

# The Researcher

The CSRG Newsletter

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## The Fourth Annual Meeting of the CSRG

The Fourth Annual Meeting of the CSRG took place in Halifax from November 25th to the 27th, 2010. Like last year, the Scleroderma Society of Canada (SSC) held their meeting in conjunction with ours.

This year, three students were chosen based on the quality of their summaries to give extensive presentations on their projects. Katherine Milette, Dr. Brett Thombs's clinical science student, Daniel You, a summer student with Dr. Marvin Fritzler and Dr. Sunil Parapuram, a basic science post-doctoral student under Dr. Andrew Leask's supervision. All three were given honorary certificates by Dr. Murray Baron on behalf of the CSRG for their outstanding research projects.

SSC had organized a "Wellness Fair" for the patients, where multiple booths had very educational and useful information. Some of those booths were also held by CSRG researchers, such as Dr. Brett Thombs and Dr. Mervyn Gornitsky. During the Wellness fair, the students also held a poster session which was very interesting and informative for all the patients



*Dr. Baron with members of SSC and the Halifax Health Minister.*

and researchers alike. We have had many positive comments for this great experience.

This year, we had a special guest join us, Dr. Sergio Toloza. He is a new rheumatologist from Argentina who is now part of the CSRG. He just started the *Argentinian Scleroderma Research Group*. Dr. Toloza and his colleague Dr. Rivero will soon be assessing hundreds of Scleroderma patients from Argentina. They will also enter their data into our Web-based CSRG database. This is opening the door to more great collaborative work, beyond our Canadian borders.

We would like to say a special thank you to our sponsors for their continued support: Actelion, Pfizer, Amgen, Wyeth, Lilly, Sanofi Aventis, GlaxoSmithKline and Roche. **Thank you!!**

Finally, we would also like to thank all our rheumatologists, researchers, trainees and students who participated and contribute to the ongoing growth of the CSRG. ■

## SSc Research in Latin America

Collaborative work between Canada and Latin American countries in the field of rheumatology is not new. In fact, the members of the Canadian Rheumatology Association (CRA) have met in Mexico twice already, along with the *Mexicano Collegio of Rheumatologia*, in order to encourage more collaborative work between the two countries. These meetings have been quite successful and have given the opportunity to our research group to go beyond the border, and work with other rheumatologists interested in better understanding Scleroderma. The CSRG is proud to announce that it now has four new recruiting sites in Argentina and one in Mexico City.

Dr. Toloza and Dr. Rivero are heading a group of Rheumatologists in Argentina, dedicated to better understanding Argentinian patients with Scleroderma and compare them to patients with the same disease who live elsewhere. We also just started working with Dr. Tatiana Rodriguez, a rheumatologist from Mexico City who is heading the Mexican recruiting site. She also just joined our Group and is starting to assess Scleroderma patients in her own country and entering their data in our database.

Our case report forms were translated into South-American Spanish and somewhat adapted to allow cultural differences when it came to education levels, income and ethnicity. Both Groups will be allowed to use our Web-based database to enter their data, making it very easy to compare our Canadian patients to those of two other countries. ■



*Drs. Murray Baron, director of the CSRG (Montreal, Canada) and Sergio Toloza (San Fernando, Argentina) at the 4th annual meeting of the CSRG, November 2010.*

# Satisfaction with Appearance

**R**ecently, the first ever body image measurement scale specifically for SSc was developed, using information from SSc patients in the CSRG Registry as well as from the Johns Hopkins University School of Medicine. This questionnaire called the Brief-Satisfaction with Appearance Scale (Brief-SWAP) has items that ask about dissatisfaction with the appearance of certain body parts, as well as feelings of being uncomfortable in different social settings. The Brief-SWAP is an ideal way to assess these issues related to body image, as it is short and easy for respondents to fill out, and it is directly

relevant to the experiences of people with SSc.

The development of the Brief-SWAP has helped to highlight the importance of appearance issues for many people with SSc and has allowed further research into what aspects of SSc are related to these kinds of body image issues. ■

This study was conducted by Dr. Brett Thombs and Lisa Jewett and CSRG researchers at the Jewish General Hospital in Montreal, as well as with collaborators from Johns Hopkins University School of Medicine in Baltimore, Maryland.

