

## The Researcher

# The Canadian Scleroderma Research Group Newsletter

Spring 2009

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### The Annual CSRG Scientific Meeting

For the third year in a row, the Annual CSRG Scientific meeting will be held in conjunction with the Scleroderma Society of Canada's (SSC) Annual Conference. This year, the participants will meet at the Delta Hotel in Winnipeg, Manitoba on October 2-4, 2009. This year's organizers have planned several "Meet & Greets", including a buffet dinner on Friday, a Trainee and Summer Student poster session accompanying the dinner and a lunch on Saturday. Several Rheumatologists and Researchers from the CSRG will also partake in the SSC conference sessions, giving talks on subjects such as "Oral Health Problems for the Scleroderma Patients" and "Scleroderma Lung Disease", among others. The CSRG members will spend the day together on Saturday, and half of the day on Sunday. This will be a valuable opportunity for both the researchers and students to present their projects, for the group to discuss administrative issues, to confer about future endeavors, and for all members to come together and encourage collaboration.

Thank you again to the generous sponsors of last year's meeting in Ottawa on September 19-21, 2008: CIHR, Actelion, Pfizer, Abbott and Amgen-Wyeth.

### The Laurentian Conference

The Laurentian Conference was held recently at the Westin Resort & Spa Tremblant in Mont-Tremblant, QC, from May 7-9. This conference, held annually by the "Association des médecins rhumatologues du Québec", is an opportunity for Quebec Rheumatologists and other health professionals to gather and discuss new developments in the field of Rheumatology. This year, the CSRG was well represented by Dr. Brett Thombs and the Behavioural Health Research Group. The group participated in a session on Scleroderma, chaired by Dr. Jean-Luc Sénécal, on Friday afternoon and gave the following presentations:

**Marielle Bassel** – "Sociodemographic, Disease and Symptom Correlates of Fatigue in Systemic Sclerosis"

**Lisa Jewett** – "Research Study: Development of Body Image Avoidance Measures for Patients with Scleroderma"

**Ruby Knafo** - "A Systematic Comparison of Sexual Impairment in Women with Systemic Sclerosis and other Chronic Disease Samples"

**Evan Newton** – "The Longitudinal Trajectory of Depressive Symptoms in Systemic Sclerosis"

**Ilya Razykov** – "Prevalence and Clinical Correlates of Pruritus in Patients with Systemic Sclerosis"

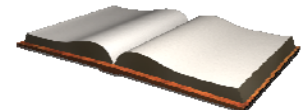
**Orit Schieir** – "Prevalence, Severity and Clinical Correlates of Pain in Patients with Systemic Sclerosis"

Congratulations to all of the presenters for a great session!

### Publications & Abstracts

To date the CSRG and its research collaborators have

- published **19** articles
- submitted **7** articles for publication
- published **19** abstracts
- presented **27** abstracts at conferences in Europe, and across Canada and the United States.



Great work everyone!!

### We would like to hear from you...

If you have any question or comment about the content of this newsletter, please contact Jessica Bernstein at (514) 340-8222 ext 3422 or at [jbernstein@jgh.mcgill.ca](mailto:jbernstein@jgh.mcgill.ca).

**One of CSRG's Members: Dr. Tamara Grodzicky**



We are very pleased to introduce Dr. Tamara Grodzicky who is the newest CSRG Rheumatologist, having recently started recruiting scleroderma patients at the Hôpital Notre-Dame in Montréal. Dr. Grodzicky graduated in medicine from the Université de Montréal in 1992 and obtained her FRCPC in Internal Medicine in 1996, and in Rheumatology in 1997. She has also done a Post-doctoral Fellowship in Basic Science (studying the role of apoptosis in autoimmune diseases, under the supervision of Dr Keith B. Elkon) at the Hospital for Special Surgery at Cornell University. Currently an Assistant Professor of medicine at the Hôpital Notre-Dame, Centre Hospitalier Universitaire de Montréal, Dr. Grodzicky has been an active member of the CSRG since November 2008. Her other interests include connective tissue diseases (she is a

member of the Connective Tissue Diseases Clinic of the Centre Hospitalier Universitaire de Montréal), as well as research, both basic and clinical, in systemic sclerosis. Her major leisure activity is taking care of her three young children (7, 5, and 3 years old) and with whatever time is left, she enjoys playing the piano, listening to music, bike riding, walking and reading.

Karine Berthiaume will be the coordinator at Dr. Grodzicky's new CSRG site.

