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MESSAGE FROM THE PRESIDENT AND THE EXECUTIVE DIRECTOR
OF SCLERODERMA CANADA – SEPTEMBER 2017

Scleroderma Canada Board remains committed to our mission to advance health care options and enrich the lives of those dealing with scleroderma through bold advocacy, research, education and counsel.

This year saw tremendous growth within Scleroderma Canada: from board development, to expanded awareness and engagement through social media platforms, to increased June Awareness Walk/Run/Bike events.

In September 2016, Scleroderma Canada Board and the Provincial Presidents crafted a strategic plan built on the operational review the year before, establishing Strategic Directions to focus the deployment of staff and volunteer resources.

The Scleroderma Canada Board, working with Provincial Scleroderma Organizations, staff and volunteers, have advanced the goals of Scleroderma Canada within these strategic directions and are pleased to report our progress:

Education

The Scleroderma National Conference is the keystone of our work in education. The 2016 conference in Montreal was the most successful and well attended conference to date with over 300 attendees from around the globe and more than 30 expert speakers from across Canada and the US. From hearing the latest in research from Dr. Senécal to a panel presentation of individuals sharing their experience and expertise in the field of scleroderma, conference attendees left empowered to take control of their wellness and to advocate on behalf of the scleroderma community.

The conference, now being held biannually, will continue to be a landmark event for scleroderma education in Canada. The 2018 conference in Calgary promises to be equally engaging and informative. We are excited to announce that we have secured two speakers of international reknown: Dr. Frederick Wigley, co-founder and Director of The Johns Hopkins Scleroderma Center, who will open the conference and Dr. Marco Matucci-Cernic, Chairman of the EULAR Scleroderma Trial and Research group (EUSTAR) and Director of the Division of Medicine and Rheumatology at the University of Florence, who will deliver the closing keynote address.

Scleroderma Canada supports the ongoing efforts of the Scleroderma Patient Intervention Network (SPIN) in the development of a Support Group Facilitator Training Program to provide training to support group facilitators.

Scleroderma Canada continues to reach out through traditional and electronic/social media to inform the general public as well as the scleroderma community on advocacy issues and fundraising initiatives. Our brochure series has been updated and expanded. Our Facebook, Twitter and e-mail reach grows significantly year after year: since last year our Facebook/Twitter followers have increased by over 80% and the SC e-mail subscriber base has grown by 30%.
Awareness

With increased information sharing through Facebook, Twitter, radio and television interviews and newspaper articles, Scleroderma Canada achieved a 32% increase in national Run/Walk/Bike revenues and a 50% increase in participants from 2016.

Five new Run/Walk/Bike events and a virtual walk component were added this year. New walks are already confirmed for 2018.

Advocacy

Maureen Worron-Sauvé, Vice President Advocacy and Public Relations, continues to spearhead advocacy and awareness efforts nationally and internationally.

Scleroderma Canada collaborates with Pulmonary Hypertension Association of Canada (PHA Canada) to advocate on behalf of patients with pulmonary arterial hypertension, including PAH secondary to a diagnosis of scleroderma (SSc-PAH). These efforts include the development of a website, letter-writing campaigns to health ministers across the country to provide public funding for a new medication (selexipag) and the recruitment of patient advocates to further support the advocacy initiative. Our partnership with PHA Canada this year resulted in over 2000 letters of advocacy being signed and delivered to decision-makers across the country. Scleroderma patient advocates are engaged and lending their support by lobbying their local MLA’s and MPP’s.

Efforts to raise awareness for clinical trials for Boehringer Ingelheim yielded six patients in Canada to join the worldwide SENSCIS trial. One of our scleroderma patients from Alberta, Lorraine Wigston, is featured prominently in BI’s international campaign to raise awareness of scleroderma and interstitial lung disease.

Scleroderma Canada continues to foster relationships with other affiliate organizations and collaborates on common areas of interest: Canadian Organization of Rare Diseases (CORD), Canadian Skin Patient Alliance, Scleroderma Research Foundation and the Scleroderma Foundation (our American counterparts and partners in the Hard Word, Harder Disease scleroderma awareness campaign).

A Repository for Scleroderma Research in Canada

Scleroderma Canada has secured a volunteer to assist with updating current lists of medical information as a preliminary step to building a comprehensive resource library of information to be made available on our website.
Good Governance and National Provincial Relationships

Scleroderma Canada has committed to the accreditation process outlined within the Imagine Canada Standards. Much work has been completed on the development of policies as they relate to board governance, financial accountability and transparency and staff management, job descriptions, and terms of reference for standing committees, all of which establish a strong foundation on which to improve overall effectiveness, efficiency, communication, responsiveness around the progress of annual work plans.

Scleroderma Canada is pleased to announce that four new board members will be joining the Board this year.

A formal liaison role for the provincial scleroderma organizations has been defined to allow provincial representatives quicker access to information and input to the board’s deliberations. Jason Doucette, President of the Scleroderma Society of Nova Scotia, has been appointed by the provincial organizations to take on this inaugural position as provincial representative.

Financial Stability

Scleroderma Canada and the provincial scleroderma organizations took a step forward with the signing of provincial MOUs to contribute financially to the sustainability of Scleroderma Canada. These agreements are the foundation of support for the national office.

Major gifts at Scleroderma Canada are primarily sponsorships associated with the National Conference. We continue to work on a major gift case for support from the partners with whom we have been cultivating relationships over the past three years.

