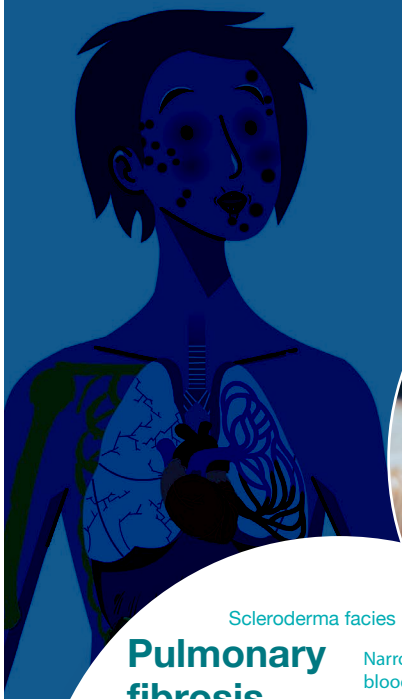
Activity Report 2022-2023

Scleroderma Quebec™



Scleroderma facies

Pulmonary fibrosis

Narrowing of blood vessels

Raynaud's Phenomenon

Skin hardening

Digital ulcers

Pulmonary arterial hypertension (PAH)

Renal crisis

Pain in joints and muscles

Calcinosis

Gastrointestinal disorders

Skin pigmentaion

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INTRODUCTION

Scleroderma Quebec is pleased to share with you its Activity Report for 2022-2023, which reflects our steadfast commitment to our tripartite mission. As we reflect on our work over the past few years, we are proud of how far we've come. At the heart of our mission, Scleroderma Quebec is fully committed to providing community support to people living with the disease, as well as to their families and loved ones.

Since our inception in 1989, Scleroderma Quebec has established itself as the leading source of French language public information on scleroderma. As a leader in funding cutting edge scleroderma research in Canada, we have committed over three million dollars to support numerous research initiatives. This demonstrates our commitment to advancing the understanding of this disease and providing critical financial support for the discovery of effective treatments. Our determination to invest in research, in collaboration with experienced investigators and renowned institutions, is aimed at improving the quality of life and life expectancy of people affected by scleroderma. Together, we can push the boundaries of knowledge and pave the way for innovative, life changing treatments.

In addition to our commitment to supporting research, we have also strengthened our role as an essential resource for patients and their families. Our services include valuable assistance, educational resources and a support network, enabling those affected by the disease to find the help they need.

HERE ARE SOME OF THE MAIN COMMUNITY SUPPORT ACTIVITIES CARRIED OUT BY SCLERODERMA QUEBEC OVER THE PAST YEAR

SUPPORT GROUPS

Our support network is made up of 14 dedicated and skilled volunteers. Our group leaders are trained through a partnership with the Scleroderma Patient-Centered Intervention Network (SPIN). Some of them organize virtual and face-to-face meetings across Quebec, enabling people with scleroderma to break their isolation, find answers to their questions about the disease or their well-being, and ultimately improve their quality of life.

These meetings allow people affected by scleroderma to come together to share experiences, gain information and support each other. These groups create a safe, caring space where participants can freely express their concerns, ask questions and benefit from invaluable peer support.

PERSONALIZED SUPPORT

Scleroderma Quebec offers personalized support to people with the disease who need specific information, advice or guidance. This can be done through telephone hotlines, emails or referrals to specialized health professionals. Our goal is to be sensitive and responsive to patients' concerns about their disease and treatment.

We would like to express our sincere gratitude to the invaluable volunteers in our support network, the true pillars of our mission. It is through their unwavering dedication that we can provide essential services to people living with scleroderma and their loved ones. "Our volunteers are not alone. They are supported by our dedicated staff, who create an environment where every gesture counts," says Gaétan Baril, President of the organization. It's because of this harmonious collaboration between our volunteers and our team that we are able to make a real and positive difference in the lives of those affected by the disease. Thank you all for your invaluable contribution.

EDUCATIONAL RESOURCES

The organization provides scleroderma educational resources in English and French, including brochures, pamphlets and fact sheets. These resources are designed to help people with scleroderma better understand their disease, manage their symptoms and make informed decisions about their health. They are also available to families and healthcare professionals.

AWARENESS

Scleroderma Quebec conducts awareness activities to increase the visibility of scleroderma and to help improve the general population's knowledge of this complex disease. Our commitment to public awareness and education also remains a priority as we seek to increase the understanding of scleroderma in society.

