

# CRAJ SCR

The Journal of the Canadian Rheumatology Association

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The CRAJ is online! You can find us at: [www.craj.ca](http://www.craj.ca)

XELJANZ (tofacitinib) in combination with methotrexate (MTX) is indicated for reducing the signs and symptoms of rheumatoid arthritis (RA) in adult patients with moderately-to-severely active RA who have had an inadequate response to MTX. In cases of intolerance to MTX, physicians may consider the use of XELJANZ as monotherapy.

Use of XELJANZ in combination with biological disease modifying anti-rheumatic drugs (DMARDs) or potent immunosuppressants such as azathioprine and cyclosporine is not recommended.

## WHEN METHOTREXATE ALONE IS NO LONGER ENOUGH, CONSIDER

<sup>PR</sup> **XELJANZ<sup>®</sup>**



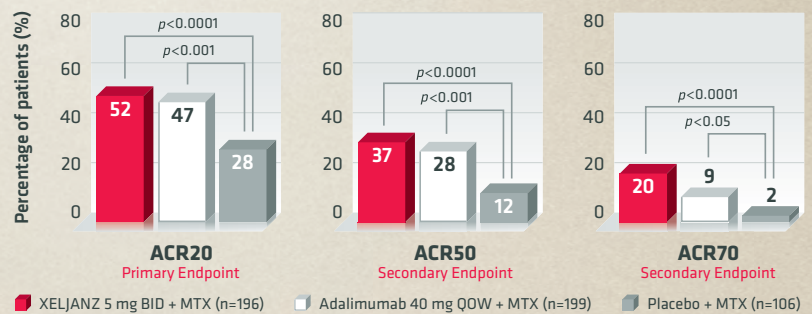
Simple, twice-daily oral dosing

### Demonstrated powerful efficacy where response to methotrexate was inadequate

Significant symptom reduction was shown at 6 months in MTX-IR patients treated with XELJANZ + MTX vs. placebo + MTX.<sup>1\*</sup>

This study was not designed to compare XELJANZ to adalimumab.

#### ACR response rates at 6 months



Significant improvement in physical functioning at 3 months was achieved in MTX-IR patients treated with XELJANZ + MTX vs. placebo + MTX.<sup>1\*</sup>

Mean HAQ-DI decrease from baseline at 3 months: -0.56 XELJANZ 5 mg BID or -0.51 adalimumab 40 mg QOW vs. -0.25 placebo ( $p < 0.0001$ ). This study was not designed to compare XELJANZ to adalimumab.

#### Most serious warnings and precautions:

**Risk of Serious Infections:** Patients treated with XELJANZ are at increased risk for developing serious infections that may lead to hospitalization or death. Most patients who developed these infections were taking concomitant immunosuppressants such as methotrexate or corticosteroids. If a serious infection develops, interrupt XELJANZ until the infection is controlled. Reported infections include: active tuberculosis, invasive fungal infections, bacterial, viral, and other infections due to opportunistic pathogens.

Treatment with XELJANZ should not be initiated in patients with active infections including chronic or localized infection.

Patients should be closely monitored for the development of signs and symptoms of infection during and after treatment with XELJANZ, including the possible development of tuberculosis in patients who tested negative for latent tuberculosis infection prior to initiating therapy.

**Malignancies:** Lymphoma and other malignancies have been observed in patients treated with XELJANZ. Epstein Barr Virus-associated post-transplant lymphoproliferative disorder has been observed at an increased rate in renal transplant patients treated with XELJANZ and concomitant immunosuppressive medications.

#### Other relevant warnings and precautions:

- Risk of gastrointestinal perforation. Use with caution in patients who may be at increased risk for gastrointestinal perforation.

- Risk of viral reactivation, including herpes zoster.
- Risk of malignancies, lymphoproliferative disorder, and nonmelanoma skin cancer.
- Risk of lymphopenia, neutropenia, anemia, and lipid elevations.
- XELJANZ should not be used in patients with severe hepatic impairment, or in patients with positive hepatitis B or C virus serology.
- Use with caution in patients with a risk or history of interstitial lung disease (ILD).
- XELJANZ can increase the risk of immunosuppression. Concurrent use with potent immunosuppressive drugs is not recommended.
- Concurrent use with live vaccines is not recommended.
- Use with caution in patients with impaired renal function (i.e., CrCl <40 mL/min).
- XELJANZ should not be used during pregnancy.
- Women should not breastfeed while being treated with XELJANZ.
- The safety and effectiveness of XELJANZ in pediatric patients have not been established.
- Caution should be used when treating the elderly because of an increased risk of serious infection.
- Use with caution in Asian patients because of an increased risk of events including: herpes zoster, opportunistic infections and ILD.
- Treatment with XELJANZ was associated with increases in creatine kinase.

- XELJANZ causes a decrease in heart rate and a prolongation of the PR interval. Caution should be observed in patients with a low heart rate at baseline (<60 beats per minute), a history of syncope or arrhythmia, sick sinus syndrome, sinoatrial block, atrioventricular (AV) block, ischemic heart disease, or congestive heart failure.
- Treatment with XELJANZ was associated with increased incidence of liver enzyme elevations.

#### For more information:

Please consult the product monograph at [http://www.pfizer.ca/en/our\\_products/products/monograph/342](http://www.pfizer.ca/en/our_products/products/monograph/342) for important information relating to adverse reactions, interactions, and dosing information which have not been discussed in this piece. The product monograph is also available by calling us at 1-800-463-6001.

Reference: 1. Pfizer Canada Inc. XELJANZ Product Monograph. April 16, 2014.

BID = Twice daily; QOW = Every other week; MTX-IR = Methotrexate Inadequate Responders

\*Multicentre, randomized, double-blind, placebo-controlled study in patients  $\geq 18$  years with active RA according to ACR criteria. Patients received MTX and were randomized to receive XELJANZ 5 mg BID (n=196), adalimumab 40 mg QOW (n=199), or placebo (n=106). The primary endpoints were the proportion of patients who achieved an ACR20 response at month 6, mean change from baseline in HAQ-DI at month 3, and the proportion of patients who achieved DAS28-4 (ESR)  $\leq 2.6$  at month 6.



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# Survey Says

By Philip A. Baer, MDCM, FRCPC, FACR

*“Opinion is the medium between knowledge and ignorance.”*

- Plato, *Republic* (original Πολιτεία), ~380 BC

Everyone knows that catch-phrase from the TV game show *Family Feud*. And, as another saying goes, “time is money.” Lately I find an increasing number of people willing to pay money for my time. Not patients, not government ministries of health, but market researchers. Invitations appear in my email on a regular basis, both from real people and imaginary ones. Laura Malett at Medefield is not a real person, nor is Victoria at Lead Physician (now retired, it seems). Apparently, providing a fictional female correspondent makes one more likely to complete a survey. Just as donating to one charity leads to solicitations from others, I find that completing one survey leads to more survey invitations from around the globe. Despite my preference to receive these invitations exclusively by email, I continue to receive phone calls from recruiters, and repeatedly stating that online contact is the only form acceptable has little effect, as is true for most telemarketers.