The inaugural Spirit of Blue event in February 2017 raised over $45,000, allocated to redesigning the SC website. Spirit of Blue was developed with a design template that can be replicated, and we envision Spirit of Blue events across the country in future years. The event is designated to February, as February is Rare Disease Month.

The annual Blue Ribbon Campaign during the holiday season will be repeated this year. The launch date is associated with Global Giving Tuesday and fueled by the power of social media and collaboration. Building effective fundraising capacity and a national donor base to ensure the ongoing success of fundraising campaigns is paramount.

Scleroderma Canada remains committed to building on the successes of the past year as we work to improve the lives of those living with scleroderma and their families. We look forward to working with each and every one of you in the year ahead.

Michelle Richard
President

Anna McCusker
Executive Director
2017-2018 BOARD OF DIRECTORS

President, Michelle Richard

President-elect, Steve Kulakowsky

Vice President, Advocacy & Public Relations, Maureen Worron-Sauvé

Vice President, Finance, Jordan Fortino*

Secretary, Susan Dyck

Provincial Representative, Jason Doucette

Directors:
  Donna Blair-Lawton*
  Mary Beth Clark
  Britta Nielsen*
  Melissa Patton
  Georges Routhier*
  David Sauvé

* new board members

Executive Director, Anna McCusker

Retiring from the Board, with thanks for their service:
Catherine Fortuné
Helen Goerzen
David Queen

PROVINCIAL PRESIDENTS

Rosanne Queen – British Columbia
Louise Goulet – Saskatchewan
Tracey Magee – Saskatchewan (Oct-17)
Gaétan Baril – Quebec

Gillian Little – Alberta
Marion Pacy – Manitoba
Rebecca Wissenz – Ontario
Jason Doucette – Nova Scotia
MISSION
To advance health care options and enrich the lives of those dealing with scleroderma through bold advocacy, research, education and counsel.

VISION
A world free of scleroderma.

VALUES
Integrity in our governance processes and transparency in our communications;

Respect and compassion for our colleagues and those we serve;

Commitment to achieving our vision through inclusion and collaboration with others;

The Business of the Society shall be conducted without monetary gain for its Members or Officers, and any profits or other accretions to the Society shall be used solely to support its objectives.

STRATEGIC DIRECTIONS

Good Governance
Develop a defined plan to go forward including a strong Board and effective, well resourced staff

Financial Stability
Robust national fundraising program with donors and sponsors

A Repository for Scleroderma Research Agenda in Canada
Leader in communication of research

Advocacy
The leading advocate for scleroderma patients on national issues such as orphaned drugs

An Effective National/Provincial Relationship
Develop and nurture the relations and help to set educational standards (i.e., National Conference) and facilitate information sharing

Education
Translation of scleroderma research and transfer of knowledge
In Edmonton we have tried to have monthly social meetings at various restaurants in the city. Attendance is varied; ranging from 6 people up to 17. I have mixed up the days and time of day to give more people a chance to attend.

Miaya Clark, one of our members, has embarked on a stem cell replacement journey. Here is her progress report:

In June 2016, I started the process of HSCT (Hematopoietic Stem Cell Transplantation) at the Tom Baker Cancer Centre in Calgary Alberta under Dr. Jan Storek. The rheumatologist that is part of the treatment (not a trial) is Dr. Sharon LeClerq.

On August 2, 2016, I had a successful transfer of stem cells back and started the roller-coaster of recovery. 3 months post-transfer, I went for testing. The good news was that mainly my lungs had no progression (on Cellcept they had continued to decline in function). They were amazed at the skin softening: at 6 months I went from a 25 skin score to a 3-5. I just celebrated my 1 year re-birthday with friends and family that were there to support me during treatment and fundraising when we were looking at leaving the country for treatment prior to it becoming available in Alberta.

Lorraine Wigston, another of our members, was chosen to represent Canada in an international scleroderma awareness campaign sponsored by Boehringer Ingelheim:

As part of an International awareness campaign sponsored by Boehringer Ingelheim, they photographed and videoed 8 individuals from 7 countries around the world to share their stories living with Systemic Sclerosis. I was chosen as the Canadian representative. I would like to share with you my story and those of the other individuals in hopes of creating more education and awareness about this rare disease the quite often goes undiagnosed for a long time.

This is the link to Boehringer Ingelheim’s website where you can view the portrait series: https://www.boehringer-ingelheim.com/respiratory/systemic-sclerosis/inside-story. There are also videos on YouTube. Here is the link to my short video story which tells you a little bit about me and how it has affected one area of my life: https://www.youtube.com/watch?v=VcdxKK3rNOA. You can also do a search on Google or on YouTube for ‘More Than Systemic Sclerosis’ if you want to watch the other individuals’ stories.

One other thing I did for awareness is that I was interviewed for a podcast with some friends of mine from San Diego, California called 'Wrinkled Not Dead' Episode 60. Here I go into a little more detail about the disease and how it has generally affected my life. If you like podcasts (this one is about 34 min long), then here is the link if you are interested in listening: https://www.podomatic.com/podcasts/wrinklednotdead/episodes/2017-06-20T13_27_55-07_00

Susan Dyck, our member from Sylvan Lake, wowed us all again with Alberta’s only Walk in the Park for Scleroderma:

Both the 126 participants and the 26,000 dollars raised were a dramatic increase from 2016. Our dollar support was more than double from 2016 to 2017! It was overwhelming to see the numbers on registration day. We had assumed we would have mostly repeat walkers but that was NOT the case: we had ordered a small supply of tee shirts for 2017 and then were scrambling to find more.