In addition, an awareness day was organized at the Quebec National Assembly on May 10, 2023, to remind parliamentarians that scleroderma is an autoimmune disease that has a devastating impact on the health of many Quebecers.

Since 2020, Scleroderma Quebec has been fully committed to organizing awareness campaigns on social media. Our efforts have paid off: to date, we've reached an impressive **354,763 people**. Our organization is particularly active during the month of June, which is dedicated to scleroderma awareness. As part of this initiative, last June we ran a successful campaign on the social networks Facebook and LinkedIn with a quiz based on our educational factsheets.

INFORMATION

We're pleased to announce that our bilingual website, **www.sclerodermie.ca**, was a huge success last year, attracting no less than **222,681 visitors**. This number demonstrates the growing importance of scleroderma and the public's increasing interest in our platform. Thanks to our informative, accessible content in French and English, we've been able to reach a wide audience and offer much needed support to those affected by this autoimmune disease. We look forward to further strengthening our impact and continuing to educate and inform the public about this multifaceted disease through our ongoing commitment to providing quality resources for the scleroderma community.

PATIENT FORUMS

Last year, Scleroderma Quebec successfully organized the 4th edition of its Patient Forums. Extremely popular with the scleroderma community, these virtual events proved to be an invaluable experience for the organization. Patients were invited to participate in these free 90 minute forums. These sessions were a great opportunity for participants to ask questions to expert speakers.

Here is a brief overview of the patient forums presented:

- On June 9, 2022, **Dr. Christophe He**, Respirologist, CIUSSS de l'Estrie, CHUS and Assistant Professor, FMSS, at the University of Sherbrooke presented **La fibrose pulmonaire associée à la sclérodermie systémique (Pulmonary fibrosis associated with systemic scleroderma)**. The Forum closed with an exercise session led by **Christophe Tousignant**, physiotherapy technologist.
- On October 7, 2022, **Dr. Sabrina Hoa,** Scleroderma Research Chair at the University of Montreal, presented and moderated a Patient Forum on **La santé osseuse et la sclérodermie (Bone Health and Scleroderma)**.
- On November 10, 2022, the **Gestion de la douleur (Pain Management)** was presented and moderated by **Dr. Anne-Marie Pinard,** chronic pain anesthesiologist, CLE holder in chronic pain Medisca, CIRRIS researcher and full professor, Department of Anesthesiology and Intensive Care, Laval University. Dr. Pinard outlined key theoretical concepts about pain and gave a few tips on how to better manage it. Then one of her doctoral students, **Pascale Marier-Deschênes**, presented her new platform, which includes exercises and a wealth of useful information to support people suffering from chronic pain.
- On May 10, 2023, **Dr. Océane Landon-Cardinal**, a rheumatologist at CHUM, presented and moderated **La scléromyosite : une atteinte spécifique de la sclérodermie systémique** ***(Scleromyositis: a specific disorder of systemic scleroderma)***, which drew 175 participants. **Dr. Landon-Cardinal** also answered more than 60 questions during the forum.

These must attend patient forums are held several times a year and bring together more than a hundred participants from Quebec, France and other French speaking countries. They generate a great deal of enthusiasm among participants, who leave happy and satisfied with their experience.

This fall, we plan to organize two new Patient Forums on scleroderma related topics.

ACTIVITIES PROGRAM

We also organize activities to promote the well-being and quality of life of scleroderma patients. These include workshops on anxiety management, breathing and mental imagery, healthy eating information sessions, and recreational outings.

These community support activities run by Scleroderma Quebec are essential in helping people with scleroderma and their families. They aim to create a strong support network, to inform and educate, and to improve the quality of life of those affected.

PUBLICATIONS

We have stepped up the production of educational factsheets, currently numbering around 30, covering a wide range of topics related to scleroderma, including its different forms, symptoms and associated complications. We continue to produce educational factsheets, which are also published on our website.

Scleroderma Quebec publishes ***THE BULLETIN*** twice a year to keep patients, the general public and healthcare professionals informed of the latest advances in research and cutting edge treatments, as well as the organization's activities. With a print run of 6,000 copies, it is sent to 4,000 medical specialists and healthcare professionals in Quebec, as well as being distributed to our members and donors.

