

Newsletter Summer 2020

Scleroderma Manitoba Virtual Walk 2020



Congratulations to the patients, caregivers, and allies who walked hundreds of kilometers all over Manitoba and beyond during the month of June in support of Scleroderma awareness and

research. At publication date over \$21,000 has been raised— more than our net proceeds of our in-person 2019 Walk after expenses – a resounding success! Our walk included 7 Teams of 28 participants. Over 170 allies made donations, and donations are still coming in. The final total will be announced at our Annual General Meeting held at our virtual Education Day on October 3, 2020.



Twenty-seven walkers from the Smirnov and Ingram families in Assiniboine Park

Our walk is so much more than reaching a financial goal. It is an affirmation of the commitment of our Scleroderma community to see a future with a cure for this disease. It was a testament to the

determination of the members of our Scleroderma Community to walk and walk and walk even when everyday life is a series of adaptations. And, it was a great reminder that those of us living with



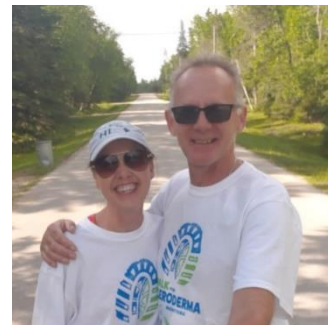
Patricia walked over 160 km!

scleroderma in Manitoba are not alone but members of a strong and supportive community.

The walk takes place during June - Scleroderma Awareness Month - and great strides in increasing education and awareness were made here as well. Sixteen walk t-shirts were distributed to new participants and supporters – all

helping to spread awareness about scleroderma.

Facebook was alive with posts of Walk pictures and proud commentary and, along with Twitter, 'followed' progress over the month. Our posts were targeted to raise awareness and increase understanding of scleroderma for a wider audience. The key to greater



The Penners helped raise awareness

awareness is more funding for research, improved treatments and knowledge in the medical community, and enhanced patient support.

Make sure to follow us on Twitter @MBScleroderma, and like our Facebook page: <https://www.facebook.com/sclerodermamanitoba> so you don't miss out on future information.



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Thank you to everyone who participated in our first, and hopefully only, virtual walk – it was an EXPERIENCE!

Canada Helps Scleroderma Manitoba Walk 2020 Donations

It is still possible to donate- follow this link :
https://www.canadahelps.org/en/charities/scleroderma-mb/?utm_expid=.Zw6wDABWRgyB0oPCIDzoRg.0&utm_referrer=https%3A%2F%2Fwww.canadahelps.org%2Fen%2Fcharities%2Fsclerodermamb%2Fp2p%2FWalk2020%2F#donate-now-pane

Scleroderma Manitoba Online

Check out the efforts of the Manitoba scleroderma community on:

Facebook <https://www.facebook.com/sclerodermamanitoba>

Twitter <https://twitter.com/MBScleroderma/>

For more information about Scleroderma Manitoba go to <https://sclerodermamanitoba.com>

Education Day

SAVE THE DATE! Scleroderma Manitoba is pleased to host an Education Day and Patient Forum on Saturday, October 3, 2020, 10:00 am to 12:15 pm CST. Due to Covid-19 and the ongoing risks of meeting inside in large groups, we will be hosting this meeting online, using the GoToMeeting platform.

The theme of our meeting this year is *Looking Forward with Hope*. Our keynote speaker will be the Chair of the Rheumatology Department at St. Joseph's Health Care, London - Dr. Janet Pope, one

of Canada's leading rheumatologists, who will speak on *How research into scleroderma is helping patients*. Dr. Pope will also join other rheumatologists and scleroderma researchers on a panel to present their view of the future of scleroderma research and take questions from our meeting attendees. Don't miss out on this opportunity to hear from some of Canada's top scleroderma specialists! *Please note: Those without computer access will be able to participate through the phone*. Registration information for the Education Day is coming soon.

Annual General Meeting

Our AGM (Annual General Meeting) will be held during our Virtual Education Day, on October 3. We encourage you to attend this meeting to stay abreast of what is happening in the scleroderma community in Manitoba, as well as to have a voice in the organization. This brief meeting will give you a say in the priorities of the board, as well as how research dollars are directed.

Holding an AGM online is challenging! How will the virtual AGM work?

