

SCLERODERMA MANITOBA

The Bulletin

SPRING-SUMMER 2026 | VOLUME 8 NUMBER 1



Scleroderma
MANITOBA

**Urinary
incontinence**

**Support
Group
Information**

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Contact :

Scleroderma Manitoba

1680 Notre Dame Ave, Unit 2

Winnipeg, MB R3H 1H6

204-510-2855

sclerodermamb@gmail.com

www.sclerodermamanitoba.com

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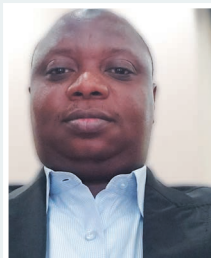
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A Huge Thank You to



We would like to emphasize the generous gesture of our partner, Merck Canada, who made possible, thanks to an educational grant, the production of this SPRING-SUMMER 2026 edition of the Bulletin.

Published under the aegis of Scleroderma Manitoba. 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.

President's Message

*Dear Members, Families,
Friends, and Supporters,*

As we welcome the warmth and energy of spring and summer, I want to take a moment to reflect on what has been a rewarding season for Scleroderma Manitoba.

Our recent awareness and fundraising efforts have been a wonderful success, and I am deeply grateful to everyone who contributed their time, energy, and generosity. Whether you attended an event, volunteered behind the scenes, made a donation, or helped spread awareness about scleroderma, your support has made a meaningful difference. Together, we are building a stronger community and bringing greater attention to a disease that affects so many individuals and families.

While fundraising is essential to support programs, education, and advocacy, the true strength of our organization lies in the people who make up our community. Every conversation, every act of kindness, and every shared experience remind us that no one has to face scleroderma alone. The connections we build through our support network continue to inspire hope, resilience, and encouragement.

We would like to appreciate Merck Canada and Boehringer Ingelheim for the continued support for our AGM and education event which comes up on September 12, 2026. We would also like to say a very big thank you to Robert Schellenberg who has made tremendous contributions through the Cigars under the Stars event as well as all other donors too numerous to mention.

We thank all Health professionals, Professional bodies, research institutions, Doctors, Nurses and Caregivers who have supported our course by way of treatment to patients, presentation of lectures and ideas at our various support group and education events, research for better and innovative treatments and all other form of support you have rendered to our community.

We have had various support group activities and fundraising events over the past months, and we have been able to fill important positions on our Board of Directors. I would like to thank all the Directors for their tremendous support and dedication to the upliftment of the Scleroderma community in Manitoba, your time and efforts are the driving wheel for this association, and I can't thank you enough.



ADEMOLA SALAMI

President
Scleroderma Manitoba

As we look ahead, we remain committed to raising awareness, supporting those living with scleroderma, and fostering opportunities for education and connection throughout Manitoba. We encourage all our members, volunteers, healthcare professionals and supporters to stay engaged, participate in upcoming activities, and continue sharing our mission with your family, friends, and communities.

On behalf of the Board of Directors, thank you for your continued dedication to Scleroderma Manitoba. Your compassion and commitment make everything we do possible. Together, we will continue to make a positive impact and ensure that those affected by scleroderma know they are supported every step of the way.

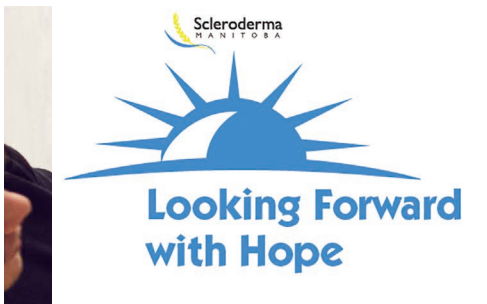
I wish you and your loved ones a safe, healthy, and enjoyable spring and summer. Thank you for being an important part of our Scleroderma Manitoba family.

With gratitude,

Ademola Salami

President, Scleroderma Manitoba .

Connections: Support Groups



SUPPORT GROUPS INFORMATION

A diagnosis of scleroderma is scary. That's why it's so very important to learn as much as you can and connect with others who understand what you are going through.

