WINTER EDITION

THE SCLERODERMA REPORTER

The Scleroderma Society Of Ontario Newsletter

A Message from John

Hello Members,

As The Scleroderma Society of Ontario enters a new fiscal year, our team is hard at work serving our worthwhile cause. With a focus on efficiencies and capacity building to increase awareness, we are also funding crucial research and supporting patients who are at the very heart of what we do.

Please read below to find out what the SSO team will be working on diligently in 2020.

WHAT'S HAPPENING AT THE ORGANIZATION?

ANNOUNCEMENT

JOHN MALCOLMSON, EXECUTIVE DIRECTOR

The SSO team will be working diligently in 2020 to provide:

- A new Board of Directors structure with a focus on representation of board members to reflect the province, by region
- Working with SPIN to establish Patient Support Group standards and training
- Establishing an SSO membership program
- Establishing a research grant application and review process
- Hosting 250 delegates from across Canada and the USA at the Scleroderma Canada National 2020 Conference in Niagara Falls, ON taking place September 18-19, 2020
- Seeking the approval of medications with the Ministry of Health, including:
  - The use of PDE5i at any dose for secondary Raynaud's associated with connective tissue disease (CTD) or vasculitis that is not responding to calcium channel blockers and is severe
  - The use of PDE5i for the treatment and prevention of digital ulcers in scleroderma or other autoimmune diseases (CTD, vasculitis)

Additionally, I'm excited to announce that we have scheduled a return visit to Queens Park on October 19, 2020 for this year's Legislative Day. Participation is encouraged and our office will be sharing further details in an upcoming notice.

We hope you enjoy the Winter edition of our newsletter and this amazing opportunity to learn about all the great research that is happening across Ontario. Soon the cold weather will be gone, and we will be planning for record attendance at our awareness walks and our 19th Bi-Annual National Conference. I hope to have the opportunity to meet you personally at these events.

Happy reading!

John Malcolmson

2020 SCLERODERMA CONFERENCE

SEPTEMBER 18-19TH | NIAGARA FALLS, ON

The SSO is thrilled to be working with Scleroderma Canada to host the 19th Bi-Annual National Scleroderma Conference. This two-day, educational event offers those living with scleroderma, their caregivers, family members and friends a chance to engage and contribute to the scleroderma community. Please join us for an opportunity to absorb the newest information, learn from the experiences of others and gain insight from researchers, physicians and professional caregivers.

Scleroderma Canada supports those affected by scleroderma and funds research that may lead to better treatments or even a cure. Scleroderma Canada also collaborates with provincial and international scleroderma organizations to advocate on behalf of the scleroderma community.

Held in beautiful Niagara Fall, ON, and hosted by The Scleroderma Society of Ontario, this year's conference offers numerous workshops, a variety of exhibitors, and the chance to meet other patients and caregivers.

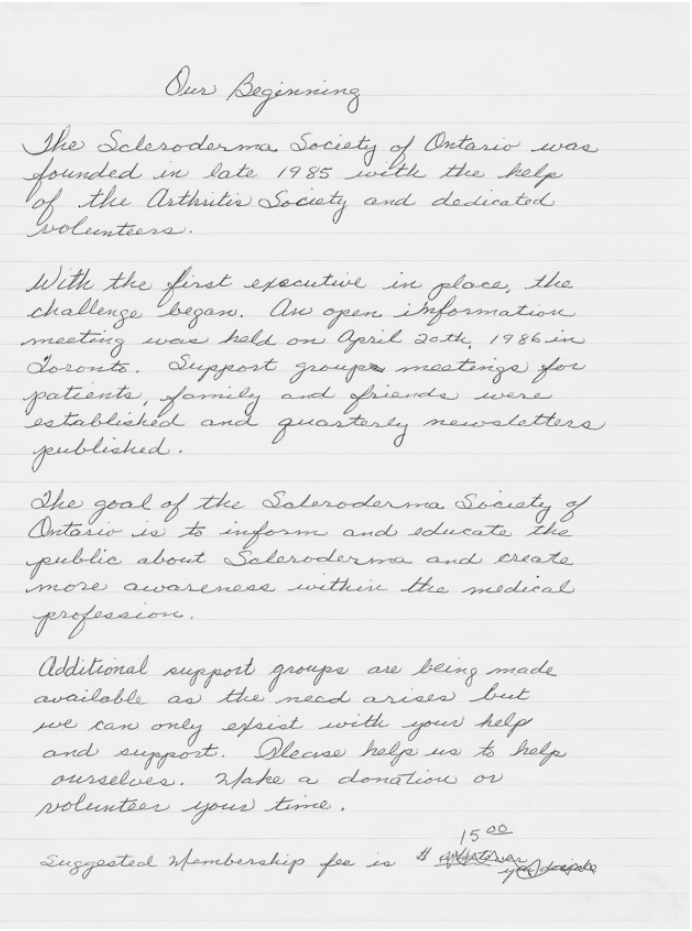
We're headed to Niagara Falls!

The 2020 National Conference hosted by Scleroderma Society of Ontario will be the largest educational conference in the history of Scleroderma Canada with over 22 educational sessions, 3 Keynote speakers and entertainment. Affordable registration rates are made possible by our generous sponsors.

Register before May 15th, 2020 to receive **Early Bird Registration and you'll save $50**. Registration fees include admission to all Conference sessions, refreshment breaks, Friday lunch, Saturday morning continental breakfast and lunch. You won't want to miss out! Please click the link below to register today.

Our esteemed speakers from across Canada and the United States will be sharing the latest information on topics ranging from holistic healing and art therapy, to pain management and stem cell transplantation.

