

Annual Report

2018 2019

We have the pleasure of highlighting Scleroderma Quebec's main achievements for the year 2018-2019 in the following activities: Research Support, Patient Support, Information, Education, and Awareness as well as funding.

SUPPORT FOR RESEARCH

In 2005, Scleroderma Quebec signed a collaborative agreement with the University of Montreal for the creation and maintenance of the Scleroderma Research Chair of the University of Montreal Health Centre (CHUM), the only one of its kind in Canada. Dr. Jean-Luc Senécal, an internationally renowned rheumatologist and the Chair holder, published in recent years a number of scientific papers on successful experiments using an experimental animal model. The Chair is a major project that has a real impact on the quality of life and life expectancy of people affected by scleroderma.

Scleroderma Quebec is the main financial contributor to the Chair financially to ensure the retention of the Chair's best scientists in basic and clinical research as well as the planned arrival of new senior scientific researchers, according to Dr. Senécal's well-documented strategic plan. The fair market value of the capitalized Chair was \$1,604,895 as of April 30th 2019.

The highlight of the 2018-2019 period was the inauguration, on October 30th, 2018 at the CHUM Research Centre of the Becton Dickinson FACSymphony High Speed cell analyser system. Scleroderma Quebec was able to contribute, thanks to an exceptional donation of \$400,000, to the purchase of this new scientific instrument, in partnership with the Canada Foundation for Innovation and the CHUM Research Centre. This device of unequaled analytical power is able to determine up to 50 extracellular and intracellular characteristics of a single cell.

We also support on a continuous basis the SPIN-SHARE program under the direction of Dr. Brett Thombs, affiliated with the Montreal Jewish General Hospital and McGill University, for an amount of \$50,000 over five years. Scleroderma Quebec continues to pay a research grant to the Lady Davis Institute for a medical research project entitled "Precision medicine and cellular epigenomics" under the direction of Dr. Marie Hudson and Dr. Celia Greenwood, for the amount of \$45,000 over three years. Also, we granted an amount of \$7,700 for a study, led by Dr. Ariel Masetto, Rheumatologist at the University of Sherbrooke, on a drug for pulmonary fibrosis.

Leader in research on scleroderma in Canada, Scleroderma Quebec to date has contributed close to three million dollars towards research.

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INFORMATION AND EDUCATION

Twice a year, in the Spring and the Fall, Scleroderma Quebec publishes *le BULLETIN* to inform the people affected by scleroderma, the general public, and the health professionals, of the latest research developments and promising new treatments. Printed in 6,000 copies, it is distributed to more than 4,000 doctors and health care workers in Quebec. Our bilingual Website (www.sclerodermie.ca/en) is a reliable source of information about scleroderma, medical articles, guides on several scleroderma-related subjects, and any new research development in this field.

Also, we will be publishing an educational poster of the symptoms and manifestations of scleroderma in the publications *Profession Santé* and *Medical Post* (December 2019 editions). These two magazines are sent to general practitioners, specialists, and pharmacists.

AWARENESS

Each year in June, we organize several walks, June being Scleroderma Awareness Month. More than a fundraiser, the activity aims to spread awareness about scleroderma with the general public. For the second year in Quebec City, the walk took place in magnificent Parc du Bois-de-Coulonge. The third edition of the Sherbrooke walk was held in Parc André-Viger, and the Mirabel walk was at the Parc du Domaine Vert. Our global goal was surpassed, having raised \$52,000. Our volunteer, Marie-France Laflamme, a communications and social media specialist, promoted it to raise awareness of our cause with the general public. Close to 400 members and volunteers participated in these activities which were highly successful.

This past October 2nd, we organized an awareness day at the National Assembly. The goal of the day was to raise awareness about scleroderma to the parliamentaries.

PATIENT SUPPORT SERVICES

Our support groups held several meetings, especially in the Eastern Townships and in Montreal, and some of them had seasoned guest speakers, including Dr. Ariel Masetto, rheumatologist and assistant professor in the rheumatology department of medicine at Sherbrooke University.

We also organized information and training sessions for our volunteer group leaders, last May in Quebec City.

Our Health Promotion Agent is available to answer any questions, and to give advice, to patients who contact her by phone or by email. Her contact information, and that of our support group leaders, are on our Website at www.sclerodermie.ca/en.

FUNDING

With regard to our fundraising activities, a benefit golf tournament, a Chic cocktail reception in Quebec City, and a benefit dinner at the Cabaret of the Montreal Casino were organized to benefit our organization.

We would like to take this opportunity to thank all of the members of our Board of Directors, our partners, our donors, and our volunteers, for their precious implication and generosity.

GAÉTAN BARIL

President, Scleroderma Quebec

DIANE COLLARD

Executive Director, Scleroderma Quebec