



Canadian Scleroderma Research Group

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NEWSLETTER

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A few numbers....

We now have **535** scleroderma patients in the Canadian Scleroderma Research Group (CSRGR) Registry. All patients were assessed by a **CSRGR** rheumatologist for their baseline visit. Two hundred and eighty-seven (287) patients have also been seen for their one-year follow-up visit and eighty-nine (89), for their two-year follow-up. Data on four hundred and twenty (420) patients have been entered in the database.

Patient participation is crucial to the success of such an initiative.

Thank you to all participants!



On June 1st, the CSRGR re-applied for the Canadian Institutes of Health Research (CIHR) *New Emerging Team Grants - New Research Teams to Enhance the Quality of Life*. Last year, we ranked third among 14 applications but only 2 grants were given-out. We really hope to receive this grant this year because it would allow the group to continue its research activities for at least another 5 years. The notification of decision was expected in November 2006.



A manuscript entitled *Depression In Patients With Systemic Sclerosis: A Systematic Review Of The Evidence*, submitted by one of our team members, Dr. Brett Thombs, a psychologist who just joined our team, was recently accepted for publication in the No. 1 journal in Rheumatology: *Arthritis Care & Research*. This great review was written by Dr Thombs with the help of other CSRGR members (S. Taillefer, M. Hudson, & M. Baron). Congratulations!

\$1,800,000 over 6 years for Scleroderma Research



Our recent application entitled "**Strategic training initiative: Canadian scleroderma research group**" to the *Training Initiative in 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**.

The Goals of this grant are to fund trainees to work with mentors in different aspects of Systemic Sclerosis, establish interactions among trainees thru frequent meetings, and disseminate our findings to the community at large by establishing knowledge translation activities. This will be done over 6 years.

Because this initiative will increase the capacity to perform Systemic Sclerosis research in Canada, this is great news for all people living with this disease.

Recent Developments

- The **CSRGR** registry is doing very well and recruitment has been underway since September 2004. However, late last summer, we had to find another database management company to take over our database. We are glad to say that January 15, CSRGR sites all over Canada have started to enter data in our new database again. Our new data management company, *Datazoom Solutions*, has done a great job setting-up the new database and making sure that all our old data is intact and new data can easily be added. *Datazoom Solutions* has made our web-based database secure, reliable and very user friendly.
- The **CSRGR** members met during the American College of Rheumatology Annual Scientific Meeting that took place from November 10-15 in Washington, DC. After Dr. Baron, director of the group, gave an update on the latest enrollment numbers and summarized the financial situation, the group discussed the authorship and data sharing issues. Following these discussions, documents about authorship and data sharing were drafted to help define members' role and tasks, and strengthen the team. These "contracts" were discussed again and agreed upon during the **CSRGR** meeting that took place in Lake Louise, AB during the Canadian Rheumatology Association Annual Scientific Meeting on February 23, from 2:00 p.m. to 4:00 p.m.

My name is Pierina Nero. I have Scleroderma. My first symptoms began at the age of 39, it was October 2000. Symptoms were: Raynauds Phenomenon, tingling and numbness of my fingers, difficulty making a fist and just plainly my "fingers hurt". After many visits to my local clinic and various doctors, I was diagnosed with Carpal Tunnel Syndrome and was put on a two-year waiting list for surgery. In the meantime, someone suggested that I go see a rheumatologist. I was given several names and called to make an appointment. I took the earliest appointment which happened to be with Dr. Murray Baron. Must have been fate from the start!!

On my first visit with Dr. Baron, he immediately ruled out Carpal Tunnel Syndrome and told me not to have the surgery. He said he wasn't sure what I had (I believe that he did know, but didn't want to say for sure at that point), but it definitely was not Carpal Tunnel Syndrome. He sent me for numerous tests and told me to come back in three months. All my tests came back negative and again he told me to come back in three months. During these intervals, I remember feeling like I was waiting to get sicker before a diagnosis could be made. In fact it was when I went for my first EKG that the receptionist said to me "oh, it must be Scleroderma day" and I replied, "no, I don't have Scleroderma" and she said, "yes, and that is what your doctor wrote on the requisition". I thought he probably just wrote that to justify why he was sending me for an EKG at such a young age. During the test, I casually asked the technician "what is Scleroderma?" It sounded harmless enough. He looked at me like I was from another planet and told me to ask my doctor. By his reaction, I realized that this thing called Scleroderma was not as harmless as I originally thought. Of course, the first thing I did when I got home was to go on the Internet. BIG MISTAKE. For all the good that the Internet brings to our lives, it can also give us "info overload" and sometimes not necessarily the correct information. Realizing that I had all the classic symptoms of Scleroderma and even though I was not officially diagnosed with Scleroderma, I knew that this is what I had. And that is the day that my life, as I knew it, would change forever. I shut down my computer and began to cry.

