

Summary of the Frontiers in Inflammatory Joint Diseases Conference

The Frontiers in Inflammatory Joint Diseases conference brought together a wide spectrum of stakeholders to help define a vision for Canadian research in inflammatory joint diseases (IJD). The scope of these diseases includes rheumatoid arthritis (RA) and its variants, juvenile idiopathic arthritis (JIA) and its subtypes, and the spondyloarthropathy (SA) group of disorders, including ankylosing spondylitis, psoriatic arthritis, and reactive arthritis. Together, these disorders affect 2% to 3% of the general population, and they often begin during the most productive stages of the individual's life, or in the case of childhood arthritis, even before this stage begins. The impact on the individual and on society is staggering. Fortunately, there has been considerable progress in the development of effective therapies for IJD, as well as in achieving a better understanding of the pathogenesis of these disorders. The challenge we collectively face is to develop approaches to the early identification of these disorders and to intervene with effective and cost-effective management strategies.

The stakeholders assembled at the Frontiers conference included patient consumer groups, government representatives, industry representatives, clinicians and scientists with expertise in basic science, clinical trials, health services research and population health. A consumer day was the first event of the conference and was organized by consumers. This was followed by a scientific program on the second day, and the third day was devoted to "synthesis." The discussions were frank and open, and were woven around presentations from national and international opinion leaders in these areas. The consensus-building process was guided by a skilled and experienced facilitator who was not a stakeholder. The primary objectives of this conference were as follows:

- To provide an opportunity for the Institute of Musculoskeletal Health and Arthritis, the Canadian Arthritis Network (CAN) and The Arthritis Society (TAS) to consult with consumers, policy makers, public agencies, national/international researchers

and industry regarding priority national research themes which can lead to improved identification, understanding and management of arthritis, particularly of early arthritis.

- To educate multiple stakeholders on the scope of current research in IJD in Canada and globally.
- To develop the Canadian research agenda in IJD.
- To identify the unique qualities, opportunities and resources that offer Canada a strategic niche in the global scene of arthritis research.

On the final day of the conference, a broad-based Forum Recommendations Working Group (FRWG) took the recommendations of the conference discussion groups and condensed these into 10 major strategic research themes:

Adaptive strategies and patient decision making. Research issues from the patient perspective, including patient education and coping, complementary and alternative medicine, innovative therapies, choice, understanding, exercise, team care, pain and fatigue.

Children and youth. FRWG members agreed that children and youth with IJD are a priority area for the Frontiers research agenda. FRWG members concluded that identifying this area as a research priority should not jeopardize the future development of integrated, comprehensive research strategies encompassing IJD across all age groups.

Early inflammatory arthritis. The notion of "early arthritis" as an immediate opportunity and an urgent challenge was a dominant theme during the forum. Research into early arthritis was felt to span the target populations (RA, JIA and SA) and the major research disciplines, and would include early identification and studies of pathogenesis through multiple approaches (e.g., genomics, proteomics, advanced imaging). The need for education around early detection and treatment was also emphasized. Longitudinal observational cohort studies would also provide insight into factors that influence progression. FRWG members noted that this is a broad theme necessitating transdisciplinary research.



Economic and psychosocial dimensions of IJD. Includes human and social issues, as well as challenges related to work and disabilities.

Health services research. Includes research into access issues and models of care.

Measurement of outcomes. Includes the development and implementation of improved measurement tools (e.g., magnetic resonance imaging of inflammatory and structural changes in the joint, and newer functional and occupational instruments).

New drug targets. Includes studies of pathogenesis, development of animal models and investigations into the biological basis of the immune and inflammatory processes in the joints seen in IJD.

Optimizing drug and nondrug therapy. Includes new and existing drug and nondrug therapies, biomarkers, cohort studies, investigator-initiated clinical trials, prognostic factors and post-marketing surveillance.

Preclinical and risk factors for IJD. Includes etiologic studies, bioprofiling of high-risk populations and studies into the genetic-environmental interactions conferring risk for IJD.

Research on knowledge transfer and exchange. Studies of how to get the message out effectively to key target groups (e.g., the public, policy makers, healthcare professionals, consumers).

