with scleroderma

- **88%** were female
- **36%** had the diffuse subtype
- **9+ years** since diagnosis (on average)

WHAT DID WE FIND?

For most participants, lower scores on:
Pain, Fatigue, Sleep disturbances, Disease severity

The higher the resilience & better mental health

For a group of participants:
Good mental health despite high pain, sleep and disease severity

Reported symptoms similar to those with low disease symptoms

We **identified** that there were factors that contribute to mental health symptoms:

Demographics:
- Age, Education, Race/ethnicity, Partner status

Disease severity:
- Diffuse disease, Tendon friction rub, Contractures, GI symptoms

WHAT HAPPENS NOW?

Understanding resilience is **key** to developing better coping protocols for patients.

1) People with scleroderma can have positive mental health despite severe symptoms of their illness → this could be because of higher resilience

2) We now plan to conduct studies to determine the factors that increase resilience in people with scleroderma and how these can be incorporated into educational or support programs.

Neyer MA, Henry RS, Carrier ME, Kwakkenbos L, Virgili-Gervais G, Wojeck RK, Wurz A, Gietzen A, Gottesman K, Guillot G, Lawrie-Jones A, Mayes MD, Mouthon L, Nielson WR, Richard M, Sauvé M, Harel D, Malcarne VL, Bartlett SJ, Benedetti A, Thombs BD; SPIN Investigators. The association of resilience and positive mental health in systemic sclerosis: A Scleroderma Patient-centered Intervention Network (SPIN) cohort cross-sectional study. J Psychosom Res. 2024 Mar 11;179:111648. doi: 10.1016/j.jpsychores.2024.111648. Epub ahead of print. PMID: 38507968.

Read here: Article

spingeneral@gmail.com
1-800-370-5099 (US & Canada)
01-86-26-53-61 (France)

www.spinsclero.com
@spinsclero
/spinsclero

November Awareness
“Holiday Spirits” Raffle

Thank you to our sponsors: **Robert Schellenberg of Thomas Hinds Tobacconist & Scott Holden from Pourium**, both from Winnipeg for the support and guidance is creating this beautiful prize basket!

The basket included lovely spirits and wines as well as the treats needed for a perfect evening at home for a **value over $1000.00!**

Congratulations to our winner
Marianne Hodges.

Thank you!

Marianne lives with scleroderma and tells us that several of the items were treasured gifts for family and friends.

The basket contained: **Honig Rutherford Sauvignon Blanc** ($59.99), **Agusti Torello Mata Ubac Gran Reserva Brut Cava** ($42.99), **Catina Terlano Pinot Grigio** ($39.99), **Venge Vineyards Scout’s Honour Proprietary Red** ($85.99), **Tinazzi Aureum Acinum Amarone Valpolicella** ($67.99), **Diplomatico Reserva Exclusiva Rum** ($66.99), **D’usse VSOP Cognac** ($89.99), **Disaronno Amaretto** ($29.99), **Macallan Classic Cut – 2025 Special Release** ($240.00), and a **Wine Night Starter Kit** ($150.00).

Protecting Lung Health: What You Should Know

Pulmonary Fibrosis

For people living with scleroderma, lung health is especially important. One condition that may come up is pulmonary fibrosis—a disease that causes scarring in the lungs. Over time, this scarring can make it harder for oxygen to move into the bloodstream, leading to symptoms like shortness of breath, a persistent dry cough, fatigue, and reduced stamina.

Learning about how the disease affects your lungs—and what options are available—can help you feel more confident asking questions and making decisions about your care.

Manitoba Lung Association
BREATHE

Radon

Radon is an invisible, odourless gas. It is the second leading cause of lung cancer behind smoking and the leading cause of lung cancer in non-smokers.

Radon comes from the natural breakdown of uranium in soil and rock. Outdoors it's diluted, but indoors it can build up over time—any home (old or new) could have high radon levels.

The only way to know if your home has radon is to test.

Scan to learn more about lung health.
mb.lung.ca

Manitoba Lung Association
BREATHE

Our Mission

As the recognized leader and primary resource in lung health,
our mission is to help Manitobans breathe with ease.

Our Vision

Healthy breathing for healthy living.

Our Core Values

Research and knowledge translation are foundational to lung health.
Partnerships and collaboration extend our reach.
We are open and accountable and treat everyone with respect.
Healthy breathing is a universal right and is vital to healthy living.
Primary prevention is pivotal to lung health.
We strive to the highest possible standards of ethics and professionalism.

For more information: www.mb.lung.ca