Gillian Little (from Edmonton) was a great support and promoted the event to all those in her support group. Last year she came by herself, but 2017 saw other patients attending: Miaya, Sylviane, Margaret – with their families. Other Central Alberta patients arrived to walk with their families: Blii, Karen, Susan
D. Susan M, Phyllis, Chantel, Brendalee, and Toni. We had a total of 11 patients (don't like to use this word but what else??) in attendance.

It was heartwarming to see support from family members who had lost a loved one of their own to this disease, some so recent in their grief. It was such a hard day for them. And then realizing that everyone present had their own story to tell of everyday struggles … Some of the patients had been contacted in advance of the walk asking if they would be willing to share the story of their own struggle with scleroderma. These stories were posted around our shelter and there was a lot of interest in reading these, though for some it was difficult: “I just could not read too many, the struggle is too hard”

Dr. Jason An, a resident from U of A Hospital, Edmonton AB came to our AB Walk, “I just needed to come and see for myself what is happening in Sylvan Lake”…I can’t believe where all these people came from!” We had posted information about Scleroderma and included a poster of the Hamilton Scleroderma Group and their eye catching photo of the group of medical professionals. Of course, Dr. An’s attention was caught by this poster (he was on a first name basis with many of the people in the photo) and so he sought me out. “Did I know these people?” he asked. No, I did not - my interest had been captured by the professionals from St. Joseph’s Hospital, Hamilton participating in fundraising for their own hospital and scleroderma research shared in one of their ‘tweets’ about the Paris to Ancaster Road Race. I told Dr. An that my dream is to have a similar team of medical professionals, informed and familiar with scleroderma, caring directly for scleroderma patients right here in Alberta. Dr. An contacted me later, thanking the organizing crew of the Sylvan Lake walk and indicating an interest in supporting our activities. We look forward to working with him.

Hopefully we will have an Edmonton walk as well as the Sylvan Lake walk next year.

Susan Dyck is now listed on SC website as a group support leader. She has obtained support from the SPIN group and is planning to use the materials in some informal group support meetings. She is also building a client base of interested patients/family members and has a current list of 27 people. Their distant locations make getting together in person a challenge. For the time being, I am doing contacts by phone and email, though I hope to at least start with a coffee get-together for as many as are available. Alberta is lacking in any sort of a formal registry - it is crucial in the next year that we establish a higher profile.

The Scleroderma National Conference slated for September 21-22, 2018 in Calgary will definitely have a huge impact for Alberta patients! I have made a connection with a doctor in residency at the U of A hospital who is interested in promoting a support network within the medical community, similar to the Hamilton Scleroderma Group program in Ontario.

When the Scleroderma Society of Southern Alberta in Calgary ceased operations, they generously gifted Scleroderma Canada with $3500 for the Calgary 2018 conference and also gave Scleroderma Edmonton $500 to use as they saw fit. I would like to use it to assist members to attend the Calgary conference with bus transportation but will be brainstorming ideas with our group.

I would like to thank everyone involved with organization and running of events this past year. The coming year is going to be busy, and we will need to invigorate some enthusiasm for the upcoming conference in Calgary.

Gillian Little
President – Scleroderma Alberta
This past year, the Scleroderma Association of Saskatchewan worked to fulfill our mandate in the following ways:

Through our support group meetings, members and their families discussed their experiences and concerns, and shared helpful hints. With the expertise of our guest speakers, we learned how to change or improve troubling issues. For example, last October our guest speaker Karen Grand, a nurse educator specializing in wound care, focused on finger ulcers. A highlight of her talk was that Fruit of the Earth Vitamin E gel, is a very effective treatment for finger ulcers. Ms. Grand stressed that platelets are crucial in the healing process and that blood vessels must be dilated enough to allow passage of platelets. A Beta Glucon cream gel is a skin regenerative and can be kept in place with Aquagel rope dressing and Transpore white tape. Various factors that affect healing were outlined.

At our April meeting, guest speaker, Dave Sereda, director of Pharmacy for Five Hills Health Region, spoke on the Changing World of Scleroderma Medications. Current therapies focus on the four main features of the disease – inflammation, autoimmunity, vascular disease and tissue fibrosis. He discussed medications currently used to treat each of these features and how effective they are. He also mentioned the use of medical marijuana and its availability. In summary, he said targeted therapies are the focus of treatment and there are new products continually being tried, but not all are promising. Presently, there are large studies underway in the U.K. and U.S.A.

This past March, SASK donated $9,000 to scleroderma research.

One of our members is scheduled to have a stem cell transplant in August. Another member has been approved for a kidney transplant as soon as a suitable donor is found. Both these procedures will take place at the University Hospital in Saskatoon. Our thoughts and prayers are with these two members for successful results.

As of October 2017, the Scleroderma Association of Saskatchewan has a new president, Tracey Magee. You may have seen Tracey and her husband, Colin, promoting our Scleroderma Awareness Walk through media events and postings on Facebook. SASK helped to sponsor Tracey and Colin in attending the U.S. National Conference in July. They will share information learned from the presenters and workshops at our October support group meeting.