Please find out more about our keynote speakers, travel/accommodation, topics and more at www.sclerodermaconference.ca.



Our Beginning

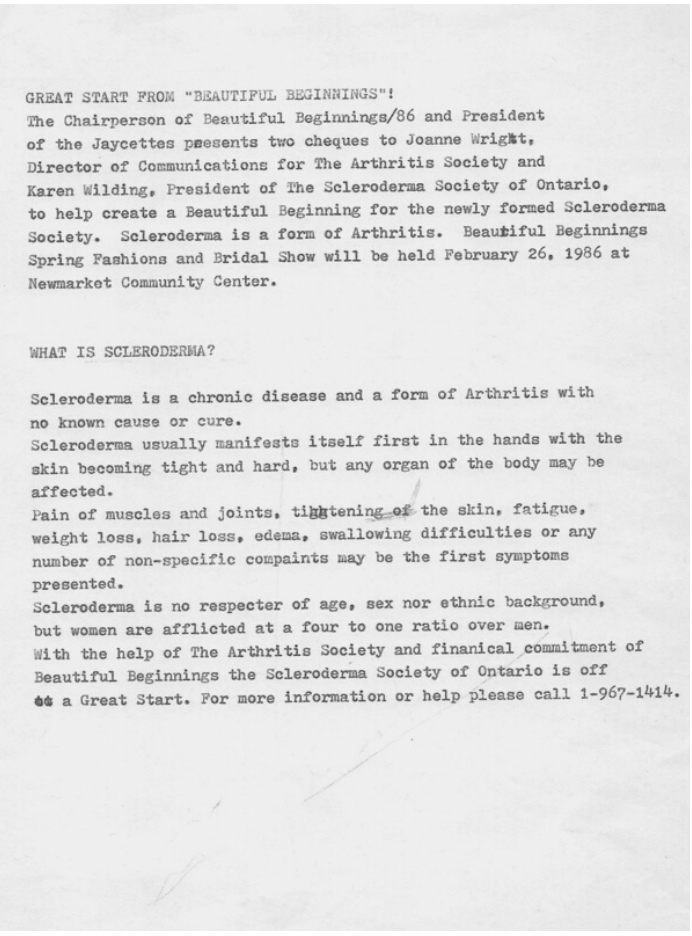
The Scleroderma Society of Ontario was founded in late 1985 with the help of the Arthritis Society and dedicated volunteers.

With the first executive in place, the challenge began. An open information meeting was held on April 20th, 1986 in Toronto. Support groups meetings for patients, family and friends were established and quarterly newsletters published.

The goal of the Scleroderma Society of Ontario is to inform and educate the public about Scleroderma and create more awareness within the medical profession.

Additional support groups are being made available as the need arises but we can only exist with your help and support. Please help us to help ourselves. Make a donation or volunteer your time.

Suggested Membership fee is $15.00



GREAT START FROM "BEAUTIFUL BEGINNINGS"!
The Chairperson of Beautiful Beginnings/86 and President of the Jaycettes presents two cheques to Joanne Wright, Director of Communications for The Arthritis Society and Karen Wilding, President of The Scleroderma Society of Ontario, to help create a Beautiful Beginning for the newly formed Scleroderma Society. Scleroderma is a form of Arthritis. Beautiful Beginnings Spring Fashions and Bridal Show will be held February 26, 1986 at Newmarket Community Center.

WHAT IS SCLERODERMA?

Scleroderma is a chronic disease and a form of Arthritis with no known cause or cure.
Scleroderma usually manifests itself first in the hands with the skin becoming tight and hard, but any organ of the body may be affected.
Pain of muscles and joints, tightening of the skin, fatigue, weight loss, hair loss, edema, swallowing difficulties or any number of non-specific compaints may be the first symptoms presented.
Scleroderma is no respecter of age, sex nor ethnic background, but women are afflicted at a four to one ratio over men.
With the help of The Arthritis Society and finanical commitment of Beautiful Beginnings the Scleroderma Society of Ontario is off to a Great Start. For more information or help please call 1-967-1414.

OUR HISTORY

Karen Wilding was living in Newmarket, ON in 1985 when her beautiful, athletic, goddaughter, Debbie was diagnosed with scleroderma. It was then that Karen, along with her best friend (Debbie's mother) Maureen Seller, formed the Scleroderma Society of Ontario, in partnership with The Arthritis Society.

At the time, very little was known about scleroderma in Ontario so their goal was to create awareness and educate the general public and medical community about this rare autoimmune disease.

Thanks to the generous support from the Arthritis Society in 1985-1988, much was accomplished by the organization. They were able to share newsletters with their members, plan the first annual 'Beautiful Beginnings', Spring Fashion Show fundraiser and host a 'Casino Night' that raised $2,300.00.

Unfortunately, Karen's husband became ill in 1988 and her role with the organization had to be adjusted so that she could devote her time to her husband and children. It was then that Karen's goddaughter Debbie Seller stepped-in to take over as President of the Board of Directors. Debbie served as President with her mother Maureen still on the Board, until she passed away from scleroderma in 1990.

Today you can find Karen living in Lyndsey, ON with her husband (she has been re-married for 25 years). She enjoys spending time with her 4 children and 9 grandchildren. This is the first time in 25 years that they have not loaded up the RV and travelled south for the winter, returning to Canada for the summer. Recently, Karen has been able to reflect on those early years with The Scleroderma Society of Ontario and remember her goddaughter, Debbie fondly. Karen and Maureen remain friends, taking turns making the drive to see one another when they can.