Recruitment for some surveys depends on completing a screener. Usually one is in the dark about what qualifies you to do the actual survey. However, occasionally, recruiters will email the screening questions in a document which also indicates what answers would exclude you from being considered a candidate. From what I have seen, devoting less than 75% of your time to clinical practice, and having been in practice for under three or more than 35 years are typical exclusion criteria. One recruiter told me they were having trouble recruiting for a particular survey. It turned out they were looking for people who cycle through three or more anti-TNF agents in RA patients before switching mechanism of action. I told her I did not practice that way, and I certainly thought she would have difficulty finding anyone who did.

Another relatively common situation these days is to receive invitations to the very same survey from multiple sources: Medefield, PSL Group, Glocalmind, M-panels, OMR Globus, MPI Research, MD Analytics, 42 Market

Research, Innomar, HAB Community, SERMO, Consumer Vision, CRC Research, MNOW, MedePanel, and Tandler Group are all familiar names in my email inbox.

Usually, one of these is the actual originator of the survey. Others are recruiters who are clearly taking their cut from the survey honoraria offered. Some are greedier than others. For instance, I have received offers to do a survey for \$150, and then an invitation from a recruiter to do the same survey for \$75. Usually, jumping at the first offer to complete a survey is a mistake as, over time, when a recruitment deadline nears, the survey incentive will be increased. As in purchasing airline or concert tickets, once you do survey Y at price X, you cannot ask for the higher incentive thereafter. Buyer's remorse ensues. On the other hand, a mispriced survey with a rich incentive should be completed immediately: The rare offer of \$150 for 15 minutes work will not last.

Given the above, it is no surprise that some surveys now conclude by asking whether you believe you have done the survey once or more than once recently. I do not have the patience to do the same survey twice. I have often wondered what would happen if someone admitted that they thought they might have done the survey more than once. Would that disqualify them from payment despite having fully completed the survey?

Surveys can be interesting. One learns which new agents are actually closest to market, and what their messaging will be. Critiquing concepts for advertisements can be challenging and also humorous. In-person surveys require travel away from the office, but avoid checking multiple mind-numbing little boxes on a computer screen, as is frequently required for web surveys.

I have certain likes and dislikes regarding online surveys. I want a realistic status bar to give me some idea of what progress I am making. It can be disheartening to work away

*Continued on page 24.*

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## AWARDS, APPOINTMENTS, ACCOLADES



**M**r. Paul Adam was the 2015 winner of the Association of Rheumatology Health Professionals (ARHP) *President's Award*. The ARHP *President's Award* is awarded to the ACR/ARHP member or team performing outstanding service within the present year in advancing the goals, ideals, and standards of ARHP. This award recognized his contributions over the past several years in the area of eLearning. Mr. Adam chaired the eLearning sub-committee for two years and was part of the team that created the concept of eBytes learning modules. This past year he wrote an *Online Learning Position Paper* which detailed a variety of strategies and recommendations for individualizing the online learning experience on the new ACR/ARHP Learning Management System. Mr. Adam is the Rheumatology Liaison & Outreach Services Coordinator at the Mary Pack Arthritis Program in Vancouver, British Columbia.



**D**r. Linda Li was selected for the 2015 Association of Rheumatology Health Professional (ARHP) *Distinguished Scholar Award*. ARHP is the health professional division of the American College of Rheumatology (ACR). This is the highest award given by the ARHP for research. The award recognized Dr. Li's key contributions to understanding help-seeking behaviour in people with arthritis and her innovative work in using digital media interventions to improve the management of arthritis.

Dr. Li is an associate professor at the University of British Columbia (UBC), as well as the Harold Robinson/Arthritis Society Chair in Arthritic Diseases and the Canada Research Chair in Patient-Oriented Knowledge Translation at UBC and Arthritis Research Canada. Her work was also recognized previously by major awards, including a CIHR *New Investigator Award*, an ACR Health Professional *New Investigator Award*, and a Michael Smith Foundation for Health Research *Career Investigator Award*.



**D**r. Robert Inman was recently honoured with the designation of *American College of Rheumatology (ACR) Master*. Recognition as a Master is one of the highest honours that the ACR bestows on its distinguished members. The designation of Master is conferred on ACR members who have made outstanding contributions to the field of rheumatology through scholarly achievement and service to their patients, students, and the rheumatology profession. Honourees have devoted their careers to furthering rheumatology research and improving clinical standards in the treatment of rheumatic diseases. The Master must be distinguished by the excellence and significance of his or her contributions to the science and art of rheumatology. "It's an honour to be recognized for my commitment to advancing the health of patients with rheumatic diseases," said Dr. Inman. "I am humbled to receive this designation and join the ranks of many distinguished rheumatologists."

Dr. Inman's research interests have focused on the interaction of infection with autoimmunity, and on clinical and basic aspects of spondyloarthritis (SpA). He has published more than 350 manuscripts and chapters. Dr. Inman is currently Director of the Arthritis Center of Excellence at the University Health Network, Director of the Spondylitis Program at Toronto Western Hospital, and Deputy Physician in Chief, Research at University Health Network, in Toronto.

## AWARDS, APPOINTMENTS, AND ACCOLADES

The *CRAJ* would like to recognize the contributions of its readers to the medical field and their local communities.

To have any such awards, appointments, or accolades announced in an upcoming issue, please send recipient names, pertinent details, and a brief account of these honours to [katiiao@sta.ca](mailto:katiiao@sta.ca). Picture submissions are greatly encouraged.

# Looking to the Future of Rheum...

By Christine Charnock, CEO of the CRA

Are you new to the “rheum”?  
Have you heard what we  
have going on?

## NRRW

The CRA has taken the National Rheumatology Residents' Weekend (NRRW) under its wing. The event was held January 22-24, 2016. The NRRW is a collaborative event bringing together rheumatology residents from across the country for sessions aimed at professional development, encompassing several different roles. Both pediatric and adult rheumatologists are able to network with colleagues across the country, as well as participate in a formal objective structured clinical examination (OSCE) and written examination. For more information, visit [www.rheum.ca/en/students/nrrw\\_presentations](http://www.rheum.ca/en/students/nrrw_presentations).

## FLIRT

The Future Leaders in Rheumatology Training (FLIRT) is a mentorship program designed for rheumatologists at an early career stage who are likely to become leaders in research and/or education and/or advocacy in Canada. Deadline to submit applications for the FLIRT mentorship was April 1, 2016; this was a joint application process that required applications be completed by the candidate and a supporter. To learn more, visit [www.rheum.ca/en/members/flirt](http://www.rheum.ca/en/members/flirt).

## TROT

Training Rheumatologists for Tomorrow (TROT) is a program focused on increasing awareness and interest in rheumatology by medical students, internal medicine residents, and pediatric residents... How do we get the word out? Please contact Dr. Alfred Cividino at [civi@cogeco.ca](mailto:civi@cogeco.ca) for more information.



## 2025 Committee

What does the future have in store? This committee explores what healthcare, rheumatology care, rheumatologists, and patients are going to look like in 2025. The first brainstorming session took place on January 22, 2016, and coun-

ted 20 fairly new, new, or trainee rheumatologists, along with a physiotherapist, nurse, and patient, sharing their projections. We ask you: What can the CRA do to help prepare its members for that future? Please contact me at [christine@rheum.ca](mailto:christine@rheum.ca) for more information or with any comments or suggestions.