I was diagnosed with Diffuse Scleroderma in May 2001, not because any tests came in positive, but merely for the physical aspect. The skin on my fingers

got really hard and tight. Within weeks this spread to my hands, arms, face, and chest. I couldn't move. I felt like my skin was two sizes too small for me. Every task required enormous effort. Finger ulcerations were unbearably painful. I had ten ulcerations going at the same time. The fatigue was paralyzing. I developed Pulmonary Fibrosis. With this came coughing and shortness of breath. I couldn't walk much distance without being completely drained. Scleroderma had taken over my life!

Looking back now on those first four years, I remember living and going through the motions and somewhere in my subconscious I was preparing to die. After all, that is the information I received from the Internet "Patients diagnosed with Diffuse Scleroderma die within the first seven years of being diagnosed". But I can't die now; I have too many things to do. I have three teenagers that need me more now than ever before. I have to see them through some of life's challenges and see their accomplishments. This is my role as a Mom and Scleroderma is not going to stop me fulfilling this role.



In 2005 I founded the Cure Scleroderma Foundation (CSF). My main goals were to raise money for the Canadian Scleroderma Research Group (CSRG) and to raise awareness. So far, with the help of my committee and through various activities we have succeeded! To date, over \$175,000.00 has been raised and many more people are aware of Scleroderma. We also arranged to be part of the Medical Report, which aired on November 16, 2006 on CFCF News

It has been six years since my first symptoms began. The skin on my hands and arms are still hard, my fingers remain in a claw-like position, ulcerations are gone and my pulmonary fibrosis has stabilized. I am still limited in my activities, but I have adjusted. With the support of my family and friends, a cocktail of meds, great medical care, keeping busy with the CSF and a positive attitude, today I feel great.

My dream come true: one day there will be answers to all the unanswerable questions about Scleroderma so that future generations can be diagnosed and treated immediately . . . and maybe, just maybe, Scleroderma can be preventable and curable.



RAISING AWARENESS ...

On November 16, CTV's Medical Report, hosted by Anne Lewis, talked about Scleroderma. The Montreal journalist and her team had come to Dr Baron's office the week before to film Dr Baron and Mrs Janet Pitcher, a patient with Scleroderma who agreed graciously to talk about her life with the disease.

During the two-minute clip presented at noon and 6 p.m. all over the country, you could see Janet talking a little bit about her symptoms and how the disease impacted her life, and Dr Baron talking about the disease in general. This brief report was a good attempt at raising awareness about scleroderma.

Thank you to Janet for taking the time to do this, for opening her house and for opening her heart to help Scleroderma research. Thank you to Dr Baron for making the time to meet with the CFCF team but most of all and thank you to CFCF for making this possible.

To read more about the Medical Report, visit: <http://montreal.ctv.ca/cfcf/news/medical&id=1391#1391>



Janet Pitcher



The Cure Scleroderma foundation has a new website

The *Cure Scleroderma* (CS) foundation now has its own official website, www.csfoundation.ca. On this website, you will find information about all the foundation's fundraising activities, available in both English and French. You can also buy their beautiful greeting cards, hand painted by Mrs Laurette V. Blouin, a very talented artist who also has Scleroderma, or make a donation to the foundation in a safe environment. Thanks to the Jewish General Hospital Foundation, you will even receive a tax receipt for donations of \$10 or more.



Gianni Crivello and his wife, Pierina Nero, the night of the 2006 CS Gala dinner.



CURE SCLERODERMA FOUNDATION

\$94 260 for Scleroderma Research

On November 4, 2006, the *Cure Scleroderma* (CS) foundation held their second annual Gala to benefit the **CSRG**. The evening was not only fun and inspiring, but it also contributed to making this year's CS fundraising events a real success. At the end of the evening, Pierina Nero, the head of the CS foundation, announced to Dr Baron and the other 300 guests that her foundation had raised a total of \$94 260 this year. Dr Baron was very happy and, on behalf of all CSRG members, thanked Pierina for all her efforts and

dedication. He also thanked the members of the CS committee for helping to organize all the activities and all the people that donated money, services and gifts to the foundation. To help Pierina to raise more money for the CSRG or to find out more about the CS foundation, please visit their website: www.csfoundation.ca

Patients' continuous support is CRUCIAL to the success of the registry

Because a few **CSRG** sites started to see patients for the registry as early as September 2004, some patients have just completed their third registry visit.