The SSO would like to thank Karen & Maureen for all that they have done to found The Scleroderma Society of Ontario and for taking the time to talk about the early days. We are looking forward sharing more stories with them in the spring, when we gather in person before Karen and her husband begin another journey across our beautiful country. Until then, we are thankful to them for our beautiful beginnings.

LOOKING BACK

SSO NEWSLETTER, 1990

Scleroderma Society of Ontario Newsletter

250 Bloor St. E. Ste.401 Toronto Ontario M4W 3P2 (416) 967-1414

11th Edition AUGUST 1990

SEASONS IN THE SUN

To Debbie, Love Mommy

"They shall grow not old, as we that are left grow old;
Age shall not weary them, nor the years condemn.
At the going down of the sun and in the morning...
We will remember them."

Laurence Binyou

On July 12, 1963 Debbie (Seller) Merk was born and on May 2, 1990, Debbie passed away. Debbie's life was an example for all of us.

Debbie was the baby of our family of three girls. She was only the baby by three minutes as Debbie had a twin sister, Dawna and another sister only 20 months older than her, Peggy-Ann.

The first years were a busy but fun time for her father and I as we saw our three girls become inseparable. Three is perfect for skipping, playing marbles, making a snowman, going on a bike hike, picnic, and doing dishes. Doing dishes...one has to wash, one to dry, and one to put away. I can still hear "I washed last night, It's your turn." I can also hear the radio blaring the current hit tune and Debbie's voice singing the loudest.

Debbie loved life and was intent in everything she did. She was not happy to just participate in Canada's Fitness program, she had to get the Award of Excellence and she did. She could be found at quiet times so engrossed in a book that she did not hear anything. She also wrote poetry to special people in her life. The most important one, her husband, William.

Debbie was very athletic and was chosen as a representative to go to Ontario Athletic Leadership Camp. Debbie met every challenge with courage and determination. She was intending to go to University of Toronto and become a physical education instructor but Scleroderma became her new challenge!

Through this new challenge she learned many coping skills. If you have not read the children's book Pollyanna, read it and see if you can figure out why that book was important to her.

Debbie always felt it was important to think of what she COULD do instead of what she COULD NOT do. That in itself was a big challenge which she met everyday of her life. She would want you to do something positive today, in her memory.

LOOKING BACK

SSO NEWSLETTER, 1990 (CONTINUED)

In closing, I would like to leave you with this quote from the Sanskrit. (Author and translator unknown)

LOOK TO THIS DAY!

> Look to this day! For it is life, the very life of life. In its brief course lie all the varieties and realities of your existence: the bliss of growth, the glory of action, the splendour of beauty. For yesterday is already a dream, and tomorrow is only a vision, but today, well-lived makes every yesterday a dream of happiness, and every tomorrow a vision of hope.
>
> Look well, therefore, to this day! Such is the salutation of the dawn.

Courage to everyone,

Sincerely,

Maureen Seller

NOTICE

S.S.O. General Meeting & Elections

Sunday, October 14, 1990

Auditorium

Women's College Hospital

- Grenville Avenue

Toronto

2:00 p.m. to 4:00 p.m.

- REFRESHMENTS -

Guest Speaker: Dr. Louis J. Cole
Gastroenterologist

NOTICE

Should you wish to nominate yourself for a position on the executive board, please contact Violet Turalba at The Arthritis Society.

Deadline - October 5, 1990

LOOKING BACK

SSO NEWSLETTER, 1990 (CONTINUED)

A CHANCE TO MAKE IT HAPPEN

A few months ago, I received a rather irate telephone call from a Society member, demanding an explanation for our long silence. This member was justifiably upset that our newsletter had lapsed. She also missed our twice-yearly General Meetings. Her upbraiding lasted for several minutes ending with the accusation that the membership had not even been warned about the Scleroderma Society's impending hibernation. With that statement, I lost my temper!

The Scleroderma Society's last newsletter (May 1989) included a separate flyer which pleaded for help and more volunteers. The flyer explained that due to various reasons, many of our executive members had to be replaced. Most had served us well for a number of years; now some wished to put more time in on family, studies or occupations. Others had scleroderma to cope with themselves. In sum, it was time for new blood to step forward or the S.S.O. would die. The response? Almost negligible.

My telephone tormentor was clearly flustered upon hearing that news! She had some good reasons for why she couldn't lend a hand: family responsibilities, a full-time job and scleroderma too, which left her no time to volunteer service on our executive board. The caller greatly desired the Society's assistance, but was unable to do more than mail in the annual membership fee.

Therein lies the problem of the S.S.O. A number of the old board members are tired, out of ideas, and have to get on with their own lives. The new, committed replacements are not there.

The S.S.O. was founded by the friends and family of our late president, Debbie (Seller) Merk. Instead of sitting by, wishing there was something they could do to help their loved one, they went out and actually DID something to help her. The result was this Society, the newsletter, General Meetings and a support group to help new patients. In addition, these people threw themselves into fundraising; to date there is roughly $45,000.00 languishing in our bank account. Without an active executive board, that money cannot be utilized to find a cure for scleroderma--the highest goal of all.

Sadly, Debbie died before that cure was found, but felt confident that we would continue on for her. Now, many projects are in limbo, the troops in disarray. We need a new president as well as a vice-president, newsletter editor and a few board members. New ideas would be greatly appreciated too!