Scleroderma Manitoba continues to host support groups and educational events for scleroderma patients and their families and supporters. Notices and invitations to attend are sent via email. Posters advertising the dates were sent to as many rheumatologists and doctors' offices as we know about.

Whether you are newly diagnosed, or have been living with scleroderma for some time, it is extremely helpful to get to know others who are living with the disease, ask questions, share concerns, ideas, learn some tips, and support each other.

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

Our next meeting will be held on **November 21, 2026 at 10:30 AM via Zoom.**

Mindset & Mental Health in dealing with Chronic Health Problems

We will be joined by **Shantelle Rank** who is a **Registered Psychiatric Nurse (RPN) and Wellbeing Leader for Shared Health in Manitoba.** With over 15 years of community mental health experience, she previously worked with Prairie Mountain Health, including the Dauphin HERO Club. She is also a recognized Métis mental health advocate. Watch for the email invitation to register later in the fall.

Our April 25/26 meeting featured Stephanie Hnatiuk who spoke with us about Nutrition in Autoimmune Diseases. This was an in-person meeting at the St. Boniface Library Community meeting Room. There were 15 people in attendance. Stephanie presented on what people should be screened for, and advised participants to focus on basic nutrients before eliminating anything from our diets. The presentation was very well received. A video of this presentation is on our website: Nutrition in Autoimmune Diseases.

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

SAVE THE DATE!

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)

WE HAVE TWO EXCITING PRESENTATIONS FOR YOU:

The First presentation will be from

Kari Driedger,

RN, Clinical Nurse

**Specialist in wound management
from Health Sciences Centre.**

Kari will share her experience in managing difficult wounds and describe strategies we can use at home to promote healing. She will share some case studies to highlight when it is important to seek professional assistance.

Our second presenter is

Dr. Claire Adams

Dr. Adams is a psychologist and postdoctoral fellow working with the SPIN team since March 2022. Claire leads SPIN's work on Patient Engagement, which aims to improve the way people with scleroderma are engaged in SPIN research and identify the best methods for sharing research results with the scleroderma community.

Claire completed her PhD in Psychology in Perth, Australia, in 2022, specializing in mental health promotion among people with chronic diseases. She was awarded a Canadian Institutes of Health Research Banting Fellowship (2023-2025) and an Arthritis Society Canada Post-doctoral Fellowship (2025-2027) to carry out her work on patient engagement with SPIN.

Claire is also involved in other SPIN projects and activities that aim to better understand and address common problems experienced by people living with scleroderma and improve quality of life.



Our AGM will present our Annual Report.

This is the first time in many years that we have a full slate of Board members!

Cigars Under the Stars

event held by Thomas Hinds Tobacconist

Thank
you



From left to right:

L-R: Ademola Salami; Jo-Ann Lapointe McKenzie; Robert Schellenberg

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 third annual "Cigars under the Stars" event.

Cigars Under the Stars

event held by Thomas Hinds Tobacconist



Thank
you

PROFILE SCLERODERMA PATIENT

Deborah Lamboo



I was born in Southern Manitoba and moved to Winnipeg shortly after completing high school. My husband Ben and I have been married for 45 years and we have two beautiful daughters. I also spend time at my Mom's Care home, she is 101 years old with advanced dementia.

I had been experiencing Raynaud's symptoms for about two years when I started having trouble breathing and other puzzling symptoms. I was diagnosed with Scleroderma in the Spring of 2025. Many of my symptoms then began to make sense.

I was familiar with health issues and autoimmune diseases as my husband has Rheumatoid Arthritis and is also a cancer survivor of Large B-cell Lymphoma. But this was different. It was ME with the diagnosis this time! I was the Mother, the wife, the caregiver, and now this! I remember leaving the Doctors office with a kind of shocked resolve. The only thing I knew about Scleroderma was that an old co-worker passed away due to Scleroderma about 40 years ago. I assured myself that strides had been made in the medical field and that I would be ok! I needed to learn as much as possible...and quickly!

