SCLERODERMA MANITOBA

The Bulletin

FALL-WINTER 2023-2024 | VOLUME 5 NUMBER 2

Scleroderma MANITOBA

Donor Recognition

Patient-reported outcomes in scleroderma: why it matters?

+

SPIN: A Patient-Researcher Partnership

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A Huge Thank You to

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We would like to emphasize the generous gesture of our partner, Janssen Canada, who made possible, thanks to an educational grant, the production of this Fall-Winter 2023-2024 Bulletin.

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WE HAVE BOARD VACANCIES TO FILL

President, Vice-President, and two additional Member-At-Large poisitons.

The term for our Board positions are 3 years for Member-At-Large.
The Vice President is a term of 3 years followed by a 3 year term as President.
The Past-President is a three year term but in a limited support capacity.
We encourage you to explore membership on our board with the people in your networks. 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

Living here in Manitoba, the weather is always on our minds. Our beautiful Fall weather lasted until almost the end of October. Now, as I write this message there is snow on the ground, the temperature is below zero and last evening five of our highways were closed due to icy conditions!

Every organization, including ours, goes through transitions and renewals. We have a small group of dedicated volunteers who commit countless hours to the work of Scleroderma Manitoba. We say thank you and farewell to Lisa Thiessen who has completed her three year term as our treasurer. Lisa has created a financial reporting structure that aligns with our strategic pillars, as well as a budgeting process that reinforces those pillars. She has completed all of the required obligations relating to Industry Canada , CRA, and the Manitoba Companies office. We are forever grateful to her for donating her time and expertise to our community.

We are delighted to welcome Mridul Bhargava as our new Treasurer. He comes to us with an impressive resume filled with the education and experience to continue the work of managing our reporting obligations and finances. He is also new to Canada and in particular, Manitoba. We are so excited to be working with him.

My term as your President is also complete. We have yet to find someone to take my place so I will continue for the short term. I can not stay on as long a Marion Pacy (27 years!) as my health is getting more and more challenging but I am willing to support the new President as they learn the role. If you know anyone who would be willing to step in as Vice-President or President-in-training please let me know. We are a small, friendly group and the more people we have to share the work the easier it is for everyone.

We are, sadly, saying farewell to Crystal Smith. She has been working hard on your behalf with the Support group team and the communications team to assist with Zoom meetings, prepare advertisements, circulate bulk email messages, and update our Facebook page. Crystal is unfortunately unable to complete her term on the Board. We will miss her enthusiasm and social media skills!

Welcome to our two newest Board members: Linda Cassell, who is a Member-at-Large *who will continue her work with the Support group team*. Linda has been involved with the support group team for a few years now and is an active member of our Scleroderma community. **Theresa Sabi, who is a Member-at-Large *will begin by assisting us with Communications***. Theresa is currently studying at the Asper School of Business working towards a degree in commerce. She has been actively involved as a volunteer with for organizations such as **LITE *(Local Investment towards employment)***, **Cancer Care Manitoba**, and the **Winnipeg Blue Bombers**. She understands how to use and create social media which will fill the gap left by Crystal.

That leaves two additional Members-at-Large position vacant: Education and Policy/Procedure. Our board meets every other month for about one and a half hours. The intervening month allows time for committee work. Each board member takes responsibility for linking to a committee, but does not have to chair that committee. If you would like to get involved at the committee level before stepping into a role on our board we would welcome members for the fundraising, education, communication, and policy/procedure committee. If you or anyone you know would be interested and willing to join us we would be thrilled. Additional information can be obtained by emailing **sclerodermamb@gmail.com**.

The board has built a strong foundation for this organization and we can only continue with the ongoing support from our community.

Our in-person education event and AGM on September 23, 2023 (Saturday) was a success. It was attended by about 35 people and the staff at the Canad Inns Fort Garry location were a huge part of our success. Dr. David Robinson presented an overview of digital ulcers and Raynaud's symptoms. His key message: keep warm! (which is always a challenge in a Manitoba winter) Dr. Shane Cameron provided us with a preview of the work he will continue as he completes his advanced education in myositis and muscle involvement in scleroderma. The presentations are available on our YouTube site.

