
The Canadian Scleroderma Research Group (CSRG)

By Murray Baron, MD, FRCPC

The Canadian Scleroderma Research Group (CSRG) was founded in 2004 and has now recruited over 1,600 patients and published about 150 articles. These papers have included studies of antibodies, which have depended on performing analyses on sera that have been stored at Dr. Marvin Fritzler's lab in Calgary. We have also used our biospecimens to collaborate on work done in other laboratories in Canada and the United States, including participating in a large genome-wide association study (GWAS).

In recent years we have expanded to collaborate with other countries on our papers. We have published several articles with the Australian group, including assessing mortality in an inception cohort with short disease duration. This has been under-studied because of the rare nature of the disease. In fact, this led to the creation of the International Systemic Sclerosis Inception Cohort (INSYNC), which we created with collaborators in Australia, the U.S., Holland, Sweden, Germany and Spain. This will allow us to study early disease and will fill an important gap as the mean disease duration of the larger cohorts in the world is about 10-12 years.

Our data were important to the development of the 2013 Classification Criteria for Systemic Sclerosis and was needed to generate these new criteria. Our data were also recently used to develop the American College of Rheu-

matology Provisional Composite Response Index for Clinical Trials in Early Diffuse Cutaneous Systemic Sclerosis (CRISS), which may become an important primary outcome measure for new trials in scleroderma.

Recently, because we expect a rise in demand for autologous hematopoietic stem-cell transplants for scleroderma, we have convened a large group of interested rheumatologists, hematologists, patients and other researchers to plan how to proceed in Canada with these transplants. We had a meeting with more than 40 interested participants in the spring of 2018, and another is planned for this spring. We will develop details of the transplant regimens to be used and a new set of inclusion/exclusion criteria. We have brought the Australian Scleroderma Interest Group on board for this project, and the development of these new criteria is well underway. In fact, we will use the CSRG/INSYNC database to record patient data before and after the transplants in Canada, Australia and several of the INSYNC countries, and will thus be able to collect prospective data on the results of the transplants.

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The Canadian Inflammatory Myopathy Study (CIMS) *(Continued from page 10)*

Myositis research registries like CIMS have the potential to greatly improve our understanding of AIM and to facilitate discovery research. In addition, there are exciting opportunities to practice precision medicine in the field of AIM. By contributing to and sharing new knowledge, CIMS will promote world-class care for Canadian AIM patients.

If you would like to know more about CIMS, refer patients or even consider participating, please contact Dr. Marie Hudson at marie.hudson@mcgill.ca.

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