2024 NATIONAL SCLERODERMA CONFERENCE

Given the growing popularity of the Patient Forums and the ever increasing number of requests, Scleroderma Quebec decided to create a unifying event that would allow all stakeholders to exchange ideas. It is with great pride that we announce that the first ever **Scleroderma Quebec National Conference** will be held on June 14 and 15, 2024 at the Hilton Hotel in Quebec City. We've worked tirelessly over the past year to develop this event and make it a reality. A dedicated website, ***(conferencenationalesurlasclerodermie.ca)***, will be launched this autumn to provide quick and easy access to registration and all relevant information.

The main objective of this flagship event is to promote in-person meetings between patients, physician researchers, healthcare professionals and organizations working in the healthcare field. The event will also provide an opportunity for interaction between our Board of Directors and members of our organization, as well as participants. We firmly believe that this unique event will allow us to exchange knowledge, share experiences, and build strong relationships so that we can combine our efforts in the fight against scleroderma.

OUR SUPPORT TO RESEARCH

During the current fiscal year, Scleroderma Quebec renewed its financial support to the main Quebec research groups in this field.

- **The University of Montral Scleroderma Research Chair** was established in 2005 through the initiative 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). The research is closely linked to the **CRCHUM's Immunoregulation Laboratory**, directed by Dr. Marika Sarfati, and the **Autoimmunity Research Laboratory**, directed by Dr. Senécal.

- **The scleroderma research team at the Sir Mortimer B. Davis Jewish General Hospital**, administered by CIUSSS *(Centre intégré universitaire de santé et services sociaux* Centre-Ouest-de-l'île-de-Montréal).

- **The Canadian Scleroderma Research Group (CSRG).**

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

Scleroderma is a highly complex autoimmune disease, and its many symptoms and manifestations highlight the need for a multidisciplinary approach to clinical and basic research. Fortunately for patients, specialized researchers at the UdeM (CHUM) Scleroderma Research Chair, the Sir Mortimer B. Davis Jewish General Hospital, and the Canadian Scleroderma Research Group are working together to find a cure. The Sir Mortimer B. Davis Jewish General Hospital and the Canadian Scleroderma Research Group (CSRG) are working together on numerous research projects, often in close inter-institutional collaboration, which is a significant benefit to patients.

In this Activity Report, we are pleased to provide an overview of the research being carried out by the scientists we support through our philanthropic efforts. Our mission is to foster major advances in the understanding and treatment of scleroderma. This report highlights our ongoing support of innovative projects led by outstanding researchers, with the ultimate goal of providing greater help to those affected by the disease. By investing in this research, we are actively contributing to tangible progress that will significantly impact patients and their families.

CRCHUM's Immunoregulation Laboratory, led by Dr. Marika Sarfati, conducts in-depth research into autoimmune diseases. These diseases occur when a person's immune system, which is supposed to protect us, mistakenly attacks the body's own tissues. The team focuses on rare conditions such as scleroderma, prescleroderma and Raynaud's phenomenon, which primarily affect the skin, connective tissues and blood vessels.

To find out why, researchers are using sophisticated techniques to study the cells and molecules involved in the immune system. In 2022, they will recruit more than 30 patients suffering from scleroderma and Raynaud's phenomenon and take samples of their blood and skin. The goal is to create a complete "identity card" of each patient's immune system by examining in detail the different immune cells and active molecules.

To achieve this, they use cutting edge techniques such as immunophenotyping to help identify different cell types, and transcriptome analysis to understand which genes are active in each cell. By combining these methods, the team is able to obtain a complete picture of the immune system.

Their studies don't stop there. They have added a new technique to visualize where immune cells are located in tissues, using special equipment to detect proteins and genes. This will help them better understand how cells interact in the body.

In 2023, they will continue their research by analyzing even more patient samples. They want to find out how these diseases develop and how to treat immune problems. The first important results will be shared with other scientists at conferences. These discoveries could pave the way for new treatments for people with prescleroderma or established scleroderma.

Dr. Sabrina Hoa, a leading rheumatologist at the University of Montreal Health Centre (CHUM), has devoted the past several years to scleroderma research, with a particular focus on interstitial lung disease, a potentially fatal complication of this autoimmune disease.

