



Canadian Scleroderma Research Group

NOVEMBER 2004

NEWSLETTER

VOL 2, NO 2

ACR/ARHP Annual Scientific Meeting
San Antonio, Texas



The **2004** Annual Scientific Meeting of the ACR/ARHP was held in San Antonio, TX, from October 16th to 21st, at the Henry B. Gonzalez Convention Center.



Some CSRGR members present at the CSRGR meeting .

(From left to right, standing: Sharon LeClercq, Terri Lupton, Sindhu Johnson; sitting: Janet Markland, Murray Baron, Mary Bell & Arthur Bookman)

SAN ANTONIO, TX ACR/ARHP MEETING October 2004

This year, the ACR/ARHP meeting was held in San Antonio, Texas. The CSRGR presented their first official poster and also met during the Conference.

FIRST CSRGR POSTER

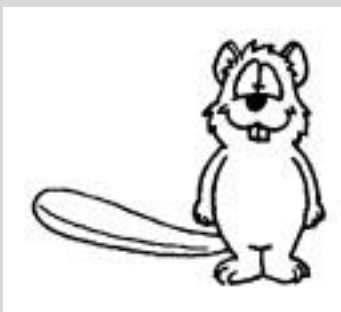
The **first** CSRGR poster entitled *Reliability and Validity of the Ophthalmologic Capillaroscopy* was presented at the meeting. Dr Baron was present during the poster session to answer all questions.

CSRGR MEETING

- ✧ A meeting of the Canadian Scleroderma Research Group was held during the ACR/ARHP meeting in San Antonio, TX on October 19, 2004.
- ✧ After a quick introduction from Dr Baron, the current state of affairs of the CSRGR as well as its present and future financial health were presented and discussed. Sites have started seeing patients for the study and feedback has been very positive.
- ✧ Thanks to generous donations and our CIHR grant, unless unforeseen expenses come up, we should be able to respect our budget until at least the end of 2005. After that, unless we come-up with other sources of funding, the CSRGR will no longer be capable of financially supporting itself.
- ✧ Therefore, it is crucial that we start right away to look for new sources of funding. This is why we are applying to the *Canadian Institute of Health and Research (New Emerging Team-New Research Teams to Enhance the Quality of Life* supported by the Institute of Musculo-



The DermLite line of devices not only enable the trained eye to detect skin cancer and other types of skin conditions early, but this digital microphotography system has been reported to be highly useful in documenting the nailfold vascular changes observed in a small sample of patients with dermatomyositis (Sontheimer RD, J Rheumatol. 2004, Mar;31(3): 539-44).



skeletal Health and Arthritis and by Pfizer). The grant application was discussed and the urgency to enroll patients and start evaluating them using the standardized forms was reiterated.

- ✦ The list of the type of investigations needed and their suggested frequency was drawn and the extent of the involvement of the center's radiologist was re-evaluated.
- ✦ The possibility of a future study particularly aimed at looking at the HRCT of the lungs in patients with scleroderma using data from our registry was talked about. Funds to be used primarily for that purpose should be asked for in the years to come.
- ✦ The purchase of a *DermLite* device for each member of the CSG, a device used by dermatologists for early skin cancer detection, was discussed and agreed upon.
- ✦ Also take note that after the CRA meeting, probably on the afternoon of Saturday March 5th, just before flying or driving back home, members of the Group are invited to come to Montreal, to Dr Baron's office at the Jewish General Hospital to get together with a few patients to try to agree on how to do the skin scoring. We will let you know when and where this will take place.

LATEST DEVELOPMENTS

- ✦ The forms are ready to be used and copies have been sent to the centers with ethics approval as well as version 1.0 of the procedure manual.
- ✦ Supplies needed for the serum sample procedure are also being sent to the centers.
- ✦ Nine centers now have Ethics approval and some have started enrolling patients. Feedback has been very positive.
- ✦ Centers now have to fax Suzanne a weekly report to help her keep track patients' enrollment.
- ✦ In the coming weeks, centers with ethics approval should be getting access to their own test-website to see how data entry will be done.
- ✦ We are presently working at defining the "controls", ways to help prevent mistakes when entering data in GEREQ's database.
- ✦ An updated version of the letterhead for the CSG is now available. Note that Dr Le Clercq will now be seeing patients in Calgary and Dr Jones is replacing her in Edmonton.

MARK IT IN YOUR CALENDAR



The **2005** Annual Meeting of the Canadian Rheumatology Association (CRA) will take place in Mont Tremblant, Quebec, Canada, from March 2nd to 5th.

Note that the **next meeting of the CSRG** will take place during the CRA Conference in Mont-Tremblant (March 2-5, 2005).
(Date and time to be confirmed.)

*The **2005** Annual Scientific Meeting of the ACR/ARHP will be held in San Diego, CA, from November 12-17.*



- ✧ We hope to have the GEREQ database ready in the beginning of December. In the meantime, centers should store the forms in a secure place and start planning data entry.
- ✧ Centers with ethics approval should make sure to mark the one-year anniversary of their ethics approval and make sure to resubmit to their ethics committee at least one month to 6 weeks prior to that date.
- ✧ A newer Investigations form including simpler questions to report results of HRCTs of the lungs have been e-mailed to the centers. If possible, centers should go back to patients' file to get that additional information and complete the form. The information included in the table on page 2 of the Investigations is no longer needed at this time and will be the focus of a specific study in the near future. Please still request a scan of the lungs annually and answer the added questions in the meantime.

Canadian Rheumatology Association Annual Meeting

Mont-Tremblant, QC, March 2-5, 2005

- ✓ The next meeting of the **Canadian Scleroderma Research Group** will be held in Mont-Tremblant, QC (date and time to be confirmed).
- ✓ The CSRG will also be getting together after the CRA Meeting, on Saturday March 5th, 2005, in the afternoon, for a training session on skin scoring and that, with the precious help of a few patients (To be confirmed).
- ✓ Six abstracts have been submitted to the CRA by members of the team. The deadline for submitting an abstract was November 1st, 2004.

OUR TEAM

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COLLABORATORS:

Mr. Robert Buzza, President,
Scleroderma Society of Canada
Dr. Gad Friedman, Gastroenterologist
Dr. Andrew Hirsch, Respiriologist
Dr. Caroline Pukall, Psychologist
Dr. Lawrence Rudski, Cardiologist
Dr. Ian Shrier, Epidemiologist
Dr. Russell Steele, Statistician

If in 1985 we were able to move a 3.2 million pound hotel six blocks down the road,
surely we can do something for patients with scleroderma!!!!!!



“The Fairmount Hotel, a three-story Victorian structure located in San Antonio, TX, was built in 1906, six blocks from its present-day location. In 1985, the Fairmount was entered in the Guinness Book of World Records when the 3.2 million pound hotel was moved intact to its current location, three blocks from the Alamo and San Antonio's popular Riverwalk. When the present site was excavated, a host of fascinating artifacts were unearthed, prompted the hotel to be named a Texas Archaeological Landmark. A glass display case in the hotel's lobby contains an array of 19th-century military objects from the Battle of the Alamo and an unusual assortment of British china. The Fairmount's wrought-iron verandas and red-brick façade provide a classic backdrop for a serene atmosphere that is enhanced by a peaceful courtyard, lush foliage and garden seating.”

National Trust for Historic Preservation



Feel free to let us know about any events or information that could be of interest for other members of our team.

Thank you!

Suzanne S. Taillefer