

The Researcher

The Canadian Scleroderma Research Group Newsletter

Spring 2008

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Congratulations to Dr. Brett Thombs!



Recently, a team of researchers from the CSRG (Principal Investigator – Brett Thombs; Co-Investigators – Murray Baron, Marie Hudson, Eva Libman, Suzanne S. Taillefer) was awarded \$217,160 over 3 years by the Fonds de la Recherche en Santé Québec to develop a systematic approach to assessing 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. Two important factors that make addressing fatigue in patients with scleroderma difficult are (1) the lack of an agreed-upon standard for identifying clinically significant fatigue related to scleroderma above and beyond other experiences of fatigue that do not necessitate medical attention, and (2) an insufficient scientific understanding of the causes of fatigue that makes developing treatments difficult. Our project will build upon work developed by cancer researchers, who have done extensive work on fatigue from cancer and its treatments, to establish a unified definition for what comprises clinically significant fatigue, to validate questionnaires that can be used in research, and to identify effective and efficient ways for physicians and other medical staff to assess fatigue as part of scleroderma care. CSRG investigators, including Dr. Stephan van Eeden of the University of British Columbia, will use data from the study to identify aspects of scleroderma, such as cytokine production, that may be associated with high levels of fatigue. Dr. Thombs and his team will be conducting telephone interviews on the experience of fatigue with patients enrolled in the CSRG Registry. If you would like more information about the project, please contact Marielle Bassel by phone (514-340-8222 ext. 3238) or via email (marielle.bassel@elf.mcgill.ca).

Congratulations to Dr. Mervyn Gornitsky!

Dr. Mervyn Gornitsky, an oral and maxillofacial surgeon and member of the CSRG, was awarded \$228,000.00 by the CIHR for a study entitled *Oral Health in Scleroderma*. Other members of the CSRG, Dr. Murray Baron, Dr. Marie Hudson and Dr. Russell Steele, will be working on this project, in addition to Dr. Marie Dagenais from McGill University. This 2-year project will look at the oral manifestations of scleroderma (saliva production, reduction of oral aperture, periodontal diseases and caries), the frequency of those manifestations, and their impact on the quality of life of scleroderma patients. The study will take place at multiple CSRG sites across Canada. Dr. David MacDonald (Vancouver), Dr. Maria Copete (Saskatoon), Dr. Dean Kolbinson (Saskatoon), Dr. Norman Thie (Edmonton), Dr. Tarek El Sayegh (London), Dr. Deborah Matthews (Halifax), Dr. Trey Petty (Calgary), Dr. Mandana Nematollahi (Winnipeg) and Dr. Getulio Nogueira (Winnipeg) will lend their expertise in the field of Dentistry to this project and will be examining patients referred to them by the CSRG. All dentists will be meeting in Montreal on June 7th-8th for a workshop, where 8 scleroderma patients will be examined and an exact dental examination procedure to follow will be determined. Study examinations will begin in September 2008. Please contact Aurée Janelle-Montcalm, coordinator of the project, by phone at (514) 340-8222 ext. 3423 or by e-mail (ajanelle@jgh.mcgill.ca) if you wish to obtain more information about the study.



Recent Publications & Presentations

We have been working hard since the creation of the CSRG in 2004. As of March 1st 2008, members of the CSRG have generated a total of 50 publications and presentations. Within 2007-2008 alone, the work of CSRG members resulted in 29 publications and presentations. Congratulations to all of our members for such a great achievement!



Visit Our Website

Since October 2007, our fully bilingual website is up and running. On it, you can find information about the CSRG Registry, our members, our training programs, our publications, ongoing research projects and upcoming events. There are also useful links to several scleroderma related websites.

Visit our website at www.csrgrcs.ca

CSRG Summer Students 2008

This summer, 5 students will be joining the CSRG as part of our Summer Studentship Training Program. During 3 months, they will work under the supervision of CSRG mentors on innovative scleroderma research projects. Students will present the results of their hard work during our Annual Meeting in September. We are pleased to welcome the following summer students to the CSRG and we hope their summer work experience will convince them to work on other innovative scleroderma research projects.

- Ms. Tamara Morrison, Nursing student at University of Northern British Columbia, will collaborate on the development of a disease assessment index for scleroderma under the supervision of Dr. Kevin Keen.
- Ms. Serena Banh, Physiology student at McGill University, will look at the role of acquired genetic mutations in scleroderma under the supervision of Dr. Mark Trifiro.
- Mr. Kun Huh, Medical Science undergraduate student from University of Western Ontario, will investigate the function of the connective tissue growth factor (CTGF) in wound healing under the supervision Dr. Andrew Leask.
- Mr. Alexandru Iorga, Anatomy & Cell Biology student at McGill University, will study the role of the growth factor TGF- β in skin thickening in scleroderma under the supervision of Dr. Anie Philip.
- Mr. Michael Benarroch, Dentistry student at Université de Montréal, will assess the presence of oxidative stress (aka high level of free radicals) in the saliva of scleroderma patients under the supervision of Dr. Mervyn Gornitsky.

2008 Canadian Scleroderma Research Group Patient Survey

In order to determine which issues are important to individuals living with scleroderma, the CSRG is working on a survey to be administered to people with scleroderma. Several topics related to scleroderma will be included in the survey, such as symptoms, healthcare, as well as social, financial, and psychological issues. Using this information, the CSRG will aim reassess its research priorities. Participation to the survey is on a voluntary basis and will be anonymous. The survey will be made public for the first time during the Scleroderma Society of Canada meeting in Ottawa next September. For more information about the patient survey, please contact Marielle Bassel at (514) 340-8222 ext 3238.



