

Scleroderma Manitoba Board

The Board has continued regular meetings during this troubling time by meeting electronically – and we are getting quite good at it.

Many decisions have been made about events and on-going activities in the time of physical-distancing. Look for updates under the headings of the **Annual Walk 2020, Education Day, AGM, and Support Group** in this newsletter.

The **Bylaws and Policy Development Committee** of the Board has revised the Scleroderma Manitoba By-Laws to clarify the Board structure, define membership, and state the functions of the AGM in clear terms. In addition this committee has developed a companion Board Governance Manual (BGM); an internal document describing the policies that will guide the operations of the organization. In many cases, the BGM reflects the policies that the Board has followed over the years. Some policies have been added to better reflect the growth that has occurred and to support growth in the future. The Board will recommend the adoption of the revised By-Laws at the AGM this year. In advance of the AGM, all members will receive a copy of the revised By-Laws for review.

Support Groups on Go To Meeting

The COVID crisis created the plan for virtual support group meetings. Coincidentally, the virtual format helps us meet our commitment to reach patients in more remote communities.

We are fortunate that the Support Group Leader, Jereleen Brydon, is technically savvy enough to set up an online environment with the Go To Meeting program. This virtual format, via internet or

telephone, will be in use until the threat of COVID-19 is gone and the public health directives allow for groups to meet.

Twelve people attended “virtually” at the March 14th meeting to connect and share our coping strategies for living with scleroderma. On April 4th Dr. David Robinson presented an overview of the current research on “The use of cannabis to treat symptoms of Scleroderma”.

Next scheduled meeting:

May 9th Jo-Ann Lapointe McKenzie, BScN, MN, will present “Living with Chronic Illness”. Retiring after 37 years in clinical nursing and health care administration, Jo-Ann was diagnosed with Scleroderma in 2009 and joined the Scleroderma Mb Board in 2019.

Plans for future meetings:

The hope is that by **November 14th** we will be able to meeting in person for a hands-on practice session regarding “**Wound Care for Fingers and Toes**”. This session will be led by a wound care specialist from the Winnipeg Regional Health Authority.

Whether newly diagnosed, or living with Scleroderma for some time, we encourage you to join the support groups and share your experiences. It is important to know you are not alone. If you are a new participant, contact jbrydon@shaw.ca for information on how to join the Virtual Support Group.

Education Day 2020 October 3, 2020

A proposal for the agenda and speakers for the 2020 Education Day was presented to the Board at the April meeting. Whether held “in-real-life” or virtually, this is a great event for you and your family to get information, and to meet others in

the Scleroderma community from around the province. Watch for an announcement about format in early July.

Annual General Meeting

The AGM will be held the same day as the Education Day. This year the agenda includes the election of new board members, ratification of the revised By-laws, and committee reports from Finance, Fundraising and Education/Patient Support Group. If the meeting is held in person or via the Go to Meeting program, all the necessary documents will be provided prior to the meeting.

Getting Creative in the Time of COVID-19 6th Annual Walk in the Park

This popular fundraising event will be held in June 2020. If the physical distancing regulations at that time allow large gatherings, we will meet again in St. Vital Park. The alternative plan is a **virtual walk**. What does that look like? Here is an example from 2019.



Just because we can't walk together in the park, we can walk (in spirit) with each other in different locations. Last year, Jereleen Brydon was travelling, so on the day of the walk, she and her husband

and travelling companions Eleanor and Dudley participated (and raised funds for Scleroderma MB) by touring Dublin on foot, proudly wearing their t-shirts.

More on this soon via the website, Facebook, and Twitter.

International Scleroderma Congress in Prague March 5-7, 2020 Cancelled

The COVID-19 pandemic forced all of us to change our professional life. After careful consideration and evaluation of the risks of the virus progression, the conference organizers have decided to cancel the face-to-face congress and to offer you a **virtual congress** experience. The congress will be available online probably on July dates and will be accessible on demand for several months. Further information will follow. The registrations confirmed for the congress will be automatically confirmed for the virtual congress. Abstracts of both oral and poster presentations will be available online. A discount of 40% on all registration fees will be applied.