In 2022, she was awarded a Project Grant from the Canadian Institutes of Health Research (CIHR). This grant was to fund her research project "Randomized Double Blind Placebo-Controlled Clinical Trial to Assess the Efficacy of Mycophenolate Mofetil in Subclinical Interstitial Lung Disease Associated with Systemic Sclerosis: a Feasibility Study". Since the CIHR approved her application in July 2002, Dr. Hoa has been actively involved in the implementation of this rigorous clinical trial. She has developed the necessary protocols and will soon begin enrolling participants at the CHUM, along with multi-institutional collaborators.

At the same time, she plays a key role in recruitment for scleroderma and pre-scleroderma immunophenotyping projects, in collaboration with the Immuno-regulation Laboratory headed by Dr. Marika Sarfati. She is also actively involved in recruitment for the research cohorts of the CRCHUM's Autoimmunity Research Laboratory (LABRAI), the Scleroderma Patient centered Intervention Network (SPIN) and the Canadian Scleroderma Research Group (CSRG).

Her research efforts focus on the development of innovative and early therapeutic approaches to alleviate the effects of pulmonary fibrosis associated with scleroderma. She is a key figure in improving the quality of life for patients and reducing the risk of potentially serious complications through her dedication and central role in scleroderma research.

As a rheumatologist at the University of Montreal Health Centre (CHUM), Dr. Océane Landon-Cardinal excels in her subspecialty of autoimmune myositis (AIM). Her clinical research focuses on scleroderma associated myositis (aka scleromyositis), an understudied manifestation of systemic scleroderma.

Dr. Océane Landon-Cardinal conducted a systematic, blinded review of muscle biopsies from patients with scleromyositis. By comparing these biopsies with samples from patients with other forms of AIM and with a French validation cohort from the University of Strasbourg, this rigorous study led to important discoveries.

Data from this study have been published in two prestigious peer reviewed journals ***(Acta Neuropathologica and Neuropathology and Applied Neurobiology)***, identifying the marked reduplication of capillary basement membranes in muscle biopsies from scleroderma patients as a distinctive lesion compared to other AIMs, particularly in "frustrated" early forms of scleroderma. This finding is of great research interest, both in terms of early diagnosis and understanding of pathophysiological mechanisms.

Dr. Océane Landon-Cardinal is currently working on the characterization of the scleromyositis patient cohort and is interested in correlating clinical manifestations with serological profiles and pathological features. She has also initiated a transcriptomic analysis project of muscle biopsies from scleromyositis patients to identify specific molecular signatures and thus potential new therapeutic targets.

Dr. Océane Landon-Cardinal's groundbreaking research continues to contribute to a better understanding and management of scleroderma. It also highlights the importance of patient education.

Dr. Brett Thombs of the Sir Mortimer B. Davis Jewish General Hospital is a leading researcher in the field of scleroderma. As founder of the **Scleroderma Patient-centered Intervention Network (SPIN)**, he is engaged in multidisciplinary research aimed at improving the management of this complex disease.

Dr. Thombs is conducting extensive research on many aspects of scleroderma. In particular, he is focusing his efforts on an important study to assess the pain associated with the disease, as well as studying oral health to develop a survey to assess oral problems specific to scleroderma. Another initiative aims to improve patient involvement in research and communication of results. Dr. Thombs is also involved in supporting the SPIN cohort and providing ongoing programs for scleroderma patients.

The impact of Dr. Thombs and his research has been significant. His work has led to major advances in understanding the challenges faced by people with scleroderma. As a founder of the SPIN network, he has helped create a patient-centered research platform that promotes a more personalized approach to disease management. His contributions have had far reaching implications on the quality of life of patients and their families.

Scleroderma Quebec is proud to support Dr. Thombs' initiatives. His commitment to cutting edge scientific research has advanced our understanding of scleroderma and opened up new avenues for improving treatments and patient support programs.

Dr. Marie Hudson of the Sir Mortimer B. Davis Jewish General Hospital is leading the CARE SSc project, a Phase I/II randomized controlled clinical trial of mesenchymal stromal cells (MSCs) in systemic scleroderma (SSc).

Dr. Hudson and her research team are focusing on the use of special cells called "mesenchymal stem cells". These cells have special properties that can play an important role in tissue repair and regeneration. These cells are derived from the umbilical cord.

The project involves a rigorous clinical trial. It is a double blind, placebo controlled study, which means that neither patients nor researchers will know which subjects are actually receiving the stem cells or the placebo (an inactive substance).

