Scleroderma Quebec™

♥ SUPPORT

♥ RESEARCH

♥ HOPE

ANNUAL Report 2024-25

« Scleroderma Québec plays a strategic role within the broader scleroderma ecosystem.

TABLE OF CONTENTS

PROLOGUE – SCLERODERMA QUÉBEC

A Catalyst for Impact and a Foundation of Trust

This annual report is more than a summary of activities. It reflects a sustained and foundational effort. **Scleroderma Québec does not simply inform: *the organization acts, supports, and drives change.***

Present in the daily lives of people living with scleroderma, through guidance, information, and connection to appropriate resources, it also contributes to scientific research by supporting projects that deepen our understanding of the disease.

In 2024-2025, every initiative pursued the same objective: to help patients live better with scleroderma, to advance medical knowledge, and to build a more attentive and equitable environment of care and research.

Scleroderma Québec reaffirmed its unique role:

- A **recognized voice** among elected officials and institutions
- A **trusted partner** for donors and foundations
- A **credible scientific** stakeholder
- A **constant presence** for individuals living with the disease and their loved ones

> ***« Our mission goes beyond awareness alone: we build lasting bridges between patients, physicians, and researchers.***

MISSION AND VALUES

OUR MISSION IS PROFOUNDLY HUMAN: To improve the quality of life of those affected and their loved ones, while contributing to advances in research and to public awareness.

For more than thirty years, we have walked alongside patients, their families, and the medical community, forging relationships grounded in listening, support, and respect.

Patient support: attentive listening, comfort, and practical resources (support groups, educational fact sheets, conferences, newsletters, and a bilingual website).

Research: support for scientific projects that open the way to new therapeutic approaches.

Awareness: campaigns, fundraising activities, and testimonials to promote greater understanding and better care.

Patient advocacy: representing individuals living with scleroderma before decision-makers and within the medical community, so their voices are heard and access to care and quality of life are improved.

MESSAGE FROM THE PRESIDENT

Chair of the Board of Directors – Armand Des Rosiers

The year 2024 -2025 was once again marked by meaningful, steady, and essential action. Through the initiatives presented in this report, Scleroderma Québec continued to pursue its mission with rigor and conviction: to inform those affected, to support patients and their loved ones, to stand behind the scientific community, and to help create the conditions for scleroderma to be better understood and better addressed, today and in the years to come.

As Chair of the Board of Directors, I see how strongly our organization is built: a professional team deeply engaged on a daily basis, dedicated volunteer board members, lasting scientific collaborations with recognized research centres, and the renewed confidence of our donors and institutional partners.

This report reflects not only the concrete achievements of the past year, but also the path we continue to build with consistency. We work to ensure that scleroderma does not remain in the shadows, that it is better understood and receives the full attention it deserves from the public, decision-makers, and the medical community.

Thank you to everyone who makes this possible.

> ***« Scleroderma Québec plays a unique role: bringing together scientific, medical, and community forces for lasting impact.***

MESSAGE FROM THE EXECUTIVE DIRECTOR

– Diane Collard

> *«Every human connection, every call, every exchange, is an opportunity to bring hope and to better support those affected.*

Leading Scleroderma Québec means witnessing each day the reality of a complex and often invisible disease, a condition that weakens the body and raises many medical questions. It is in this context that our mission takes on its full meaning: to provide reliable information, appropriate support, and clear guidance to those affected.

This year, thanks to the commitment of our support group leaders, we were once again able to offer concrete assistance to patients and their loved ones. These meetings, held in person or virtually, help break isolation, provide answers, and improve quality of life.

Our educational resources have also continued to grow: a strengthened bilingual website, new educational factsheets, and the preparation of a reference book intended for both patients and health professionals. A comprehensive resource, it will help everyone better understand scleroderma and engage with confidence throughout the care journey.

On the research front, our philanthropic support has encouraged innovative work in early diagnosis, immunology, and new therapeutic approaches. These advances pave the way toward improved care and strengthen the ability of teams to secure future funding.

This report reflects a collective effort, modest in resources, yet immense in commitment. Thank you to the researchers, the patients, and to everyone who makes these actions possible.

