



The Scleroderma Patient-
centered Intervention Network

January 2023

Progress Report



Hôpital général juif
Jewish General Hospital
Fondation | Foundation

SPIN is an organization of researchers, health care providers, and people living with scleroderma from around the world. Our mission at SPIN is to work with people living with scleroderma to identify their needs and prioritize research in the areas most important to them, as well as to develop, test and distribute programs that improve their quality of life.

SPIN has had considerable success in funding its research in a highly competitive environment. However, research funding does not cover the costs associated with the project development process, nor the ongoing dissemination of SPIN post-research programs.

SPIN would like to express its deepest gratitude to our patient partner organizations, whose support over the years has enabled the development and/or completion of several SPIN projects. We are fortunate to have you as valued partners! We look forward to continuing our work to fill the gaps in scleroderma knowledge, advancing research and producing patient-friendly resources to improve patient quality of life.

THANK YOU!



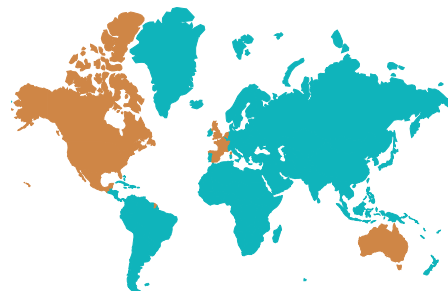
INTERNATIONAL COHORT

SPIN COHORT Patient Recruitment

The SPIN cohort was established in 2013 and now has over 1400 patients. Its longevity is possible thanks to the incredible work of over 90 researchers and clinicians, in 49 treatment centers from around the world.

The dedication of people living with scleroderma to advancing research is also a key factor in this success!

Thanks to the efforts of all our collaborators, experts, patients, and partner organizations, SPIN has been able to publish numerous studies from the analysis of cohort data.



1 464 participants

7 countries

49 recruitment sites

SPIN studies published recently using cohort data

Mental health care utilization and associated factors in systemic sclerosis: a Scleroderma Patient-centered Intervention Network Cohort study : [here](#)

Barriers and facilitators to physical activity for people with scleroderma: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort study : [here](#)

Pain intensity and interference levels and associated factors in systemic sclerosis: a cross-sectional study of 2157 participants from the Scleroderma Patient-centered Intervention Network (SPIN) Cohort : [here](#)

Pain and self-efficacy among patients with systemic sclerosis: A Scleroderma Patient-centered Intervention Network (SPIN) Cohort study : [here](#)

Assessing Differential Item Functioning for the Social Appearance Anxiety Scale A Scleroderma Patient-centered Intervention Network (SPIN) Cohort Study : [here](#)

Physical or occupational therapy utilization in systemic sclerosis: a Scleroderma Patient-centered Intervention Network Cohort study : [here](#)

Factors associated with patient reported likelihood of using online self-care interventions: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort study : [here](#)

The Scleroderma Research Topics Survey for patients and health care professionals: A Scleroderma Patient-centered Intervention Network (SPIN) project : [here](#)

Shortening patient-reported outcome measures through Optimal Test Assembly: Application to the Social Appearance Anxiety Scale in the Scleroderma Patient-centered Intervention Network Cohort : [here](#)



PATIENT PROGRAMS



SPIN-HAND

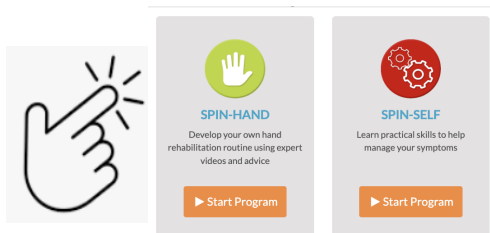
- Functional impairments of the hands are common in people living with scleroderma.
- The SPIN-HAND toolkit is the only program in the world designed specifically for scleroderma hands, with exercises to improve hand function.
- The toolkit includes instructional videos and sections to help patients develop a personalized routine, set goals and track their progress.
- SPIN-HAND has been distributed free of charge to over 500 members of the scleroderma community via tools.spinsclero.com/en

Some publications related to SPIN-HAND:

Feasibility trial protocol: [here](#)

Feasibility trial results: [here](#)

Full-scale trial results: *Trials*. In press.



