



Scleroderma Quebec Activity Report 2017-2018

We have the immense honour of highlighting Scleroderma Quebec's major achievements for 2017-2018 in the following areas of activity: support for research, patient support, information, education and awareness, and funding.

SUPPORT FOR RESEARCH

We are particularly proud to inform you that thanks to an exceptional donation of \$400,000, Scleroderma Quebec has been able to contribute, together with its partners, the Canada Foundation for Innovation and the CHUM Research Centre, to the purchase of the best version of the BD FACSymphony™ High Speed Analyzer system. This cutting-edge high parameter flow cytometer, of unparalleled capabilities enables the simultaneous measurement of up to 50 different characteristics of a single cell. This novel cell analyzer, worth close to one and a half million dollars, still has a very limited distribution in North America. The BD FACSymphony will be used primarily by the scleroderma research Chair and will also be highly sought after and made available to all medical research teams at the CHUM Research Centre.

As you may already know, in 2005 Scleroderma Quebec signed a collaborative agreement with the University of Montreal for the creation of the Scleroderma Research Chair of the University of Montreal Health Centre (CHUM), the only one of its kind in Canada, whose holder is Dr. Jean-Luc Senécal, a world-renowned rheumatologist. In recent years, the Chair has published a number of scientific papers on successful experiments using an experimental animal model of scleroderma and was awarded a major research excellence grant from the Canadian Institutes of Health Research, after receiving the highest evaluation among all the candidates who submitted projects to this competition. These scientific papers have shown the importance of having a strong animal model of diffuse scleroderma in order to achieve conceptual breakthroughs using an experimental protocol that would be ethically unacceptable in humans.

Scleroderma Quebec contributes financially to ensure the retention of the Chair 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.

To date, Scleroderma Quebec has contributed nearly \$2,600,000 in support to research.

We also provided our financial support to the SPIN-SHARE project led by Dr. Brett Thombs who is affiliated with the Jewish General Hospital and McGill University in Montreal, for a total amount of \$50,000 spread over five years. In addition, Scleroderma Quebec has confirmed a research grant to the Lady Davis Institute for Medical Research for the «Precision Medicine and Cellular Epigenomics» project, which was presented to us by Drs. Marie Hudson and Celia Greenwood, for an amount of \$45,000 spread over three years. We've also given a grant of \$7,700 to help finance a study led by Dr. Ariel Masetto, rheumatologist at the Université de Sherbrooke, on a medication used for pulmonary fibrosis.

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INFORMATION AND EDUCATION

Twice a year Scleroderma Quebec publishes a newsletter for people living with the disease, the general public and health professionals. With nearly 6,000 copies, of which more than 4,000 readers are physicians and health professionals, Le Bulletin magazine is a much-appreciated reference document. In addition, in order to reach the greatest number of people possible we have been providing a fully bilingual website for the last three years (en.sclerodermie.ca). Our readers are just a click away from a wealth of information on scleroderma, medical papers, and guides on various scleroderma-related topics as well as the latest news. We are continuously improving and adding new features to our website, including updating publications and information on the Scleroderma Research Chair. Just recently, we've created an educational poster and video, in French and English, to explain how each part of the body is affected by scleroderma.

AWARENESS

Last June, Scleroderma Awareness Month, we organized several fundraising walks as part of events held across Canada. A first edition was held at Laval University, in Quebec City, and a second edition at parc André-Viger in Sherbrooke and parc du Domaine Vert in Mirabel. Nearly 400 walkers and volunteers participated in these events. We exceeded our overall goal, as we raised nearly \$52,000. Marie-France, our communication and social media specialist (volunteer), promoted our walks and made the general public aware of our cause. Proud of this success, our volunteer organizers are already busy with the next edition of our walks.

PATIENT SUPPORT SERVICES

Scleroderma Quebec's Health Promotion Officer main objectives include promoting self-care by encouraging patients to adopt healthy lifestyle habits as well as providing comprehensive information on the disease by explaining the physical and psychological changes which may be associated with scleroderma. She also works closely with the volunteer leaders of our network of local support groups set up throughout Quebec.

This year, two leaders of our patient support network participated in a training program offered by the Scleroderma Patient-Centered Intervention Network (SPIN) for support group leaders, and we are confident that we will be able to offer this training to all our patient support group leaders in the future.

FUNDING

With regard to our fundraising activities and events, two benefit golf tournaments, a cocktail reception in Quebec City, a benefit dinner in Trois-Rivières and a fundraiser dinner-show banquet at the Cabaret du Casino de Montréal are organized for the benefit of Scleroderma Quebec. Thanks to these activities, the involvement of our honorary committees made up of several business personalities, and dedication of our invaluable volunteers and donors, we are confident to reach our ambitious target of \$600,000 in net profits from all of our fundraising activities.

GAÉTAN BARIL

President, Sclérodéma Quebec

DIANE COLLARD

Executive Director, Scleroderma Quebec