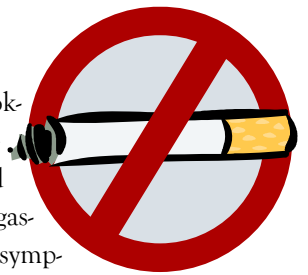
## Stop Smoking!

**D**r. Marie Hudson, a rheumatologist at the Montreal CSRG site, studied the effects of cigarette smoking in scleroderma patients. Of 606 SSc patients studied, 16% were current smokers, 42% were past smokers and 42% had never smoked. Detailed analyses showed that smoking had a negative effect on vascular, gastrointestinal and respiratory systems in scleroderma. However, quitting smoking helped to rapidly reduce some of

the symptoms of scleroderma, such as Raynaud's phenomenon. On the other hand, one of the more serious consequences of smoking was noted to be on the respiratory system, where smoking was associated with a significant deterioration in lung function. This problem appeared to persist even after patients quit smoking. Smoking is already known to increase gastric reflux among the general population, and scleroderma patients are no exception. The gastrointestinal tract of scleroderma patients is

fragile, and smoking was significantly associated with increased gastrointestinal symptoms in the study.

The proportion of smokers in scleroderma patients is surprisingly high. Dr. Hudson strongly encourages patients to quit smoking, as it can improve not only their scleroderma, but also their overall health. ■



## Highlighted Member: Dr. Geneviève Gyger

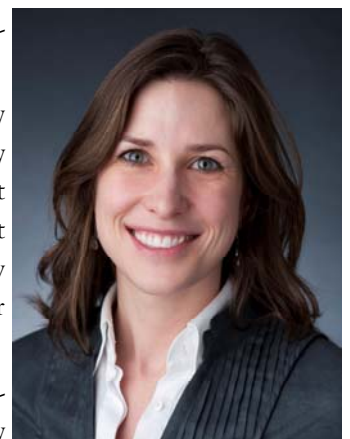
**I**t is with pleasure that I joined the CSRG this year. After a fellowship in scleroderma with Dr. Baron, I joined the rheumatology department at the Jewish General Hospital (JGH). During my fellowship, I attended a training in videocapillaroscopy, a simple technique that allows early diagnosis of scleroderma, and consequently early treatment, which could limit progression of the disease. I will run the videocapillaroscopy clinic at the JGH. I also had the chance to meet great patients and specialists, nurses, research coordinators and assistants that all work together for your interest.

I did my medicine training at Laval University in Quebec city and my rheumatology at Notre-Dame Hospital in Mont-

real. I also am a past physio-therapist.

Scleroderma can be a very debilitating disease, and my goal is to give you the best treatment, give you support and do research to find new treatment and ameliorate your quality of life.

When I'm not working, I enjoy spending time with my two young sons, Alexandre 3 ½, and Antoine 2 ½. I also enjoy travelling and playing sports. ■



# The Burden of Disease in SSc

**D**id you fill out the CSRG patient survey, back in 2008/2009? If so, you were one of the 464 people who gave us the chance to assess first-hand the burden of disease experienced by scleroderma patients.

The five highest rated symptoms in terms of frequency and moderate to severe impact on daily activities were: fatigue, Raynaud's phenomenon, hand stiffness, joint pain and difficulty sleeping. In addition to these symptoms, items related to decreased hand function (difficulty making a fist and difficulty hold-

ing objects) and pain (muscle pain and joint tenderness) were frequently reported and commonly associated with moderate to severe impact on daily activities.

This study helped identify problems for which there are large gaps in knowledge, including hand and sleep problems, and fatigue. It improves our understanding of the patients' major concerns and helps us find new research avenues. ■

This analysis was conducted by Dr. Brett Thombs, Marielle Bassel with the team at the Jewish General Hospital, Department of Psychiatry, Montreal.

## We investigate in your Sleep...

**P**atients with SSc have been found to have significantly more sleep disruption than the general population. In fact, problems with sleep are common in patients with SSc and impact daily function. Various socio-demographic (i.e. marital status, age, etc) and medical factors (i.e. gastrointestinal symptoms, breathing problems, symptoms of depression, etc) are potentially impli-

cated in the manifestation of impaired sleep and were investigated in a recent study by Katherine Milette, Dr. Brett Thombs and his team at the Jewish General Hospital, Department of Psychiatry, Montreal. Like similar studies conducted in relation to sleep and rheumatic diseases (such as rheumatoid arthritis), pain was found to be the most significant predictor of poor sleep in a sample of 70 SSc patients.