Do not worry that we are completely bankrupt in manpower because we have Joanne Wright and Violet Turalba at The Arthritis Society ever ready to assist in our resuscitation. In addition, Maureen Seller, Eric Chodak and myself are all ready to re-involve ourselves for another term, to train a new executive board. The S.S.O. will rise again - IF - you feel strongly enough to come to our next General Meeting (Sunday, October 14, 1990) to stand and be counted. Please make this act a fitting tribute to our Deb. Don't let the Sceroderma Society of Ontario die too.

Thank you,

Janice Steele

CSRG REPORT

CANADIAN SCLERODERMA RESEARCH GROUP 2019 PROGRESS REPORT

Background: The Canadian Scleroderma Research Group (CSRG) is a multi-centered research cohort established in 2004 with funding from CIHR, industry and patient societies. We now have data on over 1750 patients, with up to 13 years of follow up, in our database (Figure 1). We have become an internationally recognized scleroderma research program. Among other things, Dr Hudson has been invited to present her work in Paris, France in January 2019, as well as at the Karolinska Institute in Stockholm, Sweden in January 2020 and at the Shenzen Renmin Hospital in Shanghai, China in April 2020. Dr. Baron is on the scientific committee of the Systemic Sclerosis World Congress and is a past president of the Scleroderma Clinical Trials Consortium. He is currently chair of a task force engaged in producing a white paper for the US Federal Drug Administration (FDA) on global measures of drugs effects for clinical trials in scleroderma.

The mission of the CSRG is to **Train, Translate and Treat** to improve the lives of people living with scleroderma. With this in mind, we present here a snapshot of our ongoing activities.

TRAIN – The CSRG is an outstanding resource that allows us to train students at all levels, from medical students and residents, to graduate students. Current trainee projects that leverage the research infrastructure include the following:

Dr Sabrina Hoa, completed a postdoctoral fellowship with Dr Hudson and is now Assistant professor at the Université de Montréal. She is pursuing research in mild interstitial lung disease in scleroderma, using among other things, the CSRG database. As you know, she has identified a "window of opportunity" for treatment of ILD and er findings were just recognized by the Arthritis Society as one of the Top 10 Research Advances of 2019. She has also been awarded a travelling scholarship to present her work at the Scleroderma World Congress in Prague, Czechoslovakia in March 2020.

Dr Boyang Zheng, a rheumatology fellow from McGill University, published several articles in 2019 using the CSRG database to explore the broader meaning of using the skin score as an outcome measure in clinical trials. He is also interested in understanding the course of interstitial lung disease by autoantibody subset. He too has been awarded a travelling scholarship to present his work at the Scleroderma World Congress in Prague, Czechoslovakia in March 2020. In the fall of 2020, he will undertake a post-doctoral fellowship in interstitial lung disease at Harvard University.

Other ongoing trainee projects include the following: Dr Mayank Jha, rheumatology fellow at the University of Toronto, on biomarkers of cardiopulmonary disease, Dr Hyein Kim, rheumatology fellow from the University of British Columbia, on outcomes in scleroderma renal crisis, Dr Sophie Wojcik, rheumatology fellow at McGill University, on EKG findings in scleroderma, Emily Butler, Master student from Dalhousie University, on identifying a core set of items to classify scleroderma renal crisis, Dr Julie D'Aoust, rheumatology fellow at McGill University, on scleromyositis and global measures of disease outcome, Dr Nancy Maltez, rheumatology fellow and Master student at the University of Ottawa, on outcomes after hematopoietic stem cell transplant for scleroderma, Dr Jessica Salituri, rheumatology fellow at McMaster University, on the role of mTor in scleroderma renal crisis, and Dr Océane Landon-Cardinal, junior faculty at the Université de Montréal, on scleromyositis.

CSRG REPORT

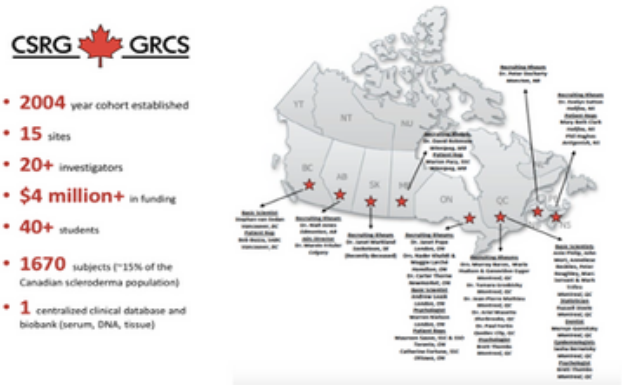
CANADIAN SCLERODERMA RESEARCH GROUP
2019 PROGRESS REPORT

TRANSLATE – Collaborations are essential to ensure the success of research in rare and complex diseases such as scleroderma. The CSRG has numerous collaborations with scientists at local, national and international levels, including : (1) Dr Celia Greenwood (Jewish General Hospital) on epigenetics; (2) Dr Anie Philip (McGill University) on animal models of scleroderma; (3) Dr Natalie Patey (Ste Justine Hospital) on histopathology of scleroderma renal crisis; (4) Dr Marvin Fritzler (University of Calgary) on autoantibody discovery; (5) Professor Dominique Farge (Paris, France) on cellular therapies for autoimmune diseases; (6) Dr Alain Meyer (Strasbourg, France) on scleromyositis; (7) Drs John Varga (Northwestern, Chicago, USA) and Christopher Denton (University College London, UK) on scleroderma renal crisis; and (8) Drs Mandana Nikpour, Susanna Proudman and Wendy Stevens (Australia) on various aspects of scleroderma. In particular, Dr. Baron established the International Systemic Sclerosis Inception Cohort (INSYNC) which, along with the Australians and researchers from Spain, Sweden, Netherlands, Germany, has allowed us to collect data on an even rarer subset of scleroderma patients, i.e. those with recent onset disease. In 2019, along with our collaborators, we have again produced many high-impact papers in peer-reviewed journals.