## Dilemma Rheum

The Dilemma Rheum is a series of educational teleconferences designed for recently certified rheumatologists and trainees. Each session will feature an expert-led discussion on a particular topic, along with a case-based Q&A session.

Topics discussed during these educational teleconferences will change, and future topic suggestions are welcome. The first session was held on March 9 on difficult RA. There was great discussion on excellent cases. Upcoming sessions include difficult connective-tissue diseases (CTD) and difficult vasculitis. Please visit [www.rheum.ca/en/education/dilemma\\_rheum](http://www.rheum.ca/en/education/dilemma_rheum) for dates and registration instructions.

We encourage all participants to contribute to the teleconferences by submitting a case, a hot button question for discussion, or a treatment dilemma at the time that they register for the session.

Christine Charnock  
CEO,  
Canadian Rheumatology Association  
Newmarket, Ontario

# CIORA: Research Updates

The CRA Research committee has launched the 9<sup>th</sup> CIORA Grant Competition. The grant application deadline was March 31, 2016 and award winners will be notified at the end of May.

A special thank you goes out to Dr. Paul Haraoui for his contribution as the CIORA/Research Committee Chair. Dr. Haraoui has served as Chair since 2006 and has provided valuable leadership and dedication. As a result, CIORA has become the third largest funding agency of rheumatology research in Canada. We would like to welcome Dr. Janet Pope as the new Research Committee Chair.



CIORA-funded research is being presented worldwide with several poster and oral presentations at American College of Rheumatology (ACR) and CRA Annual Scientific Meetings.

## At the ACR in 2015

- *A Comparison of Maternal Outcomes in Women With and Without JIA* (Oral).
- *Creating New Rheumatologists: The Canadian Experience* (Oral).
- *Enhancing Comparative Effectiveness Research by Combining Observational and Randomized Trial Data to Personalize the Choice Between Methotrexate and Triple Therapy for Methotrexate-naïve Patients with Early RA* (Oral).
- *Quantifying the Delays to Rheumatologist Consultation and Treatment Among Patients with Systemic Inflammatory Rheumatic Diseases* (Oral).
- *A Comparison of Prenatal Care in Mothers With and Without JIA: Association with Outcomes* (Poster).
- *Inflammatory Arthritis Patient Perspectives on Strategies to Support Medication Adherence: A Qualitative Study Using a Novel Group Exercise* (Poster).

- *Primary Care Management of Patients with Rheumatic Diseases Prior to Rheumatologist Consultation* (Poster).
- *Proof of Concept Study of the Arthritis Health Journal: An Online Tool to Promote Self-Monitoring in People with RA* (Poster).
- *Scoring Medication Requirements and Side-Effects in JIA: Perspectives of Patients, Parents and Clinicians* (Poster).
- *Test-Retest Reliability of the 5-Item Compliance Questionnaire Rheumatology and Factors Influencing its Assessment of Adherence in Patients with RA* (Poster).
- *Using Patient-Relevant Variables to Describe the Disease Course in Children with JIA* (Poster).

## At the CRA ASM in 2016

- *Reliability Analysis of Two Short Medication Adherence Questionnaires in Patients with RA* (Oral).
- *Characterizing Referrals to Rheumatologists to Better Understand Care Management of Patients with Rheumatic Diseases* (Poster).
- *CMA Rheumatology Wait Time Benchmarks: The Need to Tame the Queue Across the Continuum of Care* (Poster).
- *"Honestly, I'm very scared of the side effects so I don't, I won't take it." A Qualitative Study of Adherence to DMARDs in Inflammatory Arthritis Patients* (Poster).
- *Participant Recruitment for Rural RA Care Delivery Model Trial* (Poster).
- *Patient's Experience of the Diagnosis and Management of Psoriatic Disease* (Poster).
- *Proof of Concept Study of the Arthritis Health Journal: An Online Tool to Promote Self-Monitoring in People with RA* (Poster).
- *The Early Arthritis Screening and Treatment (EAST) Program for Eastern Quebec Improves Inflammatory Arthritis Care* (Poster).
- *The Quality and Continuity of Information Between Primary Care Physicians and Rheumatologists* (Poster).

CIORA's contribution to the advancement of rheumatology research in Canada is made possible by the unrestricted financial contributions of many industry partners. We would like to thank our 2016 sponsors for their continued support.



# About the Arthritis Alliance of Canada

By Janet Yale, Chair of the Arthritis Alliance of Canada

**T**he Arthritis Alliance of Canada (AAC) was formed in 2002 and exists to serve a simple goal: Improving the lives of the more than 4.6 million Canadians with arthritis.

With more than 30 member organizations, the AAC brings together arthritis healthcare professionals, researchers, funding agencies, governments, voluntary sector agencies, industry and, most importantly, representatives from arthritis patient organizations across Canada.

Members of the AAC contribute a wide range of expertise and capabilities to networks across Canada, working to provide evidence-based information to inform and support public policies that raise awareness of arthritis. Ongoing work—as individual organizations and in collaboration with other arthritis stakeholders—is essential to achieving the overall goals of mitigating the burden of the more than 100 types of arthritis, the leading cause of disability in Canada.

While each member organization continues their own work, the AAC provides a central focus and a forum for broader collaborative initiatives. A core principle underlying the work of the AAC is to put evidence-based knowledge into action. In partnership and collaboration, we have developed a national strategy based on three key pillars: Advancing knowledge and awareness; improving prevention and care; and supporting ongoing stakeholder collaboration. More details can be found at [www.arthritisalliance.ca/en/joint-action-on-arthritis](http://www.arthritisalliance.ca/en/joint-action-on-arthritis).

This strategic framework establishes research priorities, identifies principles to guide the design and delivery of care, and proposes a mechanism for the arthritis community to engage with governments and the broader



Ms. Janet Yale.

healthcare community. Most importantly, the AAC is committed to putting the person with arthritis front and centre and, to this end, we ensure that there is consumer representation at a leadership level in all our initiatives.

Since the release of our framework in the fall of 2012, much progress has been made. Beginning in the fall of 2013, we have held an Annual Research Symposium and Conference to share research discoveries, conduct working sessions in our priority areas, raise awareness of arthritis with government and external audiences, and celebrate our successes at an annual Gala Dinner. We have included the presenta-

tion of the *Qualman-Davies Arthritis Consumer Community Leadership Award* at our Gala in recognition of the key role played by effective consumer leadership and advocacy.

Over the last three years, we have also focused on improving access to care for patients with autoimmune arthritis and osteoarthritis (OA). We have developed tools to enable the improvement of outcomes through evidence-based models of care that can be adapted and implemented in local environments. This has formed the basis for our advocacy efforts with the federal government and provincial governments across the country.