In addition, a number of priority tools will be required in order to undertake integrated research projects related to the strategic themes identified above. These include:

- Clinical trials and other research networks
- Investigator-initiated studies
- Development of: a) databases that include multiple sites and provide integrated data across pillars (e.g., data on health services, clinical information, biomarkers, and/or genetics) and b) core facilities to support these databases (e.g., developing model platforms for rules on database-related issues, such as biobanking, freedom of information and consent issues).
- Training

OUTCOMES

It was recognized that the number of strategic themes identified through this process need to be distilled into a smaller number of research directions that would form the basis of a broadly funded request for applications. This process proceeded under the auspices of the Alliance—an advisory organization that brings together the spectrum of Canadian arthritis stakeholders. As a result of this process, the strategic themes were distilled as follows:

Theme I. Improved Methods for Early Detection, Diagnosis and Monitoring of IJD

- Registries
- Integrated clinical and bioprofile databases
- Imaging in diagnosis and monitoring
- Identification of at-risk populations

Theme II. Improved Therapeutics in IJD

- Pathogenesis
- Animal models
- New drug targets
- Nondrug therapies

Theme III. Improved outcomes in IJD

- Psychosocial and economic determinants of outcomes
- New tools in measuring outcomes
- Integrated prognostic models: biologic, social, environmental
- The role of knowledge transfer in determining outcomes

It is hoped that there will be a specific commitment of funding for these initiatives from the Canadian Institutes of Health Research (CIHR), CAN, and TAS. Incorporation of industry funding into the initiatives is an important priority.

A second and equally important outcome has been the establishment of an inclusive process for identifying research priorities in arthritis. The networks that were established as a result of this conference will go a long way towards ensuring the relevance of the research, while maintaining the highest levels of scientific excellence.

– Hani El-Gabalawy, MD, FRCPC
Director, Arthritis Centre, University of Manitoba

Provincial News

News from Newfoundland/Labrador

Spring in St. John's may have been wet and cold, but things were undoubtedly brewing here during that period. A Public Service Workers' strike in April—including the Health Sector Support Workers—led to cancellations and delays in appointments and procedures in hospitals. This was particularly frustrating for those of us in rheumatology, as we are already suffering from severe shortages and long waiting lists. After nearly a month of bitter dispute, the workers were eventually legislated back to work. We are still trying to catch up with the cancellations.

We continue in our active search for more rheumatologists to join our group. Newfoundland has a lot to offer for those interested.

On a lighter note, the summer shaped up to be a great time on the Rock. The weather was fine and the great outdoors invited all of us to put our rusty joints back in motion. My latest fishing trip to Labrador was a success (despite the sun burn and mosquito bites).

Dr. Proton Rahman is spending more time with his little girls while still active in his research.

Finally, our condolences to Dr. Sean Hamilton on his mother's recent passing.

– *Majed Khraishi, MD, FRCPC*



Labrador Sunrise




The Devil's Gap (Labrador)

Regional News

Rheumatology Alive and Well in Peterborough

Peterborough, Ontario is about 90 minutes northeast of downtown Toronto and is a picturesque community with a population of approximately 71,000. Peterborough has had a significant rheumatology presence for many years, with up to five rheumatologists present at one time. The last few years have seen many changes. Peterborough has

a larger population of older Canadians compared to the Ontario average, so demand for arthritis care is high. An Arthritis Society physiotherapist is available in the region and she offers assistance to patients both privately as well as in group sessions. We have magnetic resonance imaging with a fairly short waiting time, an infliximab infusion clinic, and dual-energy X-ray absorptiometry (DEXA) machines aplenty but, unfortunately, there is a major shortage of family doctors. Therefore, patients have a hard time accessing the healthcare system. As well, two of



Peterborough's rheumatologists have left arthritis care completely, with no replacements in sight, so we are now reduced to 2.5 practicing rheumatologists. There has been a dramatic increase in the number of significantly ill patients we are now seeing, due to the redistribution of the orphaned patients. Waiting lists for elective joint replacement surgery can exceed 12 months, so many patients travel to Toronto for this. Due to recent changes at our hospital, we are no longer doing regular internal medicine calls, which has allowed for more time to concentrate on arthritis care.

Peterborough rheumatologists are involved in various Phase 3 research studies and have had summer students working with us. We are also participating in the ExpertMD® training program for family physicians.

All in all, Peterborough is facing the same challenges as many other communities in Ontario and, likely, the country. But hopefully our manpower issues, with rheumatologists actually leaving the specialty completely, is not a widespread phenomenon.

– Jane C. Purvis, MD, FRCPC

Rheumatology in the British Columbia Interior

The care of rheumatic disease patients in the British Columbia (BC) interior has faced unique challenges since I opened my practice in 1975 in Penticton, where I was the only rheumatologist living between Vancouver and Calgary. Geographically, the population is scattered along various valleys separated by mountain ranges and long lakes with few connecting highways or airports. Many arthritis patients gravitated to the area, particularly south Okanagan, because of the desert-like climate and low housing costs.

