



## Looking Forward with Hope

### NEWS FEB-MARCH 2021

#### Trustworthy COVID-19 Information

Below are some credible resources if you have questions about COVID-19 or the vaccines.

Scleroderma patients are encouraged to speak to your doctor before making any changes to your treatment.

#### The Scleroderma Patient-centered Intervention

Network "SPIN" <https://www.spinsclero.com/en/about>

Living with COVID weekly webinars (see *Calendar of Upcoming Events* pg. 2 for dates)

Go to the SPIN Facebook to register

<https://www.facebook.com/spinsclero/>

#### Cross-Canada Information Session

Panel discussion: Dealing with COVID & Vaccines (discussion held February 11, 2021):

<https://www.youtube.com/watch?v=UvECbVF-N24&feature=youtu.be>

#### Scleroderma Foundation

<https://www.scleroderma.org/>

COVID-2019 ("Coronavirus") Information and Recommendations

Questions and Answers Regarding the COVID-19 Vaccine from the Scleroderma Foundation Medical & Scientific Advisory Board Leadership Committee

#### Scleroderma News

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

Information About COVID—19 for Scleroderma Patients

#### American College of Rheumatology

[www.rheumatology.org](http://www.rheumatology.org) and specifically:

<https://www.rheumatology.org/Portals/0/Files/COVID-19-Vaccine-Clinical-Guidance-Rheumatic-Diseases-Summary.pdf> Recommendations for those with Rheumatic and Musculoskeletal Diseases regarding Covid vaccination, and immune-suppressant medications.

#### Canadian Rheumatology Association:

<https://rheum.ca/wp-content/uploads/2021/02/CRA-Recommendation-on-Covid-19-Vaccination-FINAL.pdf>

#### Scleroderma Manitoba

<https://sclerodermamanitoba.com/>

#### What is New at Scleroderma Manitoba

Some talented individuals have stepped forward to volunteer their time to help us better serve the scleroderma community in Manitoba

☀️ Welcome Jennifer Clarke, our new volunteer web manager extraordinaire, who has already improved our website navigation (better menu choices) and added more relevant content.

☀️ Martin Entz, Doug Watkinson and Dr. David Robinson are volunteering their time in the newly formed Research Committee to help us better solicit and assess scleroderma research proposals and distribute funds to support scleroderma research.

☀️ Please consider volunteering some of your time – we are always looking for talented people to join our board. If you do not wish to commit to a board position, please consider assisting with one of our committees (Education, Patient Support, Communications, etc.) – you can contribute your skills and time as you are able.

#### Keeping connected...

**Primary email:** Scleroderma Manitoba uses [sclerodermamb@gmail.com](mailto:sclerodermamb@gmail.com) Please update your contact list/address book.

#### Outgoing Emails:

Rob McKenzie, a board member, has volunteered to administer our mass email campaigns. You may get emails from this email address [rbm338@gmail.com](mailto:rbm338@gmail.com)

#### Our mailing address:

16 Carlington Crescent, Oak Bluff, MB R4G 0C5

**New permanent phone number:** 204 510 2855

#### Follow us...

**Facebook** [facebook.com/sclerodermamanitoba](https://facebook.com/sclerodermamanitoba)

**Twitter** @MBScleroderma

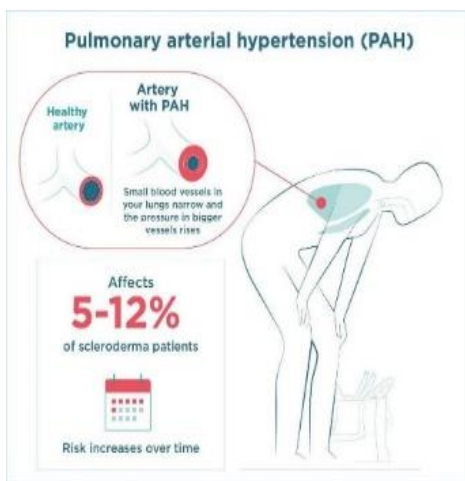
## Get Ready to Walk!