Looking ahead, the decisions the government makes today will impact patients' access to quality arthritis care in the years to come. However, we continue to face a huge challenge in having arthritis recognized as a major health concern and being prioritized for government investment. Our *Impact Report* documents the growing economic burden of arthritis, both in terms of health care and productivity costs, and outlines risk-mitigation strategies. The AAC decided to leverage this foundational



work in order to develop and implement a comprehensive advocacy plan to make the case for a national arthritis strategy.

Please read through this issue of the CRAJ to learn more about the initiatives underway at the AAC to improve

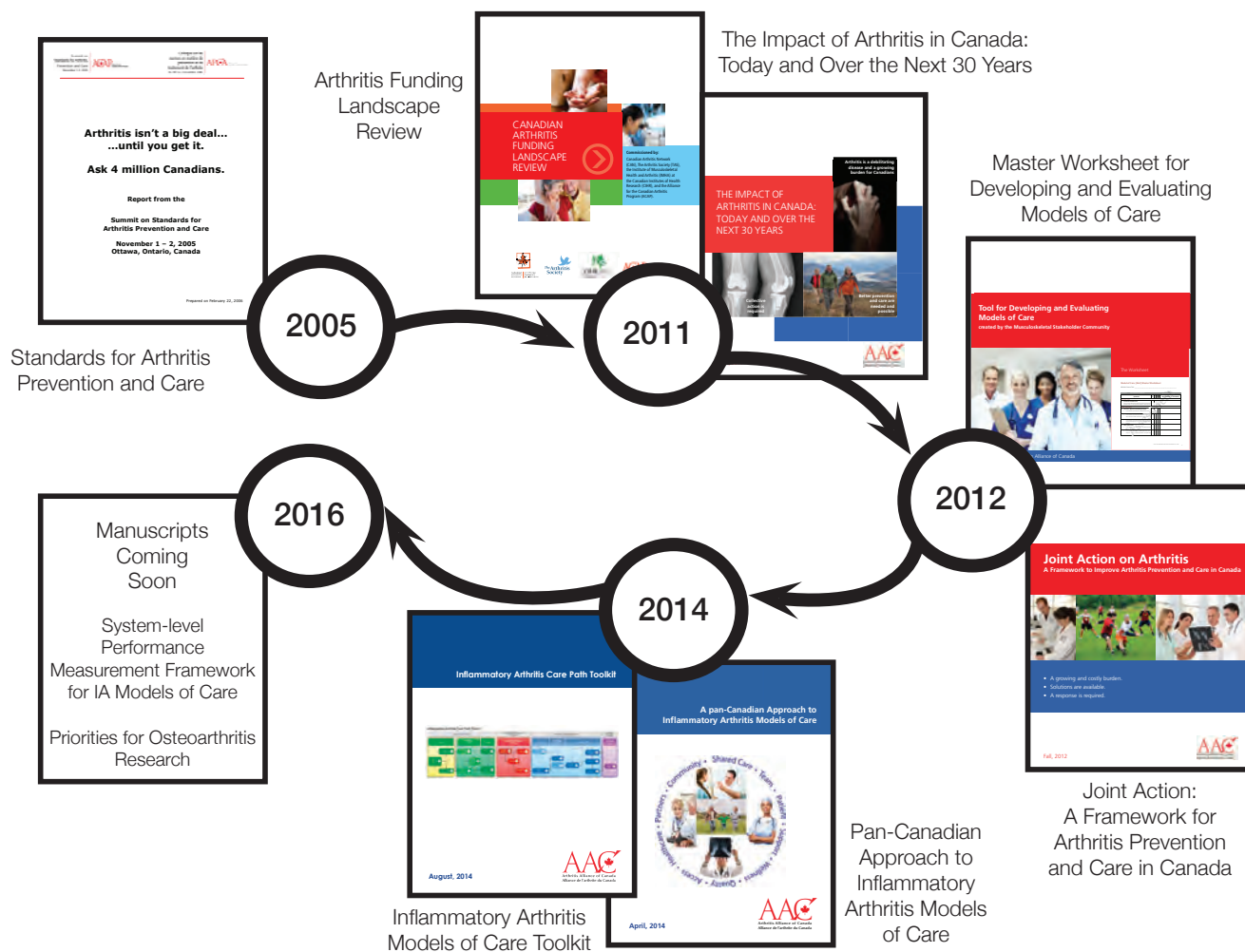
arthritis prevention and care in Canada.

To receive our monthly newsletter to stay informed or get involved, please contact Ms. Jaime Coish, Executive Director of the AAC, at [jcoish@arthritisalliance.ca](mailto:jcoish@arthritisalliance.ca).

Janet Yale  
Chair,  
Arthritis Alliance of Canada  
President and CEO,  
The Arthritis Society  
Toronto, Ontario



## A Brief History of Our Publications



# New Directions in Osteoarthritis Research

By Deborah Marshall, PhD; Kelsey H. Collins, PhD Candidate; and S. Jeffrey Dixon, DDS, PhD

On October 22<sup>nd</sup>, 2015, the Arthritis Alliance of Canada (AAC) in partnership with the Canadian Institutes of Health Research (CIHR) Institute of Musculoskeletal Health and Arthritis (IMHA) brought together more than 200 arthritis stakeholders and leading experts in osteoarthritis (OA), including scientists, engineers, healthcare providers, trainees, specialists, and people living with arthritis. A research symposium entitled *New Directions in Osteoarthritis Research* identified knowledge gaps, highlighting research opportunities in OA and promising approaches for future studies. Presenters included a panel of engaged consumers (Ms. Alison Hoens, Mr. John Coderre, Ms. Anne Fouillard, and Dr. Jean Miller), and academic experts (Dr. Gillian Hawker, Dr. Frank Beier, Dr. Nicholas Mohtadi, Dr. Carolyn Emery, Dr. Linda Li, and Dr. Ewa Roos).

A key theme reflected in all presentations is the critical need for a paradigm shift across both basic and applied research; OA is not “just” the passive degeneration of cartilage resulting from wear and tear, but rather a complex illness of multiple tissues driven by the active participation of multiple cell types. Research has recognized OA as a

heterogeneous condition with multiple pathogenic mechanisms and clinical manifestations delineating “OA phenotypes,” potentially requiring different diagnostic and therapeutic approaches. A transdisciplinary, team-based research approach across healthcare pillars is essential to describe, evaluate, and develop interventions for these subgroups of OA.

Evidence exists for the effectiveness of non-operative conservative care for knee OA, specifically for diet and exercise.<sup>1</sup> We still do not have any disease-modifying drugs for OA analogous to biologics for inflammatory arthritis (IA); this remains a key research and translational opportunity. Additional research is also needed to explore the potential of regenerative medicine approaches for the prevention and treatment of OA.

An exciting example of personalized treatment was described by Dr. Roos, who studied exercise therapy personalized for OA patients to improve their joint function and reduce OA symptoms. This program, called *Good Life with Osteoarthritis in Denmark* (GLA:D),<sup>2</sup> was successfully tested through a certification program for physiotherapists.



Ms. Alison Hoens and Dr. Jeff Dixon presenting at the AAC Annual Meeting.



Ms. Linda Wilhelm, Qualman-Davies Arthritis Consumer Community Leadership Award recipient, alongside her poster at the AAC Poster Session.

