



Scleroderma Quebec  
**Activity Report**

2020  
2021

We are proud to highlight Scleroderma Quebec's main achievements for the year 2020-2021 in the following areas of activity: research support, patient support, information and education, awareness and funding.

Since its inception in 1989, Scleroderma Quebec has become the leading source of French-language public information on scleroderma and support for scleroderma patients in Canada. A leader in funding cutting-edge scleroderma research, Scleroderma Quebec has contributed to date nearly \$3 million in research support.

#### **SUPPORT FOR SCLERODERMA RESEARCH**

Scleroderma Quebec is proud to have been able to provide substantial financial support to the main research groups in the field in Quebec, including:

- ▶ **The University of Montreal Scleroderma Research Chair**, 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). Clinical, basic and translational research is carried out in close collaboration with the Immunoregulation Laboratory of the CHUM Research Centre, directed by Dr. Marika Sarfati, and the Laboratory for Research in Autoimmunity (LABRAI), CRCHUM, directed by Dr. Senécal.

Chairholder Dr. Jean-Luc Senécal, a world-renowned rheumatologist, was invited by the chief editors of the international periodical *Journal of Scleroderma and Related Disorders* to submit an article on the pathogenic role of autoantibodies in scleroderma. New criteria for assessing the pathogenicity of autoantibodies are proposed in the article published in 2020 and 15 autoantibodies were reviewed and graded for their pathogenic role in the disease. This is an important recognition of the expertise of the Scleroderma Research Chair.

One of the highlights of the spring of 2021 was the fundraising campaign driven by Scleroderma Quebec with

Canadian scleroderma associations to enable the acquisition of the BD Rhapsody platform for the CRCHUM. Thanks to this successful national effort and an outstanding donation from a Scleroderma Quebec member, this state-of-the-art device has been installed at the Scleroderma Research Chair. The Rhapsody is a single-cell analysis system that identifies the expression of genes across tens of thousands of single cells in parallel. Like the FACSymphony with which it works in tandem, the Rhapsody requires access to valuable biological samples from patients. This instrument allows us to analyze the complete transcriptomic signature (all genes) of each cell identified by certain phenotypic criteria (determined with the FACSymphony). We can therefore identify each cell by its external (surface proteins) and internal (gene expression) characteristics.

A recent report on research progress from the University of Montreal Scleroderma Research Chair is available on our website at [www.sclerodermie.ca](http://www.sclerodermie.ca) under the “Research” tab, and in the Spring/Summer 2021 edition of Scleroderma Quebec’s magazine *Le Bulletin*.



*Photo of the Rhapsody device and its Rhapsody Express module, installed at the Immunoregulation Laboratory on the 12<sup>th</sup> floor of the CHUM Research Center.*

« I would like to express my deepest gratitude to Scleroderma Quebec, its Board of Directors, its President Gaétan Baril and its members for their unwavering and generous support of clinical and basic scleroderma research at the CHUM under the aegis of the Research Chair. Thanks to this support, which has allowed the acquisition of cutting-edge technology, our research team has made significant progress in understanding the pathogenic mechanisms of scleroderma. This is now leading us to an innovative research approach potentially aimed at the prevention of certain internal manifestations of scleroderma and the development of a personalized therapeutic approach.

**Jean-Luc Senécal, MD, FRCPC, MCRA**

- August 12, 2021

- ▶ **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 in Montreal, was established in 2004. The CSRG maintains a registry of data collected from a large number of patients and several scleroderma research projects benefit from the data contained in this valuable registry.
- ▶ **The Scleroderma Patient-centered Intervention Network (SPIN)**, led by Dr. Brett Thombs, is affiliated with the Jewish General Hospital McGill University. Its mission is to work with people living with scleroderma to develop, and disseminate accessible patient intervention programs that improve quality of life and empower people with scleroderma and their loved ones.
- ▶ **Lady Davis Institute for Medical Research** for the project entitled *Precision Medicine in Cellular Epigenomics* led by Dr. Celia Greenwood who has assembled a team of experts to develop an algorithm and software package to analyze large-scale, high-dimensional DNA methylation data, so that we can profit from the hidden potential of these data.

## INFORMATION AND EDUCATION

Scleroderma Quebec publishes **LE BULLETIN** twice a year, in the spring and fall, to inform patients, the general public and health care professionals about the latest research developments and promising new treatments. With a print run of 6,000 copies, it is distributed to more than 4,000 physicians and healthcare professionals in Quebec.

Also, we have created a series of 17 educational fact sheets on several scleroderma-related topics, including its forms, symptoms and various organ involvements. They are available on our website, in French and English, or by mail upon request. These fact sheets meet the needs not only of patients but also of healthcare professionals.

## AWARENESS

In June of each year, we usually organize several charity walks. Much more than a fundraiser, the event helps to raise awareness of the disease among the general public. Unfortunately, the pandemic has prevented us from meeting in 2020-2021, but that's only a temporary setback. Last June, Scleroderma Quebec has devised imaginative ways to develop a new fundraising approach. People interested can mobilize their network by creating a donation drive, or by planning and carrying out a personal or group challenge. Current fundraising events are posted on [www.sclerodermachallenges.ca](http://www.sclerodermachallenges.ca).