Our second Scleroderma Awareness Walk took place on Sunday, June 4th in Regina. We had 107 walkers and raised over $20,000. MLA Mohammed Fiaz brought greetings on behalf of the newly appointed Minister of Health, Honourable Jim Reiter. Mr. Fiaz presented the ‘Certificate of Recognition’, designating the month of June 2017 “Scleroderma Awareness Month” in Saskatchewan. We were also delighted to have Chief Evan Bray of the Regina Police Service bring greetings and to have Roberta Nichol, singer and songwriter, known as Saskatchewan’s Songbird, perform for us.
Just prior to our walk, we received a request from Maureen Worrnon-Sauve asking for help in raising awareness of a drug called Uptravii. This drug is used to treat pulmonary arterial hypertension (PAH) and is currently not accessible to those who rely on public funding in Canada. To date, we have 60 letters signed and ready to mail to our provincial Premier and Minister of Health. We hope to take the remaining letters and postcards to our fall meeting and have members take them into their communities and have them signed.

Louise Goulet  
President – Scleroderma Association of Saskatchewan

SCLERODERMA MANITOBA

The Scleroderma Association of Manitoba changed its name this year to Scleroderma Manitoba with a new logo.

In May, Scleroderma Manitoba held their second Educational Day. We had Dr. Mai Nguyen speak on GI Involvement, Lisa Mills-Hutton from Physiotherapy. Emily Kadolph did a 10 minute presentation on Raynaud’s. Emily is 9 years old and has won a gold ribbon for her presentation at science divisionals. Dr. Amber Cogar followed up after Emily with her presentation on Raynaud’s.

In June we saw sunshine this year for our third Walk in Manitoba. In our newsletter in the coming months we will be doing a write up on getting to know the teams that walk for Scleroderma. See everyone next year!!!

In August some of our Blue Bombers fans will be attending a game against the Edmonton Eskimos. The football organization has a fundraiser for non-profits, you purchase a ticket and some of the proceeds go back to Scleroderma Manitoba.

In September Scleroderma Manitoba will be having their fall support group after a wonderful summer vacation.

Marion Pacy  
President – Scleroderma Manitoba
SABC continues to be a strong and active organization after 34 years. Joan Kelly, one of our founding members, is continuing to answer the phone to share her knowledge and caring. Our returning board brings with it a wide range of life experiences and knowledge to form a complement of individuals that have the vision and the commitment to get things done. The leadership of the board has attracted other scleroderma patients from across the province to make a difference in their own community by organizing a walk, representing SABC at a wellness fair and being on local media. SABC is strong.

This year SABC has gone to the streets and the parks to raise awareness and much needed research funding for scleroderma. The 6th Annual Scleroderma Ride for Research (SRR) brought out riders and walkers to lift public awareness of scleroderma. The 10 km walk/ride on the seawall around Stanley Park presented beautiful city, mountain and water views; this must be one of the most beautiful walk venues in the country. Unfortunately, there were no Orcas splashing in the waters of English Bay but there were numerous groups questioned by the public along the route. What is scleroderma? Just asking the question means that we are doing our duty. Hearty riders, new and seasoned, took to the bike routes through Kitsilano along the shore of English Bay before attacking the Spanish Banks hill to UBC before heading back for lunch along some of the many bike routes through Vancouver. In conjunction with the SRR, SABC held the third community awareness hot dog barbeque in North Vancouver. Scotiabank was our corporate supporter again this year, with O’Canadawg providing the grilling and attention getting sales pitch; thanks to Kirk at Scotiabank and Nicole on the grill. The combined fundraising directed more than $55,000 directly to local research. New walks happened in Smithers and Valemount due to the determination of a couple of local scleroderma patients and support from friends and Ruth at SC. Both events were a great success in bringing awareness of this disease to their communities. Pati’s and Teresa’s commitment and effort, as they worked through their own challenges, is appreciated by SABC. Fund raising from the walks totaled about $10,000. This has been a great start to SABC’s involvement in SC’s Walk, Run or Ride for Scleroderma campaign.

Our annual conference, held in combination with our AGM, had about 80 in attendance to listen to our line-up of speakers and share their experiences. The presentations brought forward ideas on recent research, vision, mental health and alternatives to standard practice. The engaging presenters solicited comments and questions from the audience. There is no end to the thirst for knowledge and understanding; our organizing committee has done tremendously in promoting a variety of topics. Special guests this year were a variety of students in the medical field, providing an opportunity for interaction such as had taken place in previous years at the annual education day at UBC. Dianne suggested we continue the direct exchange with future medical practitioners by inviting about 12 to the conference. Embedded within the scleroderma community the students had the opportunity to learn firsthand from individuals about this disease. What a success! To everyone’s agreement, Dr. James Dunne was presented with the Gurmej Kaur Dhanda Scleroderma Community Service Award. Dr. Dunne is the Director of the Scleroderma Clinic at St. Paul’s Hospital in Vancouver and one of the prime researchers involved in SABC’s genome project.

Our members have also been increasing awareness on several fronts. One of our members, Cecille, created new posters to be available for all our events. The “What does Scleroderma look like?” poster features three of our members, who all look marvelous, with descriptions of each of their personal challenges from the disease. Nothing but good feedback on catching people’s attention and tugging on heart strings. With funding from the Canadian Skin Patients Alliance, we have created SABC outdoor banners, for use at the
walks, and pull-up banners that illustrate the wide variety of symptoms associated with scleroderma. A close working relationship with staff at the St. Paul’s Hospital Foundation is developing to assist SABC in reaching venues and opportunities that have not been cultivated in the past; more options to get the message out.

Along with educational opportunities for patients and students at our conference, members are committing to other settings where they can make a difference. SABC is represented at a few local Wellness Fairs across the province, where members provide information pamphlets for the public and share their personal stories. A major initiative that two of our board members, Dianne and Grant, are involved with is “Patients in Education” that is organized by the University of British Columbia medical education group. This is an opportunity for patients, from a variety of diseases, to make an impact on the education of students in medical fields. SABC has been involved from the initiation of the program and continue to provide a unique perspective for future development.