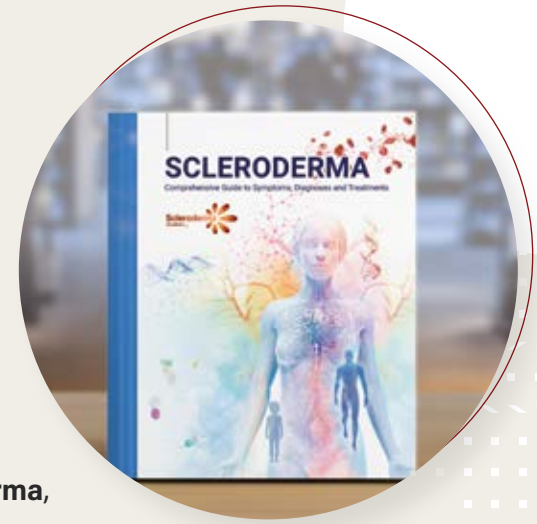
« Endless thanks to Scleroderma Québec for being there. Without the valuable documentation I received, so relevant and easy to understand, without the conferences, and without the incomparable support of the team, my mother and I would never have known about scleroderma, and the disease would most likely have progressed dangerously.
Caroline, Montreal

« I would like to pay tribute to the staff of Scleroderma Québec for their support and outstanding professionalism. Through their guidance and moral support, they brought me comfort and gave me the courage to continue my steps forward.
Marie-Andrée, Laurentides

« At first, fear dominated. Then, thanks to Scleroderma Québec, I was able to move beyond my anxiety, learn more, and regain the thread of my daily life. I found a reliable source of information, a deeply human framework of support, and encounters that helped me no longer feel alone in living with this little-known disease. Knowing that research teams in Montreal are continuing their work gives me renewed hope for the future.
Louise, Charlevoix

« At the heart of our action lies a close and constant presence alongside those who live with scleroderma each day.

AWARENESS AND SERVICES



> *« I applaud the release of this essential work on scleroderma. This comprehensive guide to symptoms, diagnosis, and treatment is an invaluable resource for patients, health professionals, and families affected by this complex disease. Shirley Dorismond, Member of the National Assembly for Marie-Victorin*

A REFERENCE BOOK ON SCLERODERMA

In 2024-25, Scleroderma Québec devoted significant efforts to the preparation of a **comprehensive reference book on scleroderma**, a landmark publication for the French-speaking community, offered in both French and English.

This publication was designed as an **essential and practical resource** for individuals living with the disease, their loved ones, and health professionals. Presented in a clear and accessible format, it brings together:

- an overview of the **symptoms and manifestations of scleroderma**,
- explanations regarding **diagnosis and medical follow-up**,
- a review of available **treatments and symptom management approaches**,
- practical guidance for living more fully with the disease on a day-to-day basis.

Soon to be available in **both print and digital formats, in French and English**, this book aims to strengthen patients' ability to take an **active role in their care journey and to better understand** the realities of this complex condition.

Through this unprecedented publication, Scleroderma Québec continues its **mission of education, support, and awareness**, while providing the community with a lasting reference tool that will shape the years ahead.

> *« The book Scleroderma is a remarkable collective work: an exhaustive and accessible synthesis, made possible through the leadership of Scleroderma Québec and the patient, dedicated efforts of its team. Dr Jean-Luc Senécal, CHUM – Université de Montréal*

PUBLICATIONS AND EDUCATIONAL TOOLS

In 2024-2025, Scleroderma Québec pursued its educational commitment with ***two new editions of its Bulletin***, distributed to more than ***6,000 individuals***, including patients, families, and health professionals. This biannual publication, recognized for the quality of its content, remains a valuable resource for information and learning.

In addition, ***three new educational factsheets on scleroderma*** were developed, in both French and English, focusing on:

- **Calcinosis**,
- **Sjögren's syndrome**,
- **Dermatological interventions**.

Written by experts, these factsheets further enrich the range of educational tools available to better understand scleroderma and to support patients throughout their care journey.

AWARENESS AND SERVICES

« Our digital presence helps inform, support, and bring the scleroderma community closer together each day, here in Québec and beyond.

