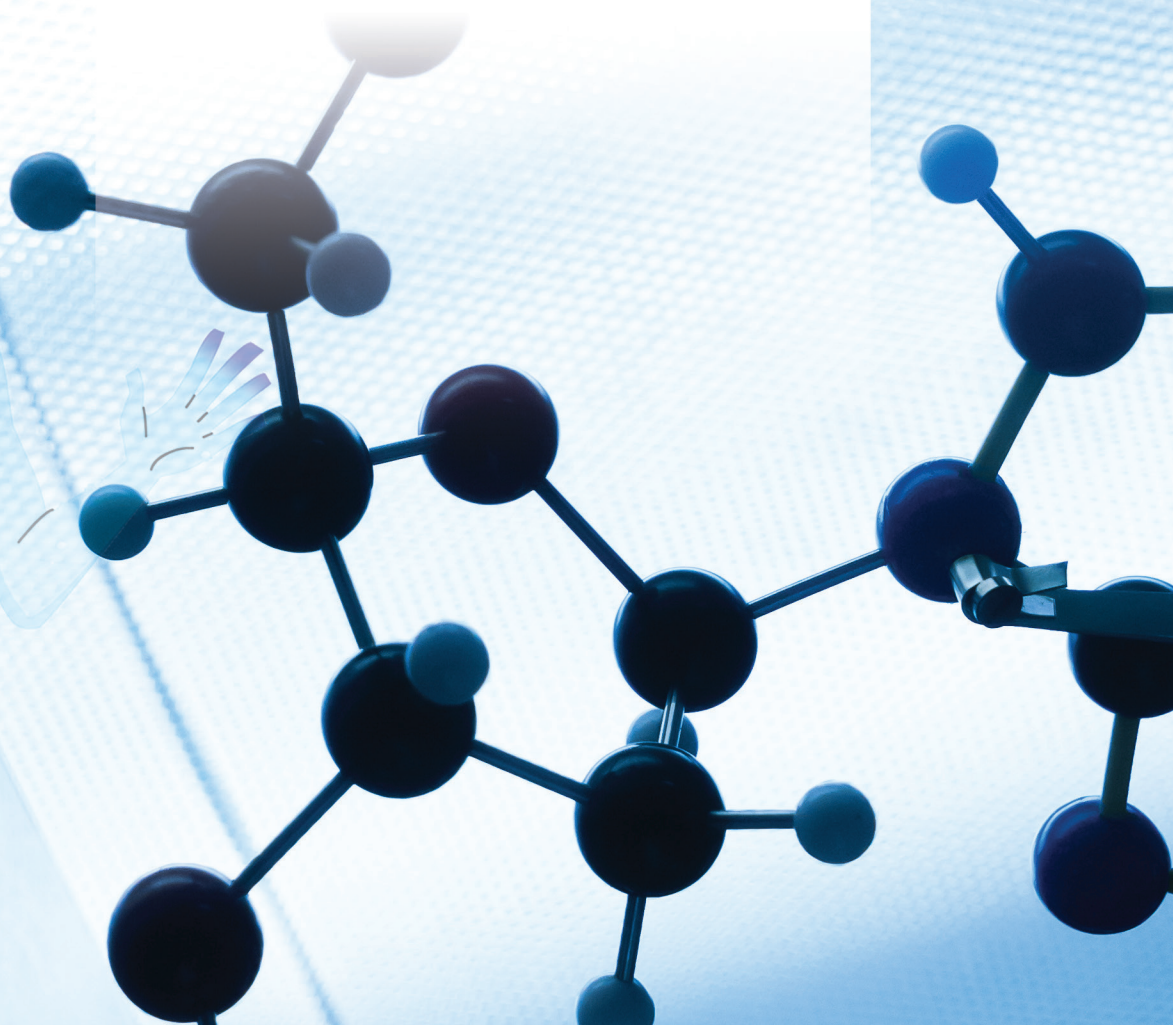
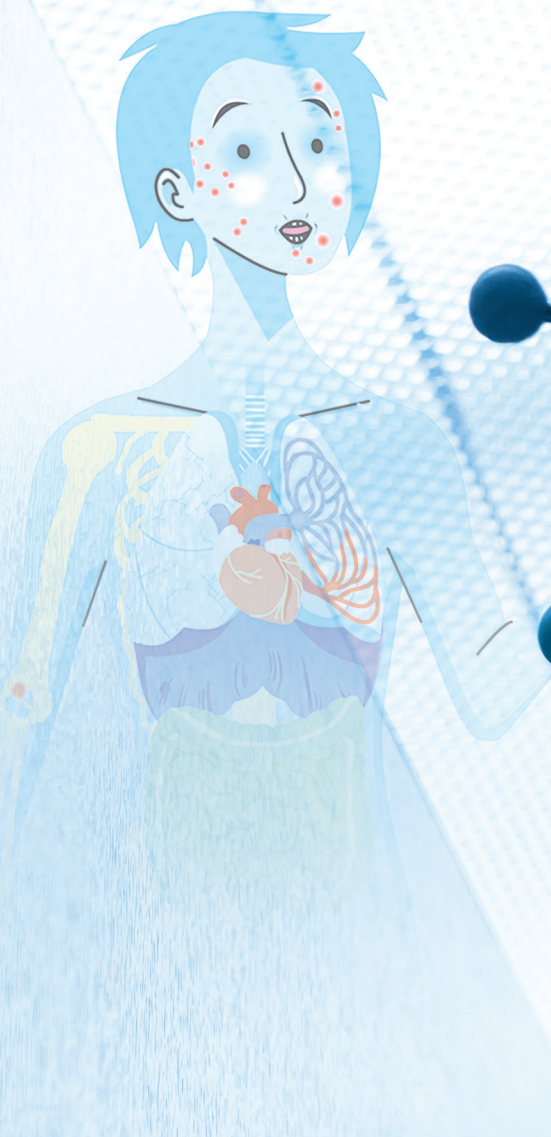