**Registry Update**



The CSRG Registry is growing with leaps and bounds! We are quickly approaching 1,000 participants, having had **962** Baseline visits, **653** 1-yr, **417** 2-yr, **252** 3-yr, **91** 4-yr and we will begin with the 5-yr visits in September 2009! Here are some interesting statistics about the CSRG Registry participants:

**Where is everyone from?**

- ❖ Alberta ..... 114
- ❖ Manitoba.....66
- ❖ New Brunswick .....35
- ❖ Newfoundland.....9
- ❖ Nova Scotia.....52
- ❖ Ontario..... 315
- ❖ Quebec..... 284
- ❖ Saskatchewan .....87

**General Statistics**

- ❖ Average Age ..... 55 y.o.
- ❖ # of Women.....827
- ❖ # of Men.....135
- ❖ Average Disease Duration..... 11 years

**Proportion of Participants with:**

- ❖ Raynaud's.....89%
- ❖ skin thickening.....72%
- ❖ joint pain & swelling.....59%
- ❖ gastrointestinal problems .....82%

**The CSRG/SSC Patient Survey**

As you may know, the CSRG and the Scleroderma Society of Canada have collaborated to develop a survey, specifically designed for individuals living with scleroderma, to help determine the important issues and how research can be better directed to address these concerns. We have decided to extend the deadline in an attempt to reach even more people, therefore if you have scleroderma and wish to complete the patient survey; it is available online in English at [www.scleroderma.ca](http://www.scleroderma.ca) and in French at [www.sclerodermie-quebec.qc.ca](http://www.sclerodermie-quebec.qc.ca). To obtain a hardcopy, please contact Marielle Bassel at (514) 340-8222 ext. 3238.



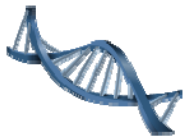
**The Oral Health Study**

The Oral Health Study is off to a great start! Thus far, all seven CSRG sites who have agreed to participate in this study have received approval from their Research Ethics Board and have already begun or will soon begin recruiting participants. We are still looking for volunteers for this great study including scleroderma patients and people who are affected by osteo-arthritis, bursitis or tendonitis. If you wish to obtain more information about this project or wish to see if you are admissible to enrol in the study, please contact Sabrina Gravel at (514) 340-8222 ext 3423.

## The Fatigue Study

Dr. Brett Thombs, a Psychologist at McGill University in Montreal, Quebec, and the Behavioural Health Research Group have recently begun a new study in collaboration with the CSRG with the goal of developing an interview and validating questionnaires to assess fatigue in scleroderma. Fatigue plays a major role in determining quality of life among individuals with scleroderma, but it is under-researched and often overlooked or ignored by health professionals. Being able to accurately assess fatigue could help us to determine possible causes and help us develop possible intervention programs to decrease fatigue. Study participants will be contacted by a trained research assistant for a structured interview about fatigue and a series of questions on related mental health problems, such as depression. Researchers hope to develop a structured interview specific to fatigue in scleroderma patients that can be used in future studies designed to improve care and quality of life. The study is up and running at the CSRG site at the SMBD-Jewish General Hospital in Montreal, Quebec, and we hope to have other CSRG sites joining the study in the near future.

## The Genome-Wide Association Scan Study in Systemic Sclerosis



The Principal Investigator, Dr. Maureen Mayes, will be running the Genome-Wide Association Scan (GWAS) study in Systemic Sclerosis from the University of Texas-Houston Health Science Center in Houston, Texas. The study, which is funded by the National Institutes of Health (NIH), will try to identify genes that may influence susceptibility to scleroderma. Members of the CSRG Registry who express interest in participating in this study, will be invited to donate blood samples. This will be used: (1) to create a bank of DNA, RNA, serum and plasma samples from scleroderma patients for future studies in scleroderma and (2) in tests for autoantibodies, as well as a Genome Wide Association Scan to help determine if there is a genetic link to scleroderma and if so, which genes are involved. The CSRG is very excited to be involved in this impressive study involving the following 10 scleroderma centers from across North America!

- ❖ Canadian Scleroderma Research Group
- ❖ University of California
- ❖ Mayo Clinic
- ❖ University of Medicine and Dentistry of New Jersey
- ❖ Fred Hutchinson Cancer Research Center
- ❖ University of Michigan
- ❖ Medical University of South Carolina
- ❖ Boston University
- ❖ Georgetown University
- ❖ Johns Hopkins University

## The Patient Assessed Disease Activity Index (PADAI)

This project was funded by the Canadian Institutes of Health Research (CIHR) in April 2007. Since then, Dr. Marie Hudson, a CSRG Rheumatologist at the SMBD-Jewish General Hospital, has been working on developing a Patient Assessed Disease Activity Index. This instrument will be very important for health measurement in SSc patients and will provide additional information to supplement traditional medical assessments. This project began with over 30 interviews and 3 focus groups at CSRG sites across Canada, which allowed researchers to obtain a pool of items related to disease activity from the patient's perspective. A first draft of the index has been developed and is currently being validated through testing with 50 patients. The results will help Dr. Hudson to narrow down the index to the most pertinent items, which will make up the final PADAI. This will be the first patient-assessed disease activity index in scleroderma!

## New Sections in the CSRG Questionnaire

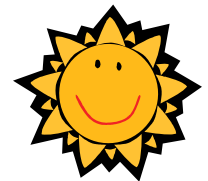
Dr. Brett Thombs and the Behavioural Health Research Group have recently added four new scales to the CSRG questionnaire, which is answered by Registry participants at their yearly visit. These new scales will address three areas that have been reported to have an impact on individuals living with SSc, but surprisingly little research has been done. They are pruritus (itching), body image and female sexuality.