As always your are not alone and we are

Looking Forward with Hope!

JO-ANN LAPOINTE MCKENZIE
President, Scleroderma Manitoba

Donor Recognition

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TO OUR DONORS

Who was Lolita Tahimic?

Lolita Tahimic was born in Punta, Tanza, Cavite, Philippines on January 19, 1950. She always aspired to travel the world, so when she was 22 years old, Lolita decided to take the voyage across the ocean with many other seamstresses to Winnipeg on May 5, 1972.

Lolita enjoyed meeting new people and as a result, she joined various networking businesses. Lolita's passion for traveling continued to grow as she became a travel agent and visited over 10 countries. Before she retired, Lolita worked at the McPhillips Street Station Casino for more than 15 years.

When she was not working, Lolita loved spending time with her children, Xandralee, Alexandra, Alexis-lee, Alexander, and all of her grandkids. She always made sure to remind everyone that there was nothing in this world more important than family.

WHAT WAS LOLITA'S EXPERIENCE WITH SCLERODERMA?

In 2012, Lolita Tahimic was diagnosed with Scleroderma. At the time, she felt like it was not really affecting her in the early stages and chose not to alarm any of her family. In December 2021, the disease started to rear its ugly head in to her life, affecting her in her breathing, stiffening her joints, and hardening of her skin.

Lolita was not aware of the journey that lay ahead. She tried to relieve symptoms holistically and spiritually after many trips to the hospital, released with the family not knowing how to properly care for her at home.

Scleroderma has changed our families' lives. Our beautiful mom, Lolita Tahimic strongly believed that she would live to be 100 years old, similar to her own mom. This rare disease didn't allow for that to happen and she passed away on September 18, 2022 at the age of 72 years old.

HOW WILL LOLITA BE REMEMBERED?

Lolita, will always be remembered as a woman who put her family first. She is the sole reason why our family and all of our relatives are here in Winnipeg, Manitoba, to this very day. Lolita was loving, kind hearted, and was loved by all.

Alexander Tahimic Jr, her son, wanted to honour her by raising money to study the disease in order to help other individuals and families affected by Scleroderma, so he ran the 2023 Manitoba Full Marathon. With the help of social media, friends, and family, he was able to raise $2,705.

Lolita was a pioneer and will continue her journey in our hearts and memories forever.

"Love your family and serve Jesus".