The prominent role of pain suggests that it may be mediating the relationship between other common SSc symptoms and sleep, and more research is needed so that well-informed interventions to improve sleep in patients with SSc can be developed, tested, and made available to patients. ■

"Sleep is the golden chain that ties health and our bodies together."

-Thomas Dekker,  
English dramatist  
(1572-1632)

## Magnifying your Fingertips

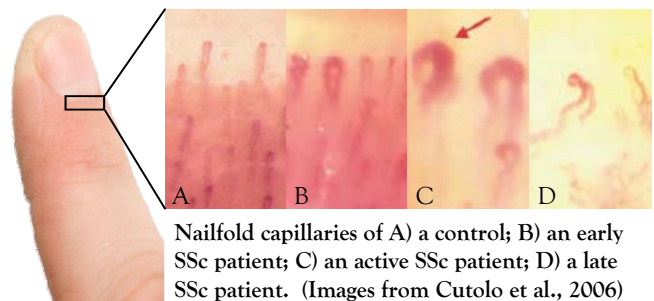
**A** new tool is being used by some rheumatologists in the CSRG: a videocapillaroscope. It resembles a big microscope, and it allows them to look at the miniature blood vessels that sit at the junction between the nail and the finger. Those blood vessels are called the nailfold capillaries.

Normally, the nailfold capillaries appear straight, with a thin hairpin loop at the end, their edges are regular and they are equally distributed along the nailfold. In scleroderma patients, especially the ones who suffer from Raynaud's phenomenon, the nailfold capillaries appear abnormal. They seem dilated, distorted, less numerous or even absent in some areas.

Examining the nailfold capillaries is useful for a number of reasons. It can be used as a tool for the diagnosis and prognosis of Raynaud's phenomenon, scleroderma and other

connective tissue diseases. It also gives information on the severity of a patient's disease and possible vascular complications in scleroderma, including pulmonary arterial hypertension. Finally, researchers believe that capillaroscopy could also help them monitor a patient's response to certain treatments that could be evaluated in clinical studies.

A large capillaroscopy study by the CSRG, and in particular Drs Masetto and Gyger, is currently underway in order to demonstrate the validity of this technique. ■



Nailfold capillaries of A) a control; B) an early SSc patient; C) an active SSc patient; D) a late SSc patient. (Images from Cutolo et al., 2006)

**Our Managerial Team**

**Director**

Dr. Murray Baron  
E-mail: mbaron@rhu.jgh.mcgill.ca

**National Study Coordinator**

Suzanne S. Taillefer, Ph.D.  
E-mail: sstaillefer@videotron.ca

**Research Assistants**

Mireille Guirguis, B.Sc.  
E-mail: mguirguis@jgh.mcgill.ca  
Sabrina Gravel, M.Sc.  
E-mail : sgravel@jgh.mcgill.ca  
Maria Scolack, B.Sc.  
E-mail : mscolack@jgh.mcgill.ca

**Our Rheumatologists**

Dr. Murray Baron, Montreal  
Dr. Peter Docherty, Moncton  
Dr. Geneviève Gyger, Montreal  
Dr. Tamara Grodzicky, Montreal  
Dr. Marie Hudson, Montreal  
Dr. Niall Jones, Edmonton  
Dr. Elzbieta Kaminska, Hamilton  
Dr. Nader Khalidi, Hamilton  
Dr. Sharon LeClercq, Calgary  
Dr. Sophie Ligier, Montreal  
Dr. Ariel Masetto, Sherbrooke  
Dr. Janet Markland, Saskatoon  
Dr. Shikha Mittoo, Winnipeg  
Dr. Janet Pope, London  
Dr. Jean-Pierre Mathieu, Montreal  
Dr. David Robinson, Winnipeg  
Dr. Douglas Smith, Ottawa  
Dr. Evelyn Sutton, Halifax  
Dr. Carter Thorne, Newmarket  
Our Collaborators  
Dr. Sasha Bernatsky, PhD  
Mr. Robert Buzza, Scleroderma Society of Canada  
Dr. Marvin Fritzer, Mitogen Advanced Diagnostics Lab  
Dr. Mervyn Gornitsky, DDS  
Mr. Phil Hughes, Patient Representative  
Dr. Kevin Keen, Statistician  
Dr. Andrew Leask, PhD  
Dr. John S. Mort, PhD  
Dr. Warren Nielson, Psychologist  
Dr. Anie Philip, Ph.D.  
Dr. Anneliese Recklies, PhD  
M. Normand Ricard, Scleroderma Society of Canada  
Dr. Peter Roughley, PhD  
Ms. Maureen Warron Sauvé, Scleroderma Society of Canada & Scleroderma Society of Ontario  
Dr. Marc Servant, PhD  
Dr. Russell Steele, Epidemiologist  
Dr. Brett Thombs, Psychologist  
Dr. Mark Trifiro, Endocrinologist  
Dr. Jenny Walker, Rheumatologist  
Dr. Stephan van Eeden, PhD