SPIN-SELF

(Disease self-management)

- Improving disease self-management is essential for people living with a chronic disease.
- The SPIN-SELF toolkit is specifically designed to help people with scleroderma better manage certain common symptoms (fatigue, pain, itching, skin care, changes in physical appearance, etc).
- The first SPIN-SELF feasibility trial was conducted with 40 participants, giving them access only to the online toolkit, but few used it.
- The second feasibility trial was launched in September 2021 (80 participants). This new iteration of the program includes 8 group videoconferences, in addition to online access to the toolkit.
- The full-scale randomized trial will begin in 2023.

Some publications related to SPIN-SELF:

Feasibility trial protocol: [here](#)

1st feasibility trial results: [here](#)

Feasibility trial protocol with progression to full-scale trial: [here](#)



SPIN-SSLED

(Support group leader education program)

- The SPIN-SSLED Support Group Leader Education Program (13 sessions) is the only evidence-based program of its kind for people living with a disease (all diseases included).
- SPIN-SSLED provides information, resources and training to effectively facilitate support groups for people with scleroderma.
- Over 200 support group facilitators have now been trained by SPIN, and post-training support is also provided monthly to SPIN-SSLED graduates.

Some publications related to SPIN-SSLED:

Non-randomized feasibility trial results: [here](#)

Randomized controlled trial protocol: [here](#)

Randomized controlled trial results: [here](#)



SPIN-CHAT

(Reducing isolation during the pandemic)

- The SPIN-CHAT trial tested a program to reduce social isolation during the early weeks of the pandemic.
- A total of 172 participants from 12 countries were recruited for this trial.
- Divided into subgroups, the participants met virtually 3 times a week for 4 weeks.
- The results show that the program significantly reduced symptoms of anxiety and depression among participants.

Read the results of the study published in *Lancet Rheumatology*: [here](#)



OTHER PROJECTS



SPIN-VAX

(COVID-19 vaccination and scleroderma)

- This study investigated experiences and perceptions of vaccination among participants in the SPIN-COVID-19 cohort.
- The study found that a smaller proportion of the cohort was hesitant to get vaccinated compared to the general population.
- Additionally, the results showed that only a small percentage of participants needed to change their medication before receiving the vaccine.
- The side effects of the vaccine experienced by the participants were very similar to those experienced by the general population.
- No major side effects were reported.
- As of May 15, 2021, 75% of participants had received at least one dose of the vaccine.

Read the results of the study published in *Lancet Rheumatology*: [here](#)



MENTAL HEALTH

(Scleroderma and mental health before and during the pandemic)

- This study was the first to report changes in the mental health status of vulnerable individuals with pre-existing illness.
- The study investigated levels of anxiety and depression among participants in the SPIN-COVID-19 cohort, many of whom are also participants in the regular SPIN cohort, for which we have pre-pandemic data.
- The results show that symptoms of depression remained more or less consistent, both before and during the pandemic.
- In contrast, anxiety symptoms increased in the early months of the pandemic and then declined to pre-pandemic levels in the summer of 2021.

Read the results of the study published in *Lancet Rheumatology*: [here](#)



WORK AND EMPLOYMENT



SOURCES OF PAIN



PAIN LEVELS

- Scleroderma impacts the ability to work, but little research has been done on work and disability in people with scleroderma.
- SPIN researchers from Canada, the Netherlands and Australia have developed a study to assess and collect data on work and employment among people with the disease.
- This study will examine factors associated with employment and disability that could be targeted to improve the ability to work for people with scleroderma.
- Pain is very common in people with scleroderma and reduces their ability to carry out daily activities.
- There is little research on pain in scleroderma patients, much less than in other diseases that cause similar levels of pain, such as rheumatoid arthritis.
- SPIN is working to develop a research program that will help us better understand the sources of pain, its characteristics and effective management options.
- This study measured pain levels and the interference of pain with daily activities among members of the SPIN cohort.
- The study found that the majority of participants live with pain on a daily basis and that it interferes with their daily activities.
- Pain is associated with certain manifestations of the disease such as joint contractures, digital ulcers and gastrointestinal symptoms.
- The study concludes that pain is a common phenomenon in people with scleroderma and should be considered in the treatment of patients.