For the safety of our scleroderma community, we are once again planning for a Virtual Walk in June. This is our major fundraising event, and we hope that you will consider participating this

year. Funds raised in this walk enables patient support initiatives here in Manitoba, as well as supporting scleroderma research studies. Watch your email, our website, Facebook, and Twitter for ways in which you can participate.

**Cross-Canada Virtual Information Series:** Several provincial scleroderma patient organizations are pooling resources to offer a series of virtual support/educational meetings. Watch our website for dates and registration information as it is available.



Graphic from the Scleroderma Atlantic webinar held on February 21st: Scarring on the Lungs, and Pressure in my Heart: An Overview of Lung Disease in

Systemic Sclerosis with respirologist Dr. Vidyasankar.

<https://www.youtube.com/watch?v=XF8LhJTfjBY>

## Scleroderma Manitoba

Jo-Ann La Pointe Mckenzie, President  
204 510 2855

## Calendar of Upcoming Events

<b>February 28</b>	<b>International Rare Disease Day</b> <b>NEW DOCUMENTARY on A&amp;E</b> <b>Beyond Breathless</b> <b>A documentary featuring Queen Latifah &amp; NY Yankees legend Bernie Williams who both lost a parent to interstitial lung disease. Airing on Rare Disease Day 2/28 @12PM EST.</b>
<b>March 20</b> <b>10:30 am</b> <b>CST</b>	<b>Manitoba Support Group Meeting</b> <b>"Asking for help"</b> email <a href="mailto:jbrydon@shaw.ca">jbrydon@shaw.ca</a> , or call 204 256-0225
<b>March 10<sup>th</sup></b> <b>and 23rd</b>	<b>SPIN_CHAT Webinar: Worry management (Part 2) - Ghassan El-Baalbaki</b> Register at: <a href="https://www.facebook.com/spinsclero/">https://www.facebook.com/spinsclero/</a>
<b>March 17th</b>	<b>SPIN_CHAT Webinar: Relaxation techniques (Part 2) - Ghassan El-Baalbaki</b> Register at: <a href="https://www.facebook.com/spinsclero/">https://www.facebook.com/spinsclero/</a>
<b>March 23rd</b> <b>2:00 CST</b>	<b>Oral and Dental Care Webinar for Scleroderma Patients</b> hosted by Scleroderma Saskatchewan Virtual invitation TBC <a href="http://sclerodermasaskatchewan.ca">sclerodermasaskatchewan.ca</a>
<b>March 24th,</b>	<b>SPIN_CHAT Webinar Adapted home exercise (Part 2) - Kelsey Ellis &amp; Delaney Duchek</b> Register at: <a href="https://www.facebook.com/spinsclero/">https://www.facebook.com/spinsclero/</a>
<b>March 31st</b>	<b>SPIN_CHAT Webinar Home activity engagement (Part 2) - Laura Bustamante</b> Register at: <a href="https://www.facebook.com/spinsclero/">https://www.facebook.com/spinsclero/</a>
<b>April 7th</b>	<b>SPIN_CHAT Webinar: Worry management (Part 3) - Ghassan El-Baalbaki</b> Register at: <a href="https://www.facebook.com/spinsclero/">https://www.facebook.com/spinsclero/</a>
<b>April 14th</b>	<b>SPIN_CHAT Webinar: Adapted home exercise (Part 3) - Kelsey Ellis &amp; Delaney Duchek</b> Register at: <a href="https://www.facebook.com/spinsclero/">https://www.facebook.com/spinsclero/</a>
<b>May 15</b> <b>10:30 am</b> <b>CST</b>	<b>Manitoba Support Group Meeting: Topic TBC</b> email <a href="mailto:jbrydon@shaw.ca">jbrydon@shaw.ca</a> , or call 204 256-0225
<b>June</b>	<b>Scleroderma Awareness Month</b> <b>International Scleroderma Awareness Day (June 29)</b> <b>Fundraising Walk for Scleroderma Manitoba Date TBD</b>