« Last year, the SPIN-CHAT trial, including nearly 200 people, showed that our SPIN-CHAT group intervention was an effective source of mental health support in the early stages of the pandemic. And this year, SPIN is launching a randomized trial of a scleroderma self-management program to help people with scleroderma cope with the most difficult aspects of the disease.

None of this would be possible without the financial support and partnership of Scleroderma Quebec, which has worked with SPIN every step of the way to ensure that all Quebecers benefit from the SPIN programs!

**Brett D. Thombs, PhD**

- August 16, 2021

« The support of Scleroderma Quebec allowed us to develop a new method for analyzing methylation data (the addition of a methyl molecule to a cytosine in DNA, which can block access to the DNA by other molecules). This method has been shown to be much more powerful in identifying factors that can alter the epigenome. (The epigenome is the set of epigenetic modifications to DNA, or changes in gene activity.

**Celia Greenwood, PhD**

**James McGill, Professor**

- August 13, 2021



## MUTUAL ASSISTANCE AND SUPPORT FOR PATIENTS

Building on the success of the four Patient Forums held in the fall of 2020, Scleroderma Quebec decided to repeat this rewarding experience by organizing three new virtual forums. Patients were invited to participate in the forums and to ask questions to the speakers. The different topics covered in the spring of 2021 were the following:

- ▶ **COVID-19 vaccination and Scleroderma**, presented by **Dr. Ines Colmegna**, Rheumatologist and Associate Professor, Division of Rheumatology, McGill University Health Centre; **Dr. Marie Hudson**, Rheumatologist at the Jewish General Hospital, Epidemiologist and Full Professor, Department of Medicine, McGill University; and **Dr. Gerasimos J. Zaharatos**, attending physician at the Jewish General Hospital, Assistant Professor, Division of Infectious Diseases, Department of Microbiology, McGill University;
- ▶ **Pulmonary fibrosis and Scleroderma**, presented by **Dr. Geneviève Dion**, Respirologist at the Quebec Heart and Lung Institute Research Centre;
- ▶ **Cellular Therapies in the Treatment of Scleroderma**, presented by **Dr. Marie Hudson**, Rheumatologist at the Jewish General Hospital.

As these webinars have been very popular, a new series is planned for 2022.

Our patient support groups have also adapted to hold several virtual meetings, led by our volunteer group leaders in the Eastern Townships, Outaouais and Montreal. Also, the Eastern Townships support group organized a virtual meeting in April 2021 with Mr. Ghassan El-Baalbaki, a professor in the psychology department at UQAM, who gave a lecture on the topic of anxiety.

« Thanks to research support from Scleroderma Quebec and its members, we are pushing the boundaries of knowledge about interstitial lung disease (pulmonary fibrosis), in order to predict at disease onset which patients are at risk of developing progressive lung disease and when is the optimal time to treat and prevent this progression. Research gives us hope that one day the treatment of scleroderma will be aimed at the prevention of complications rather than palliation.

**Sabrina Hoa, MD, MSc, FRCPC**  
- August 13, 2021



« I would like to thank Scleroderma Quebec for its invaluable support to research that has led to a better understanding of the clinical features of muscle involvement in scleroderma, to the discovery and characterization of new autoantibodies and the identification of a vasculopathic signature in the muscle biopsies of patients. This will improve the early identification of these muscle disorders to improve the clinical management and prognosis of patients.

**Océane Landon-Cardinal, MD, FRCPC**

- August 13, 2021

« Much more than research funds, Scleroderma Quebec allows me to give hope to my patients. This is invaluable.

**Marie Hudson, MD, MPH, FRCPC**

- August 13, 2021

« Thanks to the unwavering support of Scleroderma Quebec, the recent acquisition of new state-of-the-art equipment, the Rhapsody, in combination with the FACSymphony, allows us not only to progress in our research on the immunopathogenesis of scleroderma but also to offer the necessary support for the basic research component of the projects for which we have initiated very promising productive collaborations.

**Marika Sarfati, MD, PhD**

- August 13, 2021

## FUNDING

### Due to the pandemic:

The 19<sup>th</sup> edition of the golf tournament organized by Éric Canuel, Luc Tétréault and Richard Tremblay, was transformed into a round of golf that was a great success. In 19 years, this event has raised \$213,560.

Our annual fundraising events in Montreal and Quebec City were replaced in 2020 by a virtual fundraising campaign. Thanks to the members of our Honorary Campaign Committee and our generous donors, the goal of \$200,000 in donations was largely exceeded, as we raised more than \$300,000. This is truly a huge success despite the pandemic! We hope that the new fundraising campaign launched last June will be just as successful, allowing us to continue our commitment to support world-class research conducted right here in Quebec.

We would like to take this opportunity to extend our warmest thanks to all the members of Scleroderma Quebec's Board of Directors, the members of our Honorary Campaign Committee, our partners, our donors and our volunteers for their invaluable contributions and generosity.

With all our gratitude,

**GAÉTAN BARIL**  
President  
Scleroderma Quebec

**DIANE COLLARD**  
Executive Director  
Scleroderma Quebec