

### Upcoming events:

- The First Canadian Scleroderma Research Group Annual Scientific Meeting  
Coast Plaza Hotel  
Calgary, AB  
Sept. 29-30, 2007
- The Canadian Rheumatology Association Annual Meeting  
Mont Tremblant, QC  
March 5-7, 2008

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## A word from the CSRG Director, Dr. Murray Baron

The Canadian Scleroderma Research Group (CSRG) is a group of rheumatologists who decided to join forces in 2004 to better treat scleroderma patients all across Canada. Our main goal is to promote research on scleroderma and to gather information on the nature and severity of the disease, as well as care and treatments available to people suffering from scleroderma.

I am proud to say that since then, we have received 3 major grants from the Canadian Institutes of Health and Research (CIHR). The first grant was obtained in 2004 and allowed the group to establish itself and start the first Canadian registry of adult patients with scleroderma. The CIHR *New Emerging Team grant* was received earlier this year and will allow

us to continue and significantly expand our work in the field of scleroderma. The CIHR *Strategic Training Initiative in Health Research grant*, also received earlier this year, is strictly dedicated to supporting research trainees in the field of SSc, allowing us to increase the capacity of performing future research on this potentially deadly disease.

I hope that the mentorship program, the summer studentship program, the weekly video courses, the dedicated website, regular web conferences, as well as this newsletter will all contribute to foster new interests in scleroderma in both trainees and mentors. The need for experienced mentors in the field of scleroderma is crucial to the success of this initiative and I would like to take this opportunity to thank all

the mentors that have already accepted to take on such an important role and the ones that will join our team in the coming months and years. Thank you also to all the trainees, past, present and future, for your commitment and for contributing to increasing knowledge about systemic sclerosis.

Murray Baron, MD

## Why did we develop the CSRG Training Program?

If the CSRG is already up and running, why do we need a training program? Well, as it turns out, research in scleroderma has actually been quite slow and there has not been much integration between the clinical and basic aspects of the disease.

How can we resolve this problem?

We can train our laboratory and clinical teams to work together on inter-disciplinary research that will focus on multiple aspects of scleroderma.

This way, we can have an interchange of information between academics, clinical researchers, and patients so that we could eventually provide an effective manner to treat scleroderma. An integration between all these viewpoints is crucial because scleroderma is heterogeneous and any new findings that will contribute to therapy depend on the manifestations and the phase of the disease.





*"The training team consists of researchers that work on different aspects of scleroderma."*

*Our recent application entitled "Strategic Training Initiative: Canadian Scleroderma Research Group to the CIHR Training Initiative and Health Research: Training Program Grants to Enhance Quality of Life with a focus on Skin Disease and Musculoskeletal Rehabilitation grants competition has been peer reviewed and approved for funding in the amount of \$1,800,000 over 6 years. The goals of this grant are to fund trainees to work with mentors in different aspects of SSc, establish interactions among trainees through frequent meetings, and disseminate our findings to the community at large by establishing knowledge translation activities.*

## Our Training Team

The training team consists of researchers that work on different aspects of scleroderma. Here is a little summary of each researcher that works with us, to familiarize yourself with their research area. **Dr. Marie Hudson** is a rheumatologist and epidemiologist working on several projects including developing indices of disease activity, severity and damage, and assessing health related quality of life in scleroderma.

**Dr. Janet Pope** is looking at areas of classification criteria in the CSRG database that need revision. She is also working on studies concerning work disability and osteoporosis in scleroderma, using the CSRG dataset to answer key questions.

**Dr. Murray Baron** is the founder and director of the CSRG. He recruited all collaborators and researchers, oversaw the development of the data collection forms and chose all the patient self-administered

questionnaires used for the CSRG cohort. He oversees multiple ongoing clinical projects on the database and also provides clinical research mentorship to rheumatologists in the scleroderma field.

**Dr. Brett Thombs** is the CSRG leading psychologist, in charge of training psychologists in other sites to investigate the psychological consequences of scleroderma and to develop interventions to help patients and families cope with the disease.

**Drs. Andrew Leask** and **Anie Philip** oversee laboratory training and are currently researching how scleroderma cells (fibroblasts) contribute to the fibrotic phenotype of scleroderma.

**Drs. John Mort** and **Peter Roughley**, along with **Dr. Anneliese Recklies**, are overseeing laboratory research. They have collaborated for the past twenty years on various aspects of connective tissue and its

degradation.

**Dr. Russell Steele** is currently overseeing graduate statistical and biostatistical work. He is involved in handling the statistical analyses for the SSc disease.

**Dr. Van Eeden's** work is about using cytokine as a marker of the SSc disease. His group will measure serum cytokine levels in SSc and relate them to disease duration, activity and severity and to ongoing fibrosis and vascular damage.

**Dr. Mark Trifiro's** focus is genetics. His expertise is a key element for a genetic profiling of the disease. His focus is mainly on gene expression analysis between affected cells and non-diseased cells. This might be able to provide some insight as to why certain cells are affected and what triggers scleroderma.

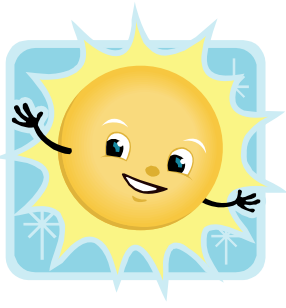
## Being a part of our team: are you interested?