TREAT – Many of our projects focus on measuring the effectiveness of various treatments on outcomes of importance using observational study designs and advanced statistical modelling to inform clinical practice. As far as interventional trials are concerned, in 2016, we initiated a pilot cluster-randomized clinical trial on small intestinal bowel overgrowth. Results are expected 2020. Since 2018, we have undertaken investigator-initiated studies in cellular therapies, including hematopoietic stem cell transplant and mesenchymal stromal cells.

Dr Hudson has recently received a large grant from the CIHR to conduct a Phase I/II trial of umbilical cord-derived mesenchymal stromal cells in patients with severe scleroderma. We also participate in multi-centered, industry-funded Phase II and III randomized clinical trials. Because of its unique position in Canadian scleroderma research, the CSRG has led a national effort to standardize the approach to hematopoietic stem cell transplants for scleroderma. In collaboration with Australia, we have developed a completely new set of inclusion and exclusion criteria for such transplants and will present the results at a workshop during the annual Canadian Rheumatology Association meeting in Victoria, BC in February 2020.

IMPACT – The CSRG is conducting outstanding research, allowing patients to participate fully in the research experience, building research capacity and promoting world-class care for Canadian scleroderma patients. The comprehensive CSRG database and experienced research staff are key assets that facilitate this work and ensure that we can accelerate progress in this devastating disease.



The Canadian Scleroderma Research Group in numbers.

LONDON UPDATE

REPORT ON RESEARCH ACTIVITY IN SCLERODERMA AT THE RHEUMATOLOGY DIVISION, WESTERN UNIVERSITY

Main investigator: Janet E Pope
Research team: Sarah Hewitt-McDonald, Louise Vanderhoek, Tatiana Nevskaya, Jillian Bylsma, Mikameh Kazem, Andreu Fernández-Codina
Affiliations: Rheumatology Division, University of Western Ontario, London, ON, Canada

Dear SSO members,

The Systemic Sclerosis (SSc) research group at Western greatly appreciates the SSO's efforts to promote new advances regarding the study of this challenging disease. With your generous help we have several projects in scleroderma to try to improve this disease for patients.

Thanks to one of the SSO's grants, we have completed the design and made fully operational our new database for the Pragmatic Clinical Trials in SSc. The database already aggregates clinical data from 170 patients, and more than 100 blood samples in our biobank. We expect to be able to enroll the majority of the SSc patients in our community to build a powerful tool to look for some answers in SSc.

We are currently working in a subproject trying to assess the usefulness of high dose vitamin D supplements to treat fatigue in SSc, which has proved to be beneficial in lupus patients. Some preliminary results, which will be presented at the World Systemic Sclerosis Congress (Prague, Czech Republic, March 2020), show that the levels of vitamin D and treatment with low doses of vitamin D (1000 IU a day) did not influence the levels of fatigue. The final results to see if high dose vitamin D is helpful is not yet known. In another study (which will be presented at the same congress, and has been accepted for publication), we found that tadalafil cream added to the usual treatment, was beneficial for treating Raynaud's phenomenon and digital ulcers in SSc patients. The potential financial cost would be significantly lower than with similar oral drugs (PDE5 inhibitors). We are working with a pharmaceutical company to develop a randomized clinical trial to confirm the results. In the future we expect to try to address other practical questions, i.e. what treatment should be used for gastroesophageal reflux when high doses of proton pump inhibitors aren't fully effective? Our pragmatic study allows for trials to compare one treatment for a symptom or abnormal organ compared to another in real world clinical trials. This way we will try to use more wisely the treatments that we already have. We are also doing a trial to treat small bowel overgrowth.

In the recent years, we have seen that immunosuppression might be a way to turn off the inflammation switch. We are now recruiting patients with diffuse cutaneous SSc to try a new immunosuppressor drug named brentuximab vedontin. This is a phase IIb clinical trial with an intravenous drug previously approved for hematological conditions. We will be using it added to standard treatments like mofetil mycophenolate to improve the skin thickening.

Finally, in collaboration with the Canadian Scleroderma Research Group, we reported that in patients with early diffuse SSc, individuals who have an improvement of their skin score in the first 2 years of disease had a milder involvement in other organs, resulting in a better prognosis. These findings highlight the importance of the skin score as an outcome measurement in clinics and in research.

TORONTO UPDATE

THE TORONTO SCLERODERMA PROGRAM UPDATE 2020

The Toronto Scleroderma Program established in 1970, is the largest longest running single center scleroderma cohort in the Canada, and top five in the world. It is a tri-hospital network comprised by the Toronto General Hospital, Toronto Western Hospital and Mount Sinai Hospital. Our team consists of three physicians, research assistants, research coordinators, clinical trial nurses, and administrative assistants.

We aim to provide patient care, research and education on the scleroderma spectrum of disease, which includes systemic sclerosis, eosinophilic fasciitis, mixed connective tissue disease, Raynaud's phenomenon, juvenile onset scleroderma, and morphea. We have a network of specialists (gastroenterologists, respirologists, & nephrologists), who also have a special interest in scleroderma.

Furthermore, our program is fundamental in developing the next generation of scleroderma experts. Clinical research fellows, from local and international institutions, train with us to gain expertise in the scleroderma spectrum of diseases. After training with our program, graduating scleroderma fellows establish new Scleroderma Clinics at their institutions in Canada and around the world.