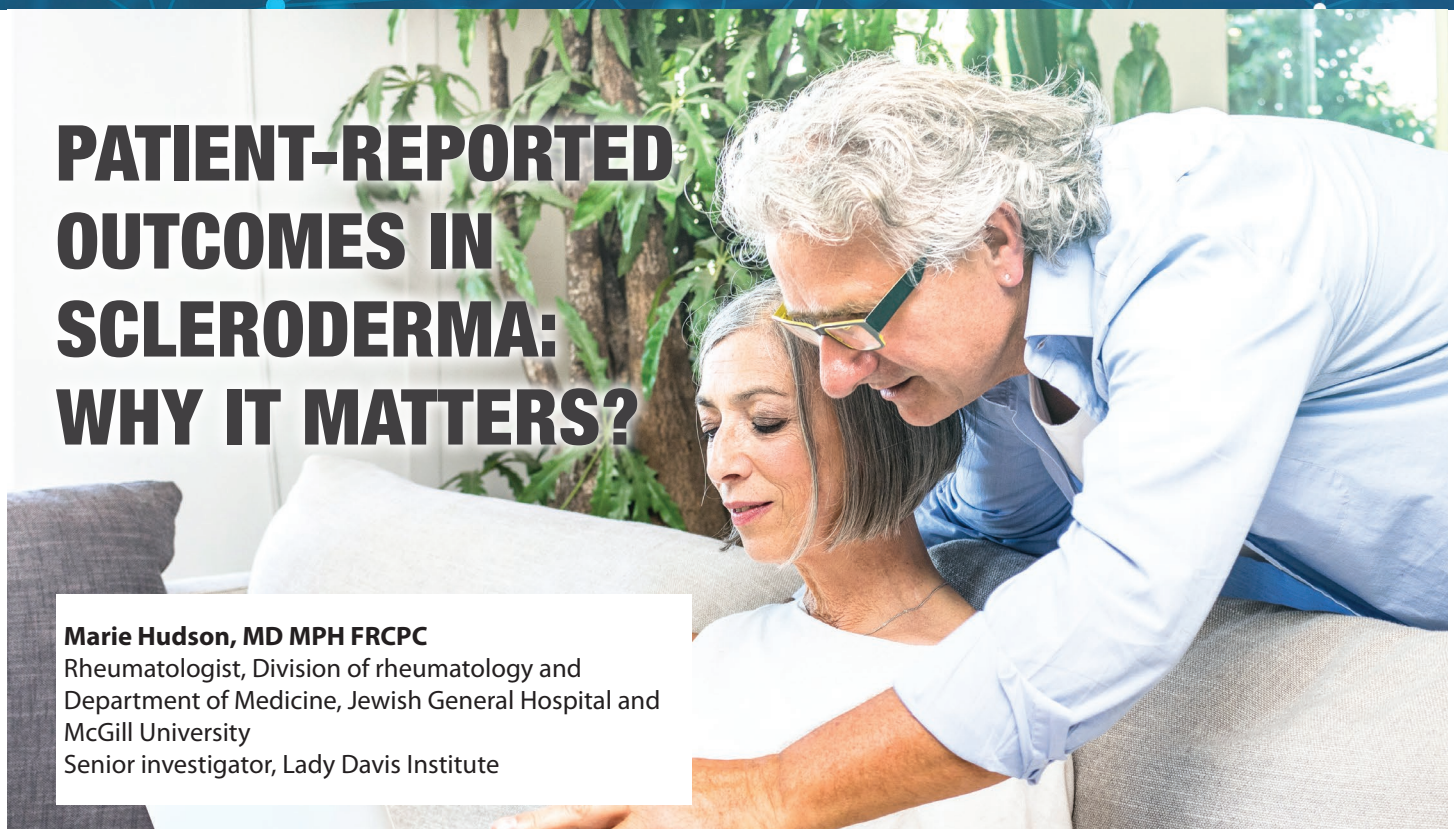
Jim lived his daily life with Scleroderma for about 6 years. The disease had a significant affect on various parts of his body and it's functions. Daily we strived to modify different areas of his life to make him feel more comfortable. Jim never wanted to be a bother to anyone and I now know that he suffered far more than what he spoke of... *"Suffered in silence"*. He was known for having such a big and caring heart and in the end it was the disease that stopped his heart from beating.

Jim lived his daily life with the words of his late grandmother, *"Love your family and serve Jesus"*. This Legacy he instilled in myself, our children and our grandchildren and these words live on in us as in our grief we seek to honor him in everything that we do and say.

With gratitude for an amazing man,

LEIANNE SHEARER

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?



Marie Hudson, MD MPH FRCPC
Rheumatologist, Division of rheumatology and Department of Medicine, Jewish General Hospital and McGill University
Senior investigator, Lady Davis Institute

