

Looking Forward With Hope NEWS

Connecting the Manitoba scleroderma community and beyond: Patients, Caregivers, and Allies

A publication of Scleroderma Manitoba Inc.

February 2022

News

February is Rare Disease Month, and Scleroderma Manitoba in partnership with Scleroderma Canada is happy to present a Virtual fund-raising Trivia Night event on Saturday, February 19 at 6 pm CST. Registration for a household is \$25 and \$20 from each ticket sold will count as a charitable donation to support Scleroderma Manitoba. You can join camera on or off from the comfort of home, participate as much as you'd like, and win prizes by chance rather than by score! There will be door prizes, and more. Get ready to answer Canadian, general and scleroderma trivia questions, have some fun, and support our community in Manitoba too!

For more info, visit sclerodermamanitoba.com.



Update on the Walk for Scleroderma Manitoba

Planning is underway for this important annual event. While we are hoping to hold in-person walks this June, the Walk team is planning a hybrid event in case we must stay virtual due to Covid concerns and patient safety.

While virtual walks can be held throughout the month of June (Scleroderma Awareness Month), in-person walks are tentatively scheduled for Sunday, June 26. Watch our website and stay tuned for more information.

Mark Your Calendar!



Our Support Group continues to meet virtually reaching out across Manitoba. Our next meeting is scheduled for **Saturday, April 23 at 10:30 am**.

Whether you or a loved one are newly diagnosed, or have been living with scleroderma for some time, it is important to connect with others who know what you are experiencing, and we share and support each other. Patients, caregivers, family members, friends and allies are all welcome.

Future Meetings are scheduled for September 17, and November 26 in 2022. For more information, visit sclerodermamanitoba.com, or call 204 256-0225.

February is a busy month: It is both Rare Disease Awareness Month, and Raynaud's Awareness Month. February 28th is Rare Disease Day.

Watch for our [Facebook](#) and [Twitter](#) (@MBScleroderma) postings.



Patient Community Support – #YouAreNotAlone



On Saturday, January 22, approximately 20 community members joined together for small group discussions. After introducing ourselves, and a brief practice session with online breakout rooms, we separated into smaller groups to discuss different symptoms of scleroderma. Participants were able to choose the topic of their choice by choosing a breakout room. Topics were: Fatigue, Reynaud's/Finger and Toe Sores, Lung Issues, Gastrointestinal issues, and Pain and Stiffness.

Meeting in a smaller group enabled us to share our experiences, ask questions, and compare coping strategies. After a 20-minute discussion, we reconvened in the “main meeting room” and the four facilitators gave a brief summary of the discussions. We then chose a different topic/symptom to discuss and held another 20-minute small group discussion group.

The groups came up with many coping strategies. For a full summary of the discussions, visit sclerodermamanitoba.com

Thank you to Linda Cassell, Linda Clark, Debbie Robitaille for facilitating some great discussions and Dianne Brydon for technical support that helped us all get into the breakout room we wanted.

Join us for our next Support Group meeting on Saturday, April 23rd. Watch our website for more info and a registration link.

Community Connections



A Pioneer of AWARENESS... was the headline of an article in the Free Press on February 7 featuring Marion Pacy, Past President and long-time volunteer and board member with Scleroderma Manitoba.

The article celebrated Marion's lengthy commitment to raising awareness of the disease and providing support to patients and their families since 1994. We share a deep gratitude for the work she has been doing on behalf of us all.

For those wishing to read the article, you can [find it here](#).

Join us! We are seeking volunteers with a background in education and fundraising to join the Scleroderma Board as members-at-large. If this sounds like you, or you'd like more information, please contact us at sclerodermamb@gmail.com or call 204 510-2855.

Patient Poll



We want to hear from you! Answer our Patient Poll Question and enter your name for a prize. This issue's question:

“On what topics do you need more or better information as you live with Scleroderma?”

We will use your answer to guide the content of our website, newsletters, patient support group topics, and social media focus. **Respond by:**

email: sclerodermamb@gmail.com | **phone:** 204 510-2855 | **mail:** 16 Carlington Cres. Oak Bluff MB R4G 0C5

Coping and Conquering



With smaller mouths and less functional esophagus', soup can be an ideal meal for scleroderma patients.

Enjoy this hearty and delicious recipe for Roasted Butternut Squash Soup with Curry Condiments, from *Barefoot Contessa Back to Basics*, by Ina Garten.

Roasted Butternut Squash Soup and curry condiments

From: *Barefoot Contessa Back to Basics* by Ina Garten

Ingredients

3 to 4 pounds butternut squash, peeled and seeded
2 yellow onions
2 McIntosh apples, peeled and cored
3 TBSP good olive oil
Kosher salt and freshly ground black pepper
2 to 4 cups chicken stock
½ to 1 tsp good curry powder

Condiments for serving

Green onions, white and green parts, trimmed and sliced diagonally
Flaked sweetened coconut, lightly toasted
Roasted salted cashews, toasted and chopped
Diced banana

Instructions

- i) Preheat the oven to 425 degrees
- ii) Cut the butternut squash, onions and apples into 1-inch cubes. Place on a sheet pan, and toss with olive oil, 1 tsp salt and ½ tsp pepper. Divide the squash mixture between 2 sheet pans and spread in a single layer. Roast for 35 to 45 minutes, tossing occasionally until very tender.
- iii) Meanwhile, heat the chicken stock to a simmer.
- iv) When the vegetables are done, put them in batches through a food processor with the steel blade. (Add some of the chicken stock and coarsely purée). Place the processed vegetables in a large pot and add enough chicken stock to make a thick soup.
- v) Add curry powder, 1 tsp salt and ½ tsp pepper. Taste for seasonings to be sure there's enough salt and pepper to bring out the curry flavour.
- vi) Reheat and serve hot with condiments either on the side or on top of each serving.

Notes

- ☀ Look for pre-cubed butternut squash in the produce section or buy frozen.
- ☀ Use parchment paper on sheet pans for easier clean up.
- ☀ I use the full 4 cups of chicken stock.
- ☀ I use at least 1 tsp curry powder.
- ☀ I like to add all four condiments for sweetness and texture.