We are leaders in conducting studies of new treatments of scleroderma. We are a recruiting site for the Scleroderma Patient-centered Intervention Network (SPIN).

SPIN is an international organization of researchers, health care providers, and scleroderma patient advocates. As a first step, SPIN is establishing the SPIN Cohort, which is a group of people with scleroderma around the world who participate in SPIN studies via the internet. The ultimate goal of the SPIN study is to develop online programs to help individuals cope with their illness.

In addition, we are a recruiting site for the juvenile systemic sclerosis study, led by Dr. Ivan Foeldvari at the Hamburg Center for Pediatric and Adolescent Rheumatology. We are studying how scleroderma affects children compared to adults.

This year saw a major scientific breakthrough for the treatment of scleroderma lung disease (also called pulmonary fibrosis). We were a site in a clinical trial looking at a new medication, Ofev (also called nintedanib). Based on data from this study, the medication was approved by the U.S. Food and Drug Administration (FDA) and Health Canada. This is a great example of how collaboration with patients to do research can improve outcomes for patients with scleroderma in real-time. We couldn't do this without you.

In 2020, we will be studying three novel treatments for scleroderma. These treatments are meant for patients in the first three to five years of disease. As you can see, this is an exciting time for scleroderma research. Please contact Keshini Devakandan (416-586-5912) if you are interested. By working together, we hope to find a cure.

Members of the Toronto Scleroderma Program team: (Left to right). Top Row: Dr. Bader AlMehmadi, Jewel Ang, Shafina Hasmani, Dr. Ivo Verhagen Bottom Row: Deiter Baig, Dr. Sindhu Johnson, Keshini Devakandan, Judith Guthrie, Dr. Jennifer Lee, Masoomeh Ashrafi and Dr. Nezar Bakhsh.

HAMILTON UPDATE

HAMILTON SCLERODERMA GROUP RESEARCH PROJECTS

The Hamilton Scleroderma Group consists of specialists including; rheumatology, respirology, cardiology, nephrology, immunology, gastroenterology and psychology all working together to help promote better care, education and research in scleroderma.

Scleroderma and Interstitial Lung Disease
Scleroderma-related Interstitial Lung Disease (SSc-ILD) is being investigated through a review of data in the Canadian Scleroderma Research Group Registry as well as Hamilton-based Scleroderma clinics. We will look at the clinical presentation and natural course of SSc-ILD and changes in pulmonary function, current prescribing practices for therapies in SSC-ILD. We are also looking at quality improvement determining to what extent patients with SSc are receiving appropriate investigations to assess for ILD and pulmonary hypertension.

Responses of Immune Cells to Proteins Present in Patients with Scleroderma
Given that there are no current disease-modifying or curative treatments for Scleroderma, the purpose of this study is to explore a more effective and definitive treatment for this disease. To do so, we are studying the behaviour of immune cells in response to proteins causing the disease in patients with Scleroderma. We are comparing the results obtained in people with Scleroderma with those who do not have any history of autoimmune diseases in order to gain a better understanding of what causes the disease and how to "switch the disease off".

The Role of CXCL4 in Scleroderma
This study involves the analysis of CXCL4, a chemical secreted by a type of cell in the blood, called the platelet. This protein plays a role in regulating blood vessels that we know are abnormal in scleroderma. CXCL4 has been found in to exist in higher levels in patients with Scleroderma compared with people who do not have Scleroderma. Understanding the exact impact of CXCL4 in patients with Scleroderma compared to people without may help us explain the mechanism by which certain complications such as Raynaud's phenomenon and pulmonary hypertension occur. Importantly, the study will also evaluate a commonly used anticoagulant as a potential therapy for Scleroderma.

Prostaglandin Database
The purpose of this database is to capture clinical outcomes of patients treated with Prostaglandins (Low dose Alprostadil (Outpatient), High dose Alprostadil (Inpatient) and Iloprost) for prevention of digital ulcers related to Raynaud's phenomenon associated with Scleroderma. The database will also serve as a quality improvement project which will allow investigators to observe patient preferences and the impact of such treatments on quality of life as it relates to inpatient versus outpatient infusion administration.

The Molecular Mechanism of Autophagy in Scleroderma and its Clinical Implications
Scleorderma is an autoimmune disease of unknown cause characterized by ongoing scarring (fibrosis) of skin and multiple internal organs. The cells inside the connective tissue responsible for the fibrosis process in Scleroderma are regulated by certain mechanisms. This project will analyze the proteins that are involved in the skin fibrosis process. This proposed research will enhance the understanding of the causes of Scleroderma, will characterize the cellular responses associated with this disease, and will shed light on the discovery of new medications.

Scleroderma Progression and Pregnancy
We have conducted a study looking at the effect of pregnancy on the progress of Scleroderma using data from the Canadian Scleroderma Registry Group. We have compared disease progression in women with Scleroderma who have never been pregnant to with those who have had at least one pregnancy since their diagnosis of Scleroderma. The outcomes of interest in our study were changes in digital ulcers, lung disease, heart disease and kidney disease over time. The results suggest there isn't a difference between groups, suggesting that pregnancy does not worsen the progression of Scleroderma. More research is required to provide definitive answer, but this preliminary research provides a hopeful message for women with scleroderma who are considering pregnancy.

Many of these studies involve you! We would like to invite you to participate by donating blood, urine and sometimes skin biopsy specimens for our ongoing important research to work on improving lives of patients with Scleroderma.