How do we select trainees? Here is a sneak peak at how we do it. Generally, a supervisor is identified by the applicant, either before or during the time of the application. To apply, students must submit formal applications consisting of their academic record, letters of reference and a description of themselves, their interests and their future goals. They must also have the necessary skills and be able to work with us as a team. The Application Committee, who is responsible for the training awards, meets by teleconference twice a year to consider applicants and decides who can be accepted to the CSRG. *Who usually applies?* Students who are already enrolled in Masters or PhD programs, but who want to change their research projects are also allowed to apply for training.

Physicians who have completed their rheumatology training and would like to enroll in a 1-2 year fellowship in scleroderma research are welcome to apply. However, we also offer graduate training for students, even before they are enrolled in the program!



Please contact M. Marwen Naim, National Training Coordinator, for more information on our mentorship program:  
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*“Hiring summer students allows our research plans to prosper and it may also spark the students’ interest in scleroderma research.”*

## 2007 Summer Students and Their Projects

We are very fortunate to be able, thanks to our newly acquired *Training* grant, to hire summer students to work with us at the CSRG. This benefits both us and the students. Hiring summer students allows our research plans to prosper and it may also spark the students’ interest in scleroderma research.

Every summer, we hire five students to work with selected CSRG mentors all across Canada for a period of three months. Every student is assigned to a specific supervisor, and at the end of the summer, the students and his/her supervisor are both evaluated on their work. First, the students send us a lay summary as well as a scientific summary that describes his/her research project. Students spend the summer working on the project, and at the end of the summer, they provide us with a final lay and scientific summary about their achievements on the

project. They prepare posters for their projects and the posters are presented at the CSRG Annual Scientific Meeting. All students who intend on staying to work with us on scleroderma research in the future are invited to attend the Canadian scleroderma research group annual meeting.

This summer, the projects varied from Quality of Life, to Predictors of Improvement in Scleroderma. Dr. Pope has been directing the summer studentship program for the national Canadian Rheumatology Association for 5 years, and is now in charge.



*“The Scleroderma Society of Canada was founded in 1999 by six individuals who had scleroderma, and hoped to provide an active approach to the disease.”*

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## The CSRG and the Scleroderma Society of Canada: How are we connected?

**What is the Scleroderma Society of Canada (SSC)?** The Scleroderma Society of Canada was founded in 1999 by six individuals who had scleroderma, and hoped to provide an active approach to the disease. The mission of the SSC is to raise awareness (education and support), funding for research, and a cure for scleroderma.

### **So what is the link between the CSRG, the SSC and the Training grant?**

The CSRG and the SSC work together and make the information on scleroderma available to the public. Together, the two groups share information via their respective Newsletter, evaluate the lay summaries that the CSRG trainees provide, and ensure that this information is written in a simpler, more coherent, public-friendly language. This collaboration runs through a common committee: The Advocacy/Knowledge Translation & Exchange (AKTE) Committee.

This committee includes members from both SSC and CSRG. The committee has a mandate

to ensure that advocacy and knowledge translation fundamentals are reflected in all of the research undertaken by the CSRG. As a result, a ‘lay language’ template will be provided to each of the 9 summer students and their mentors with the request that a ‘lay language’ summary of their research be prepared and submitted.

Phil Hughes, one of the patient-representatives in the CSRG AKTE Committee, reviews the trainees’ lay summaries and recommends modification, if any. His comments help the trainees to provide a summary in lay language. This information then becomes accessible to the public. The lay summaries can then be distributed to patients via the SSC.

Long life to this great collaborative work!



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We will soon be on the Web!  
Stay tuned!



## Graduate students: What's been done so far

One of the major focuses of the CSRG training program is to recruit graduate students who are either in a Masters, Doctorate, or Post-doctorate program. We are doing this every year, starting the academic year of 2007-2008, and for the duration of the STIHR – CIHR grant which lasts 6 years. We have started recruiting for our first year in early June. The CSRG has already hired 9 trainees for this year. The candidates were selected by CSRG Mentors to fill these positions and the CSRG Training Committee started evaluating their applications at the end of July. The majority of the positions were filled by the end of August and the students are now beginning to train with their mentors in their laboratories in the month of September.

On behalf of the CSRG, we would like to extend a warm welcome to Orit Schieir (Dr. Brett Thombs' Trainee), Sarah McLean (Dr. Andrew Leask's trainee), Danny Di Capua (Dr. Mark Trifiro & Dr. Baron's trainee), Celeste Loewe (Dr. Stephan Van Eeden's trainee) and Corinne Coulter (Dr. Janet Pope's trainee). We look forward to working with you during this period of time! Our recruiting process is still on the run, and we are expecting a few more applications by December.



## Our first annual scientific meeting

On your flights, get set, go! On September 29, the CSRG is holding its very first annual scientific meeting. This will take place in Calgary, AB and we already have about 50 guests that have confirmed their attendance!

Our meeting will occur at the same time and place as the **Scleroderma Society of Canada Annual General Meeting (AGM)**. This will be a great opportunity to meet with the scleroderma patients that are attending from all over the country.

But that's not all! We are pleased to tell you that there are three guest speakers attending the meeting. **Dr. Jan Storek**, (Canada Research Chair in Molecular Medicine at the University of Calgary) will be speaking about hematopoietic cell transplantation for autoimmune disease. Along with him, **Dr. David Courtman**,

professor in the faculty of Medicine at the University of Toronto, will be speaking about Progenitor Cell Therapy for Pulmonary Hypertension and **Dr. Virginia Steen**, who works in the Division of Rheumatology and Georgetown University Hospital, will tell us all about her studies on pulmonary hypertension (PHAROS).

Also, don't forget about dinner on Saturday night at *Osteria de Medici*... This will be a great opportunity to meet your colleagues and have a delicious meal.

We hope to see you in Calgary!