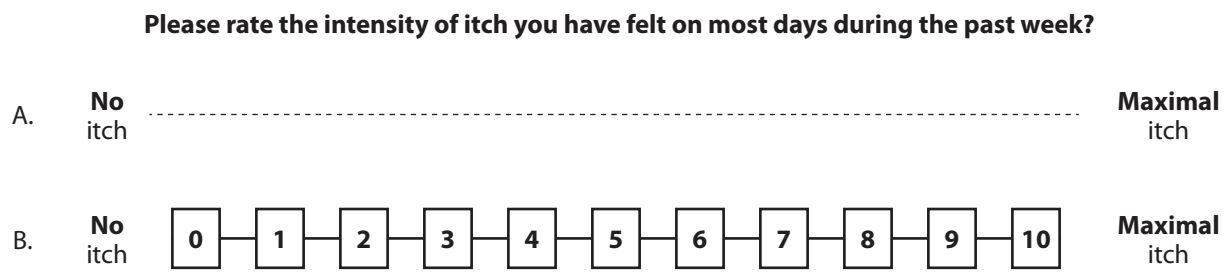
Scleroderma patients are the experts in how they feel and function. They are the only ones capable of describing first-hand the long list of symptoms associated with scleroderma, including Raynaud's, skin changes, gastrointestinal problems and breathlessness to name a few, and how these impact their day-to-day life. They also have lived experience with the disfigurement and the complex psychosocial impacts of this disease.

The growing recognition that patients have unique experiences and values has resulted in a paradigm shift in the 21st century from a traditional paternalistic model of medicine with the physician deciding what is in the best interest of the patient to one of patient-centered care where patients are at the center of the health care continuum and their specific needs and goals are the driving force behind all health care decisions. Patient-centered care paved the way for patient-centered research.

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

FIGURE 1

EXAMPLES OF (A) VISUAL ANALOGUE AND (B) NUMERICAL RATING SCALES



PROS AND PROMS

Patient-reported outcomes (PROs) are defined as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else". [1] PROs is an umbrella term that covers not only symptoms but also function, health-related quality of life (HRQL), satisfaction and so on. They capture patient experiences of disease that clinical assessments, blood tests, imaging (eg. CT scans and cardiac echocardiograms) and biopsies cannot. PROs have in fact become a central part of drug approvals as regulatory agencies including Health Canada, the US Food and Drugs Administration and the European Medicines Agency now require data not only on survival (and other measures of biological effectiveness) but on how patients "feel and function" when considering applications for new drug approvals.

Patient-reported outcomes measures (PROMs) are the questionnaires that measure PROs in a standardized way. PROMs are either generic, in that they can be used across various health conditions, or specific, in that they aim to capture aspects of disease that are particular to a certain condition.

GENERIC PROMS

The three most commonly used generic PROMs in scleroderma are patient global assessments, the Health Assessment Questionnaire (HAQ) and the Medical Trust Short-Form 36 (SF-36). The Patient-Reported Outcomes Measurement Information System-29 (PROMIS-29) is emerging as a novel generic PROM for scleroderma.

Patient Global Assessments of disease generally ask patients to rate their overall health over a given period of time (eg. past week, past month), for example using a 10 cm visual analogue scale or numerical rating scale ranging from 0 to 10 (Figure 1). Studies have shown that scleroderma patients often rate disease severity as worse compared to physician ratings, suggesting that patient ratings capture different, possibly more complex psychosocial factors that physicians do not take into account. [2] On the other hand, in a disease as heterogeneous as scleroderma, with some patients having predominantly skin, others gastrointestinal and others still respiratory symptoms, Patient Global Assessments lack granularity.

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

The HAQ is one of the earliest PROs used in rheumatic diseases. It is a questionnaire developed in 1980 to assess functional ability in patients with rheumatoid arthritis. It includes 20 questions in 8 categories (dressing and grooming, arising, eating, walking, hygiene, reach, grip, and performing activities). The patient rates his/her difficulty over the past week in performing the specific tasks in each category as none, mild, moderate or severe difficulty. The final score ranges from 0 (no disability) to 3 (severe disability). Although the HAQ is widely used, including in scleroderma, it has some limitations. It focuses mainly on musculoskeletal function and does not take into account the panoply of other functional limitations encountered in scleroderma, for example from breathlessness, gastrointestinal symptoms or body image distress. Also, there are concerns that even as a measure of musculoskeletal function, it may be outdated. For example, it does not include hand function such as keyboarding or using a cell phone, which is often compromised in scleroderma.