NATIONAL CONFERENCE (JUNE 14-15 2024)

A highlight of our 35th anniversary, the National Conference held in Québec City brought together **140 participants**: patients, loved ones, researchers, and health professionals.

- Plenary presentations by Dr Sabrina Hoa and Dr Marie Hudson.
- Workshops on pain management, energy conservation, pulmonary fibrosis, PAH, Raynaud's phenomenon, and innovative therapies.
- A welcome reception encouraging dialogue and connections.
- **Presentation of the 2023 Maureen Sauvé SPIN Inspiration Award** to Ms Violet Konrad, a volunteer from the Estrie region, in recognition of her dedication.

SUPPORT NETWORK AND PEER GROUPS

Our support network grew stronger with **14 volunteers trained through our partnership with SPIN.**

- Regional and virtual meetings fostering the sharing of experiences.
- Personalized guidance and moral support to reduce isolation.
- Recognition of key resource persons during the National Conference.

These support groups remain an essential pillar in improving the quality of life of people living with scleroderma.

DIGITAL PRESENCE AND ONLINE OUTREACH

Scleroderma Québec also maintains a strong online presence through its **bilingual website** and its activities on **social media (Facebook and LinkedIn)**.

- Steady traffic reflects growing interest in our educational resources.
- Publications and educational information sheets are widely consulted and shared.
- Our platforms have become a trusted reference for patients, families, and health professionals.
- Visitors to our website come from many countries, confirming the relevance and international reach of our content.

RESEARCH AND SCIENTIFIC PARTNERSHIPS

AN ESSENTIAL DIALOGUE

On May 3, 2025, Scleroderma Québec brought together in Montréal its Board of Directors and several researchers actively engaged in the study of scleroderma. This gathering was not an isolated event: it represented the point of convergence of a long preparatory process. The resolutions, commitments, and collaborations developed throughout 2024-25 found in this meeting a space for dialogue and validation.

Before the Board members, many of whom are directly affected by the disease, the scientists presented their most recent work: clinical trials, biomarker identification, new therapeutic approaches, experimental models, patient-centred initiatives, and training the next generation of specialists and researchers. Open and concrete discussions helped illuminate both the challenges encountered and the immediate and potential impact for people living with scleroderma.

This meeting highlighted an essential truth: the philanthropic support championed by Scleroderma Québec, often carried out quietly, is what makes these projects possible. This direct and meaningful dialogue between researchers and Board members strengthened the conviction that every decision made by the Board carries hope for those affected.

> *« The support we provide today fuels the discoveries of tomorrow.*

Front row, left to right: **Me Audrey Robitaille**, Board member;
Diane Collard, Executive Director; **Gaétan Baril**, Board member;
Dr Sabrina Hoa, rheumatologist at CHUM, Chairholder of the University of Montréal Research Chair in Scleroderma and clinician-scientist at CRCHUM;
Dr Marie Hudson, rheumatologist at the Jewish General Hospital, Chief of the Division of Rheumatology at the Jewish General Hospital, and Director of the Division of Rheumatology at McGill University.

Second row: **Yvon Léveillé**, **Marylène Sacy Reeves**, **Simon Telles**, and **Bernard Grandmont**, Board members;
Dr Elena Netchiporouk, dermatologist and Assistant Professor at McGill University; **Marie-Eve Carrier**, Co-Director of the SPIN Network;
Dr Marika Sarfati, immunologist, Full Professor at the University of Montréal and Director of the Immunoregulation Laboratory at CRCHUM;
Dr William Berthelot, rheumatology resident at Université Laval;
Carla Bobica, Master's student at McGill University; **Me Mathieu Gagné**, Board member;
Armand Des Rosiers, Chair of the Board of Directors of Scleroderma Québec.

RESEARCH AND SCIENTIFIC PARTNERSHIPS

THE IMPACT OF STRATEGIC SUPPORT

For more than twenty years, Scleroderma Québec has served as an essential catalyst for scientific and medical research. The philanthropic support it provides enables teams to reach crucial milestones: launching new studies, generating preliminary results, building patient cohorts, and preparing larger funding applications to national and international organizations.