We are happy to report that a number of these patients are doing better or have at least stabilized. Some are even wondering if their participation in this study is still needed because of the improvement of their condition. In fact, these days, it is not rare to hear a returning patient say something like "Why do you need me to do this again this year? It won't help you! I am the same as last year".



We urge **all** patients in the Registry to continue to come for their yearly visit, not just the ones whose condition is failing to improve. In order for the Registry to be useful, information about all scleroderma patients needs to be known. If only patients whose condition has worsened in the past year participate, then the results will be biased and the wrong lessons may be drawn. We need to identify both sides of the coin, the good and the bad, to be able to identify which treatments work better and which ones don't work as well. Thank you to all **CSRG** patients for their continuous support. Without you, the Registry would not exist!

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.jgh.mcgill.ca

STUDY COORDINATOR:

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

RHEUMATOLOGISTS:

Dr. Maysan Abu-Hakima, Calgary
Dr. Murray Baron, Montreal
Dr. Peter Docherty, Moncton
Dr. James Dunne, Vancouver
Dr. Marie Hudson, Montreal
Dr. Niall Jones, Edmonton
Dr. Nader Khalidi, Hamilton
Dr. Elzbieta Kaminska, Hamilton
Dr. Proton Rahman, St-John's
Dr. Sharon Le Clercq, Calgary
Dr. Sophie Ligier, Montreal
Dr. Janet Markland, Saskatoon
Dr. Ariel Masetto, Sherbrooke
Dr. Jean-Pierre Mathieu, Montreal
Dr. Janet Pope, London
Dr. David Robinson, Winnipeg
Dr. Jean-Luc Senécal, Montreal
Dr. Douglas Smith, Ottawa
Dr. Evelyn Sutton, Halifax

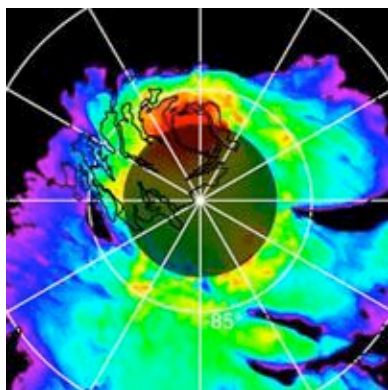
COLLABORATORS:

Mr. Robert Buzza, Past-President,
Scleroderma Society of Canada
Dr. Donald Duerksen,
Gastroenterologist
Mr. Grant Dustin, Treasurer
Scleroderma Society of Canada
Dr. Marvin J Fritzler, Advanced
Diagnostic Laboratory
Mrs Shirley Haslam, President,
Scleroderma Society of Canada
Dr. Andrew Hirsch, Respiriologist
Mr. Normand Ricard, President,
Sclérodémie Québec
Dr. Lawrence Rudski, Cardiologist
Dr. Russell Steele, Statistician
Dr. Brett Thombs, Psychologist
Dr. Jenny Walker, Rheumatologist

This newsletter is also available in
French.

If we can probe Mars' surface using an instrument named the Mars Advanced Radar for Subsurface and Ionospheric Sounding (MARSIS), surely we can do something for all patients with scleroderma!!!!!!

NASA Reveals Mars' South Pole Ice Deep and Wide ...



“Pasadena, Calif. March 15, 2007 -- New measurements of Mars' south polar region indicate extensive frozen water. The polar region contains enough frozen water to cover the whole planet in a liquid layer approximately 11 meters (36 feet) deep. A joint NASA-Italian Space Agency instrument on the European Space Agency's Mars Express spacecraft provided these data.

This new estimate comes from mapping the thickness of the ice. The Mars Express orbiter's radar instrument has made more than 300 virtual slices through layered deposits covering the pole to map the ice. The radar sees through icy layers to the lower boundary, which is as deep as 3.7 kilometers (2.3 miles) below the surface.”

You can find out more about the Mars by visiting the NASA website at: www.nasa.gov.

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