I found the Scleroderma Manitoba website. I emailed them and was sent a comprehensive package of very helpful information. After pouring through all the information sent to me, I started going to support group meetings through Scleroderma Manitoba. I have found the in-person and virtual meetings quite interesting! I followed advice in the brochures and started gathering a care team. I have never had so many "ologists" in my life! I have a Rheumatologist, Respiriologist, Dermatologist and Neurologist! I thought I had all my bases covered. In time though, I found I did not.

I was struggling emotionally from time to time. I lost my mojo, my hobby of paper-crafting, card-making and even gardening suffered. I no longer had it in me! That's when I realized I needed help. My family doctor referred me to Health Sciences Clinical Psychology. I now have another "ologist" to add to my list! Our sessions focus on acceptance with an emphasis on values. What makes me me, is not the diagnosis, my core values and how I choose to live with the diagnosis is the important part. Speaking to someone who is trained to show you another way of looking at things has been extremely helpful. I am now back to gardening and cardmaking but make sure I listen to my body and be gentle with myself.



Winner of the



Russell Lawton

Our second annual on line 50/50 raffle was held throughout the month of June as a way of raising awareness about scleroderma and to draw attention to World Scleroderma day.

**This year we sold 1,979 tickets,
collected \$2,355.00 in sales
and awarded our winner \$1,177.50!**

Congratulations to Russell Lawton. Mr. Lawton is a long time supporter of our organization. He is Bronwyn Lawton's father. Bronwyn served as our Scleroderma Manitoba President in 2018. Sadly Bronwyn passed away in August of 2019, far too soon.

SPIN Info Graphics

Understanding Pain in Scleroderma



What was the research about?

- Pain is **very common** in scleroderma and can come from many different sources.
- Existing questionnaires only ask about pain overall and not where it comes from or how it is experienced.
- No research has been done** on different sources of pain in scleroderma.
- The goal of this study was to **create a mapping tool** of the many different pain sources in scleroderma.



What did the research team do?

- SPIN researchers, led by graduate student Tiffany Dal Santo, worked together with 4 patient partners to **co-design an initial tool**.
- 22 other people with scleroderma provided input on the tool in 6 different **discussion groups**.
- 18 health care providers who care for people with scleroderma also provided feedback.
- After the tool was refined, **additional patients tested** the questionnaire to make sure it was **easy to understand and use**.



What were the results?

- The SPIN Pain Assessment Tool includes **18 specific pain sources**:

Raynaud's phenomenon
 Joints
 Gastrointestinal
 Oro-facial
 Tight, thick, hard or irritated skin
 Muscles
 Ulcers on skin
 Dry eyes
 Tendons
 Calcinosis
 Points on the body that are hypersensitive to touch
 Carpal tunnel syndrome
 Chest
 Ulcers on mouth or nose
 Gangrene in fingers or toes
 Phantom pain
 Auto-amputation and related complications
 Surgical amputation and related complications



- For each pain source experienced, survey respondents can rate **how strong the pain is, how often it happens, and how it feels**.



How can people use the results?

- The SPIN Pain Assessment Tool is being used in the SPIN Cohort to collect data from people with scleroderma.
- Because **researchers and patients worked together** to make sure that the tool accurately addresses patient experiences, we are confident in the quality of the data being collected.
- This information will help SPIN researchers and others **understand how different pain sources affect people with scleroderma**.
- The data we are collecting on pain and its sources, over time, may help **improve pain management** in scleroderma.



Reference: Dal Santo T, Carrier ME, Nassar EL, et al. Development of a tool to map systemic sclerosis pain sources, characteristics, and management experiences: the SPIN pain assessment tool. *Rheumatology (Oxford)*. doi:10.1093/rheumatology/keaa039

Do rheumatology researchers share study results with participants?



WHAT IS THE RESEARCH ABOUT?

participant → study → result sharing

- Research participants often want to know study results.
- Research ethics guidelines require that researchers share results with participants.
- Before this study, no one had examined whether rheumatology researchers actually do this.