Dr. Li described how implementation of research knowledge continues to lag behind discovery, and that greater efforts are needed to translate our findings. This may involve capacity building in the fields of knowledge translation, implementation science, and patient engagement. An example presented by Dr. Emery was the recommendation to implement targeted injury prevention strategies in youth sport and recreation, where studies have shown a significant reduction in injuries with a neuromuscular training warm up.

The consumer panel highlighted the ongoing need to change the culture around patient engagement and emphasized the roles of patients. Such roles include identifying relevant research questions, aiding in the design of studies, interpreting findings, and translating knowledge, as well as working with other members of the OA community to advocate for adequate research funding.

On the day following the symposium, AAC members, partners, and stakeholders met in a workshop format. Building on the outcomes of the symposium, goals of the workshop were to: Identify knowledge gaps in OA, synthesize and prioritize key research questions, and identify programs and strategies to tackle the most critical questions in OA research. A report detailing the conclusions from the symposium and workshop is presently in preparation.

PowerPoint presentations from the research symposium and workshop are available on the AAC website; please visit [www.arthritisalliance.ca/en/aacannual/14-data-articles/173-2015-annual-conference-ppt](http://www.arthritisalliance.ca/en/aacannual/14-data-articles/173-2015-annual-conference-ppt) to access this content.

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(Left to right): Dr. Deborah Marshall, Ms. Alison Hoens, Ms. Anne Fouillard, Mr. John Coderre, and Dr. Jean Miller.

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Arthritis Alliance of Canada (AAC)  
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<p><b>THURSDAY, OCTOBER 22, 2015</b></p> <p>8:00 am - 12:00 pm CIHR - IMHA "Young Investigator Forum"</p> <p><b>Research Symposium: "New Directions in Osteoarthritis Research"</b></p> <p>12:45 pm - 1:00 pm Arthritis Alliance of Canada: Welcoming Remarks</p> <p>1:00 pm - 5:00 pm Research Symposium: "New Directions in Osteoarthritis Research"</p> <p>6:15 pm - 6:45 pm Reception</p> <p>6:45 pm - 9:00 pm Gala Tribute Dinner "Dr. Cy Frank and The Rocky Mountain Pioneers"</p>	<p><b>FRIDAY, OCTOBER 23, 2015</b></p> <p>8:30 am - 9:00 am AAC Annual General Meeting</p> <p>9:00 am - 10:15 am AAC Models of Care Workshop</p> <p>10:45 am - 12:00 pm AAC Research Workshop</p> <p>12:30 pm - 1:45 pm AAC Advocacy and Awareness Workshop</p> <p>8:00 am - 1:00 pm CIHR - IMHA "Young Investigator Forum"</p> <p>8:00 am - 1:00 pm The Arthritis Society Trainee Session</p> <p>1:00 pm - 3:00 pm Joint Poster Session: IMHA "Young Investigators", The Arthritis Society Trainees and Arthritis Consumer Organizations in Canada</p>
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# Towards a Performance Measurement Framework for Inflammatory Arthritis Care in Canada

By Claire Barber, MD, FRCPC, PhD; Diane Lacaille, MD, FRCPC, MHSc; Dianne Mosher, MD, FRCPC; and Deborah Marshall, PhD

**A**utoimmune inflammatory arthritis (IA), including rheumatoid arthritis (RA), spondyloarthritis (SpA), and juvenile idiopathic arthritis (JIA), is estimated to affect over one million Canadians; in many regions there is a shortage of arthritis healthcare providers. In response to these pressures and in an effort to optimize care delivery,

the Arthritis Alliance of Canada (AAC) launched the *Pan-Canadian Approach to Inflammatory Arthritis Models of Care* in 2014. The model describes an approach to care delivery that may be applied in whole or in part in different healthcare settings depending on the context. A toolkit for implementation accompanies the model.

There exists across Canada a variety of innovative models of care. For example, to ensure early access for patients with IA a number of centres have implemented central intake and triage systems. Other centres have increased clinic capacity through the use of nurse-led clinics or primary-care-provider-led clinics. In rural and remote settings, telehealth and outreach clinics have likewise improved access to care.

However, how do we know if implementing a new model of care has improved the quality of clinical care? How do we evaluate our current care delivery to ensure our patients are getting the highest level of care and achieving the best outcomes? Such questions are important to answer not only when evaluating potential gaps in care, but also when advocating for healthcare resources.



Healthcare quality refers to the degree to which clinical and healthcare services are aligned with best practices; quality is assessed on six principle domains that reflect the provision of safe, effective, patient-centered, timely, efficient, and equitable care. A performance measure is a metric to evaluate care delivery along these

domains of quality. The AAC and its stakeholders have begun work on the development of performance measures for an evaluation framework for IA.

For Phase I, in collaboration with IA stakeholders from across Canada, a set of six system-level performance measures were developed based on guidelines and harmonized, where appropriate, with existing measures from other countries. The measures capture access to care and treatment for patients with IA at the health-system level (e.g., clinic, region, or provincial level). Our findings will be published in the March 2016 issue of the *Journal of Rheumatology (JRheum)*.

The measures are currently being tested in five Canadian provinces, in 10 arthritis-care settings. The present measures, however, do not address best practices at the patient-provider level or patient outcomes. Phase 2 of the development of the AAC Evaluation Framework is to develop and test measures that will cross the care continuum for patients with IA. The framework will be a key tool for centres and practitioners wishing to evaluate the care they currently provide, and also for the evaluation of new models-of-care.

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# A Pan-Canadian Clinical Dataset for Rheumatology

By Vandana Ahluwalia, MD, FRCPC; Claire Barber, MD, FRCPC, PhD; Dianne Mosher, MD, FRCPC; Michel Zimmer, MD, FRCPC; and Sandra Couto, BSc Pharm

**H**ealthcare systems across the globe are undergoing transformations to improve access and quality of care, value for money, and the patient experience. In Canada, the drive towards improving access to care and improving the quality of medical care is building on the foundation of a strong healthcare system. Measurement is an integral part of this process, and defining a common dataset for Canadian rheumatologists will allow us to further drive improvement. Electronic Medical Records (EMRs) and other databases are the necessary tools which have the potential to transform the delivery of care.

Over the last eight years in Canada, the adoption of EMRs by primary-care physicians has more than doubled, moving from 23% in 2006 to 75% in 2014. The adoption of EMRs by community-based specialists has also increased from 28% in 2007 to 70% in 2014.<sup>1</sup>

The EMR landscape continues to evolve with physicians increasingly realizing the value of implementing an EMR system in their daily practice. Initially, EMR systems were developed for primary-care physicians, and the biggest concern for specialists was the lack of available integrated specialty-specific tools. For hospital- or university-based specialists, there is often no ability to influence or alter templates or data collection within the EMR. Recovery of data is also difficult.

Canadian rheumatologists have taken a leadership role not only in their adoption of EMRs, but in their ability to develop EMR-based tools that allow for more meaningful optimization of these platforms. Clinical forms, disease activity calculators, and capture of patient-reported outcome measurements are some of the important tools that now exist within EMRs thanks to Canadian rheumatologists.