Read the results of the study published in *Lancet Rheumatology*: [here](#)



OTHER PROJECTS



SPIN-DINE

- Many resources on nutrition are available, but very few are specific to the management of gastrointestinal symptoms in people with scleroderma.
- This study identified the resources used by scleroderma patients to obtain information about nutrition and diet, and the perceived advantages and disadvantages of these resources.
- This is the first study aimed at identifying nutrition information resources for people with scleroderma.

Read the results of the study : [here](#)



ORAL HEALTH

- Oral health is an essential component of overall health for people with scleroderma.
- SPIN has identified an array of academic articles to begin addressing oral health issues.
- This study aims to identify what research has been conducted on oral health and where the gaps are in the current literature.
- This will allow us to conduct relevant SPIN studies on oral health and will help other researchers to initiate clinical research.
- We hope to contribute to the establishment of appropriate oral health care for people with scleroderma.



ENGAGING PATIENTS IN RESEARCH

- Patients are at the heart of everything we do, and SPIN is a leader in the development of research in partnership with patients and patient organizations.
- Despite this, SPIN hopes to do even better and aims to constantly improve the way we involve patients in our projects, as well as how we communicate the results of our research to them.
- This project includes 1) a synthesis of the evidence on patient involvement in research and on communication of results, and 2) the development and evaluation of various communication tools.
- This work will enable patients to participate more effectively in scleroderma research, and will help researchers and patient organizations better communicate research findings to patients.



RESILIENCE

- Resilience reflects the ability to adapt to life's obstacles and maintain good mental health despite adverse circumstances.
- In the case of scleroderma, resilience varies widely among individuals with similar disease characteristics, but factors associated with resilience as well as strategies to support resilience have never been studied.
- This study will first validate a questionnaire on resilience with participants of the SPIN cohort, and then identify factors that can positively or negatively influence resilience.



FUTURE PATIENT PROGRAMS



SPIN-COACH

(Coping appearance changes)

- This project focuses on how changes in physical appearance impact people with scleroderma.
- The program includes two modules that focus on managing negative thoughts and increasing self confidence in social situations.
- Our creative team will soon start designing animations to accompany the modules.
- The randomized trial of the SPIN-COACH program will begin in 2023.



SPIN-COPE

(Coping with emotions)

- This program contains 7 modules, each addressing an aspect of the emotional burden associated with scleroderma, such as worry, depressive thoughts, and anger management.
- The majority of the SPIN-COPE program modules have been finalized and the online program will be developed in the coming years.



SPIN-PACE

(Increasing physical activity)

- We conducted interviews with patients to identify the barriers and facilitators to physical activity.
- In October 2019, we invited SPIN cohort participants to complete a survey to assess the importance of 20 barriers to physical activity and the likelihood of using certain facilitators.
- These results will help us develop an online program to support physical activity in people with scleroderma.

Some publications related to SPIN-PACE :

Interview results: [here](#)

Survey results: [here](#)

Honouring Joep Welling's involvement with SPIN

For the past 12 years, SPIN has had the honour of counting Joep Welling as part of its most precious patient collaborators. Joep has decided to step down from SPIN's activities to focus on his health.

Over the years, Joep displayed unwaivered and inspirational dedication to SPIN's mission in progressing research dedicated to scleroderma patients. From contributing to all SPIN projects as a member of the Steering Committee, to travelling to Paris to film videos for the SPIN-HAND intervention, Joep's input and help on SPIN's projects were always greatly appreciated.

Joep was the proud recipient of the first Maureen Sauvé Inspiration Award in 2018.

Joep, you will always be a pillar for the international scleroderma community. We consider ourselves lucky to have had the opportunity to work with you for so many years. Thank you!

The SPIN Team

Thank you,
Joep