WHAT ARE THE RESULTS?

Contacted **141 researchers** from top rheumatology journals.

From 108 Researchers:



18% shared results with **study participants**.

13% shared results **publicly** (e.g., social media or patient organizations), but **not directly with participants**.

- Most who shared **plain-language summaries**.
- Some shared only **academic materials**, such as journal articles.

WHO WAS IN THE STUDY?



- We reviewed **141 rheumatology studies** published in **2022** and contacted authors **3 years later**. **108 authors** completed the survey.

WHAT DID THE RESEARCH TEAM DO?

- We emailed study authors and asked them to complete a **short online survey (under 5 minutes)**.
- The survey asked **whether and how** results were shared with participants.



WHAT WERE THE LIMITS OF THE STUDY?

- We relied on **authors' self-reports**, which may not always be accurate.
- We only included studies from **top rheumatology journals**, so findings may not apply to all rheumatology research.



*Studies published in top journals may have **more resources** to share results than other studies.*

HOW CAN PEOPLE USE THE RESULTS?

Researchers

- More researchers should share results in **clear, easy-to-understand ways**.
- Ethics committees, funders, universities, and journals** should do more to require researchers to share results with participants.

Participants

HOW WERE PEOPLE WITH SCLERODERMA INVOLVED?

- People with scleroderma were **not directly involved**.
- However, the **SPIN Steering Committee**, which includes people with scleroderma, identified **patient communication of study results** as an important research priority.

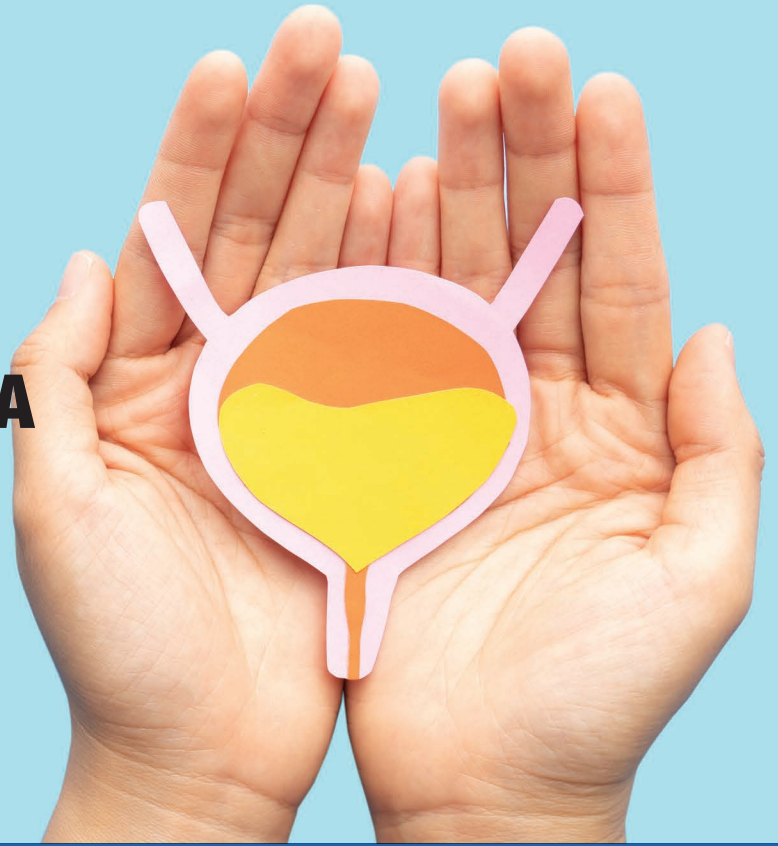


Nassar, E.L., Pierson, G., Adams, C., Nassar, M., Boruff, J., Nordlund, J., Dal Santo, C., Rice, D.B., Thoms-Vite, M., Co, N., Cook, V., & Thoms, B.D. Dissemination of Study Results to Participants in Rheumatology Research: A Meta-Research Review of Studies Published in High-Impact Rheumatology Journals. *Lancet Rheumatology*. S2665-9913(26)00113-X. [https://doi.org/10.1016/S2665-9913\(26\)00113-X](https://doi.org/10.1016/S2665-9913(26)00113-X)

