

Update on Recent SPARCC Initiatives

By the SPARCC Executive Committee

Background

The Spondyloarthritis Research Consortium of Canada (SPARCC) is a transdisciplinary national research program focusing on studies and outcome measures in patients with spondyloarthritis (SpA), extending from genetics to pathogenesis and clinical epidemiology. The objective of the SPARCC research program is to improve the health of SpA patients in Canada by better defining, diagnosing, and treating ankylosing spondylitis (AS) and psoriatic arthritis (PsA). The three key goals of the SPARCC research network are: Improved understanding of the biological basis of SpA, improved clinical outcomes in SpA, and improved assessment of the impact of SpA in Canada. The results of the SPARCC program has delivered important benefits for Canada. SpA has a significant prevalence and high burden of illness in the Canadian population. Our studies have addressed the biological basis of this arthritis and the impact on individuals and society, through a multidisciplinary approach which draws expertise across the spectrum of health research.

CRA-SPARCC Management of SpA Guidelines

The most recent achievement of SPARCC is the development of the CRA-SPARCC Management of SpA Guidelines, spearheaded by Dr. Sherry Rohekar, SPARCC Executive Board member. To ensure the guidelines reflect CRA as well as SPARCC recommendations, a survey of the CRA membership was then distributed. The recommendations have now been published.^{1,2}

Objective I: The Biologic Basis of SpA

The organizational model of SPARCC has evolved; recently, we have established the Newfoundland site as the genetics core of SPARCC, under the direction of Dr. Proton Rahman. This provides SPARCC investigators with state-of-the-art technology and expertise on next-generation sequencing, copy number variation analysis, and epigenetics. Advances currently being pursued include:

- The identification of Sec16a as a novel genetic marker of familial axial SpA.

- DNA methylation as a distinct signature of degree of responsiveness to tumour necrosis factor inhibition in PsA. Translational research studies are continuing, with ongoing studies into:
- DNA methylation and parental imprinting in the transmission of PsA.
- Novel cytokine profiles of activity and progression in AS.
- Distinctive Th17 profiles in AS.

Objective II: Clinical Outcomes in SpA

The SPARCC Executive Board is actively engaged in refining and improving the database which underlies studies into clinical outcomes of SpA. There have been two major initiatives in this regard in the past year. The first is the migration of the clinical database platform to DADOS, a new informatics platform hosted by University Health Network (UHN). This move is both cost-effective and will establish a more user-friendly site for contributing centres to enter and access clinical information. The second is the development of a stream-lined data capture form (Protocol Lite), which allows sites lacking the infrastructure of the core sites to more efficiently enter clinical data on their respective patient cohorts. This is an important advance which will facilitate recruitment of additional SpA patients from across Canada.

Objective III: The Impact of SpA and Access to Care

A major achievement in 2015 was being ranked in the final group of competing proposals for a major new Canadian Institute of Health Research (CIHR) program, entitled Strategy for Patient Oriented Research (SPOR). This innovative, multidisciplinary proposal focused on new models of care to facilitate early diagnosis and treatment of joint diseases such as AS and PsA. The established SPARCC network was one of the key strengths of the proposal, which was ranked fourth out of 120 proposals submitted. Dr. Dafna Gladman, Dr. Nigil Haroon, Dr. Vinod Chandran, and Dr. Robert Inman are all part of the planning team, and Dr. Rahman is on the SPOR steering committee. The principal investigator is Dr. Raj Rampersaud, Orthopedic Surgeon at Toronto Western Hospital. The SPOR submission exemplifies

the leveraging power of a well-established network poised at all times to take advantage of new strategic initiatives.

SPARCC Pilot Projects

Since 2009, SPARCC provides annual seed funding to support research proposals aligned with its primary objective. Within the Pilot Projects program, SPARCC provides one-year seed grants awarded on a competitive basis to innovative proposals in the area of SpA research. The Program is open to Canadian investigators; membership in SPARCC is not a prerequisite. Grants will be for a one-year period with a maximum amount of \$25,000. The results of the projects are presented during SPARCC annual scientific meetings. The criteria for the grants include the research record of the principal applicant, the quality of the research proposal, and the potential impact for advancing knowledge in SpA. Priority is given to innovative new research themes with potential for capturing future peer-reviewed funding. Two Pilot Projects were funded this year, both from the University of Saskatchewan.

SPARCC Training for Fellows

Since 2012, SPARCC conducts a training workshop for residents and research fellows in rheumatology. This annual event hosts more than 20 rheumatology fellows from across Canada who are nominated by the program directors in their respective provinces. The purpose of this training is to provide rheumatology fellows who treat SpA with up-to-date information on early diagnosis and optimal intervention to improve outcomes, and share strategies used by SPARCC to treat patients with severe forms of AS and PsA. The management of extra-articular manifestations of SpA is addressed via innovative presentations and small-group workshops. Prominent speakers in the fields of gastroenterology, dermatology, ophthalmology, and medical imaging present lectures on extra-articular manifestations of SpA.

SPARCC Continuing Medical Education (CME) Workshops for Practicing Rheumatologists

In 2015, we conducted an SpA Update for practicing rheumatologists in Quebec, reaching about 60 rheumatologists and selected nurse practitioners in SpA. This bilingual event was spearheaded by Dr. Michel Zummer. Given overwhelming demand in the other provinces, we are adapting this model across Canada, making these workshops part of the next phase of SPARCC's research strategy. The Quebec event also illustrated the value of strategic partnerships, as the Quebec Division of The Arthritis



Society and the Canadian Spondylitis Association (CSA) worked closely with SPARCC.

CSA

In a collaborative effort with SPARCC, SpA patients from across Canada formed the CSA, a national non-profit patient association, in April 2006. The mission of the CSA is to provide the most current information and resources for people with SpA. Through combined efforts of the CSA and SPARCC, a realistic goal is for SpA patients to be diagnosed and treated within two years of the onset of symptoms, representing a significant improvement over current practice. This will be contingent on developing innovative effective communication strategies with primary-care physicians and rheumatologists. A CSA website has been established (www.spondylitis.ca). With the advent of new therapies with the potential to alter late outcomes, there is an imperative to improve early detection and treatment. We will continue the annual combined meeting of CSA and SPARCC, along with joint SPARCC-CSA patient symposiums across Canada, aiming to provide the latest updates and new discoveries related to SpA, including medical treatment of AS and PsA. The integration of patient-consumers into research planning is a cornerstone of the research plan of SPARCC.

References

1. Rohekar S, Chan J, Tse SM, et al. Update of the Canadian Rheumatology Association/Spondyloarthritis Research Consortium of Canada treatment recommendations for the management of spondyloarthritis. Part I: Principles of the Management of Spondyloarthritis in Canada. *J Rheumatol* 2015; 42(4):654-64.
2. Rohekar S, Chan J, Tse SM, et al. Update of the Canadian Rheumatology Association/Spondyloarthritis Research Consortium of Canada Treatment Recommendations for the Management of Spondyloarthritis. Part II: Specific Management Recommendations. *J Rheumatol* 2015; 42(4):665-81.

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