To participate in the study, patients must meet certain criteria, such as the duration of the disease, the presence of specific symptoms, and so on. There are also exclusion criteria for safety reasons.

This research represents a promising step towards new treatment options for SSc patients.

Dr. Marie Hudson's expertise is evidenced by her extensive research in scleroderma, including the Phase I/II randomized controlled trial of umbilical cord derived mesenchymal stem cells in SSc, as well as her collaborations with renowned institutions such as the University of Montreal Health Centre (CHUM), and many others. Dr. Hudson who exemplifies professional collaboration and dedication, has made a significant contribution to the advancement of SSc research and care.

DR JEAN-LUC SENÉCAL:
A pioneer in scleroderma research

Dr. Jean-Luc Senécal, MD, Full Professor, Department of Medicine, Faculty of Medicine, University of Montreal, has been an invaluable pillar in the fight against scleroderma. Since the creation of the Scleroderma Research Chair, he has embodied determination and commitment to research and advancing the understanding of this complex disease.

Dr. Senécal, who has held the role of Chairholder since its inception, has not only brought his medical and scientific expertise to the cause but has also become a mentor and source of inspiration to all researchers involved in scleroderma research. His passion for innovation and his desire to advance medical knowledge have been driving forces in the pursuit of the Chair's ambitious goals.

Under his leadership, the Scleroderma Research Chair has played a key role in the collaboration between several institutions, including the Université de Montréal, its Faculty of Medicine, CHUM and the CHUM Research Centre. This philanthropic initiative, established in 2003 in partnership with Scleroderma Quebec, has catalyzed significant advances in the understanding and treatment of scleroderma.

By working closely with colleagues in fields such as immunoregulation and autoimmunity, Dr. Senécal has demonstrated the importance of multidisciplinary research. His efforts have led to groundbreaking discoveries, many of which have been published in leading scientific journals.

In addition to his scientific contributions, Dr. Senécal has been a strong advocate for scleroderma awareness. His presentations at conferences and meetings have helped demystify the disease, educating physicians, patients and the general public about its complexities and implications. His role as a communicator and educator has not only informed but inspired other researchers and clinicians to become more involved in the quest to better understand SSc and find more effective treatments.

As we close this period marked by significant achievements for the Scleroderma Research Chair, it's important to stress that this milestone does not mean the end of our efforts. The Chair, with its unwavering commitment and unshakeable determination, continues to pave the way for research and discovery. In this transition to the future, past achievements represent a solid foundation for future breakthroughs in understanding, treating and ultimately resolving scleroderma.

In recognition of his dedication, scientific contributions and advocacy work, we hereby honour and commend Dr. Jean-Luc Senécal for shaping the future of scleroderma research. His legacy will continue to guide and inspire future generations of researchers and healthcare professionals in the fight against this devastating disease. It's because of passionate, dedicated individuals like Dr. Senécal that people living with scleroderma have a renewed sense of hope and optimism going forward, as the road to more effective treatments is paved with passion, perseverance, and the relentless pursuit of innovation by researchers.

ON BEHALF OF THE BOARD OF DIRECTORS

Gaétan Baril, President
Diane Collard, Executive Director
Scleroderma Quebec

FUNDRAISING ACTIVITIES

The 21st edition of the Friendly golf tournament organized by **Éric Canuel, Luc Tétreault and Richard Tremblay** took place last June. We are extremely grateful to these volunteers for their tireless efforts over the years that have created strong bonds with participants, partners and members of our organization. Many thanks to Éric, Luc and Richard for their generous commitment!

Our long awaited benefit evening finally took place on October 18, 2022, at the Montreal Casino Cabaret, marking our return to full in-person activities after a two year hiatus due to the pandemic. The 23rd edition of our event exceeded all our expectations and was even more successful than previous editions. This has allowed us to continue our commitment to supporting world class research that is being carried out right here in Quebec. We would like to extend our deepest appreciation to all the members of the Honorary Committee, whose generosity and remarkable dedication made this fundraising evening such a success. We would also like to express our sincere gratitude to our partners, to the participants in our fundraising events, and to our donors and members, for their invaluable support.

We would also like to thank the dedicated members of our Board of Directors. Their unwavering support and invaluable collaboration are paramount to the pursuit of our mission. We are eternally grateful for your steadfast commitment to the scleroderma community.

We thank you all from the bottom of our hearts.

Gaétan Baril

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Diane Collard

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