URINARY INCONTINENCE IN PEOPLE LIVING WITH SCLERODERMA

Olivia Dubois, MPT, PhD

*Pelvic Floor Rehabilitation Physiotherapist
Director of Knowledge Mobilization*



Urinary incontinence is defined as the involuntary loss of urine ([Haylen et al., 2010](#)). It affects 49% of women and 15% of men living with scleroderma ([Sanchez et al., 2016](#)). Several types exist, but the two most common are stress urinary incontinence and urgency urinary incontinence.

STRESS URINARY INCONTINENCE

Stress urinary incontinence occurs during physical activity or an action that increases pressure in the abdomen. This pressure pushes on the bladder and increases its internal pressure. When pressure in the bladder exceeds the urethral closing pressure (the tube leading out of the bladder), urine is propelled into the urethra, resulting in stress urinary incontinence. Coughing, sneezing, lifting loads, running, and jumping are just a few examples of factors that can cause stress urinary incontinence.

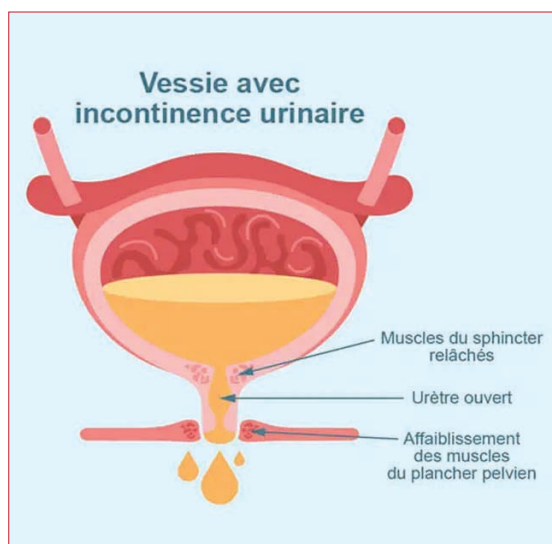
URINARY INCONTINENCE IN PEOPLE LIVING WITH SCLERODERMA

TWO IMPAIRMENTS ARE PRIMARILY RESPONSIBLE FOR THIS TYPE OF URINARY INCONTINENCE:

1. IMPAIRMENT OF SPHINCTER FUNCTION:

This impairment is characterized by the inability of the pelvic floor muscles, smooth muscles (sphincters), and vascular elements of the urethral mucosa to close the urethra in a watertight manner. In addition, in postmenopausal women, the lack of estrogen leads to a reduction in tissue quality. The urethra becomes more rigid, which interferes with its occlusion. In these women, there is also a decrease in vascularization and in the production of intra-urethral mucus.

To better understand this last factor, one can think of two glass slides held together by a drop of water. As long as the drop of water is present, the two slides are difficult to separate. However, if the water disappears, the two slides can be separated easily. As in postmenopausal women, scleroderma causes a decrease in intra-urethral mucus, affects the vascular plexuses, and stiffens the urethra, leading to insufficient occlusion (slides easily separated).

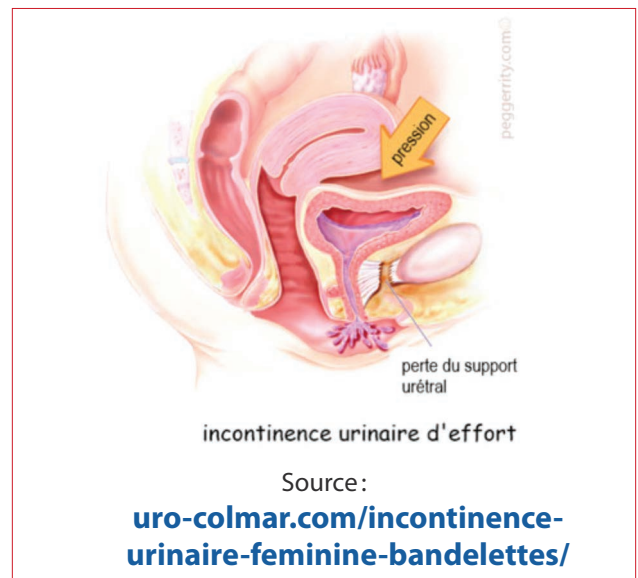


Source:

www.assura.ch/fr/sante/conseils-sante/incontinence-urinaire

2. IMPAIRMENT OF SUPPORT FUNCTION:

This impairment is characterized by a lack of support of the urethra and bladder neck by active structures (pelvic floor muscles that are too weak or lack tone) and/or passive structures (fascia, ligaments) (**DeLancey & Ashton-Miller, 2004**). The urethra becomes hypermobile, which complicates the pelvic floor's task of compressing it against the pubic bone. Pregnancy and childbirth are examples of events that can affect support function.



In people living with scleroderma, a third causal factor is added: myopathy of smooth muscles (urethral sphincters) and striated muscles (pelvic floor muscles). This may be caused by necrosis, inflammation, fibrosis, or acute neurogenic atrophy (**Paik 2016**). Smooth and/or striated myopathy compromises the watertight closure of the urethra, predisposing individuals to stress urinary incontinence.

URINARY INCONTINENCE IN PEOPLE LIVING WITH SCLERODERMA

URGENCY URINARY INCONTINENCE

Urgency urinary incontinence is associated with a sudden, compelling urge to urinate ([Haylen et al., 2010](#)), with urine leakage occurring while the person is on their way to the toilet. This phenomenon is explained by impaired bladder compliance.

Under normal conditions, the bladder can increase in volume (fill) without its internal pressure increasing proportionally (sensation of urge). However, scleroderma can cause bladder fibrosis, which decreases compliance and creates sudden, intense urges that result in urinary incontinence.

One study reports that 67% of people living with scleroderma experience urgent urinary urges that may lead to urgency urinary incontinence ([Pacini et al., 2020](#)). People who experience this type of incontinence are often able to identify triggering factors such as cold feet, running water, putting the key in the door, arriving at the bathroom/toilet, etc

MIXED URINARY INCONTINENCE

When the two types of urinary incontinence—stress and urgency—coexist in the same person, the individual is considered to have mixed urinary incontinence.

PELVIC FLOOR REHABILITATION

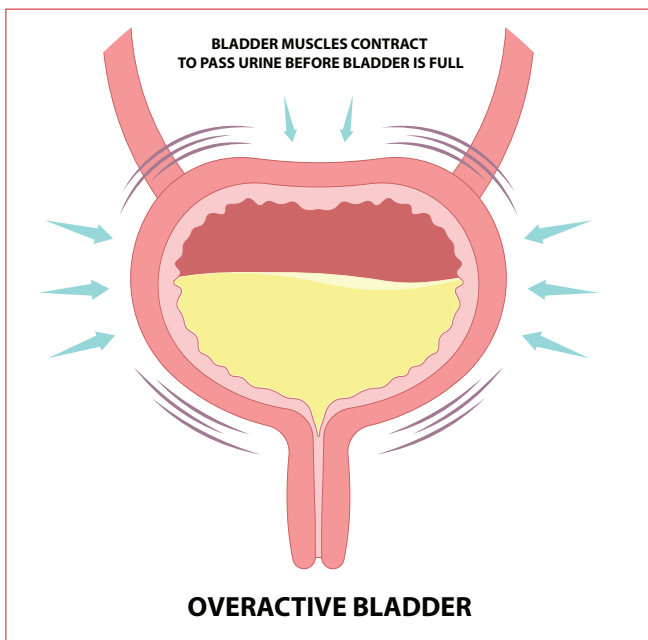
According to the International Consultation on Incontinence, pelvic floor rehabilitation is the first therapeutic option that should be attempted to treat urinary incontinence, well before medication and surgery ([Dumoulin et al., 2016](#)).

