



# Canadian Scleroderma Research Group

MAY 2006

NEWSLETTER

VOL 4, NO 1

## The 2006 Annual Meeting of the European The European League Against Rheumatism (EULAR)

will be held in Amsterdam, Netherlands  
from **June 21-24**.

(<http://www.eular.org/>)

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## The 9<sup>th</sup> International Workshop on Scleroderma Research

will be held in Boston, Mass, USA  
from **August 5-9**.

(<http://www.sclerodermaworkshop.org/>)

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## The 2006 Annual Meeting of the American College of Rheumatology (ACR)

will be held in Washington, DC, USA  
from **Nov. 10-15**.

(<http://www.rheumatology.org/annual/index.asp>)

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**Sclérodermie Québec** launched a new and  
improved website in October

<http://www.sclerodermie-quebec.qc.ca/>

This is a French only website but

**Sclérodermie Québec** intends to make it  
bilingual in the coming years.

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On February 1<sup>st</sup>, the **CSRG** submitted an  
application for a training grant from the  
Canadian Institutes of Health Research (CIHR)  
. The purpose of this training is to develop the  
skills needed by researchers wishing to  
become part of the CSRG. Over time, this will  
enable them to acquire the expertise to run  
independent research programs on multiple  
aspects of scleroderma, both clinically and in  
the laboratory.

We will also be reapplying for the Canadian  
Institutes of Health Research (CIHR) New  
Emerging Team Grants - New Research  
Teams to Enhance the Quality of Life. The  
deadline for the application is June 1<sup>st</sup>, 2006.  
One of these grants would allow the CSRG to  
continue its research activities for at least  
another 5 years. The anticipated notification of  
decision is expected in November 2006.

## RECENT DEVELOPMENTS

✧ We now have **419** Canadian scleroderma patients from all over the country in the Canadian Scleroderma Research Group (**CSRG**) registry. All patients were assessed by a **CSRG** rheumatologist for their baseline visit. One hundred and nineteen (119) patients have also been seen for their one-year follow-up visit. Data on **355** patients have been entered in the database. In *Looking Closer At Our Data* this month, we will summarize some of the characteristics of scleroderma patients with complete data.

✧ Dr Proton **Rahman** will be joining the group of **CSRG** rheumatologists in the coming weeks and will be seeing patients for the registry in **St John's, Newfoundland**, where he will take over for Dr. Khraishi. A biographical summary appeared not too long ago in the *Globe and Mail* (April 2004): "*A doctoral graduate of Memorial in 1990, Dr Rahman then studied rheumatology and genetic epidemiology at the University of Toronto, returning to Memorial in 1999 as assistant professor of medicine. Concurrently, he became staff rheumatologist at St. Clare's Mercy Hospital in St. John's. In 2000, he also became chief scientific officer of Newfound Genomics Inc., a biotech firm that is studying the gene structures of Newfoundlanders, to learn more about obesity, diabetes, arthritis and inflammatory bowel disease. (Newfoundland is suitable for this research because its population is quite homogeneous.)... Dr Rahman developed arthritis of the spine at the age of 17 and this pretty much shaped his future as a health professional... Today, he is Associate Professor of Medicine at Memorial University in St. John's, Newfoundland*". On behalf of the group, we extend a warm welcome to Dr Rahman!

✧ As the National coordinator of the **CSRG**, I will have the pleasure of visiting the **CSRG** sites for the first time since this project started over 2 years ago now. First, from May 7 to May 12, I will visit our **CSRG** teams in Winnipeg, MB, Saskatoon, SK, Calgary, AB, Edmonton, AB and in Vancouver, BC. Later, in June, I will visit our **CSRG** teams in Moncton, NB, Halifax, NS and in St John's, NL. The only remaining **CSRG** sites to visit will be the ones in Ontario (Hamilton, London, Toronto and Ottawa) and I hope to visit these before the end of the year. Dr Baron will also be visiting Calgary and Edmonton in May, and Moncton in June. We greatly appreciate *Actelion* for partially subsidizing these visits.



CURE SCLERODERMA FOUNDATION

## The Jewish General Hospital Foundation Pays Tribute To An Exceptional Woman!



On January 24, 2006, The Jewish General Hospital Foundation officially acknowledged Pierina Nero's 2005 achievements and presented her with a commemorative plaque, inscribed with the following tribute:

THE SIR MORTIMER B. DAVIS, JEWISH GENERAL HOSPITAL ACKNOWLEDGES WITH GRATITUDE PIERINA NERO FOR HER DEDICATION AND EFFORT IN RAISING FUNDS FOR SCLERODERMA RESEARCH 2005.

Pierina Nero, who was diagnosed with scleroderma in 2000, is the founder of the *Cure Scleroderma Foundation* (CSF), which is dedicated to help finance the Canadian Scleroderma Research Group.