Scleroderma Quebec
Activity Report

**2021
2022**





We are pleased to present the 2021-2022 activity report of Scleroderma Quebec. In this report, you will find the organization's main achievements as well as some testimonials from our members and caregivers.

We are very proud of the new initiatives developed this year despite the constraints imposed by the COVID-19 pandemic, particularly the production of a scleroderma medication guide as well as a guide for the volunteers of our support network.

When we take stock of the work accomplished over the past few years, we can only rejoice in the progress made, in keeping with the objectives of our threefold mission. Since its founding in 1989, Scleroderma Quebec has become the leading French-language source of public information on scleroderma and support for scleroderma patients in Canada. A leader in funding cutting-edge scleroderma research, Scleroderma Quebec has contributed more than \$3 million in research support to date.

RESEARCH SUPPORT

During this fiscal year, Scleroderma Quebec renewed its financial support to three major research groups in the field of scleroderma in Quebec.

The Scleroderma Research Chair at the University of Montreal, a philanthropic chair established in 2005 at the instigation of Scleroderma Quebec and Dr. Jean-Luc Senécal, in partnership with the University of Montreal, its Faculty of Medicine, the CHUM and the *CHUM Research Centre (CRCHUM)*. Research is conducted in close collaboration with the *CHUM Research Centre's Immunoregulation Laboratory*, directed by Dr. Marika Sarfati, and the *Autoimmunity Research Laboratory*, directed by Dr. Senécal.

The Canadian Scleroderma Research Group (CSRG) at the Jewish General Hospital in Montreal, in partnership with McGill University and the Lady Davis Institute for Medical Research (LDI) in Montreal, was established in 2004. The CSRG maintains a registry of data collected from a large number of patients. Researchers who are conducting several promising research projects in scleroderma benefit from the valuable data stored in the registry.

The Scleroderma Patient-Centered Intervention Network (SPIN), led by Dr. Brett Thombs, affiliated with the Jewish General Hospital and McGill University. SPIN's mission is to work with people with scleroderma to disseminate accessible interventions that improve their quality of life and increase their independence.



Scleroderma is a very complex disease, and the many symptoms and manifestations demonstrate the growing need for clinical and basic research in scleroderma. Fortunately for patients, specialized researchers from the University of Montreal Scleroderma Chair, the *Canadian Scleroderma Research Group (CSRG)* and even from abroad, regularly work in close interinstitutional collaboration, which is a valuable advantage.