Pelvic floor rehabilitation is performed by a physiotherapist, a health professional recognized by Québec's public health care system and regulated by a professional order. The Ordre professionnel de la physiothérapie du Québec is mandated to monitor the quality of services provided by physiotherapists, to issue practice permits, and above all, to protect patients receiving physiotherapy care (www.oppq.qc.ca).

TYPICAL COURSE OF A PELVIC FLOOR REHABILITATION CONSULTATION

The physiotherapist first carries out a subjective assessment of the condition using a fairly comprehensive questionnaire, in order to differentiate stress urinary incontinence from urgency urinary incontinence and to identify potential causes.

Next, a physical assessment is performed, including—but not limited to—the pelvic floor muscles and deep abdominal muscles, to determine whether dysfunctions are present. If so, appropriate treatment modalities are implemented. As needed, an exercise program targeting muscular weaknesses is initiated, while taking care to respect muscular fatigue, which is often present in people living with scleroderma.



URINARY INCONTINENCE IN PEOPLE LIVING WITH SCLERODERMA

In women for whom strengthening alone would not be sufficient to resolve stress urinary incontinence, the use of a pessary with a knob may be appropriate. A pessary is a silicone device inserted into the vaginal canal and can serve two roles: supporting the pelvic organs and closing the urethra. This latter function is made possible by the presence of a knob at the front of the pessary, which provides additional pressure on the urethra during increases in abdominal pressure. The physiotherapist is able to fit the pessary and provide follow-up care for the patient, once it has first been prescribed by the treating physician.

In cases of urgency urinary incontinence, the physiotherapist will teach urgency-suppression techniques and, as needed, in women, a support pessary may be inserted. If relevant, modifications to dietary and fluid intake habits will also be suggested.

Source:

www.canadapessary.ca/products/ring-pessary-with-knob-online

WHERE TO FIND PELVIC FLOOR REHABILITATION CARE?

On the website of the Ordre professionnel de la physiothérapie du Québec, a search engine allows you to find, in your region, a physiotherapist working in pelvic floor rehabilitation under the Care and Services section:

(oppq.qc.ca/trouvez-un-professionnel/resultats/).



BIOGRAPHY

Olivia Dubois graduated from the Master's program in Physiotherapy at the Université de Sherbrooke, the graduate microprogram in pelvic floor rehabilitation at the Université de Montréal, and the PhD program in Clinical Sciences at the Université de Sherbrooke. A private-clinic physiotherapist for 14 years, she also holds the position of Director of Knowledge Mobilization at the Cigonia Clinic, ensuring a practice based on the most recent evidence. In addition, she is a lecturer at the School of Rehabilitation at the Université de Sherbrooke and a laboratory supervisor in the pelvic floor rehabilitation microprogram at the Université de Montréal. Finally, she is Executive Director of Professor Simon Décary's Research Laboratory on Health Care Integration at the Université de Sherbrooke.

EULAR & CSRC EUROPEAN CONGRESS OF RHEUMATOLOGY

June 3-6, 2026 — London, England

When SPIN begins a new research project they assemble a team to guide the work. Each team is a blend of Researchers and patient partners who work together to ensure the study is grounded in the patients perspective so that the results have meaning not only for scientists but also those of us living with scleroderma. I had the honour of being invited to co-present, with members from the SPIN Team, the findings of two studies that I participated in:

1. COURSE OF ITCH FROM SYSTEMIC SCLEROSIS ONSET:

A Scleroderma Patient-centered Intervention Network Cohort Study (Meira Goldberg et al)

Presented by Meira Goldberg and Jo-Ann Lapointe McKenzie



Meira Gildberg and
Jo-Ann Lapointe McKenzie

Conclusion: We modelled the probability of having any itch and, if present, itch severity. We accounted for both normal aging and SSc disease duration by including age of onset of non-RP symptoms and time since onset in our models. For all non-RP symptom onset ages and times since onset, predicted past week itch probability was between 35% and 37%.

