

FROM RESEARCH TO REAL LIFE:

HOW SPIN SUPPORTS THE SCLERODERMA COMMUNITY



The **Scleroderma Patient-centered Intervention Network (SPIN)** is a Canadian-led research network. SPIN's mission is to learn about challenges faced by real people with scleroderma and to build, test, and share resources to address these challenges.

SPIN researchers and patient partners work together closely to make sure SPIN studies address real patient needs. This includes partners from Scleroderma Manitoba. As a result, SPIN is a **world leader** in research that matters to people with scleroderma.



SPIN provides training for support group leaders, has a free [online hand exercise program](#), and will soon be offering a scleroderma self-management program.

SPIN and Scleroderma Manitoba have **partnered** on two recent initiatives, "***What's New in Scleroderma Research***" and "***The Patient's Pick***".



What's New in Scleroderma Research: *An Online Event for Patients & Families*

SPIN invited patients and family members from **across the world** to attend a free, online, videoconference research event. The goal was to **present recent scleroderma research in a clear and practical way**. SPIN patient partners picked the studies that were presented. More than 200 people attended. Attendees were able to ask the researchers questions. They also rated the presentations. These ratings will help researchers **learn how to communicate better with patients**. What a nice way to learn about important scleroderma research!



THE PATIENT'S PICK: RESEARCH UPDATES



This past December, **SPIN** launched *The Patient's Pick: Research Updates*. The goal of this initiative is to **provide patients with updates on the latest scleroderma research**. The research shared is chosen by patient partners. *The Patient's Pick* presents research updates in a short, clear, patient-friendly format. SPIN also asks for patient feedback after each update. This helps SPIN researchers to **learn how to best communicate research results with our community**.



Want to receive short scleroderma research updates by email every couple of months? Email info@spin-sclero.com

WHY THESE PROGRAMS MATTER

What's New in Scleroderma Research and ***The Patient's Pick*** are important because they give patients easy access to research results. With these projects, SPIN supports patients to better understand research findings.

This highlights the **good things that are happening in scleroderma research**. And, it helps SPIN to improve how we share research results in clearer and more patient-friendly ways. **This is how SPIN brings research to real life!**