My office opened to a waitlist of three months, which rapidly grew to three-to-five years. The Arthritis Society (TAS) and Penticton Regional Hospital were very helpful in establishing a unique and comprehensive arthritis program, which included an eight-bed rheumatic disease unit (RDU) serving the vast BC interior, and a team of physiotherapists, occupational therapists, social workers and a disease-modifying anti-rheumatic drug (DMARD) clinic nurse. Arthritis patients were treated by the same team whether they were inpatients or outpatients. A DMARD clinic was established in 1975 for monitoring gold and D-penicillamine and has

grown to an average of 450 active patients to date. Orthopedic, fibromyalgia and other programs were added or pioneered. Dr. Kathy Gross established the Interior Children's Arthritis Program which follows approximately 50 children through the Penticton centre.

The major problem for many years was the lack of rheumatology manpower residing in the interior—a void which has been gradually filled by rheumatologists moving to the major communities in the Thompson-Okanagan region. Chronologically, the following rheumatologists have discovered the unique beauty and lifestyle of the area: Dr. Jan Navritil (Kamloops), Dr. Dan McLeod (Kelowna), Dr. Mike Puttick (Kelowna), Dr. Stuart Seigel (Kelowna), Dr. Nancy Hudson (Kamloops), Dr. Barb Blumenauer (Kamloops) and Dr. Jackie Stewart (Penticton).

There are large areas of the BC interior where patients are still a long distance from a rheumatologist. Some of these areas are served by TAS's Travelling Consultation Service from Vancouver, while other areas are covered by internists with special expertise or interest in rheumatic diseases, including Dr. Phil Malpass (Nelson), Dr. Mike Buchanan (Prince George), and Dr. Danny Myers (Salmon Arm).

The whole region has recently been consolidated under the Interior Health Authority and is fairly self-sufficient for orthopedic and diagnostic services, with major joint replacements being done in most centres, hand and spinal surgery being done in Kamloops and Kelowna, and shoulder and ankle replacements being done in Penticton.

The rheumatologists get together for Continuing Medical Education (CME) events several times a year—usually in Kelowna, which is most central—and for the Western Alliance of Rheumatology (WAR) meeting organized annually in Kelowna by Drs. Paul Davis and John Esdaille. The now famous Okanagan wines are a highlight of most meetings.

In the past two years we have established the Interior Osteoporosis Physicians group, which has membership from seven different specialties and family practice, and has representation from most of the major interior communities. The focus has been educational, with the intent of raising the standards of osteoporosis prevention and care, and a consultative role to the health region.

The future of rheumatology in the rapidly developing BC interior appears very bright. I predict that in the next two years there will be a freestanding arthritis treatment centre located in increasingly cosmopolitan Kelowna, rheumatology trainees rotating through the Penticton

Joint Communiqué



Dr. Robert Offer (left) and Dr. Michael Puttick with a view of Penticton, BC in the background.

arthritis program, and more effective outreach programs will link underserved interior communities to the rheumatologists in the Thompson-Okanagan corridor.

All of which is good news for people with arthritis.

– Robert Offer, MD, FRCPC

Rheum with a View in the Greater Toronto Area

I return home, a summerless, soggy Torontonian, after wandering the hollowed (sic) halls of Queen's Park, halogen lantern in hand, searching for an honest politician. Healthcare is again politicians' re-election currency, both on federal and provincial shores. Three successive Ontario governments (I never learned Latin in medical school but am sure the linguistic root for government has nothing to do with the English word "govern") have platted on healthcare reform and have dutifully fixed the system into its current "quackmire."

I ready myself for another long office day tomorrow. Ten extra minutes are added to all scheduled appointments, not because I am slowing down (though I am), but to accommodate for three minutes of complaints about the hospital's new parking fees, five minutes of carping about my waiting list, nearly two minutes of fielding Limited Use Form explanations, and the polite two seconds of greeting. By the time I finish debating

self-diagnosed Internet research and stamping the disabled parking permit, there's nary time for a history and physical (should I bill for counseling I wonder?).

Each patient agonizingly complains about the intolerable delays for imaging tests, in-hospital physiotherapy (discretionary funds being exhausted on chiropractic and shark cartilage), and surgical lotteries (I now ask not only the month of upcoming scheduled joint replacements but also the year). But I inform them that there are actually "no waiting lists," as per Prime Minister Martin's recent election promise. Even in our affluent bedroom community, many patients no longer have a family doctor. They bring all their sundry ills to me for healing. I worry that I could lose my license, if not a finger or two, if forced to do a pap smear. Gone is time for practicing medicine, replaced by the exhausting swim upstream to spawn care in an overloaded system.

The Canadian Rheumatology Association (CRA) publishes guidelines for early treatment in rheumatoid arthritis (RA). Meanwhile, the panacea window expires early on my imaginary waiting list. A guarantee for shorter waiting lists? How many rheumatologists will be required to service an aging population and replace our retiring colleagues? Can we entice more trainees or are the health ministry doyens intent on shopping on eBay?