The principal investigators in charge of research projects also obtain the collaboration of associate investigators, often within a multidisciplinary and interinstitutional framework, to increase the possibility of completing projects within the established deadlines.

As such, we are proud to have been able to contribute in 2022 to several research projects, including:

- A clinical research project on interstitial lung disease associated with scleroderma. Dr. Sabrina Hoa of the CHUM, an interinstitutional collaboration, including researchers from the CSRG.
- A research project on muscle involvement in scleroderma (Scleromyositis). Dr. Océane Landon-Cardinal of the CHUM, an interinstitutional collaboration.
- A new research protocol at the *CHUM Immunoregulation Laboratory*, aimed at characterizing the global immune landscape of scleroderma and pre-scleroderma and establishing the immune identity map at the molecular and cellular level in individual scleroderma patients. Dr. Sarfati, Dr. Metha, Dr. Hoa, Dr. Koenig and Dr. Sénécal.
- A *Scleroderma Patient-Centered Intervention Network (SPIN)* research project to better understand pain, including sources and possible remedies. Dr. Brett Thombs, Jewish General Hospital, Lady Davis Institute for Medical Research (LDI).
- And we have renewed our financial support for the maintenance of the CSRG database. Dr. Marie Hudson, Jewish General Hospital.

In addition, several reports on the progress of scleroderma research can be found under the Research tab on our website www.sclerodermie.ca/en/.



Testimonial

I would also like to pay tribute to the staff of Scleroderma Quebec for their support and great professionalism.

Today, my scleroderma seems to me like a spider that has settled inside of me. I understand that I will always have to use all the tools at my disposal for my well-being and serenity.

MARIE-ANDRÉE PÉPIN, The Bulletin, Spring-Summer issue 2022

INFORMATION AND EDUCATION

Scleroderma Quebec publishes **THE BULLETIN** twice a year to inform people living with the disease, the general public and health care professionals about the latest developments in research and cutting-edge treatments, as well as the organization's activities. With a print run of 6,000 copies, it is distributed to more than 4,000 physicians and healthcare professionals throughout Quebec.

In addition, we have intensified the production of our educational fact sheets, which now include 20 sheets on a variety of topics related to scleroderma, including its forms, symptoms and various organ involvements. We are also continuing to develop educational fact sheets that will be published by next spring. Like the first series, the new sheets will be available in both French and English, on our website or by mail upon request.

One of the highlights this year was the development of the Scleroderma Medication Guide in collaboration with medical specialists and a pharmacist. While there is no cure for scleroderma, there are effective treatment options to help reduce symptoms and slow the progression of the disease. This guide, which is available in both French and English on our website, is a popular resource for patients and healthcare professionals.

AWARENESS

June, Scleroderma Awareness Month, is a great time to inform as many people as possible about the existence of this disease and the vital importance of research to find a cure. Scleroderma Quebec is particularly active in June on social media. Also, an awareness day at the Quebec National Assembly was held on June 1, 2022, to remind Members of Parliament that scleroderma is an autoimmune disease that has devastating effects on the health of many Quebecers.

Scleroderma Quebec has reactivated its virtual platform, **Challenges for Scleroderma**, which was launched in the spring of 2021 and allows people to create and manage their fundraising campaigns for the organization. People interested can mobilize their network by creating a donation drive or a personal or group challenge. Current fundraisers are posted on www.defissclerodermie.ca. In addition to being an excellent opportunity to show solidarity, this annual campaign aims to raise awareness about scleroderma, raise crucial funds for cutting-edge research and provide services to people living with scleroderma.



Testimonial

An infinite thanks to Scleroderma Quebec for existing! Without the valuable, relevant and easy-to-understand documentation received, without the conferences and the incomparable support of the team, my mother and I would never have known about scleroderma and the disease would undoubtedly have progressed dangerously.