The SF-36 is possibly the most widely used generic measure of health-related quality of life. It is composed of 36 questions that can be grouped into 8 domains: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. The scores of the domains and summary scores are standardized with means of 50 and standard deviations of 10. Lower scores represent worse health-related quality of life. A systematic review of the literature reported that the Physical component summary score of the SF-36 was more than 1 standard deviation below the general population (38.3; 95% credible interval 35.2, 41.5).[3] This translates into saying that, on average, scleroderma patients are among the 15% of the population with the worst physical health-related quality of life. The SF-36 has the advantage that it has been used in many diseases and allows for cross-disease comparisons. The impairments in SF-36 in scleroderma are worse than the general population and as high if not higher than other more common chronic diseases namely heart disease, lung disease, hypertension, diabetes, and depression.[4] This provides valuable information to advocate for health care resources for scleroderma, which remains relatively unknown among the public and health care decision-makers.

PROMIS-29 is a more recent generic measure of health-related quality of life developed by the National Institutes of Health (**https://www.healthmeasures.net**). It has the advantage of including a domain for sleep, which is often impaired in scleroderma. A study from the Scleroderma Patient-centered Intervention Network (SPIN) cohort showed that joint contractures and gastrointestinal symptoms were the strongest predictors of worse PROMIS-29 scores,[5] providing valuable priorities for further scleroderma research with the potential to improve health-related quality of life.

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

FIGURE 2

SYMPTOM SCALES OF THE S-HAQ

1. In the past week, how was your overall health?

No disease — 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 — **Very severe** disease

2. In the past week, how much has *Raynaud's* interfered with your daily activities?

Raynaud's does **not** limit activities — 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 — **Very severe** limitation

3. In the past week, how much have your *finger ulcer(s)* interfered with your daily activities?

Finger ulcers do **not** limit activities — 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 — **Very severe** limitation

4. In the past week, how much have your *intestinal problems* interfered with your daily activities?

Intestinal problems do **not** limit activities — 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 — **Very severe** limitation

5. In the past week, how much have your *breathing problems* interfered with your daily activities?

Breathing problems do **not** limit activities — 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 — **Very severe** limitation

PROMS SPECIFIC FOR SCLERODERMA

As mentioned above, the HAQ is a generic measure of musculoskeletal function. To supplement the HAQ with scleroderma-specific content, Steen and Medsger proposed in 1997 to add 5 symptom scales asking patients to rate how much overall disease, Raynaud's phenomenon, finger ulcers, breathing and gastrointestinal problems interfere with daily activities (Figure 2).[6] Higher scores represent worse symptoms. The addition of these symptom scales to the HAQ, which is commonly referred to as the Scleroderma-HAQ or S-HAQ, was an important first step towards developing scleroderma-specific PROs and capturing important information from the patient's perspective.

The extent of skin disease has traditionally been measured by the modified Rodnan skin score (mRSS), which is an assessment of skin thickness ranging from 0-3 in 17 areas of the body performed by a physician (range 0-51, with higher scores representing worse skin thickening). The mRSS is commonly used as a primary endpoint in clinical trials as it has been shown to predict internal organ involvement and mortality in scleroderma. However, it does not capture the subjective experience of skin changes in scleroderma. The Scleroderma skin patient-reported outcome (SSPRO) was recently developed with the input of patients to capture the patients' experiences of skin-related health changes in scleroderma.[7] It is an 18-item patient questionnaire that assesses 4 domains: physical effects, physical limitations imposed by skin tightness, emotional effects and social effects, with each item being graded from 0 to 6 (range 0-108, with higher scores representing worse assessments). The SSPRO has been shown to capture how a patient feels and functions (by correlating it with traditional PROMs). Interestingly, in one clinical trial, the SSPRO correlated only moderately with the mRSS,[8] indicating that there are likely additional factors beyond assessments of skin severity by physicians that shape the experience of SSc patients regarding their skin condition.