In 2024-25, several advances illustrate this impact:

- Significant scientific progress, already shared within the international community through major conferences and globally recognized publications.
- The securing of major grants (notably from the Canadian Institutes of Health Research) made possible by the results generated with the philanthropic support of Scleroderma Québec. Our support for Dr Marie Hudson, for example, contributed to the success of her project on the anti-fibrotic mechanisms of mesenchymal cells, which now benefits from substantial funding.
- The strengthening of collaborative initiatives such as with the SPINNetwork, which is developing new ways to involve patients in research and in the dissemination of knowledge.

These outcomes remind us that behind every dollar invested lies a long-term strategy: enabling researchers to move faster and further, and ultimately, to improve both the quality of life and life expectancy of people living with scleroderma.

« Far more than financial support, Scleroderma Québec allows me to bring hope to my patients.
Dr Marie Hudson,
Jewish General Hospital,
McGill University

« The work of many researchers within our Faculty has greatly benefited from the support of Scleroderma Québec over the years.
Dr François Madore,
Executive Vice-Dean and Network Lead
Faculty of Medicine, University of Montréal

RESEARCH AND SCIENTIFIC PARTNERSHIPS

« Behind every scientific project we support, there are faces, stories, and a desire to make a difference.

RESEARCHERS SUPPORTED IN 2024-25

Active Projects

- **Dr Sabrina Hoa** (CHUM, University of Montréal) Clinical research on pulmonary fibrosis and Chairholder of the Scleroderma Research Chair.
- **Dr Marika Sarfati** (CRCHUM) Immunophenotyping and translational research on pre-scleroderma.
- **Dr Océane Landon-Cardinal** (CHUM) Characterization of scleromyositis (scleroderma with associated myositis).
- **Dr Elena Netchiporouk** (McGill University) Study of environmental triggers in localized scleroderma.
- **Dr Marie Hudson** (Jewish General Hospital, McGill University) Clinical and basic research projects in scleroderma, including a component focused on mesenchymal cells.
- **Dr Brett Thombs** (McGill University / Lady Davis Institute) SPIN Network (Scleroderma Patient-centered Intervention Network): development of patient-centred tools and interventions.

Confirmed Resolutions for 2024-25 (Upcoming Actions)

- **Dr William Berthelo**t (Université Laval) Training in rheumatology and clinical research (support planned for Fall 2025). Ultimately, this training will lead to the creation of a dedicated scleroderma clinic in Québec City, a crucial step toward reducing delays in access to specialized care for patients in regional areas.
- **Dr Thaïsa Cotton** (McGill University) Clinical and scientific training in scleroderma (planned for Fall 2025). This specialization in hematopoietic stem cell transplantation opens the way to the eventual implementation in Québec of a highly valuable treatment option for certain patients.

A VISION BEYOND THE NUMBERS

Scleroderma Québec does not limit itself to funding projects. The organization acts as a true research partner: connecting researchers to one another, bringing patients closer to scientific advances, and enabling the next generation of medical specialists to be trained in a highly specialized field.

This spirit guides every one of our decisions. By supporting research in a focused and strategic manner, we create unique conditions in which innovation is placed in the service of improving lives, and each scientific advance becomes a promise of hope.

THANK YOU TO ALL WHO SUPPORT OUR MISSION

Scleroderma Québec extends its heartfelt thanks to the individuals, volunteers, businesses, foundations, and organizations who, through their generosity and commitment, help advance our mission.

We wish to highlight in particular the contribution of several generous foundations, including the **Joey and Odette Basmaji Foundation**, the **Laure-Gaudreault Foundation – Montréal Island Region**, the **McCall MacBain Foundation**, the **Belmira Jaime Fund**, as well as many other donors and partners who share our vision and support our work.

Scleroderma Québec also wishes to thank the Government of Québec for its financial support.

Thanks to you, we are able to provide support to people living with scleroderma, fund research, and strengthen awareness efforts among the general public and the medical community.

Your support is a source of hope and solidarity for the entire scleroderma community.

THANK YOU FOR BELIEVING IN OUR MISSION.

« Supporting patients also means preparing the ground for tomorrow's discoveries.

