



A Special COVID-19 Thank You from the SPIN Team to Our Scleroderma Community

Dear Friends,

Two important events occurred recently. One was the 3-year anniversary of the declaration of COVID-19 as a pandemic here in Canada. The second was a publication by one of the “non-SPIN” parts of our team here in Montreal of the [most comprehensive review of evidence on COVID-19 mental health](#) in the world in the British Medical Journal.

In that review of the evidence, we examined almost 95,000 studies for relevance and included results from all 137 studies in the world that have compared mental health from people prior to the pandemic to mental health from those same people during the pandemic. We found that overall mental health has not changed as much as people thought; when we detected changes, they were not very large. The pandemic has been a difficult experience for many of us, and people have sustained important losses. Most of us have faced major challenges, including emotional challenges. Some have struggled with mental health, beyond our normal negative emotional reactions to difficult situations, but, overall, there has been a lot of resilience, and people have done a lot of good things to support each other. This part of the story has often been forgotten.

One part of our review that most people did not notice, is that only one study in the world tracked how people were doing before the pandemic and then at regular intervals across the pandemic. This study was our [SPIN COVID-19 Cohort study](#). Almost 800 people with scleroderma signed up for this study at the beginning of the pandemic, and many continued to complete surveys about their experience during COVID-19 all the way through to August 2022 when we closed the study. We found that anxiety spiked at the beginning of the pandemic then returned to pre-COVID-19 levels by mid-2020 and has stayed there ever since. Depression did not change from prior to the pandemic. We are updating the study and have found that fear and loneliness were at their peaks in the first months of the pandemic but have come down since then. These findings are averages, and we know that some people did better and some worse. But it is clear that there was a lot of resilience in our community too, despite special challenges, and that people did a lot to help each other out.

Our COVID-19 team has also reviewed [all the trials of COVID-19 mental health interventions](#) that have been conducted around the world. We reported in a 2022 article that there were only 3 high-quality trials of these interventions that were designed specifically for COVID-19. One was a large trial of an internet tool for COVID-19 anxiety conducted by Swedish researchers in partnership with the Swedish government. The second was a creative intervention done by researchers in Texas to address loneliness among older adults who received meals through the Meals on Wheels program. The third was our own [SPIN-CHAT Trial](#).

In the SPIN-CHAT Trial, members of the SPIN Team and our patient partners put forth Herculean efforts and worked with lightning speed to put together the program and get it to people early in the pandemic. We went from an initial idea to meeting with our COVID-19 Patient Advisory Team, developing a programme and trial strategy, obtaining ethics approval and initial funding, and launching the trial in about 3 weeks. In April and May 2020, 172 people with scleroderma were able to participate in a 3 times per week program that lasted for 4 weeks. Sessions included fun activities (led by a recreational therapist), strategies for mental health coping (from health professionals) and group support (led by trained support group leaders).

The program resulted in reduced anxiety for participants and showed what a small and determined group of people can achieve! A unique feature of the program was that it blended professional mental health education and skills training with peer support groups led by trained members of our community. This is something that, quite literally, would only be possible in scleroderma – we are the only community in the health world with a cadre of well-trained peer support group leader volunteers who were ready and willing to take this on (see information on SPIN-SSLED below)!

As I reflected on these achievements this week, which were highlighted by our COVID-19 evidence reviews, I realized that SPIN has done a lot more during the pandemic. Indeed, there was much more:

- In partnership with Scleroderma Canada and others, SPIN hosted a series of COVID-19 informational webinars to link patients and Canadian and international experts, including [Scleroderma and COVID-19: A Conversation with the Experts](#) (March 21, 2020; 210 attendees); [COVID-19 and Vaccines](#) (February 11, 2021, 100 attendees); [Facing Post-COVID-19 Frontiers for People Living with Scleroderma: What Do I Need to Know?](#) (April 12, 2022; 65 attendees).
- In April 2020, SPIN collected input from 121 people with scleroderma on their fears in the first weeks of the pandemic and developed the [COVID-19 Fears Questionnaire](#) that allowed SPIN and other researchers to consider the role of COVID-19 fears in people's experiences during the pandemic.
- SPIN Investigators published the only large study, which included over 900 participants, on the experiences and perceptions of [COVID-19 vaccination in scleroderma](#). We found that most people had gotten vaccinated, that few had changed their medications before receiving a vaccine, and that side effects were generally minimal and similar to those experienced in the general population. A follow-up study is currently being completed.
- SPIN completed a trial of our 13-session [SPIN-SSLED Support Group Education Program](#). Leading support groups can be a tricky task for group leaders, who are also living with a bad, burdensome disease, and our program was designed to provide skills to do this more effectively and, hopefully, with less burden for leaders. This was the first trial with any patient group in the world that tested a support group leader training program. We found that SPIN-SSLED substantially increased trainees' confidence that they have the skills and knowledge to lead successful groups. Even the most experienced leaders who did the training made huge gains. We have continued to provide training since the trial finished and have now trained over 200 support group leaders from more than 10 countries. We are also providing ongoing monthly booster sessions for program graduates. Thanks to Laura Dyas from Michigan, the United States, for her stellar training and to Violet Konrad (Sclérodemie Québec) who stepped up to lead our French-language training groups.
- SPIN Investigators completed and published the [largest study of pain in scleroderma ever](#), which included over 2200 participants from the SPIN Cohort. We found that pain levels in scleroderma are similar to those in rheumatoid arthritis, which is known for pain, and we identified disease manifestations, such as joint contractures, digital ulcers, and gastrointestinal symptoms that are associated with greater pain. This led to our forming a SPIN Pain Patient Advisory Team and obtaining funding to do more work on pain in scleroderma. We are working with our patient partners to better understand people's experience with pain and develop a scleroderma-specific assessment tool that will, hopefully, lead to more research and better pain management for people with scleroderma.
- We conducted an initial test of our [SPIN-SELF scleroderma disease management program](#) and are preparing for our full-scale trial. SPIN-SELF is an 8-week videoconference-based program that provides tools for coping with a range of scleroderma challenges in a warm and friendly group setting, led by a trained member of our scleroderma community. We will be opening enrollment for the full trial soon!

Believe it or not, that is not all the SPIN Team has done during the pandemic! Members of the team have been busy behind the scenes, as well, doing the development work that leads to new projects.

So, how is it that, as a small community of people with a rare disease, we could accomplish all of this? I first began to work with people in our community in 2006 and quickly found myself in meetings where I met dedicated and enthusiastic patients like Maureen Sauvé, Marion Pacy, and Shirley Haslam, as well as patient advocates like Bob Buzza. It is not hard, even many years later, to remember some of the things they said and did that inspired me then and continue to inspire today. Over the years, members of our team have been fortunate to get to know many people in our community and to make many lasting friendships – and we are inspired every day by what people out there in our community are doing.

There is no other place like ours – our community is remarkable in what it achieves through its tremendous patient organizations, active patients, and smart and dedicated leadership. My colleagues with SPIN and I live this every day and know how fortunate we are to be a part of this community. Everything that SPIN accomplished during COVID-19 was possible only because of our community and because so many people gave of themselves and pitched in to make it happen.

So, congratulations to everybody in our community on all that we have been able to achieve together! No other rare disease group has done anything like this. We cannot begin to thank everybody, including the thousands of people living with scleroderma who participate in SPIN studies, as well as health professionals and other personnel at [SPIN sites in 7 countries around the world](#). Please know that we are deeply grateful for all that you do. Meanwhile, we want to recognize some of the people and organizations, listed below, who pitched in to make SPIN's COVID-19 work possible.

If you live with scleroderma, and you would like to join us, either by participating in the SPIN Cohort or in another way, please send us an email (spingeneral@gmail.com).

Thank you!

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