General donations for research come from a variety of sources over the year that, when combined with 100% of the fundraising from the Scleroderma Ride for Research, is currently directed towards research in British Columbia. The Scleroderma Clinic at St. Paul’s Hospital conducts some research, but the primary research project is the genome study with Dr. Dunne heading the team, with Kevin Keen and others. Skin and blood sampling is continuing for both scleroderma patients and “normal” people in preparation for the genome sequencing. This is an exciting program with SABC directly involved in the research team and connected with the primary researchers.

All that SABC has been able to accomplish this year and plan for the year to come is driven by the board and made possible by the many people that make it happen. SABC continues to be successful by holding to the vision of improving the life of scleroderma patients. I want to thank the board members that keep us running, though they may be working through serious health issues or squeeze the demands into their working life. Now that is commitment! Then there are the members and our friends that continue to stand with us to spread awareness and caring to the community. Each person makes a difference! It is surprising to find out who you know have also been touched by scleroderma, once you talk about it. We also appreciate the help from our corporate sponsors, Scotiabank and Park Insurance.

SABC is committed to making a difference and we will.

Rosanne Queen
President – Scleroderma Association of B.C.
SCLERODERMA SOCIETY OF ONTARIO

We are all part of the scleroderma community because we have been inspired by either our own diagnosis, the diagnosis of a friend or loved one, professional interest, or simply by a desire to provide help where it is needed.

My involvement with the Scleroderma Society of Ontario (SSO) started in 2012 and was the result of my son’s diagnosis years before. At that time, my goals for volunteering were all related to him. However, the more I do with the Society, the more motivated I am to continue building on its long and productive history of good works for the scleroderma community at large. We are, after all, in this together! I am immensely proud of our organization and our three-pronged mission of enhancing public awareness of scleroderma, supporting patients in their quest for better health, and contributing to scleroderma-related research.

PUBLIC AWARENESS & FUNDRAISING

Awareness and fundraising events continue to be successful for SSO. Thanks to our friends and supporters, in 2016 SSO raised funds in excess of $375,000 with the following activities:
• Blue Ribbon holiday campaign
• Mississauga Gala
• 8th Annual Hamilton Scleroderma Golf Tournament, Dinner and Auction
• 2016 Walk, Ride or Run in the Park events in Hamilton, Ottawa, Toronto and London

We look forward to an even more active 2017, having already participated in several successful events, including:
• Dave and Joe’s 1st Annual Scleroderma Awareness Golf Classic in Ancaster
• Slappin’ a Headlock on Scleroderma in Hamilton, a wrestling event with over 350 attendees
• 2017 Walk, Ride or Run in the Park, in 5 parks across Ontario, where an incredible 916 walkers raised more than $275,000

We look forward to the 9th Annual Hamilton Scleroderma Charity Golf Tournament in September, and plans have also begun for a spectacular gala dinner in February, themed “Fire & Ice”, to be held in Windsor in 2018 – not to be missed!

June Awareness Month was highly successful and involved media and social media campaigns promoting events that significantly increased awareness. Between SSO’s Twitter and Facebook platforms, social media posts in June reached an audience of 216,562, an increase of 28% from 2016. Broadcast and print media coverage of June events included a poignant full page patient story in the Stoney Creek News that also promoted the Hamilton Walk, a one hour panel discussion on the top rated Bill Kelly Show on AM900 CHML radio and a segment featuring the Toronto East Don Parkland Walk on CityNews Weekend.

Three Ontario landmarks were illuminated scleroderma blue to promote awareness in June: Toronto’s CN Tower, Niagara Falls and Hamilton City Hall blazed blue to advocate our cause.
Through Scleroderma Canada, we are partnered with the Pulmonary Hypertension Association of Canada (PHA Canada) to advocate on behalf of patients with pulmonary arterial hypertension, including PAH secondary to scleroderma (SSc-PAH). These efforts include a letter-writing campaign to the Ontario Premier and Minister of Health to provide public funding for a new medication (Uptravi/selexipag). Over 800 letters were signed at June events.

Ontario also hosted the inaugural “Spirit of Blue” event in Richmond Hill, arranged by Nancy Morency, in support of Scleroderma Canada. Award-winning Canadian singer-songwriter Chantal Kreviazuk entertained more than 400 people in a truly magical evening that introduced many new supporters to the scleroderma community.

**PATIENT SUPPORT**

We continue to collaborate with the Scleroderma Patient Intervention Network, the Hamilton Scleroderma Group, and a Youth Support Group initiative through SickKids Hospital to develop meaningful patient supports and ensure that no one will be left to cope with this disease alone.

**SCLERODERMA RESEARCH**

SSO continues to provide significant, ongoing financial support of the scientific community. In 2016, we directed **$128,600** to the following research:

- Dr. Janet Pope: development of a protocol of all treatment options for patients at certain treatment points to develop insights into best clinical practices.

- Dr. Sindhu Johnson: study of RNA polymerase III antibodies in systemic sclerosis as a disease biomarker to facilitate timely diagnosis.

- Dr. Maggie Larché – activities of Hamilton Scleroderma Group, an interdisciplinary clinic at St. Joseph’s Hospital Hamilton, providing holistic, research-based clinical care to scleroderma patients.

- Dr. Murray Baron – the Canadian Scleroderma Research Group (CSRG), fostering collaborative research into scleroderma in order to better treat patients affected by the disease.