FINANCES

Société de sclérose systémique (sclérodermie) du Québec Inc. Excerpt from the financial statements for the fiscal year ended April 30, 2025

	2025	2024
REVENUES		
Fundraising Event – Greater Montréal	$602,892	$538,753
Donations	$119,384	$113,204
In-kind Contributions of Goods and Services	$87,697	$65,758
National Scleroderma Conference	$64,106	-
Golf Tournaments	$16,500	$20,000
Scleroderma Reference Book	$15,000	-
Interest Income	$12,067	$11,870
Awareness Activity	$400	$2,985
	$918,046	**$752,570**
EXPENSES		
Fundraising Activities	$202,553	$170,191
Operations	$182,570	$171,268
	$385,123	**$341,459**
EXCESS OF REVENUES OVER EXPENSES BEFORE PROGRAM ALLOCATIONS	**$532,923**	**$411,111**
Program Contributions		
Support and Peer Assistance	$283,584	$196,705
Research	$195,909	$181,250
Awareness and Information Campaign	$41,633	$31,474
	$521,126	**$409,429**
Excess of Revenues over Expenses	$11,797	$1,682
NET ASSETS AT BEGINNING OF YEAR	**$360,692**	**$359,010**
NET ASSETS AT END OF YEAR	**$372,489**	**$360,692**

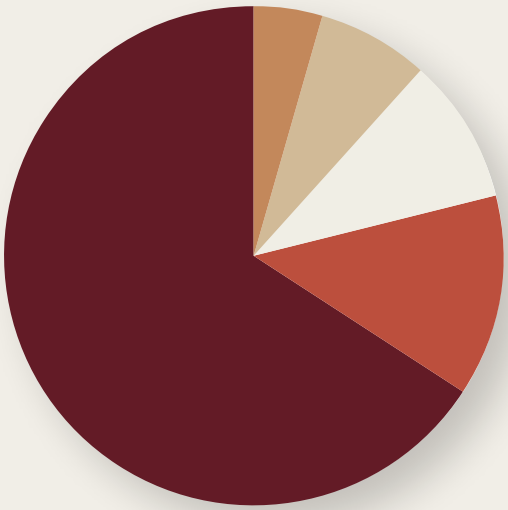
The financial information presented in this report is drawn from the audited financial statements of the Systemic Sclerosis (Scleroderma) Society of Québec, operating under the name Scleroderma Québec, for the fiscal year ended April 30, 2025.

The audit, conducted by LFB CPA, Chartered Professional Accountants, resulted in an unqualified opinion.

FINANCES

Société de sclérose systémique (sclérodermie) du Québec Inc. Excerpt from the financial statements for the fiscal year ended April 30, 2025

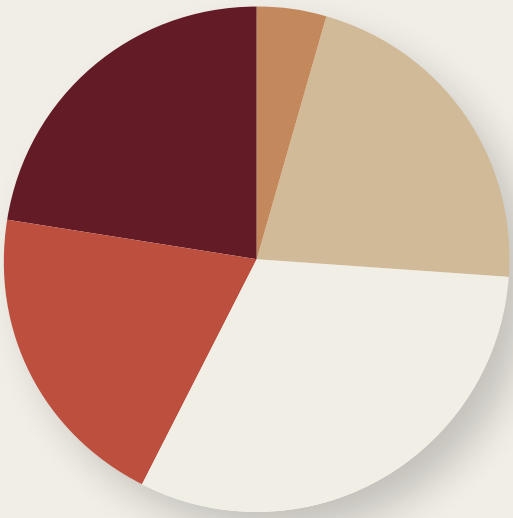
REVENUE BREAKDOWN



Sources of Revenue

- Fundraising Activities: 65.7 %
- Donations: 13.0 %
- Partnerships / In-kind Goods and Services: 9.6 %
- National Conference: 7.0 %
- Other Activities: 4.7 %

EXPENSE BREAKDOWN



Expense Categories

- Fundraising Activities: 22.4 %
- Operations: 20.1 %
- Support and Peer Assistance: 31.3 %
- Research: 21.6 %
- Awareness and Information: 4.6 %

« Together, we are changing the course of scleroderma.

Scleroderma Quebec™

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