The **7th edition of the congress in 2022 is confirmed to be in Prague**. Official dates will be announced soon.

Scleroderma Manitoba Answers SPIN Request for Funds

The Board approved a contribution of \$5000 for a SPIN (Scleroderma Patient-Centered Intervention Network) research project to understand the impact of COVID-19 on the mental health of people living with Scleroderma.

The Scleroderma Patient-centered Intervention Network (SPIN) is an organization of researchers, health care providers, and people living with scleroderma from around the world. Individuals and organizations involved in SPIN are working on a novel research project with the goal to develop, adapt and test new and existing programs to help people with scleroderma cope with their illness and manage their daily lives.

For more information: www.spinsclero.com

Ready to Welcome New Board Members

The Scleroderma MB board has openings for several important positions including Member At Large. As a part of the Board of Directors team, you'll learn more about the Scleroderma

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Scleroderma Manitoba: building Scleroderma awareness and to providing information and support to patients and their families and their support networks. Visit us at www.sclerodermamanitoba.com or call 204 417-6017

community here in Manitoba and make a real and lasting difference!

If you live outside Winnipeg, we can connect virtually on Go To Meeting. Contact Marion Pacy at 204 417-6017 or email sclerodermamb@gmail.com for more information.

Scleroderma Manitoba Mandate

- to build awareness of Scleroderma
- to provide information and support to patients and their families and supporters

Scleroderma Manitoba is a non-profit organization with provincial charitable status. We rely on donations to help fund awareness initiatives, patient support activities such as our **Patient Forum/Education Day** and **Support Group** meetings, and to support research that benefits Scleroderma patients. We look forward to your future support to Scleroderma Manitoba so that we may continue with awareness and research initiatives in Manitoba. Donate at www.sclerodermamanitoba.com or call 204 417-6017

Helpful Links

Scleroderma Patient Intervention Network (SPIN):

Scleroderma and Coronavirus: A conversation with the

Experts: <https://www.spinsclero.com/en/news-media/news>

Scleroderma Research Foundation:

Learn how to stay well during Covid-19, a webinar featuring Dr. Tracy Frech, Univ of

Utah: <https://srfcure.org/>

Covid-19 Updates:

<https://srfcure.org/wp-content/uploads/2020/04/Coronavirus-Info-SRF-3-30.pdf>

Scleroderma News Today

<https://sclerodermanews.com/information-about-covid-19-for-scleroderma-patients/>

American Autoimmune Related Diseases Association (AARDA)

National Briefing: CDC on Covid-19 and Autoimmune

Disease: <https://www.aarda.org/autoimmune-disease-covid-19/>

Looking Forward With Hope

Scleroderma Manitoba will continue to reach out to people living with Scleroderma, their caregivers, and health care professional to build a community of support throughout Manitoba.



CALL-OUT - THE SPIN-COVID-19 STUDY:

Mental health during the COVID-19 pandemic

SPIN invites you to participate in its most recent research endeavour! Whether you are a SPIN Cohort participant or not, you are invited to take part in the SPIN-COVID-19 Study.

Your answers will help us better understand the impact of the COVID-19 outbreak on mental health in people living with scleroderma. You may also be eligible to try out our new SPIN-CHAT Program [COVID-19 Home-isolation Activities Together]. Simply follow this link to find out more:

survey.col.qualtrics.com/jfe/form/SV_9pEX616Lo6t0fBz

Three SPIN-COVID-19 participants who complete all scheduled questionnaires will be randomly selected to win a **free trip to a scleroderma patient congress in 2021** (flight, hotel and conference registration).

www.spinsclero.com | [@spinsclero](https://twitter.com/@spinsclero) | [/spinsclero](https://www.facebook.com/spinsclero) | spincovid19@gmail.com | 1-800-370-5099 (US & Canada) | 01-86-26-53-61 (France)

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