- Dr. Ronald Laxer - development of a specific patient-reported outcome measure for patients with localized scleroderma involving the face and head. This measure will include the patient’s voice in assessing what is really important to patients in terms of outcome.

As an SSO donor or volunteer (or both!), you contributed to a 2016 full of hope and progress. We make progress because you give us the resources and the opportunities. Our accomplishments are your accomplishments. You make us a stronger organization and provide the resources to help even more people in more ways. You are our champions and we thank you from the bottom of our hearts.

Rebecca Wissenz
President – Scleroderma Society of Ontario
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.

**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.

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) 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 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 17th 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!

Gaétan Baeril  
Président – Sclérodermie Quebec
J’ai l’immense honneur de souligner les principales réalisations de Sclérodermie Québec pour l’année 2016-2017 dans les secteurs d’activités suivants : soutien à la recherche, soutien aux malades, information et éducation ainsi que nos activités-bénéfice réalisées au cours de la dernière année.

SOUTIEN À LA RECHERCHE

Grâce à notre première campagne de financement, Sclérodermie Québec a collaboré à la mise en place de la Chaire de recherche en sclérodermie située au Centre hospitalier de l’Université de Montréal (CHUM), la seule du genre au Canada, et a contribué près de 2 000 000 $ à la recherche. En outre, nous avons récemment versé une subvention de 25 000 $ au capital de la Chaire de recherche en sclérodermie et une autre subvention de 25 000 $ à un Fonds de souscription lié à la Chaire de recherche en sclérodermie. Aussi, nous prévoyons verser un autre 50 000 $ cette année à ce fonds de souscription et nous sommes toujours à l’affût de projets de recherche visant à améliorer la qualité de vie et l’espérance de vie des personnes atteintes de sclérodermie. La liste des subventions accordées par notre organisme est disponible sur le site Web www.sclerodermie.ca.

INFORMATION ET ÉDUCATION

Dans le cadre de notre mission d’information et d’éducation, nous avons publié plusieurs nouveaux documents à l’intention des personnes atteintes de sclérodermie et leurs aidants naturels, qui sont disponibles en français et en anglais sur notre site web www.sclerodermie.ca.

Un des volets importants de notre mission consiste à informer et sensibiliser la population à propos de la sclérodermie, notamment les différentes formes de la maladie, ses symptômes, etc. Un des moyens que s’est donné l’organisme pour atteindre cet objectif est de publier deux fois l’an un bulletin d’information destiné aux personnes atteintes, au grand public ainsi qu’aux professionnels de la santé. Le magazine Le Bulletin est un document de référence tiré à près de 6 000 exemplaires dont plus de 4 000 lecteurs sont des médecins et des intervenants de la santé. De plus, afin de rejoindre le plus de personnes possibles, notre site Web (www.sclerodermie.ca) est bilingue depuis deux ans déjà. Un seul clic et vous aurez accès à une mine d’information sur la sclérodermie, des articles d’ordre médical et des guides sur divers sujets en lien avec la sclérodermie, ainsi qu’aux toutes dernières nouvelles. Nous avons continué à enrichir notre site Internet bilingue à plusieurs niveaux, notamment par l’ajout de publications, d’un guide sur les symptômes et médicaments reliés à la sclérodermie, et de l’information mise à jour périodiquement sur la Chaire de recherche en sclérodermie.

CAMPAGNE DE SENSIBILISATION

Dans le cadre de notre mission de sensibilisation, Sclérodermie Québec a lancé une vaste campagne publicitaire à l’échelle du Québec au printemps-été 2016, comprenant des annonces diffusées gracieusement à la télévision, à la radio, sur le Web et dans les magazines ainsi que des affiches spécialement conçues pour les abribus, afin de sensibiliser la population québécoise à la sclérodermie. Notre campagne de sensibilisation a porté fruit et les visites du site www.sclerodermie.ca ont quintuplé au cours de cette campagne.
Aussi, en juin dernier, nous avons mis de l’avant deux nouveaux événements dans le cadre du Mois de Juin, mois de sensibilisation à la sclérodermie et des marches organisées à travers le Canada, soit une Marche à Mirabel et une Marche à Sherbrooke, avec une participation totale de 260 marcheurs et bénévoles ainsi que de nombreux généreux donateurs. Tout un succès pour une première édition!

**ENTRAIDE ET SOUTIEN AUX MALADES**

L’infirmière de Sclérodémie Québec a pour principaux objectifs de sensibiliser les personnes atteintes à l’importance d’adopter de saines habitudes de vie, ainsi que de les renseigner sur la maladie et les changements physiques et psychologiques qu’elle implique. Notre infirmière collabore aussi étroitement avec les responsables bénévoles de nos groupes de soutien à travers le Québec.

**FINANCEMENT**

En ce qui a trait à nos activités de financement, précisons qu’il y a eu 4 activités-bénéfice organisées au profit de notre organisme : deux tournois de golf-bénéfice, un souper-bénéfice au Cabaret du Casino de Montréal, un souper-spectacle et un cocktail dinatoire sous le thème « Choco-champagne » au Terminal de Croisières à Québec.

En terminant, Sclérodermie Québec est heureuse d’avoir collaboré avec Scleroderma Canada à l’organisation de la 17e CONFÉRENCE NATIONALE BILINGUE sur la sclérodermie qui s’est déroulée les 16 et 17 septembre 2016 à Montréal, avec un nombre record de participants. Plusieurs d’entre eux ont vanté la diversité des sujets abordés, la qualité des conférenciers ainsi que le partage d’information. La conférence fut un immense succès et nous tenons à remercier tous les acteurs, participants et bénévoles qui ont contribué à cette belle réussite!