While adoption rates continue to increase, there remains much cross-province variation with respect to how clinical data is captured by clinicians, as well as what data they are collecting. In an effort to qualify and quantify this variability and achieve consensus for harmonization and standardization, the Arthritis Alliance of Canada (AAC) organized two strategic

planning meetings bringing together a small working group of rheumatologists with a specialized interest in data collection for clinical care, quality assurance, and research. The first meeting was held in June 2015 at the University of Calgary; the focused working objectives at hand were to:

- Create consensus that a national framework is needed to stimulate harmonization of datasets amongst provincial groups.
- Identify barriers that may need to be overcome to initiate the discussion around an approach to national harmonization of data collection.
- Define the minimum rheumatology clinical data sets to be collected cross-provincially.
- Agree on rheumatology indicators (patient care and system indicators) that can easily be captured and reported within EMR and other data platforms.
- Determine resources needed to support this work.

This initial strategy meeting was instrumental in confirming the need for standardization of a rheumatology-specific core dataset.

Taking advantage of the excitement and engagement coming out of the June meeting, the working group immediately planned to reconvene in October 2015, at the AAC Annual Meeting in Kananaskis, Alberta. The second meeting included an expanded group of stakeholders, helping to further define the approach to a pan-Canadian clinical dataset in rheumatology. In preparation for the October meeting, a survey was conducted amongst major investigator-led registry initiatives in Canada to better understand current data-collection methods. Additionally, data was collected to outline the EMR landscape in Canada, and the ability for data to be accessed and retrieved through EMRs. The October meeting shared key findings from these assessments and identified opportunities to maximize existing tools. Moreover, the meeting established an initial framework towards a pan-Canadian clinical dataset for rheumatology, identifying key elements that should be considered in the formation of the core clinical dataset.



The initial framework put forward for review and development considers three breadths:

- **Core Clinical Dataset for Best Practices**

A core clinical dataset recommended for data collection in everyday practice by all Canadian rheumatologists. This includes such data as tender and swollen joint counts, calculated measures of disease activity, and functional status. This dataset will be used in new models of care and will be based on clinical practice guidelines in rheumatology.

- **Comparative Effectiveness Dataset**

An expanded clinical dataset that builds on the core clinical dataset for use in registries and clinical trials to support research and improve clinical practice. This includes such data as enhanced adverse event reporting, quality-of-life measures, patient-reported outcome and experience measures, as well as work productivity measures.

- **Extended Dataset**

A linked dataset that combines data from other sources such as administrative data that reflects health resource utilization (e.g., total physician visits, procedures, imaging, hospitalizations) and costs.

Final efforts are underway to re-group at the 2016 CRA Annual Scientific Meeting (ASM). The initial working committee will be expanded to broaden stakeholder participation thereby increasing the awareness and understanding of what data variables are being collected within provinces and the national consensus for standardization of a rheumatology-specific core data set.

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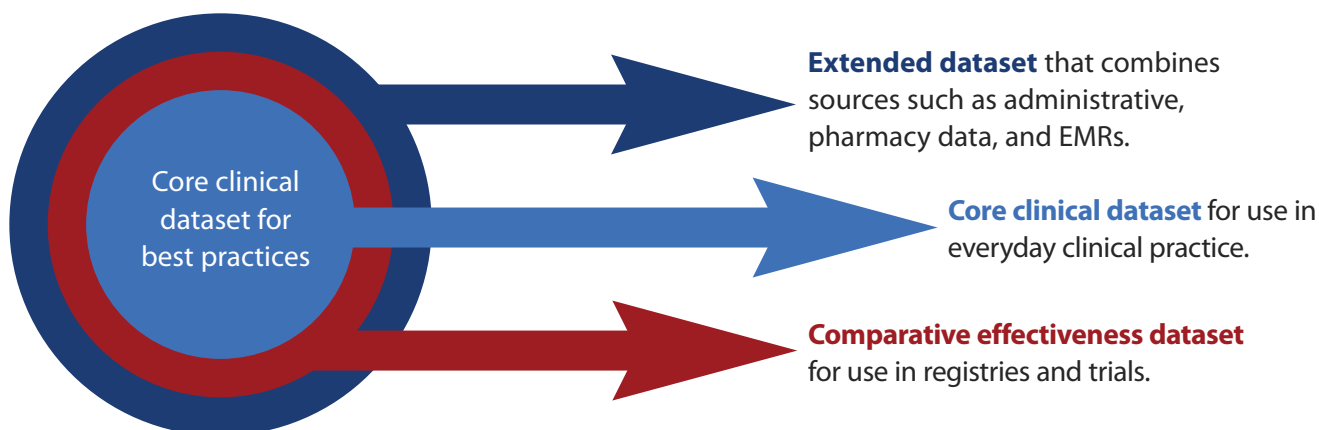
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- Reduction of signs and symptoms, induction and maintenance of clinical remission and induction of mucosal healing in pediatric patients with moderately to severely active UC who have had an inadequate response to conventional therapy (i.e., aminosalicylate and/or corticosteroid and/or an immunosuppressant)
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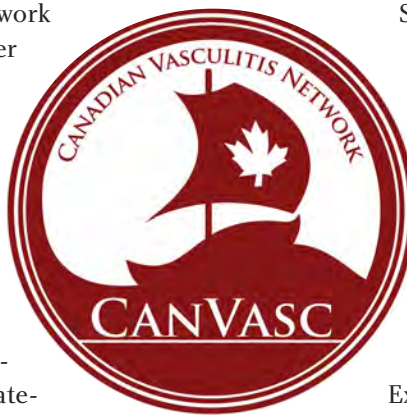
# Update on Recent CanVasc Initiatives

By Christian Pagnoux, MD, MSc, MPH

The Canadian Vasculitis Network (CanVasc) was founded in November 2010. Its core committee includes more than 20 physicians from various medical specialties across Canada, as well as many collaborators, all of whom have expertise and interest in vasculitis. CanVasc ultimately aims to optimize the management of vasculitis in Canada through the development of—or assistance with the development of—guidelines, educational materials on vasculitides, and awareness programs for healthcare providers.

The core members of CanVasc have initiated and achieved several important projects. The first CanVasc recommendations, for the diagnosis and management of anti-neutrophil cytoplasmic antibody (ANCA)-associated vasculitis, have just been published in rheumatology and nephrology journals.<sup>1,2</sup> It took almost three years to achieve this major step, which solidifies the national existence of CanVasc and introduces us to the international vasculitis research community. Work is currently under way to develop similar recommendations for Takayasu arteritis, for which dedicated guidelines have been lacking, and for giant cell arteritis, focusing on some specific aspects of its management.

Several tools are available or are under development to help disseminate these recommendations and their practical appendices, promoting their use in routine practice to improve patient outcomes. The number of daily visits to the CanVasc website ([www.canvasc.ca](http://www.canvasc.ca)) has regularly increased since its creation; the site offers practical information and resources for healthcare providers. The development of new educational materials (*Canadian Vasculitis Learning Initiative [CaVALI]: An Approach To Vasculitis Through Interactive Clinical Cases*) will further emphasize how CanVasc initiatives can enhance the training and learning of physicians managing vasculitis.