QUEEN'S PARK

NOVEMBER 27TH, 2019

The Scleroderma Society of Ontario used funds secured through Scleroderma Canada, from Boehringer Ingelheim to coordinate an extremely successful day of advocacy at Queen's Park. With the assistance of Temple Scott Associates, we were able to schedule over 20 meetings with MPP's and staff. Our group was invited to spend time with Premier Doug Ford in his office and also had the privilege of a 30 minute meeting with Christine Elliott, Minister of Health, to discuss what the government can do to help with drug approvals for our patients.

This day was about listening, creating awareness and supporting our patients. Today, tomorrow and the year ahead will be about making sure we remain successful.

Returning October 19th, 2020!

> *I'm rising to speak to the reason that many of us are wearing these ribbons today: scleroderma.*

BUTTERFLY EFFECT

DECEMBER 1, 2019

The Butterfly Effect Brunch raised $10,500 for The Scleroderma Society of Ontario!

On December 1, 2019 approximately 275 guests braved the elements, to attend brunch in loving memory of Mara Celli.

Jack Celli, Mara's husband, planned and sold tickets for the first annual memorial brunch which he called The Butterfly Effect.

The SSO assisted Jack by providing a lapel pin to each guest along with a small gift to take home. We look forward to this becoming an annual event in Mara's memory.

> *Changing one thing, can change everything...*

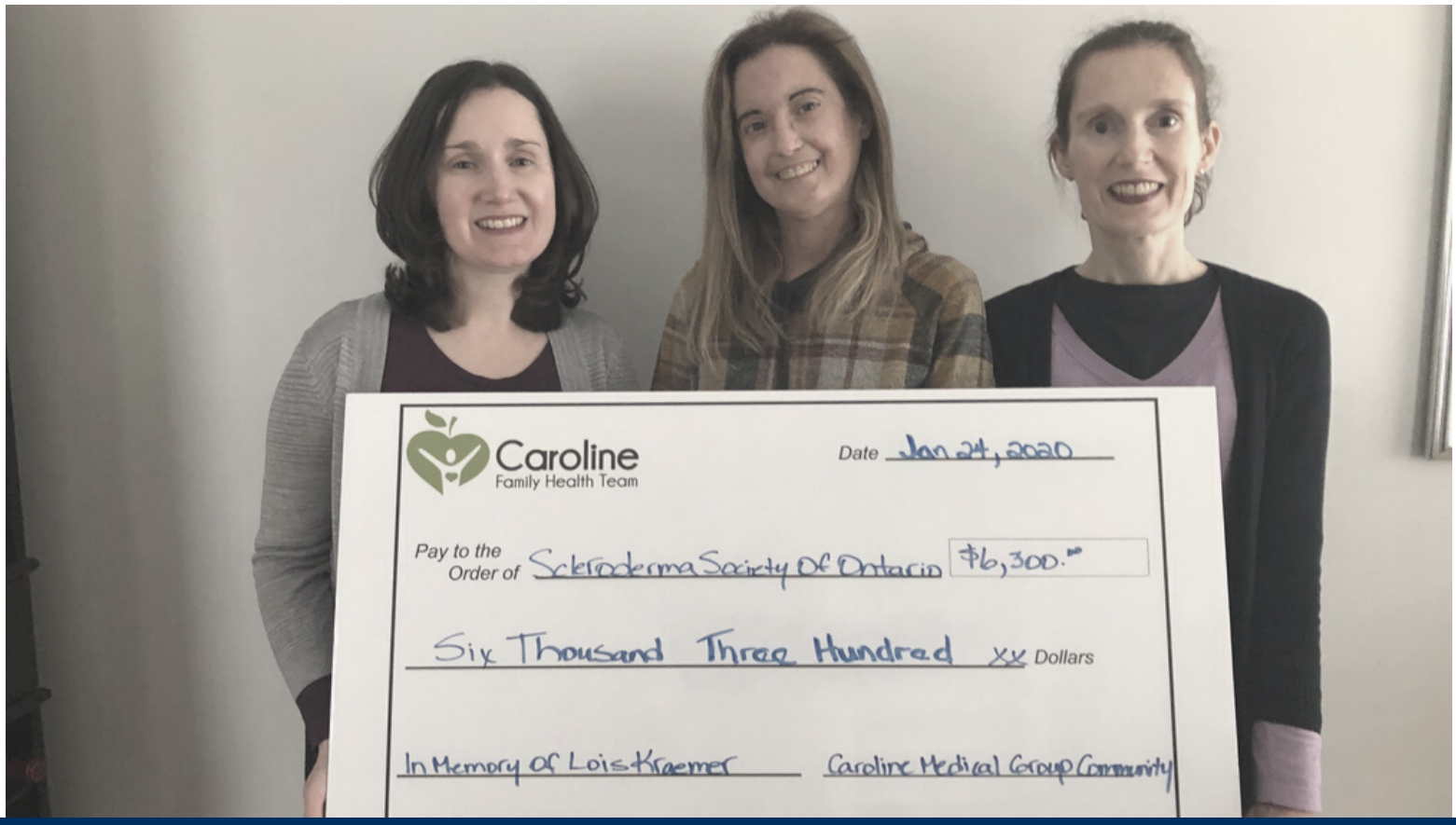
ANNUAL BOOK SALE

READING FOR A CURE

Jennifer Botehlo, Director on the SSO Board, had the pleasure of meeting Julie Kraemer at her daughter's school, Guardian Angels Catholic Elementary. Julie's Mother, Lois passed away in 2011 from scleroderma. Julie, her father Dr Jim Kraemer, a Doctor at Caroline Family Health Team (CFHT) and sister Jane, started a book sale in the summer of 2012 in her Mother's memory. The Caroline Family Health Team has 9 family doctors, nurse practitioners, a pharmacist, social workers & a diabetes team. Their mission is to provide comprehensive primary care to the patients they serve and to work together to develop innovative approaches to enhancing primary care in their community. Julie's Mom was a big reader so after she passed, her Dad suggested a book sale for CFHT staff.

