

Scleroderma Quebec Activity Report



We are proud to highlight Scleroderma Quebec's main achievements for the year 2019-2020 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 primary source of French-language public information on scleroderma in Canada and support for scleroderma patients. A leader in funding cutting-edge scleroderma research, Scleroderma Quebec has contributed nearly \$3 million to date in support of research.

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** is a philanthropic Chair established in 2005 at the instigation of Scleroderma Quebec and Dr. Jean-Luc Sénécal, in partnership with the University of Montreal, its Faculty of Medicine, the CHUM and the CHUM Research Centre. Clinical, fundamental and translational research is conducted in close collaboration with the Immunoregulation Laboratory of the CHUM Research Centre (CRCHUM), directed by Dr. Marika Sarfati. >>

Chairholder Dr. Jean-Luc Senécal, an internationally renowned rheumatologist, was invited by the editors of the international publication *Journal of Scleroderma and Related Disorders* to submit a paper on the pathogenic role of autoantibodies in scleroderma. New criteria for assessing the pathogenicity of autoantibodies are proposed in this year's paper and 15 autoantibodies have been revised and graded for their pathogenic role in the disease. This is an important recognition of the expertise of the Scleroderma Research Chairholder.

We would like to acknowledge the distinguished award of Master conferred recently to Dr. Senécal by the Canadian Rheumatology Society, and we offer him our most sincere congratulations for this honorary distinction.

- ▶ **The Canadian Scleroderma Research Group (CSRG)** of 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 from a large number of patients and several scleroderma research projects benefit from the data collected in this valuable registry.
- ▶ **The Scleroderma Patient-Centered Intervention Network (SPIN)**, led by Dr. Brett Thombs, affiliated with the Jewish General Hospital and McGill University. SPIN's mission is to work with people with scleroderma to identify their needs and prioritize research in areas most important to them and to develop, test, and disseminate accessible patient programs that improve quality of life and empower people with scleroderma and their loved ones.
- ▶ **The Lady Davis Institute for Medical Research** for the project entitled *Precision Medicine in Cellular Epigenomics* led by Dr. Celia Greenwood. The research group is developing an algorithm and software package that will allow the analysis of DNA methylation data so that we can profit from the hidden potential of these data in scleroderma.

INFORMATION AND EDUCATION

Scleroderma Quebec publishes *LE BULLETIN* twice a year, in the spring and fall, to inform scleroderma patients, the general public and healthcare professionals of 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 throughout Quebec.

Our bilingual website (www.sclerodermie.ca) has been streamlined to make its content more accessible to all and is a reliable source of information on scleroderma, medical articles, guides on various scleroderma-related topics and all new research developments in the field. We have also added a COVID-19 section to answer questions raised in recent months.

Also, we have created a series of 14 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 health care professionals.

AWARENESS

A social media campaign with the theme *Demystify Scleroderma* took place during June, Scleroderma Awareness Month, and all performance indicators saw exceptional growth, particularly in the reach of our publications. >>

In June of each year, we usually organize several fundraising walks. Much more than a fundraiser, the activity serves to raise awareness of the disease among the general public. This summer, virtual walks and personal challenges raised \$39,000 in donations to fund research and patient support. Unfortunately, this year COVID-19 may have prevented us from meeting in person, but it hasn't stopped us from getting together, sparking new ways of connecting and engaging with each other. We tell ourselves that there will be another time.

MUTUAL ASSISTANCE AND SUPPORT FOR PATIENTS

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.

A highlight this year was the organization of a series of four virtual forums that brought together patients and physicians to discuss scleroderma. Patients were invited to participate in the forums and ask their questions to the speakers. The various topics covered were as follows:

- ▶ **Scleroderma 101**, presented by **Dr. Ariel Masetto, rheumatologist and Assistant Professor in the Department of Rheumatology** at the Université de Sherbrooke;
- ▶ **Medical management and follow-up**, presented by **Dr. Marie Hudson, rheumatologist** at the Jewish General Hospital;
- ▶ **Current treatments for scleroderma**, presented by **Dr. Sabrina Hoa, rheumatologist** at the CHUM;
- ▶ **Pulmonary complications associated with scleroderma**, presented by **Dr. Deborah Assayag, respirologist and assistant professor** at the McGill University Health Centre.

As these webinars were very well received, a new series of virtual patient forums is planned for 2021.

FUNDING

Due to the pandemic:

The **18th edition of the golf tournament** organized by Éric Canuel, Luc Tétreault and Richard Tremblay, was transformed into a virtual fundraiser that was a great success.

Our annual benefit evenings in Montreal and Quebec City were replaced by a virtual donation campaign. Thanks to the members of the honorary committee of this campaign, our partners and our generous donors, the objective of \$200,000 in donations was surpassed as we raised over \$290,000. It is a huge success!

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

With all our gratitude,

GAÉTAN BARIL
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Sclérodérma Québec

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