Several CanVasc centres and core members have been active participants in the North American Vasculitis Clinical Research Consortium (VCRC); stronger connections with this major and longer-standing research network will be nurtured. This collaboration provides further opportunities for Canadian centres—part of the CanVasc network or not—to participate in prospective, international therapeutic studies. Plasma Exchange and Glucocorticoid Dosing In the

Treatment of ANCA-associated Vasculitis (PEXIVAS), driven in Canada by Dr. Michael Walsh, an associated CanVasc core member from Hamilton, Ontario, has been a tremendous success and showed that Canada is now a major player in vasculitis research.<sup>3</sup> Other therapeutic studies are coming soon, some designed by our members in collaboration with the VCRC. CanVasc led studies must be conducted in parallel. A few have been completed, including the largest case series on patients with vasculitis and inflammatory bowel disease (IBD).<sup>4</sup> CanVasc has just finalized its database for adults with vasculitis, which will allow for various descriptive studies and comparisons with the existing Registry for Childhood Vasculitis (ARCHiVe) database or other international cohorts. Core members have also been involved in the launch of the adult BrainWorks database for patients with suspected central nervous system vasculitis. The pediatric database, developed eight years ago by Dr. Susanne Benseler, CanVasc core member in Calgary, Alberta, has also been very successful.

Hence, it is difficult to summarize what has been initiated and accomplished by all CanVasc core members since 2010. CanVasc is now an established not-for-profit corporation and research network. It needs to keep working hard to sustain its recently acquired position in the vasculitis field. Everyone is welcome to join and help!

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## The CanVasc core members centers



## WELCOME TO THE RHEUM & FAREWELL AS YOU LEAVE

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Antonio Cabral, Ottawa, ON  
 Stephanie Garner, Calgary, AB  
 Tara McGrath, Edmonton, AB

Chris McKibbin, Sudbury, ON  
 Karen Pont, Cranbrook, BC  
 Nadil Zeiadin, Kingston, ON

### Congratulations are offered to:

Dr. Peter Dent as he embarks upon his retirement. The CRA wishes you the very best!



# 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.<sup>1,2</sup>

## 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](http://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.

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### **SPARCC Executive Committee:**

*Dafna G. Gladman, MD, FRCPC;*  
*Robert D. Inman, MD, FRCPC, FACP, FRCP Edin;*  
*Proton Rahman, MD, FRCPC;*  
*Sherry Rohekar, MD, FRCPC; and*  
*Michel Zummer, MD, FRCPC*

# The CRUS Research Scholarship

By Lihi Eder, MD, PhD

**You have been instrumental in spearheading the creation of the Canadian Rheumatology Ultrasound Society (CRUS) Research Scholarship. Why is this scholarship so important?**

As a researcher I was very interested in using ultrasound (US) as a research tool. I completed the CRUS basic US course in 2013. Despite having access to excellent US equipment, the greatest challenge I was facing at that time was the lack of a mentor who had expertise in musculoskeletal (MSK) US and could guide my research efforts. US is a great tool applicable to many research fields in rheumatology, yet, currently there is little use of MSK US in Canadian research. One of CRUS's aims is to promote research using MSK US. The *CRUS Research Scholarship* will support people interested in gaining research experience with MSK US by connecting them with experts in the field and providing access to advanced US equipment.

## **What types of projects are eligible for submission?**

The range of topics for eligible research projects is broad—US can be used in many research fields including translational research, clinical practice, medical education, and health services research. Any project relevant to the use of MSK US for the management of rheumatic conditions and involving actual use of US as part of the research protocol is a viable candidate for submission.

The scholarship will cover a 10-week research term, performed consecutively over an elective term or intermittently over the course of one academic year.

## **Who can apply to the scholarship?**

I encourage anyone who has at least basic skills in MSK US and who is interested in gaining some research experience to consider applying for the scholarship. From my personal experience, performing US as part of a research project significantly improves US scanning skills. The scholarship is open to rheumatology residents and research fellows as well as to rheumatologists within



five years of the completion of their training. We will give priority to applicants who are currently enrolled or have completed the CRUS basic US training course.

## **How will the scholarship be awarded?**

Adjudication is by a selection committee and will be competitive. Applications will be reviewed and scored based on their scientific merit and relevance to MSK US research, the mentor's credentials as related to the project and his or her experience in MSK US research, the quality of the mentorship environment provided by the mentor, and the appropriateness and feasibility of the awardee's role in the project. The scholarship is valued at \$10,000 CAD. It will be awarded in September 2016.

## **Anything else applicants should be aware of?**

The applicants will need to identify a mentor and a research project prior to submitting their application. Mentor must be a CRUS member in good standing and have a record of research in the field of MSK US. We have identified a number of such experts willing to serve as mentors. However, applicants could select other mentors as long as they meet the criteria mentioned above.

*Lihi Eder, MD, PhD  
CRUS Research Officer  
Assistant Professor of Medicine,  
Women's College Research Institute  
Division of Rheumatology,  
Women's College Hospital,  
University of Toronto  
Toronto, Ontario*

## **The CRUS Research Scholarship**

**Scholarship Amount:** \$10,000 for a 10-week research term.

**Application Deadline:** All applications must be submitted online by **July 4, 2016 at 5:00 PM ET**.

For questions regarding the award or the submission process, contact Ms. Alyssa Long at [along@crus-surc.ca](mailto:along@crus-surc.ca).

Further details are available at <http://crus-surc.ca/en/research/>.

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# Looming Rheumatologist Shortage a Cause for Concern

**F**redericton rheumatologist Dr. Jamie Henderson wants to see a potential RA patient within six to eight weeks of symptoms starting. He knows the earlier he sees them, the better the outcome. He heads out regularly into the community to address this need with local family doctors.

Dr. Henderson practised for 35 years before retiring this fall. He had a heavy workload, a waiting list, and sometimes could not get to a new RA patient within that two-month zone. New RA cases are common, and it is a disease that stays with a person for life. Over the years, Dr. Henderson accumulated several thousand patients who relied on him to monitor their medications and disease progression.

But as he neared retirement, there was nobody set to take Dr. Henderson's place. There was no succession plan to take on his growing list of patients.

"That thought would keep me up at night," Dr. Henderson says. "We need more bodies at the front lines."

He believes Canada is facing a watershed moment for rheumatologists. Over half of Canadian rheumatologists are older than 50, and many are working into their 70s. "They are leaders of the pack. Who is going to fill their shoes? Some will work past age 65, and some will not."

**"That thought would keep me up at night," Dr. Henderson says. "We need more bodies at the front lines."**

If patients cannot access a rheumatologist, it can compromise their care. Even if a person with arthritis is on treatment, he or she needs to visit a rheumatologist at least once a year to be monitored. If inflammatory arthritis (IA) is active, and new medications are being tried, the frequency of visits escalates to every three months.

"These therapies are absolutely critical," Dr. Henderson says. "People of my generation, who are coming to the end



Dr. Jamie Henderson.

Photo credit: Dr. John Hanly, 2015.



of their careers, know how devastating RA can be and have seen the results of that devastation."