- (1) Pruritus: Pruritus is an issue that has been generally ignored in scleroderma research. Dr. Thombs and his team are currently working to modify and validate a new questionnaire to assess pruritus in scleroderma, which they will eventually integrate into the CSRG questionnaire.
- (2) Body Image: To date, dissatisfaction with appearance associated with SSc has not been measured with a scale that is specific to SSc. The scale on body image that has recently been added to the CSRG is one that assesses satisfaction with particular body parts and social discomfort related to disfigurement, and has been validated in a scleroderma patient population.
- (3) Female Sexuality: Two new scales have been included in the CSRG questionnaire that will be answered by female participants only. They measure female sexual function and relationship satisfaction. Researchers would like to determine the amount of sexual activity in women with SSc, the extent of symptoms that cause sexual dysfunction and the association of sexual dysfunction with quality of life and with quality of the relationship with one's partner.

### CSRG Summer Students

This year, the CSRG is funding seven students who will work throughout the summer on various scleroderma-related research projects. These seven students will work closely with six CSRG Mentors who are all experts in their respective fields. The results of these summer projects will be displayed in a poster session at the Scleroderma Society of Canada conference in Winnipeg, Manitoba on October 2-4, 2009 and will also be available on the CSRG website come September 2009. Please see below for a list of the 2009 CSRG Summer Students, their Mentor and research project title.



Summer Student/Mentor	Project Title
Michael Bennaroch/Dr. Mervyn Gornistky	Salivary Redox Study in SSc Patients and Controls Involving Proteins, Lipids and DNA
Sarah Harding/Dr. Janet Pope	Best Practices in Scleroderma
Sarit Khimdas/Dr. Janet Pope	Are Digital Ulcers associated with PAH and can they be a marker of early PAH?
Ilya Razykov/Dr. Brett Thombs	Development and Validation of a Pruritus Measure for Patients with Systemic Sclerosis
Dr. Reza Taghavi/Dr. Andrew Leask	Is PTEN a potential target for anti-fibrotic drug intervention in SSc?
Alissa Trzeciak/Dr. Anie Philip	Investigation of the Role of CD109 in Scleroderma
Terence Yung/Dr. Stephan Van Eeden	Circulating Biomarkers Predicting Lung Involvement in Scleroderma

#### Our Managerial Team

##### Director

*Dr. Murray Baron*

E-mail:

[mbaron@rhu.igh.mcgill.ca](mailto:mbaron@rhu.igh.mcgill.ca)

##### National Study Coordinator

*Suzanne Taillefer, Ph.D.*

E-mail: [sstaillefer@videotron.ca](mailto:sstaillefer@videotron.ca)

##### Research Assistants

*Jessica Bernstein, B.Sc.*

E-mail: [jbernstein@jgh.mcgill.ca](mailto:jbernstein@jgh.mcgill.ca)

*Sabrina Gravel, M.Sc.*

E-mail: [sgravel@jgh.mcgill.ca](mailto:sgravel@jgh.mcgill.ca)

*Natalie Martin, B.Sc.*

E-mail: [nmartin@jgh.mcgill.ca](mailto:nmartin@jgh.mcgill.ca)

#### Our Rheumatologists

*Dr. Maysan Abu-Hakima, Calgary*

*Dr. Murray Baron, Montreal*

*Dr. Peter Docherty, Moncton*

*Dr. Tamara Grodzicky, Montreal*

*Dr. Marie Hudson, Montreal*

*Dr. Niall Jones, Edmonton*

*Dr. Elżbieta Kaminska, Hamilton*

*Dr. Nader Khalidi, Hamilton*

*Dr. Sharon LeClerq, 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*

#### Our Collaborators

*Dr. Sasha Bernatsky, PhD*

*Mr. Robert Buzza, Scleroderma*

*Society of Canada*

*Dr. Ann E. Clarke, MD, MSc*

*Mr. Grant Dustin, Scleroderma*

*Society of Canada*

*Dr. Marvin Fritzier, Mitogen*

*Advanced Diagnostics Lab*

*Dr. Mervyn Gornistky, DDS*

*Mrs. Shirley Haslam, Scleroderma*

*Society of Canada*

*Dr. David Hart, PhD*

*Mr. Phil Hughes, Patient*

*Representative*

*Dr. Kevin Keen, Statistician*

*Dr. Andrew Leask, PhD*

*Dr. John S. Mort, PhD*

*Mrs. Marion Pacy, Scleroderma*

*Society of Canada*

*Dr. Warren Nielson,*

*Psychologist*

*Dr. Anie Philip, Ph.D.*

*Dr. Anneliese Recklies, PhD*

*M. Normand Ricard,*

*Scleroderma Society of*

*Canada*

*Dr. Peter Roughley, PhD*

*Dr. Marc Servant, PhD*

*Dr. Russell Steele,*

*Epidemiologist*

*Dr. Brett Thombs, Psychologist*

*Dr. Mark Trijiro,*

*Endocrinologist*

*Dr. Jenny Walker,*

*Rheumatologist*

*Dr. Stephan van Eeden, PhD*