

## Scleroderma Quebec

### Activity Report 2016-17

It is my pleasure and honour to highlight Scleroderma Quebec's main achievements for the year 2016-2017 in the following areas: research funding, patient support services, information and education as well as our fundraising activities carried out over the course of the past year.

#### Research funding

Thanks to our first major fundraising campaign, Scleroderma Quebec has been instrumental in the establishment of the Scleroderma Research Chair, located at the *Centre hospitalier de l'Université de Montréal (CHUM)*, the only one of its kind in Canada, and contributed nearly \$2,000,000 to research. In addition, we recently gave a \$25,000 grant to the Scleroderma Research Chair's capitalized fund and another \$25,000 grant to the Scleroderma Research Chair's subscription fund. We also plan to contribute another \$50,000 this year to the subscription fund, and we are always on the lookout for new research projects aimed at improving the quality of life and life expectancy of scleroderma patients. The list of grants awarded by our organization is available on our website at [www.sclerodermafoundation.ca](http://www.sclerodermafoundation.ca).

#### Education and Information

As part of our information and education outreach mission, we have published several new documents intended to scleroderma patients and their informal caregivers, which are available in French and English on our website at [www.sclerodermafoundation.ca](http://www.sclerodermafoundation.ca).

One of the important components of our mission is to inform and educate the general population about scleroderma, including the different forms of the disease, its various symptoms, etc. One of the ways that our organization strives to achieve this goal is through the publication of a biannual newsletter intended for people living with scleroderma, the general public as well as health professionals. The magazine *Le Bulletin* is a reference document with a circulation approaching 6 000 copies, including more than 4,000 readers which are either doctors or health stakeholders. In addition, in order to reach the greatest number of people possible, our website ([www.sclerodermafoundation.ca](http://www.sclerodermafoundation.ca)) has been fully bilingual for over two years now. Accessing a wealth of information and resources on scleroderma, medical articles, and guides on various scleroderma-related topics as well as the latest news is just a click away. At the same time, we have continued to expand and enhance our bilingual website content and outreach materials in several ways in order to offer a truly comprehensive online resource, including the addition of publications, a guide on scleroderma-related symptoms and drugs, and providing detailed updated information about relevant activities and progress of the Scleroderma Research Chair.

#### Awareness campaign

As part of our outreach mission, in the spring/summer of 2016 Scleroderma Quebec launched an extensive Quebec-wide advertising campaign, featuring free-to-air television, radio, web and magazine adds as well as posters specially designed for bus shelters, to help promote public awareness about scleroderma throughout Quebec. Our advocacy and awareness campaign has paid off for visits to [www.sclerodermafoundation.ca](http://www.sclerodermafoundation.ca) have increased fivefold during this campaign.

Also, in June of this year, we launched two new events as part of June's Scleroderma Awareness Month and walks organized all across Canada: a Walk was held in Mirabel and another Walk in Sherbrooke, with a total participation of 260 walkers and volunteers as well as many generous donors. What a success for a first edition!

#### Patient Support Services

Scleroderma Quebec's nurse 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. Our nurse also works closely with the volunteer leaders of our network of local support groups set up throughout Quebec.

#### Funding

With respect to our fundraising activities, we would like to point out that 4 fundraising events were organized for the benefit of our organization: two benefit golf tournaments, a fundraising dinner held at the Montreal Casino's Cabaret, and a cocktail reception and show, under the theme "choco-champagne", held at the Quebec City Cruise Terminal.

Finally, Scleroderma Quebec is proud to have partnered with **Scleroderma Canada** in the organization of the 17<sup>th</sup> National Scleroderma Bilingual Conference that was held on the 16 and 17 of September 2016 in Montreal, with a record attendance and a roster of top-tier speakers and sponsors. Many attendees praised the wide variety of topics covered, raved about the quality of the speakers as well as the information sharing among participants. By all accounts, this was our best conference yet. Indeed, the conference was truly a remarkable happening and we would like to thank all of those involved, including guest speakers, exhibitors, organizers, attendees, and volunteers for making this high-profile event such a resounding success!