If you would like to support the Cure Scleroderma Foundation, please contact Pierina Nero by email at [curescleroderma@yahoo.ca](mailto:curescleroderma@yahoo.ca), or by mail at 3755, Cote Ste-Catherine Rd, Suite A216, Montreal, QC, H3T 1E2 Canada.

## THE CSRG: ONE MEMBER AT A TIME...

In this issue, our featured member is ...

### Dr. Janet Markland, M.D. F.R.C.P. B.Sc.

Rheumatologist at the University of Saskatchewan, Saskatoon, Saskatchewan, Canada and Member of the Canadian Scleroderma Research Group



Edith, Dr Markland and Amanda

I am a Saskatchewan-born and -bred Rheumatologist with 24 years of practice under my belt. My parents were farmers and my 82 yr old mother still lives on the farm.

Before entering Medicine I obtained an Honours degree in Molecular Genetics and worked on Serum Ceruloplasmin Levels in Aborigines. I have always been interested in rare and unusual cases, which could explain my interest in the connective tissue disorders.

In addition to having a very busy private practice, I am also a Clinical Professor in Rheumatology and Internal Medicine at the University of Saskatchewan. In this province there are nine rheumatologists, four of whom practice at the University Hospital, and two that practice in Regina. Two of the nine do more Internal Medicine, and two work part-time. Because of the number of patients I have seen over the years (88,000) and the large number that I continue to follow, I am now changing over to a "paperless" or electronic medical records system.

I first worked with Dr. Janet Pope several years ago when we were trying out the effects of Methotrexate on Scleroderma patients. I am especially concerned for early scleroderma patients with apparent rapidly progressive disease. Fortunately this type of patient is rare. I am looking for something to help with the early intervention of disease recognition and arrest of disease progression. The Canadian Scleroderma Registry is giving us all an opportunity to follow many more patients with all aspects of the disease, to determine how frequently and silently pulmonary hypertension develops as well as many other aspects. I hope to lend some of my experience to all the people involved with the study. In addition, I am grateful for all the work that Dr. Murray Baron and Suzanne Taillefer have done to get the CSRG going.

I have excellent support from my staff and from the local Scleroderma group. My research assistant, Edith, has been a faithful coordinator and I have recently acquired a young and keen research nurse, Amanda.

My favourite past time is gardening. I have a rose garden, a lily garden, an herb garden and a water garden. I love trying out new and exotic plants and seeing if I can find a niche where they can survive in our harsh 2b climate. As a result, perhaps, our daughter is a horticulturist. I am also proud of our son who follows in his father's steps as an engineer. As well as being an electrical engineering student, my son has interests in chemistry and is a licensed pyrotechnician.

JM



## LOOKING CLOSER AT OUR DATA . . .

The following statistics were calculated on the first **266** patients in the registry who, as of mid-January 2006, had complete data available for their baseline visit.

### Sociodemographic information

Patients' age varied between 18 and 88 years old with a mean age of 55.8 years. More than three quarters were women (78.2%), 68% were Anglophone Canadians and 72% had children. The majority of patients were married (63.1%) and 41% had at least finished high school.

### Environmental Exposures

Patients were asked to identify the substances to which they were commonly exposed to. *Paint thinners/removers* (15.4%) and *industrial fumes* (9.6%) were the most frequent answers. Patients also reported being exposed to other various industrial products while working (16.7%).

### Onset of Symptoms

Almost all patients suffered from Raynaud's phenomenon (257/262) and had been suffering from it for an average of 13.9 years ( $\pm$  12 years). Patients have had scleroderma for 8.1 ( $\pm$  7.6) years on average.

One third (32.4%) of patients had at least one hospitalization for scleroderma and 6% had a previous malignancy. Almost half of all patients suffered from scleredema displaying puffy fingers (48.7%) and 8.7% had at least one active finger ulcer.

### Treatments and Severity of Disease

The most common medications used by patients in the CSRG registry were *calcium Channel Blockers* (19.5%), *Corticosteroids* (15.8%), *d-penicillamine* (11.7%) and *Methotrexate* (11.1%). More than one third of patients suffered from Diffuse Scleroderma (38.3%).

For each patient, the CSRG rheumatologist was asked to rate the severity, activity and damage associated with the patient's disease. On average, for all patients, on a scale of 0 (no disease) to 10 (extreme disease) **severity** of the disease was scored 2.9, **activity**, 2.3 and **damage**, 3.3.

It will be interesting to continue monitoring these characteristics in the subsequent visits.



### A special thank you to the SSC on behalf of all the CSRG patients...

The Scleroderma Society of Canada (SSC) has donated 400 sets of cards and 400 scleroderma pins to the CSRG. These gifts will be given to patients who are part of the CSRG registry. The cards are original watercolors by scleroderma patient Jocelyn Barber. Each patient will receive a set of cards as well as a pin when they come for their first-year follow-up visit. Thank you to the SSC for these beautiful cards and pins.