- We will make every effort to keep the meeting as brief as possible (no longer than 15 minutes).
- Registration for the Education Day, and attendance at the AGM agenda gives you automatic membership and voting rights.
- The meeting will include brief reports from the Board of Scleroderma Manitoba.
- The Board has developed a revised By-Laws document to better reflect how our organization has grown since inception and to support more growth in the future. The

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revised By Laws document will be available for your review before the meeting.

- AGM attendees will be asked to vote on a motion to adopt the revised By Laws.

More detailed information, including relevant information you need to approve the Board's proposals will be coming soon.

Patient Support Group

One of the most important mandates for Scleroderma Manitoba is that of patient support. We have been holding patient support groups more regularly, and it is gratifying to see newly diagnosed patients, as well as those who have been living with scleroderma for decades, come together to share their concerns, questions, solutions, and ideas. Although each patient is unique, we all benefit from hearing about the experience of others.

On Saturday, May 9, Jo-Ann Lapointe McKenzie presented on Living with Chronic Illness. Her extensive experience in Nursing and in Healthcare Administration, as well as living with scleroderma made her uniquely qualified to lead us through this topic. Jo-Ann shared her own personal diagnosis story and shared an interesting concept for thinking about the work and effort required in managing life with scleroderma. She summarized there are 3 different types of work associated with a chronic disease : a) Life work- the work that everyone needs to do – employment work, washing the dishes, doing the laundry, grocery shopping, etc., b) Personal work - Personal maintenance, which requires many adaptations

when living with a chronic disease and c) Disease work – the extra work, time and effort we experience specific to managing our disease – extra appointments, managing prescriptions, medical files, etc. It is important to both acknowledge the extra workload, but also to be deliberate in determining the balance for these three “buckets” of work. Thanks to Jo-Ann for the interesting presentation.

On Saturday, July 11, we had an informal coffee and chat time. Some of us got to know each other a little better, shared some concerns, and suggestions and gave each other hope. That is what a support group is all about!

Our next support group (after the Education Day) is scheduled for November 14, 10:30 a.m. to noon. Watch the website, Facebook and twitter for more information.

The inability to meet in person due to the risks associated with Covid-19 has meant that we have shifted our meetings online. While we miss the camaraderie of in-person meetings, this shift has allowed greater access to those who live outside of Winnipeg, and/or do not have the ability to travel to a meeting. No matter what happens in the future, we will continue some mixture of online and in-person meetings to ensure greater inclusion. If you have any questions or ideas about the support groups, please email jbrydon@shaw.ca, or call 204 256-0225.

The Scleroderma Community Needs You! The Board of Scleroderma Manitoba is hard at work to increase awareness, provide education and patient support, and raise funds for scleroderma research. We need your help in

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supporting the board and strengthening the scleroderma community. ***Please consider joining the Board of Directors and applying your skills where they fit best.*** Due to online technology, you do not have to live in Winnipeg to participate! We estimate this commitment will take about 8 hours a month. Email us at sclerodermamb@gmail.com or call 204 417-6017.

THE BULLETIN

The Bulletin is a magazine put out by the alliance of

Scleroderma Manitoba, Quebec, and BC, in support of our mandate for education and building awareness about scleroderma. We hope you are enjoying receiving the



Bulletin. The Spring/summer issue included research updates from various scleroderma specialists across Canada. If you are not receiving The Bulletin, please send an email with your correct mailing address to: sclerodermamb@gmail.com.

Scleroderma Manitoba Supports the SPIN-CHAT “spin-off” SPIN-SHARE Program

In late June, Scleroderma Manitoba partnered with other regional patient organizations to help ‘jump-start’ the SPIN-CHAT research programs’ COVID-19 activities lead by Dr. Brent Thombs and his McGill research team. Since then, Dr. Thombs group reported that his group has received major funding from the Canadian Institutes of Health Research. Scleroderma Manitoba has agreed to have our funding applied to the SPIN-SHARE program that works to make sure that people with scleroderma can access the SPIN programs free-of-charge once the research stage concludes. Scleroderma Manitoba continues to support scleroderma research in Canada as part of its organizational objectives.

For more information on SPIN-SHARE project go to:

<https://www.spinsclero.com/news-media/2018/03/20/the-spin-share-projet-making-spin-s-online-support-programs-accessible-for-free>