For participants with itch, predicted severity on a 0-10 scale was between 4.1 and 4.4 points for all onset ages and times since onset. Our findings suggest that itch may not be as closely related to disease duration in SSc as previously thought. It is possible, despite attempting to account for both chronological age and disease duration, that normal aging and disease processes may have countered each other to some extent.

However, the stability of estimated prevalence and severity across onset ages and over time within onset ages suggest that any such effects would be minimal. Research is needed to elucidate the pathophysiology of itch in SSc and identify effective management strategies.

2. THE EPIDEMIOLOGY OF PAIN IN SYSTEMIC SCLEROSIS:

A Scleroderma Patient-centered Intervention Network (SPIN) Cohort Study (Tiffany Dal Santo, et al)

Presented by Dr. Brett Thombs and Jo-Ann Lapointe McKenzie

Conclusion: The SPIN Pain Mapping Study is the first large study to comprehensively evaluate the range of possible pain sources in SSc and, for each source, to assess critical components, including intensity, interference with daily activities, temporality and predictability, variability across episodes and sensory experience descriptors. The main finding was that 8 of 18 possible pain sources (not counting sub-categories) were experienced by over half of participants. Pain is common in SSc and can stem from many different sources within and across patients. Results from our study can be used to develop research programs on pain in SSc with the goal of improving pain management.

Canadian Skin Research Conference

June 27-29, 2026
Calgary, Alberta

Dr. Brett Thombs and I co-presented the Pain study at this conference along with three poster presentations: the **itch study**, a **study comparing infographic to plain language summaries of research results**, and an **evaluation of patient and researcher co-presentations of research results**.

Dana Geis, the *Executive Director of the Canadian Skin Patient Alliance* led a work shop called *Voices That Matter: Patient Advocacy, Mental Health, and the Power of Being Heard*. **Lavonne Schill** and I participated in the presentation of this workshop.



Jo-Ann Lapointe McKenzie
and Dr. Brett Thombs

New Member Profiles

AKASHDEEP DEO **Vice-President**

AKASH JOINED OUR BOARD IN MARCH OF 2026

He has a diploma in Computer Science from Langara College in Vancouver and is working on a Bachelor of Commerce Degree at the Asper School of Business. Akash is interested in working in environments where precision, confidentiality and prioritization are essential. His interest in joining our board is to increase the visibility of our organization as a way of increasing awareness of this rare disease.

He has some wonderful ideas about how to improve our use of social media platforms and at the same time broaden our connections to corporate donors.



NAFIJ TALUKDER **Treasurer**

Nafij is working on a Bachelor of Commerce Degree at the University of Manitoba. He has experience as a supervisor/manager in the hospitality sector where he was responsible for staff scheduling, monthly financial reporting, inventory management and labor cost monitoring. His interest in joining our board is to contribute to our financial monitoring, budget development and improve his understanding of the non-for-profit/charity framework.



**JOIN US ON
SATURDAY, NOVEMBER 21, 2026,
for What's New in Scleroderma Research 2026:
An Online Event for Patients & Families,
organized by the
Scleroderma Patient-Centred Intervention Network (SPIN)
and its partners, including Scleroderma Manitoba.**

Designed specifically for the scleroderma community,
this unique international online event brings together people living
with scleroderma, their families, researchers, and patient partners.

Presentations will feature recent scleroderma studies selected by people
with scleroderma and will be co-presented by a researcher and a patient.

The event will be offered in **English at 4:00 p.m. EST (3:00 p.m. CST)**
and in **French at 12:00 p.m. EST (11:00 a.m. CST).**

WHY SHOULD YOU ATTEND?

- Event planned by researchers and patients for patients.
- Hear about the latest top scleroderma studies selected as high interest by patients for patients.
- Presentations tailored for people with scleroderma
- Opportunities to ask questions to researchers

Follow SPIN on social media for
more information on how to register!



/spinsclero



@spinsclero

For more information, visit our website at:
sclerodermamanitoba.com