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

FIGURE 3
RAYNAUD'S CONDITION SCORE

The Raynaud's Condition score is your rating of how much difficulty you had with your Raynaud's **TODAY**. Consider how many attacks you had and how long they lasted. Consider how much pain, numbness, or other symptoms the Raynaud's caused in your fingers (including painful sores) and how much the Raynaud's **ALONE** affected the use of your hands today.

SELECT the number that best indicates the difficulty you had today with your Raynaud's condition by marking an ''X'' in the appropriate box:

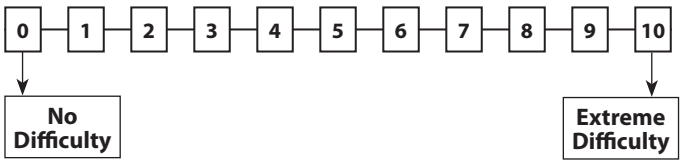
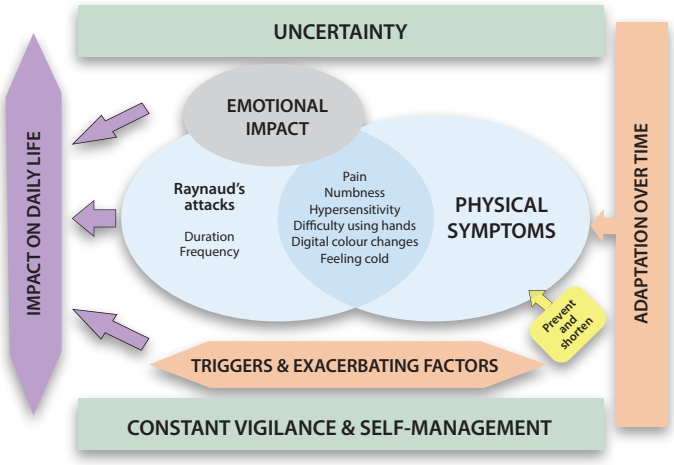


FIGURE 4
CONCEPTUAL MAP OF THE PATIENT EXPERIENCE OF SCLERODERMA-ASSOCIATED RAYNAUD'S PHENOMENON



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Raynaud's phenomenon is highly variable and episodic. By its nature, it is one of the symptoms of scleroderma that is best measured by patient reports. In the past, many studies of treatments for Raynaud's phenomenon used Raynaud's Condition Score (Figure 3). Patients are asked to rate their Raynaud's phenomenon from 0–10, taking into account the frequency, duration, pain, numbness, and impact of RP attacks on that day. An average can be taken when the questionnaire is rated on multiple days using a diary. However, several clinical trials of potent vasodilators such as tadalafil, selexipag and bosentan have not shown the expected beneficial results when using Raynaud's Condition Score, while other PROs such as the HAQ showed improvement. This suggests that the single item Raynaud's Condition Score does not capture the multifaceted experience of Raynaud's phenomenon.

In recent years, there has been remarkable progress in better measuring Raynaud's phenomenon. Extensive patient input was collected to develop a conceptual framework for capturing the lived experience of how scleroderma patients "feel and function" concerning their Raynaud's (Figure 4).[9] From this, a novel scleroderma-specific measure of ***Raynaud's phenomenon, the Assessment of Systemic sclerosis-associated Raynaud's Phenomenon (ASRAP) questionnaire***, was developed and recently published.[10] It consists of 10 items covering not only frequency and duration of attacks but also facets such as 'emotional distress', 'exacerbating factors', 'self-management' and 'adaptation'. The ASRAP should provide a more nuanced measure of Raynaud's phenomenon in scleroderma and provide a useful tool to test new treatments for this often debilitating problem.

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

TABLE 1

THE QUESTIONS IN THE BODY CONCEALMENT SCALE FOR SCLERODERMA (BCSS)

I wear clothes I do not like.

I wear long sleeves to hide skin changes.

I avoid wearing revealing clothes (eg. bathing suits, tank tops, or shorts).

I wear clothes that hide the changes to my skin.

I wear clothes that will divert attention from my appearance.

I wear gloves to hide my hands.

I avoid shaking hands with people.

I hide my hands so that people do not see them.