# CSRG Meeting in 2011

The CSRG's next Annual Scientific Meeting will be held within the Canadian Arthritis Network's yearly meeting, next October, 2011 in Quebec City. This meeting is jointly organized by the Scleroderma Society of Canada and Sclérodemie Québec.

There will be workshop sessions which include topics such as lung involvement gastro-oesophageal complications, occupational therapy, quality of life, psychological health and well-being. Conference attendees will

have the opportunity to interact with experts to ask questions and make comments.

For English Registration information, please contact Ms. Norma Augustine: norma@sclerodermaontario.ca or visit [www.scleroderma.ca](http://www.scleroderma.ca).

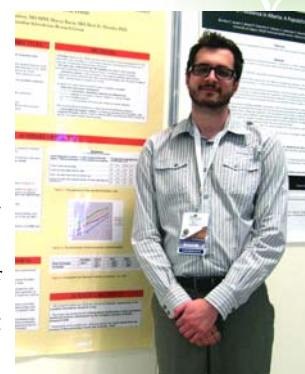
For French Registration and information, please contact Ms. Diane Plante:

sclerodermiequebec@videotron.ca or visit [www.sclerodermie.ca](http://www.sclerodermie.ca)



## CRA in Cancun

The Canadian Rheumatology Association (CRA) held their 66<sup>th</sup> annual scientific meeting in Cancun Mexico from February 10<sup>th</sup> to the 15<sup>th</sup>. Not only was the location beautiful, but the meeting was very interesting and filled with rheumatologists from all over Canada and Mexico. One of the CSRG's own trainees, Ilya Razykov, also attended to present a poster.



The CSRG is very proud to announce that two of our recruiting rheumatologists were distinguished with awards at the conference. Dr. Marie Hudson received a Young Investigator award and Dr. Nader Khalidi was awarded a Teacher-Educator distinction. ■

**The Canadian Scleroderma Research Group (CSRG), under the direction of Murray Baron, MD, is a group of Canadian rheumatologists and researchers working towards the same goal: better understand Systemic Sclerosis (or scleroderma) in order to better treat the people suffering from it.**

In order to achieve their objectives, the CSRG has created a registry of adult patients suffering from scleroderma in Canada. They received grants from the Canadian Institutes of Health and Research (CIHR) to create this database, and as of today there are more than 1100 patients in the registry. The CSRG also have received support from private donations, the Cure Scleroderma Foundation, Scleroderma Society of Canada, Scleroderma Ontario, as well as several Canadian pharmaceuticals companies. This has allowed researchers from across Canada and from various disciplines to study the specificities and manifestations of the disease, looking for commonalities in the data. Since the CSRG started in 2004, more than 85 scientific papers on Scleroderma have been published.

### The Cure Scleroderma Foundation

Pierina Nero, a patient who was diagnosed with Scleroderma in 2000, established the Cure Scleroderma Foundation (CSF) in 2005 in order to raise much needed funds which will enable the CSRG to continue with their research into Scleroderma and to promote awareness about this rare and uncommon disease.



FONDATION CURE SCLÉRODERMIE  
CURE SCLERODERMA FOUNDATION

To make very much needed donations, please contact the Cure Scleroderma Foundation via our own website:

[csrg-grcs.ca](http://csrg-grcs.ca)