If you want to learn more about scleroderma, read about the Society's activities, become a member or make a donation, please visit their website: <http://www.scleroderma.ca>.



### Artists' talents to benefit scleroderma research...

The 8th annual *Artists in Bloom* was held at Dawson College on April 20. The annual event raised \$5,500 and all the money went to the Canadian Scleroderma Research Group.

During the annual event, 20 young and very talented arts students sat down at their easels to paint for two hours. Their paintings were then auctioned-off to benefit the CSRG. Rob Laurie from CFCF-Montreal acted as auctioneer and the event even made the late evening news on CFCF that night. The evening was not only very interesting but also a success and it was tremendous fun.

## OUR TEAM

### DIRECTOR:

Murray Baron, MD  
Suite A216  
3755 Cote Ste-Catherine Rd  
Montreal, QC  
H3T 1E2  
Tel: 514-340-8231  
Fax: 514-340-7906  
E-mail:  
[mbaron@rhu.igh.mcgill.ca](mailto:mbaron@rhu.igh.mcgill.ca)

### STUDY COORDINATOR:

Suzanne S. Taillefer, Ph.D.  
E-mail: [sstaillefer@videotron.ca](mailto:sstaillefer@videotron.ca)

### RHEUMATOLOGISTS:

Dr. Maysan Abu-Hakima, Calgary  
Dr. Murray Baron, Montreal  
Dr. Mary Bell, Toronto  
Dr. Arthur Bookman, Toronto  
Dr. Peter Docherty, Moncton  
Dr. James Dunne, Vancouver  
Dr. Marie Hudson, Montreal  
Dr. Sindhu Johnson, Toronto  
Dr. Niall Jones, Edmonton  
Dr. Nader Khalidi, Hamilton  
Dr. Proton Rahman, St-John's  
Dr. Sharon Le Clercq, Calgary  
Dr. Janet Markland, Saskatoon  
Dr. Jean-Pierre Mathieu, Montreal  
Dr. Janet Pope, London  
Dr. David Robinson, Winnipeg  
Dr. Douglas Smith, Ottawa  
Dr. Evelyn Sutton, Halifax

### COLLABORATORS:

Mr. Robert Buzza, President,  
Scleroderma Society of Canada  
Dr. Donald Duerksen,  
Gastroenterologist  
Dr. Marvin J Fritzler, Rheumatologist  
(Advanced Diagnostic Laboratory)  
Dr. Andrew Hirsch, Respiriologist  
Dr. Caroline Pukall, Psychologist  
Dr. Lawrence Rudski, Cardiologist  
Dr. Russell Steele, Statistician

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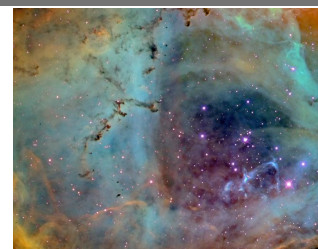
A special thank you to **Raymond Bourgeois** for editing this issue of the Newsletter.



If, each day of the year, the NASA can post a different picture of our universe on one of their websites, surely we can do something for all patients with scleroderma!!!!!!

### ASTRONOMY PICTURE OR IMAGE OF THE DAY...

Each day, since June 16, 1995, a different image or photograph of our fascinating universe is featured on one of the NASA's websites, along with a brief explanation written by a professional astronomer (<http://antwrp.gsfc.nasa.gov/apod/archivepix.html>). The pictures that you will see on this website are amazingly beautiful. The technology required to produce many of those interesting and amazingly beautiful pictures is mind baffling. First of all, do not forget that the telescope was just introduced to astronomy in 1609, that the magnification was then very limited (--up to 30 times for Galileo-- ) and that it had a narrow field of view; Galileo could see no more than a quarter of the moon's face without repositioning his telescope. Also a century later, around mid-1827, using material that hardened on exposure to light, Joseph Nicephore Niépce, produced the first successful picture. This picture required an exposure of eight hours. We have gone a long way in a short period of time when it comes to studying Space.



### LAST MINUTE NEWS...

The Cure Scleroderma Foundation (CSF) held their first meeting of the year on April 10. They started planning this year's events. *Shaving for Scleroderma*, a disco Bowlethon and a golf tournament at Le Manitou in Mont Tremblant this summer are among the many events that will take place this year, all benefiting the Canadian Scleroderma Research Group. And don't forget the **2006 Cure Scleroderma Gala** scheduled on **Saturday, November 4th, 2006** at **Le Crystal**, in Ville St-Laurent. Last year's fundraising activities were a true success: the CSF raised more than \$81,000.00. They plan to raise even more money in 2006. Stay tuned for more information...

Feel free to let me know by email or mail about any events or information that could be of interest for other readers.  
Thank you!  
Suzanne S. Taillefer