I avoid directly giving change or other items to people.

TABLE 2

SELECTED PROMS COMMONLY USED IN SCLERODERMA RESEARCH

	PROMS	SCLERODERMA SPECIFIC
RESPIRATORY SYMPTOMS	Mahler Dyspnea Index	NO
	St George's Respiratory Questionnaire	NO
	Borg Dyspnea Scale	NO
	Leicester Cough Questionnaire	NO
GASTROINTESTINAL SYMPTOMS	UCLA Scleroderma Clinical Trial Consortium Gastrointestinal Tract 2.0 questionnaire	YES
	Patient-Reported Outcomes Measurement Information System (PROMIS) Gastrointestinal symptom scales	NO
HAND FUNCTION	Cochin Hand Function Scale (CHFS)	NO

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

FIGURE 5

THE EULAR SYSTEMIC SCLEROSIS IMPACT OF DISEASE (SCLEROID) QUESTIONNAIRE

How much have the different aspects of systemic sclerosis affected you during the last week?
Please make your responses on the scale by choosing the appropriate no for each of the following dimensions during the last week:

Raynaud's phenomenon:											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Hand function:											
No limitation	0	1	2	3	4	5	6	7	8	9	10	Extreme limitation
Upper gastrointestinal tract symptoms (eg. swallowing difficulties, reflux, vomiting):											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Pain:											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Fatigue:											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Lower gastrointestinal tract symptoms (eg. bloating diarrhea, constipation and incontinence):											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Limitation of life choices and activities (eg. social life, personal care, work):											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Body mobility:											
Not affected	0	1	2	3	4	5	6	7	8	9	10	Extremely affected
Breathlessness:											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme
Digital Ulcers:											
None	0	1	2	3	4	5	6	7	8	9	10	Extreme

Reproduced from: Becker MO, Dobrota R, Garaiman A, et al. Development and validation of a patient-reported outcome measure for systemic sclerosis. Ann Rheum Dis 2022;81(4):507-15.

Visible disfigurement especially of the face and hands is common in scleroderma and has been associated with body image dissatisfaction and social discomfort. Body image is inherently personal and PROs have been developed and tested in scleroderma. In particular, the Body Concealment Scale for Scleroderma (BCSS) was developed to capture the unique body image concerns of scleroderma patients (Table 1).[11]

Many other PROMs cover a broad range of scleroderma patient experiences including breathlessness, gastrointestinal symptoms and hand function (Table 2). Most of the measures are limited to a single organ and are not specific to scleroderma. The EULAR ScleroID is a novel, disease-specific, composite PROM that was designed to capture the global burden of disease (Figure 5).[12] It consists of 10 items including pain and fatigue. Each of the items is weighted and the final score ranges from 0 to 10, with higher scores indicating worse disease. It is a promising new tool to capture patient experience in future studies of scleroderma.

Although there has been tremendous progress in measuring PROs in scleroderma in the last 2 decades, the disease-specific instruments developed with extensive patient input, in particular the ASRAP and EUSTAR ScleroID, have yet to be used in clinical trials. Those studies are highly anticipated.

PATIENT-REPORTED OUTCOMES IN SCLERODERMA: WHY IT MATTERS?

IMPORTANCE OF MEASURING PROS

PROs provide a unique opportunity to capture the personal experiences of scleroderma patients and add tremendous depth to our understanding of how they "feel and function", above and beyond standard biomedical measures of disease. PROs are used to identify research priorities of relevance to patients, to advocate for health care resources and for regulatory drug approvals. Although more work on PROs in scleroderma remains, the advances of the last two decades have given a voice to scleroderma patients that can only get stronger with time.

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Connections: Support Group

Looking Forward with Hope

THE POWER OF SUPPORT GROUPS

Our patient support activities are designed to build community, create connections, and provide support to those living with scleroderma. We know from research that peer support programs improve a person's ability to self-manage their disease and increase their self-esteem and confidence so that they can achieve specific goals.