CAROLINE CÔTÉ, The Bulletin, Fall-Winter 2021-2022 issue



MUTUAL AID AND SUPPORT

Building on the success of its *Patient Forums* held in the past year, Scleroderma Quebec has decided to repeat this rewarding experience. Patients were invited to participate in the forums and ask their questions to the speakers. Three *Patient Forums* were held in the spring of 2021, and topics covered included COVID-19 vaccination and scleroderma, lung disease and scleroderma, and cellular therapies for the treatment of scleroderma.

A new series of *Patient Forums* began in June 2022, the first of which focused on pulmonary **fibrosis associated with systemic scleroderma**, conducted by **Dr. Christophe He**, respirologist, CIUSSS of the Eastern Townships, CHUS and assistant Professor, FMSS, at the University of Sherbrooke. This Forum ended with a physical exercise session, given by **Christophe Tousignant**, a physiotherapy technologist.

Two other *Patient Forums* were held this fall: **Bone Health and Scleroderma** has been conducted and moderated on October 7, 2022, by **Dr. Sabrina Hoa**, a rheumatologist and clinical researcher at the CHUM Research Center.

Pain management has been conducted and moderated on November 10, 2022, by **Dr. Anne-Marie Pinard**, anesthesiologist in chronic pain, holder of the Teaching Leadership Chair (TLC) on chronic pain - MEDISCA, a researcher at CIRRIIS and full professor, Department of Anesthesiology and Intensive Care at Laval University.

Those interested can register for our free virtual *Patient Forums* on our website at www.sclerodermie.ca.

Our support groups held several virtual meetings, facilitated by volunteer resource persons. Also, the Eastern Townships support group organized two virtual meetings with Mr. Ghassan El-Baalbaki, a professor at UQAM's Psychology Department, who presented a conference on the topic of anxiety and breathing as well as mental imagery.

New self-help groups have been formed since the beginning of the year: a support group for men and a support group that organizes evening and weekend meetings.

To support and equip the resource persons in our support network, we have just written a guide to help them in their support tasks with people with scleroderma and their caregivers. A big thanks to our wonderful volunteers who help us provide services to people living with scleroderma and their informal caregivers.

Testimonial

|| *Scleroderma Quebec helps me by providing a home base, a good listening ear, good advice and the opportunity to share with other women and men struggling with this mysterious condition.*

MARIE F. BOLDUC,
www.sclerodermie.ca/en/support-and-assistance/testimonials-faces-of-hope/



FUNDING

The 20th edition of the friendly golf tournament organized by Éric Canuel, Luc Tétréault and Richard Tremblay was held last June. We salute the dedication of these volunteers who, over the years, have built strong ties with the participants, partners and members of our organization. A warm thanks to all of you!

Due to the pandemic, our in-person fundraising events have been replaced in 2021, as well as in 2020, by a virtual donation campaign. Thanks to the generosity of our donors and partners, we have been able to renew our support for cutting-edge research and publish new information tools for Quebecers so that they can deepen their understanding of scleroderma and make informed decisions about their journey with the disease. We would like to extend our deepest thanks to the volunteers of our fundraising campaigns for their incredible involvement.

This year, Scleroderma Quebec's Annual Benefit Evening was held on October 18 at the Montreal Cabaret Casino and marked our return to in-person activities. The fundraiser was even more successful than previous editions, allowing us to deliver on our commitment to support world-class research, right here in Quebec.

In closing, we would like to take this opportunity to express our warmest thanks to all the members of the Board of Directors of Scleroderma Quebec, the members of the Honorary Committee of our fundraising campaign, our partners, our donors and our volunteers for their unwavering commitment and generosity. We can't thank you enough for your unfailing support and dedication. It is people like you that make it possible for Scleroderma Quebec to move forward and continue its mission.

With all our gratitude,

Handwritten signature of Gaétan Baril in black ink.

GAÉTAN BARIL
President
Scleroderma Quebec

Handwritten signature of Diane Collard in black ink.

DIANE COLLARD
Executive Director
Scleroderma Quebec



Testimonial

The day I realized that a team of doctors and researchers were working together to find treatments for the disease, I felt very reassured. I felt less afraid and less alone dealing with the disease and more confident about the future.

LOUISE BOURGAULT,
www.sclerodermie.ca/en/support-and-assistance/testimonials-faces-of-hope/