The fundraiser has ballooned into a huge sale, consisting of 7 tables of books that patients now buy for $2 each, or 3/$5. Amazingly, the donations of gently used books, CD/DVD's continually come in from patients, friends, family, community and beyond. Throughout the years, they have raised over $70 000. Proceeds are split equally between The SSO and Sick Kids Hospital. The Scleroderma Society of Ontario is honoured and grateful for the hard work and dedication that the Caroline Family Health Team gives to this annual fundraiser. Keep up the great work!

For more information on how you can start your own fundraiser for the SSO, please contact us toll free at 1-888-776-7776 or by email at info@sclerodermaontario.ca.



"It's when you give of yourself that you truly give."

UPCOMING 2020 EVENTS

AROUND THE BAY RACE
March 29th

PAINT NIGHT AT FISHER'S PIER 4 PUB
TBA: April

PARIS TO ANCASTER 20KM BIKE RACE
April 26th

TORONTO SOCIAL
TBA: May & October

2ND ANNUAL MOTORCYCLE RIDE
May 23rd

HAMILTON GOLF TOURNAMENT
June 20th

RBC CANADIAN OPEN
June 8th – 14th | St.Georges G&CC

HAMILTON'S SHOUT IT FROM THE ROOFTOP SOCIAL
September 9th

SCLERODERMA NATIONAL CONFERENCE
September 18th-19th | Niagara Falls, ON

LEGISLATIVE DAY
October 19th, 2020 | Queen's Park

YOGA DAY
Spring/Fall

BUTTERFLY EFFECT BRUNCH
TBA

BOOK SALE
TBA

JUNE 2020 AWARENESS

Scleroderma can be an isolating disease but, thanks to the attention received through our national Walk, Run or Ride in the Park for Scleroderma initiative, an important step is being taken to help those affected by this rare disease. In many ways, participation across the country initiates communication and awareness for those impacted and helps bring scleroderma to the forefront. We are not only helping to raise much-needed funds but also creating awareness. Often patients can feel alone in their journey, and these events help to bring everyone together, letting our patients know that they are supported and are not alone.

In 2019, we had 9 Walks across the country, and thanks to our June Awareness campaign, we raised close to $185,000. This year we are hoping to increase the number of walks and funds raised. The more we can make those around us aware of scleroderma, the more they will be willing to support this rare disease and contribute to funding research, which is our only hope in finding a cure.

There are currently 4 walks scheduled to be held in Ontario:

LONDON
June 6 | Gibbons Park

OTTAWA
June 13 | Vincent Massey Park

HAMILTON
TBA

TORONTO
June 27 | Budapest Park

If you are interested in participating in or organizing a new walk, we're here to help every step of the way. Please contact us at 1-888-776-7776.

CONGRATULATIONS, MAUREEN SAUVÉ

The Scleroderma Society of Ontario is pleased to announce Maureen Sauvé as the recipient of the "Patient for Active Engagement in Arthritis Research Award"!

This prestigious award goes to Maureen in recognition of her countless contributions to numerous patient engagement projects, through our valued partnership with the Arthritis Society. Maureen's notable achievements make it clear why The SSO loves her.

FILL YOUR LIFE WITH PASSION

Maureen has successfully advocated to governments for improved access to medications and raised awareness of scleroderma in Ontario, across Canada, and internationally.

Maureen provides hope and a sense of empowerment for people living with scleroderma in Canada and across the world. Congrats Maureen!

B.O.D. RECRUITMENT

NEW BOARD MEMBERS WANTED

We're looking for a few talented and conscientious volunteer board members to lead and strengthen our programs, for people with scleroderma and their families.

If you can contribute your time, attention and leadership skills for a 2 hour meeting, approximately 3-4 times per year and are interested in joining our B.O.D., please contact John Malcolmson at executive@sclerodermaontario.ca to find out if this volunteer opportunity is right for you.

We're especially looking for folks from the north, near north and south western Ontario regions.

The SSO Board of Directors are looking for one new member from each of the six regions. More than one member per region is welcome.

The SSO Board meets 3 to 4 times a year:

- Tuesday, March 24th, 2020
- Tuesday, May 5th, 2020 (AGM)
- Tuesday, September 29th, 2020
- Tuesday, December 15th, 2020

REVAMPED PROGRAMS

Keep an eye out for our two new revamped programs:

- SSO Membership program being launched this April
- New research grant application process. Application submissions begin in April. You can access and download the application at www.scleroderaontario.ca effective April 2020.

WAYS TO GIVE

MONTHLY & ONE-TIME DONATION OPTIONS

Ontarians living with this rare and debilitating condition face significant physical and emotional challenges, often resulting in feelings of helplessness, hopelessness and being a burden to society. But with despair there is hope. The Scleroderma Society of Ontario is an organization that is focused on raising awareness, raising funds and raising support for those with this disease, in an effort to find a cure.

Please choose your way to give:

$500 Scleroderma Peer-to-Peer/Social Fundraising Campaign (**$41.66/mo**)

$250 Fitness, exercise & therapy assistance for a patient in need (**$20.83/mo**)

$100 Patient transportation to medical appointments (**$8.33/mo**)

$50 Patient Care Package (gloves, hat & scarf) (**$4.17/mo**)

To donate today, please go to www.sclerodermaontario.ca or call us at 1-888-776-7776.