Rheumatoid Arthritis in First Nations: Defining the Road Towards Disease Prevention

By Irene Smolik, PhD; and Hani El-Gabalawy, MD, FRCPC

Summary of Meeting Hosted at Hotel Fort Garry Winnipeg, Manitoba, October 4-5, 2012.

Emerging scientific evidence in the fields of autoimmune diseases and genetics has spotlighted real-time prevention strategies that might not only halt the progression of rheumatoid arthritis (RA), but ultimately prevent RA development. University of Manitoba rheumatologists, as clinician-researchers, felt a workshop/symposium was needed to discuss state-of-the-art findings within this area of rheumatology.

Dr. Hani S. El-Gabalawy is the principal investigator spearheading the Early Identification of Rheumatoid Arthritis in First Nations study at the University of Manitoba. The project includes Irene Smolik, PhD research associate, Donna Hart, RN, a research coordinator and several rheumatology colleagues, in particular, Dr. David Robinson, who sees RA patients in two remote Manitoba northern communities (which have research agreements with the university).

In these communities, the research team has the valuable assistance of two local research assistants: Mr. Hubert McDougall of St. Theresa Point and Ms. Olivia Hart (BN, RN) of Norway House. At this event, Hubert and Olivia presented demographic and cultural details about their communities, spoke about recruitment, and offered a reflection on the first-ever rheumatology prevention focus group, held in each community.

Recommendations Focused on RA Prevention

Out of the formal and semi-structured sessions, researchers from various institutions (Stanford University, University of Colorado, University of Toronto, University of Calgary, McGill University, Alaska Native Tribal Health Consortium, Assembly of Manitoba Chiefs, and Arthritis Research Centre [ARC]), learnt that within First Nations communities are persons who, in the 21st century, still “suffer in silence” with RA. Important research themes that emerged from this event include, but are not limited to, the following:

1. First Nations communities must be engaged at the inception of any research strategy.
2. Environment and the socio-economic situation of First Nations peoples in Canadian society may predispose these individuals to risk factors associated with RA development, as well as other diseases (smoking and oral health impact on RA development).
3. Any research design and collected data must be situated in a manner that is iterative; there must be on-going, transparent, and clear dialogue between all involved.
4. A prevention trial must be tailor-made to each community, considering its location politically, spatially, geographically, and historically.
5. Researchers would benefit the entire community if prevention activities were partnered with other programs within the community.
Scientific evidence shows a higher frequency of predisposing shared-epitope (SE) alleles in many North American First Nations populations. However, this alone does not explain their high prevalence of RA.

Researchers know of biomarkers relevant to predicting imminent RA. Science is in a position to apply RA-risk models, and do so in communities willing to engage prevention strategies.

Prevention strategies provide a vehicle to employ and educate individuals in First Nations communities; at the same time, they sensitize researchers to health needs in these communities. Such models engage First Nations as co-researchers within Community Participatory Action Research.

In order to break the pain and suffering of RA, stemming from delayed diagnosis and inadequate treatment of First Nations peoples, all attendees of this conference realized that the scientific and medical community holds knowledge that can influence early detection of RA and establish early RA-prevention strategies within local communities.

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Mary Pack Arthritis Program: Outreach to First Nations People in British Columbia

By Alice Klinkhoff, MD, FRCPC; Angela How, MD, FRCPC; and Paul Adam, MSW

The Mary Pack Arthritis Program (MPAP) operates under the auspices of the Vancouver Coastal Health Authority with a provincial mandate to provide outpatient and inpatient services in British Columbia from standing clinics in Vancouver, Victoria, Penticton, and Cranbrook. Communities with limited access to care are serviced through separate travelling occupational therapy and rheumatology services that provide care to 13 and 26 communities, respectively (see map on next page).

As arthritis places a disproportionate burden on First Nations people in Canada, MPAP has intentionally focused on outreach to aboriginal communities. Using Ministry of Health annual funding for physician, nursing, and allied health services, there has been an expansion from the first travelling consultation trip in 1951, to a network of physician and occupational therapy trips, and nascent tele-health and distance nursing support services. In 2012, there were 14 British Columbia rheumatologists funded by two full-time salaries and four part-time occupational therapists engaged in outreach to all patients in the province, including those of First Nations descent, at an approximate cost of $1,100,000.

In one example, in the last 18 months Dr. Angela How instituted tele-health services from Vancouver to the Gitxsan community of Hazelton. The First Nations people in this community experience a high prevalence of multiple inflammatory autoimmune diseases. Dr. Jenny Lee, who has spent time in Dr. How’s practice, facilitates the service at that site. Exit interviews have shown the service to be well received and the wait list has been dramatically reduced. Expansion of this tele-health program to other isolated communities will allow more people living