Our Zoom meetings allow people from across the province to participate, but we are considering having some in-person meetings this year. 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 and Twitter.

MEETINGS PLANNED FOR 2023 & 2024

November 25, 2023
Time to share all our tips and ideas for managing life with scleroderma!

January 27, 2024
Financial Literacy
A virtual presentation about Qualifying for Borrowing, Coverages and the Registered Disability Savings Plan

Please email to **sclerodermamb@gmail.com**, or call **204-510-2855** for more information.

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

The National Scleroderma Foundation: scleroderma.org

Scleroderma News: sclerodermanews.com/

Stuff that Works: stuffthatworks.health/scleroderma/symptoms

Scleroderma Australia: sclerodermaaustralia.com.au

THE SCLERODERMA PATIENT-CENTERED INTERVENTION NETWORK (SPIN) PAIN PROJECT:

A Patient-Researcher Partnership


Tiffany Del Santo

Imagine living in a world where pain isn't just a symptom that pops up when you stub your toe or bang your knee, but is something that is always present and permeates into every aspect of your life. This is how it is for many people with scleroderma. In fact, a recent **SPIN study** found that people with scleroderma experience as much pain as people living with rheumatoid arthritis, a condition that is practically defined by pain.

Unlike people with rheumatoid arthritis, however, most people with scleroderma are not receiving help for their pain. Indeed, pain management was identified as a top intervention research priority by people with scleroderma in a patient – health care provider **survey**, but no health care providers who completed the same survey identified pain as a priority. Doctors don't ignore pain in scleroderma because they don't care. Many are simply not aware how bad pain can be for people with SSc, and there isn't much research on the topic. Consistent with this, no clinical trials in scleroderma have tested interventions to manage pain.

Pain in scleroderma is complicated. Unlike rheumatoid arthritis, where pain comes from inflamed joints, pain in scleroderma can come from many different sources and can look very different from one person to the next. One person might be dealing with severe pain from Raynaud's phenomenon and gastrointestinal symptoms, another might be dealing with sharp, acute pain from ulcers, and another might be dealing with some other combination of pain from these sources or others, such as dental pain or joint contractures.

Nobody has ever mapped the different sources of pain for people with scleroderma or investigated the nature and impact of these sources on how people live their lives. Thus, SPIN researchers are working together with a team of 7 patient partners, including Jo Ann Lapointe McKenzie of Scleroderma Manitoba, to develop a survey tool to map the important sources of pain for people with scleroderma, the nature of that pain – such as how constant or episodic it is and when it occurs, and how people attempt to manage their pain. Our team has created an initial version of this tool. Our next step is to get feedback from other people who live with scleroderma. Once we refine the tool based on this feedback, we will administer the final version to people from Canada and 4 other countries who participate in the SPIN Cohort.

Mapping the experience of pain in scleroderma will open the doors to investigations of treatments for different sources of pain, and, hopefully, lead to reducing pain for people who live with the disease. If you are interested in participating in the study or in other SPIN projects, SPIN would be happy to hear from you at **spingeneral@gmail.com**.

OVER THE PAST YEAR WE HAVE HELD THREE FUNDRAISING EVENTS

Our first ever Wing Night held in May;
our annual Walk in June;
and our Seed Campaign which began in June.

THESE EVENTS COMBINED HAVE RAISED A TOTAL OF $11,150

We raised **$11,150** Thank You!

We are so grateful to everyone who has generously supported our organization as it allows us to continue to address the needs of our community.

The Seed Campaign was accomplished with the assistance of Scleroderma Canada with the seeds and packaging donated by Stokes Seeds in Ontario.

Scleroderma is a chronic autoimmune connective tissue disorder that affects one in every 2,500 Canadians. It is caused by an overproduction of collagen resulting in thickening, hardening and scarring of tissues. It also affects major organs.

There is no known cause or cure to this disease.

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

Thank you to **Annette Desaulniers** from **Roseau River Manitoba** for sharing pictures of her beautiful sunflowers as they grew and began blooming.