Gaétan Baeril
Président – Sclérodémie Quebec
The Scleroderma Society of Nova Scotia has had a busy and productive year.

Nova Scotia’s 6th Annual Run/Walk in the Park was held on June 17, 2017. Although the weather was not cooperative, the event was a huge success. Approximately 150 people braved the rain and the event saw many new faces and teams joining us for the first time. More than $26,000 was raised, including support from our corporate sponsors (Scotiabank, FYidoctors-Halifax, Shane Richard Holdings, and RCS Construction). Run Nova Scotia provided a full finish line experience including their inflatable arch, timing services and music. The Honourable Geoff Regan, Speaker of the House of Commons & MP for Halifax West, brought greetings on behalf of the Government of Canada. The Honourable Kelly Regan, Nova Scotia’s Minister of Community Services & MLA for Bedford, proclaimed June as Scleroderma Awareness Month on behalf of Premier Stephen McNeil. Virgin Radio was also on-site promoting the event through their summer cruiser and gave away free product to those in attendance. The family BBQ was as popular as ever and there were many door prizes available to be won. The organizing committee is looking forward to building on this year’s momentum and growing the event next year.

Although the Run/Walk is the society’s primary fundraiser, additional fundraisers were held over the past year including an online auction and a benefit concert, both of which were held in conjunction with Ovarian Cancer Canada, with proceeds shared among the two groups.

We continue to promote the David Shea Memorial Patient Support Fund, which financially assists those who are incurring expenses as a result of the management of Scleroderma. Expense reimbursements have been made to a number of patients to date.

The Society continues to provide ongoing support to patients, including support group meetings and an art therapy program. The Board will use data collected from a recent patient questionnaire to set program priorities and budget allocations for the next fiscal year.

The Society has continued to focus on increasing awareness of the disease and of our Society. To accomplish this, public information sessions have been held where patients, families, caregivers, and other stakeholders are invited to learn more about Scleroderma and to build connections. The Society attended the recent Doctors Nova Scotia AGM where connections were made with a number of provincial physicians. The Society would also like to broaden its reach to the remaining Atlantic Provinces, as there are no formal support services offered in these areas.

The Scleroderma Society of Nova Scotia would like to extend a heartfelt welcome to the Scleroderma Canada Board Members and the Presidents of the Provincial Scleroderma organizations. We hope that you will enjoy your time in our beautiful province!

Jason Doucette
President – Sclérodermie Society of Nova Scotia
# Financial Statements

For the year ended May 31, 2017

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<th>Page</th>
</tr>
</thead>
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<td>Financial Statements</td>
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<td>Statement of Operations and Changes in Net Assets</td>
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<tr>
<td>Notes to Financial Statements</td>
<td>6-7</td>
</tr>
</tbody>
</table>
Independent Auditor’s Report

To the Board of Directors of Scleroderma Canada

We have audited the accompanying financial statements of Scleroderma Canada (the “Organization”), which comprise the statement of financial position as at May 31, 2017, and the statements of operations and changes in net assets and cash flows for the year then ended and a summary of significant accounting policies and other explanatory information.

Management’s Responsibility for the Financial Statements
Management is responsible for the preparation and fair presentation of these financial statements in accordance with Canadian accounting standards for not-for-profit organizations, and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor’s Responsibility
Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with Canadian generally accepted auditing standards. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor’s judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity’s preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity’s internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained in our audit is sufficient and appropriate to provide a basis for our qualified audit opinion.

Basis for Qualified Opinion
In common with many charitable organizations, the Organization derives revenue from donations, the completeness of which is not susceptible to satisfactory audit verification. Accordingly, our verification of these revenues was limited to the amounts recorded in the records of the Organization. Therefore, we were not able to determine whether any adjustments might be necessary to revenue, deficiency of revenue over expenses and cash flows from operations for the years ended May 31, 2017 and 2016, current assets as at May 31, 2017 and 2016, and net assets as at June 1 and May 31 for both the 2017 and 2016 years. Our audit opinion on the financial statements for the year ended May 31, 2016 was modified accordingly because of the possible effects of this limitation in scope.

Qualified Opinion
In our opinion, except for the possible effects of the matter described in the Basis for Qualified Opinion paragraph, the financial statements present fairly, in all material respects, the financial position of Scleroderma Canada as at May 31, 2017, and the results of its operations and its cash flows for the year then ended, in accordance with Canadian accounting standards for not-for-profit organizations.

BDO Canada LLP
Chartered Professional Accountants, Licensed Public Accountants
Burlington, Ontario
September 16, 2017
# Statement of Financial Position

**May 31**

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash - Unrestricted</td>
<td>$91,272</td>
<td>$157,592</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>$1,926</td>
<td>-</td>
</tr>
<tr>
<td>HST receivable</td>
<td>$18,782</td>
<td>$14,424</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>$32,688</td>
<td>$16,852</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>$144,668</td>
<td>$188,868</td>
</tr>
</tbody>
</table>

| **Liabilities and Net Assets** |          |          |
| **Current**                 |          |          |
| Accounts payable and accrued liabilities (Note 2) | $73,015  | $76,893  |
| Deferred conference sponsorships | $24,599  | $36,500  |
| **Total**                   | $97,614  | $113,393 |
| **Net Assets**              |          |          |
| Unrestricted                | $47,054  | $75,475  |
| **Total**                   | $144,668 | $188,868 |