Scleroderma Fact!

Scleroderma is considered to have been first described by Curzio in Naples in 1753.

Nutrition and Scleroderma

On June 6th 2008, a research workshop on nutrition organised by Dr. Murray Baron will take place at the Jewish General Hospital in Montreal. Dr. Baron has invited nutritionists, gastroenterologists, and rheumatologists to present their current research projects and to discuss challenges related to nutrition and gastrointestinal issues in scleroderma. Among the participants, we are glad to receive:

- Dr. Dinesh Khanna, rheumatologist from University of California in Los Angeles, CA
- Dr. Philip P. Toskes, gastroenterologist from University of Florida College of Medicine in Gainesville, FL
- Dr. Mark DeLegge, gastroenterologist from University of South Carolina in Charleston, SC
- Dr. William Paterson, gastroenterologist from Queen's University in Kingston, ON.
- Dr. Gad Friedman and Dr. Andrew Szilagy, gastroenterologists at the Jewish General Hospital in Montreal, QC
- Dr. John Hoffer, internist at the Jewish General Hospital in Montreal, QC
- Dr. Linda Wykes, from the Nutrition department of McGill University in Montreal, QC
- Mrs. Paule Bernier, Mr. Louis-François Côté, Mrs. Norma Ishayek and Mrs. Norma Schafer, nutritionists at the Jewish General hospital in Montreal, QC
- Dr. Mervyn Gornitsky, from the Dentistry department at the Jewish General Hospital in Montreal, QC
- Dr. Marie Hudson, rheumatologist at the Jewish General Hospital in Montreal, QC

We believe that such a group of experts will be able to pinpoint which problems of the gastrointestinal system and which nutrition obstacles are worth investigating to improve the quality of life of scleroderma patients. So stay tuned, for this is the beginning of a new research initiative.



Web Courses

As part of a training initiative, weekly Web courses have been given by CSRG members and other scleroderma experts for our members, trainees and collaborators. These weekly lectures started in October 2007 and will end on May 22nd 2008. Their goal is to broaden the knowledge of our trainees regarding scleroderma research that is taking place in various fields (statistics, medicine, molecular biology, etc.) and to keep them up to date with ongoing research projects of CSRG members. Web links to all of the lecture recordings will be available on our website as of June 1st 2008 and we are looking forward to having more interesting Web Courses next year!

Our Annual Meeting is Coming Up!

The 2nd Annual Scientific Meeting of the Canadian Scleroderma Research Group will take place at the **Crowne Plaza Hotel** in Ottawa on **September 19th-21st 2008**. Many CSRG rheumatologists, researchers, collaborators and trainees will attend this meeting, where they will share their findings and discuss future research projects and collaborations. Once more, our annual meeting will be held at the same time as the Annual conference of the Scleroderma Society of Canada (SSC). The CSRG and SSC will be mingling throughout the weekend, and will share a buffet dinner on Friday and a lunch on Saturday. Several presentations and workshops will be given by CSRG members at the SSC conference, including CSRG trainees and summer students, who will be presenting their research results to the SSC participants during a poster session on Saturday. This is a great opportunity for patients and health professionals alike to share their thoughts on the future and the challenges of scleroderma research and to learn more about each other at the same time. For more information about the SSC Conference agenda, or to find out how to register, contact Aline Laporte at (613) 745-7829 or visit SSC's website: <http://www.scleroderma.ca/>. For more information regarding the CSRG meeting and events, please contact Aurée Janelle-Montcalm at (514) 340-8222 ext. 3423.

Our Managerial Team

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Our Rheumatologists

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Dr. Peter Docherty, Moncton

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. Janet Pope, London

Dr. Jean-Pierre Mathieu, Montreal

Dr. David Robinson, Winnipeg

Dr. Douglas Smith, Ottawa

Dr. Evelyn Sutton, Halifax

Volunteers Needed!

On June 7th 2008, dentists participating in the Oral Health project will be meeting at the Jewish General Hospital in Montreal to establish the dental examination procedure for this project. We need to recruit 8 English-speaking patients. These 8 patients have to be already enrolled in the CSRG scleroderma registry and have to be followed at the Jewish General Hospital. If you want more information about this workshop, please contact Maura Buchignani at (514) 340-8222 ext. 3468.

Goodbye!

We would like to say goodbye and wish good luck to Kalina Borrissova, Beatrice Garfinkiel and Marwen Naim, who have recently left the CSRG.



Our collaborators

Dr. Sasha Bernatsky, PhD

Dr. Ann E. Clarke

Dr. Marvin Fritzier, Advanced Diagn. Lab.

Mrs. Shirley Haslam, Sclero. Soc. of Canada

Mr. Phil Hughes, Patient Representative

Dr. Andrew Leask, PhD

Mrs. Marion Pacy, Sclero. Soc. of Canada

Dr. Anie Philip, Ph.D.

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Dr. Anneliese Recklies, PhD

Dr. Peter Roughley, PhD

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We would like to hear from you...

If you have any question or comment about the content of this newsletter, please contact Audrée Janelle-Montcalm at (514) 340-8222 ext 3423 or at ajanelle@jgh.mcgill.ca.