Are novel solutions in the offing? The federal health minister rails against privatization. The Ontario government plans to unprivatize a den of diagnostic clinics which are billing through the Ontario Health Insurance Program (OHIP) at no extra cost to the provincial coffers. It is a fiscal philosophical nightmare that private interests have dared to save the government capitol equipment costs, all the while providing service to needy patients. People continue to suffer through our "to-tears" system.

My present waiting list stretches past the next American College of Rheumatology (ACR) conference. Most days feel like the final hours at the Alamo. I propose a "single-blind" experiment. Please record your baseline wait times and we'll tally the changes at 12 and 24 months (or just before the next election).

For the academics amongst us, the "single-blind" refers to our politicians.

– Diogenes the Cynic (i.e., frustrated, stand-up rheumatologist in the greater Toronto area)*

*Author prefers to remain anonymous

News from Université de Sherbrooke

It's been busy in Sherbrooke!

Artur de Brum-Fernandes, MD, PhD was appointed President of the Ethics Review Board of the *Centre hospitalier Université de Sherbrooke* (CHUS) in January 2003 as well as Head of the Rheumatology Division in March 2003, promoted to Full Professor at the *Université de Sherbrooke* in June 2003 and awarded a Senior Clinical Scientist award from the *Fonds de la Recherche en Santé du Québec* (FRSQ).

The main research thrust of the Division is on bone metabolism and prostanoid receptors, with the collaborated work efforts of Dr. Fernandes (FRSQ; The Arthritis Society [TAS], Canadian Institutes of Health Research [CIHR]), Jean-Luc Parent, PhD (CIHR investigator; Canadian Foundation for Innovations [CFI], TAS, Kidney Foundation) and Sophie Roux, MD, PhD (FRSQ Junior I Clinical Scientist; TAS).

Following the recruitment of Dr. Roux (July 2002) and David Hercelin, MD, DEA (March 2003)—both trained in France—and the return of Patrick Liang, MD (post-doc at The Cleveland Clinics), multidisciplinary clinics were set up for specialized metabolic bone diseases (Dr. Roux), systemic vasculitis and connective tissue disease (Dr. Liang).

Dr. Julie Beauchemin completed her rheumatology training in June 2004 and joined the staff at *Hôpital Charles-Lemoyne*, a *Université de Sherbrooke*-affiliated teaching hospital close to Montreal. Another rheumatology fellow, Dr. Isabelle Deschênes, is currently completing her training. Expectations are high for admission of new fellows next year.

Gilles Boire, MD, MSc is on sabbatical leave for the full 2004 year. Dr. Boire is spending this year in research on early polyarthritis (TAS-sponsored) and on the molecular biology of the Ro autoantigen (part of a ribonucleic acid-protein interaction; Group of Excellence from the *Université de Sherbrooke*).

Following a significant dedicated gift to the *Université de Sherbrooke* from André Lussier, MD, professor emeritus and former president of the Canadian Rheumatology Association (CRA), three annual awards (\$12,000 in total) have been established: the most meritorious fourth-year medical student, the most meritorious first- or second-year resident rotating in rheumatology and the most meritorious graduate student from the wet labs of the Division.

– Gilles Boire, MD, MSc, FRCPC
Professor of Medicine, *Université de Sherbrooke*

News from Dalhousie University

The Division of Rheumatology at Dalhousie University—one of 15 divisions within the Department of Medicine—has three full-time rheumatologists (Drs. Evelyn Sutton, Volodko Bakowsky and John Hanly), in addition to three community-based rheumatologists (Drs. Dianne Mosher, Siraj Ahmad and Souad Shatshat), who also run a private office practice. For many years there have not been dedicated inpatient beds for rheumatology; the majority of our services are now provided in an ambulatory setting. The Rheumatology Clinic is a provincial and regional referral centre and has approximately 7,000 patient visits per year. The relocation of this ambulatory service to the Nova Scotia Rehabilitation Centre (NSRC) site of the Queen Elizabeth II Health Sciences Centre in July 2002, and the establishment of the Arthritis Centre of Nova Scotia, have provided a more accessible, patient-centred, interdisciplinary model of care for patients with arthritis. One of the unique features of our centre is the inclusion of a satellite office of The Arthritis Society (TAS) of Nova Scotia through which TAS's educational and service-related programs are promoted.

All members of the rheumatology division participate in the undergraduate teaching programs at Dalhousie and the post-graduate rheumatology training program remains active.

Members of the rheumatology division are currently involved in a number of clinical research projects studying the effectiveness of new therapies, the role of genetics and long-term outcomes in different patient groups, including those with rheumatoid arthritis, psoriatic arthritis and systemic lupus erythematosus.

– John Hanly, MD, FRCPC
Professor and Head, Division of Rheumatology,
Director, Arthritis Centre of Nova Scotia,
Dalhousie University and QEII Health Sciences Centre,
Halifax, Nova Scotia