The accompanying notes are an integral part of these financial statements.
Scleroderma Canada
Statement of Operations and Changes in Net Assets

For the year ended May 31

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations</td>
<td>$186,281</td>
<td>$69,607</td>
</tr>
<tr>
<td>Restricted donations</td>
<td>-</td>
<td>100,000</td>
</tr>
<tr>
<td>Conference sponsorships</td>
<td>80,690</td>
<td>53,520</td>
</tr>
<tr>
<td>Special event revenue</td>
<td>81,392</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td>348,363</td>
<td>223,127</td>
</tr>
</tbody>
</table>

| **Expenses**        |        |        |
| Advertising and promotion | -      | 2,624  |
| Conference expenses  | 115,003 | 48,021 |
| Development and training | 24,017 | 20,100 |
| Insurance            | 653    | 796    |
| Meeting and travel   | 22,735 | 8,678  |
| Office and general   | 20,799 | 11,605 |
| Platform fees        | 4,025  | 2,165  |
| Professional fees    | 27,681 | 9,590  |
| Public awareness and advocacy | 63,707 | 43,258 |
| Research             | -      | 100,000|
| Salaries and benefits (Note 2) | 64,612 | 45,540 |
| Special event expenses | 29,716 |       |
| Telephone            | 2,101  | 1,680  |
| Utilities            | 1,735  | 1,628  |
| **Total Expenses**   | 376,784 | 295,685|

| **Deficiency of revenue over expenses for the year** | (28,421) | (72,558) |
| **Net assets, beginning of year**                  | 75,475    | 148,033  |
| **Net assets, end of year**                        | $47,054   | $75,475  |

The accompanying notes are an integral part of these financial statements.
### Scleroderma Canada

#### Statement of Cash Flows

For the year ended May 31

<table>
<thead>
<tr>
<th>Description</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash flows from operating activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deficiency of revenue over expenses for the year</td>
<td>$ (28,421)</td>
<td>$ (72,558)</td>
</tr>
<tr>
<td>Adjustments to reconcile deficiency of revenue over expenses to cash provided by operating activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in non-cash working capital balances</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HST receivable</td>
<td>(6,284)</td>
<td>(11,478)</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>(15,836)</td>
<td>(11,137)</td>
</tr>
<tr>
<td>Accounts payable and accrued liabilities</td>
<td>(3,878)</td>
<td>31,243</td>
</tr>
<tr>
<td>Deferred donations</td>
<td>-</td>
<td>(100,000)</td>
</tr>
<tr>
<td>Deferred conference sponsorship</td>
<td>(11,901)</td>
<td>36,500</td>
</tr>
<tr>
<td><strong>Decrease in cash during the year</strong></td>
<td>(66,320)</td>
<td>(127,430)</td>
</tr>
<tr>
<td><strong>Cash, beginning of year</strong></td>
<td>157,592</td>
<td>286,022</td>
</tr>
<tr>
<td><strong>Cash, end of year</strong></td>
<td>$ 91,272</td>
<td>$ 157,592</td>
</tr>
</tbody>
</table>

The accompanying notes are an integral part of these financial statements.
May 31, 2017

1. Significant Accounting Policies

Nature of Organization
The Scleroderma Canada (the “Organization”) was incorporated on April 10, 2000, without share capital, under the Canada Corporations Act and is a registered charity under the Income Tax Act and, as such, is exempt from income taxes. The Organization was established to promote public awareness, provide education and support and funding research.

Basis of Accounting
The financial statements have been prepared using Canadian accounting standards for not-for-profit organizations.

Revenue Recognition
The Organization follows the deferral method of accounting for contributions which include donations. Unrestricted donations are recognized as revenue when received or receivable if the amount to be received can be reasonably estimated and collection is reasonably assured.

Externally restricted donations are recognized as revenue in the year in which the related expenses are incurred. To the extent such donations are unspent at year end, they are presented as deferred revenue on the statement of financial position.

Conference sponsorships are recognized as revenue in the year in which the conference takes place. Sponsorships received in advance are recognized as deferred revenue until the conference takes place.

Special event revenues are recognized as revenue in the year in which the special event takes place. Revenues received in advance are recognized as deferred revenue until the special event takes place.

Financial Instruments
Financial instruments are recorded at fair value when acquired or issued. In subsequent periods, financial instruments are reported at cost or amortized cost less impairment, if applicable. Financial assets are tested for impairment when changes in circumstances indicate the asset could be impaired. Transaction costs on the acquisition, sale or issue of financial instruments are charged to the financial instrument for those measured at amortized cost.

Contributed Goods and Services
Volunteers contribute a substantial number of hours each year to assist the Organization in carrying out its activities. Because of the difficulty in determining their fair value, contributions of such services are not recognized in these financial statements. There were no contributed materials received in the year.

Use of Estimates
The preparation of financial statements in accordance with Canadian accounting standards for not-for-profit organizations requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities at the date of the financial statements, and the reported amounts of revenue and expenses during the reporting period. Actual results could differ from management’s best estimates as additional information becomes available in the future.
Scleroderma Canada
Notes to Financial Statements

May 31, 2017

2. Related Party Transactions

The Organization has common management with the Scleroderma Society of Ontario. During the year, the Organization reimbursed salaries and benefits costs of $64,612 (2016 - $45,540) to Scleroderma Society of Ontario.

Accounts payable and accrued liabilities include $31,569 (2016 - $15,067) owing to Scleroderma Society of Ontario.

These transactions occurred in the normal course of operations and are recorded at the exchange amount as agreed to by the related parties.