The need for more rheumatologists is only rising in Canada. That need is illustrated no more pointedly than in smaller regions that may have one or none. It is not unusual for Canadians to drive many hours to the nearest rheumatologist, of whom there are fewer than 425 in the country.

This shortage is why The Arthritis Society is seeking ways—like salary awards—to incite a new generation of rheumatologists to provide front-line care to people with arthritis. It makes a difference. Please visit [www.arthritis.ca/research/research-investments/2015-salary-awards](http://www.arthritis.ca/research/research-investments/2015-salary-awards) for more information.

"When I was studying, my first year was funded by The Arthritis Society," Dr. Henderson explains. "Had that funding not been available, I probably would not have become a rheumatologist."

Society funding is bringing more medical students to rheumatology to help fill that gap for communities across the country, but more funding is needed.

"We were lucky—we have finally been able to recruit someone to take over my practice in the spring. But with so many of my colleagues at or near retirement, we need to do more to ensure we have enough promising young clinicians coming into the field to meet the needs of patients."

The Arthritis Society thanks Dr. Henderson for sharing his insights. If you want to help address the shortfall in rheumatologists in Canada, please consider supporting The Arthritis Society / CRA **Every Member** campaign by contacting Sandra Dow at [sdow@arthritis.ca](mailto:sdow@arthritis.ca), or by phone at 416-979-7228 ext. 3343.

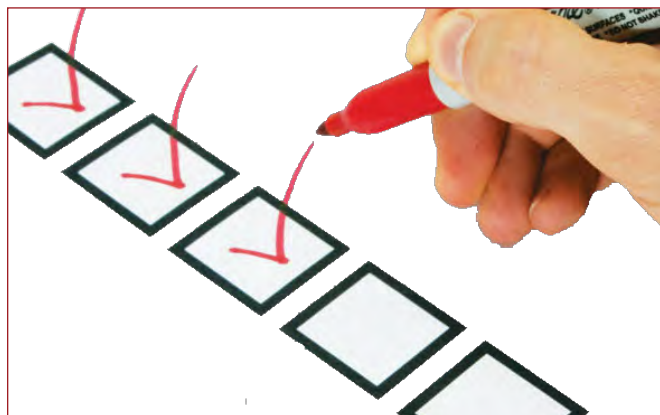
*Continued from page 3.*

for 20 minutes and find that one has covered only 20% of a survey that is supposed to take 30 minutes. Often in this situation, at some point one magically jumps from 30% to 90% completion. I also like to see a survey that shows signs of intelligent construction by the IT department. If I am asked to divide my use of agents among nine choices adding up to 100, and my first four choices total 100, please do not have me manually enter zeros in the other boxes. Some survey design teams master that; for others it seems to be impossible.

Some survey designs are quite impressive. If one races through too quickly, a pop-up will appear indicating that you may not have thought about your answers thoroughly. “Would you like to reconsider?” Sometimes there are simple arithmetic questions interspersed. I gather this ensures that it is a real rheumatologist, not a rheum-bot, completing the survey. The same question may be asked with the scale of answers reversed, to be sure you are paying attention.

Surveys that reflect the real world of rheumatology are preferable. For instance, I categorize my patients with RA based on being in remission, or showing low, moderate, or high disease activity. However, every survey ever written asks me how many RA patients I have who are mild, moderate, or severe. Surveys on PsA often have a category for DMARD therapy and another category for “conventional therapy;” I still am not sure what the latter means.

Other common questions that I really do not know how to answer include how many patients I actually have in my practice with each of the common rheumatic conditions, or how many I have seen within the last week, month, or three-month period.



A recent insight occurred when I was asked to do a survey in pilot form, providing my comments to the survey designers who were listening in. This one turned out to be one of the worst designed surveys I had ever seen, with screen after screen of drop-down menus and clickable boxes requiring, by my calculation, over 500 mouse clicks to get through the core of the survey. I told the designers I was using a 25 inch monitor and still could not fit the entire survey spreadsheet on my screen. A few weeks later, I was offered the chance to complete the survey for \$90 over 30 minutes. As soon as I launched it, I realized that none of my comments had been taken into account, and that the survey would certainly take longer than 30 minutes. Fortunately I had been paid more handsomely for critiquing the pilot, and felt quite comfortable closing the actual survey without completing it.

In-person surveys have their own challenges. I have no trouble with the audiotaping and videotaping, or having people watching me from behind a one-way mirror. However, please don't ask me what model of car each biologic reminds me of. Or what personality a given biologic would have if they were people walking into a room. The usefulness of this line of questioning escapes me. However it seems to be a staple of marketers everywhere.

Getting paid for surveys done by email is the subject for another editorial in and of itself. Since Laura and Victoria are fictional, writing to them usually does not produce any results. Often the cheques one eventually receives have no information linking them to a particular survey, so keeping a list of surveys one has completed is futile.

Finally, I have to touch on surveys done for free. Of course, if you receive any survey from the CRA, the CRAJ, or a provincial rheumatology association, you should complete it on a priority basis. However, there is a limit to my willingness to complete every survey sent by aspiring Masters and PhD candidates that will “only take 30 minutes” and will lead to “invaluable leaps in human knowledge.” Behavioural psychology lesson: Offer something, whether a chance to win a coffee shop gift card, or a \$2 donation to The Arthritis Society, and your completion rate will improve. Time is money, and the competition for my time is fierce these days.

*Philip A. Baer, MDCM, FRCPC, FACP  
Editor-in-chief, CRAJ  
Scarborough, Ontario*



## REGIONAL NEWS



### **Roberta Berard** @drrobertaberard

Western University and the Department of Pediatrics are pleased to announce the addition of Dr. Daniela Ardelean to our faculty. Dr. Ardelean is a pediatric rheumatologist and clinician scientist focusing on translational research. Our section will be holding our second-annual patient and family education day for children with juvenile idiopathic arthritis (JIA), this spring; called *Project Thrive*, this is a joint partnership with The Arthritis Society.

### **Gordon Soon** @drgordonsoon

In a joint effort, Dr. Nicholas Blanchette and Dr. Gordon Soon are helping provide care for patients and families throughout northern Ontario. The satellite pediatric rheumatology clinic runs every two to three months; both are thrilled to work with such a dedicated and talented team at Health Sciences North in Sudbury, Ontario.



#LookingsharpinSudbury #HealthSciencesNorth #Sudbury

### **John Thomson** @drjohnthomson

Ottawa has welcomed five new rheumatologists to our wonderful city over the past two years: Dr. Sibel Aydin, Dr. Antonio Cabral, Dr. Raj Gill, Dr. Ines Midzic, and Dr. Ramin Yazdani. Dr. Cabral is our new Division Head of Rheumatology. We are very excited to have added such a dynamic and talented group of rheumatologists. Dr. Bob McKendry has recently retired after a long and distinguished career; Dr. McKendry started the Division of Rheumatology in Ottawa.

### **Shirley Chow** @drshirleychow

The University of Toronto Division of Rheumatology adult and pediatric residents and clinical fellows enjoyed a meal together at the CRA meeting in Lake Louise. Looks like everyone had a good time learning among the beautiful mountains!



#Rheums&trainess #Toronto

### **Deborah Levy** @drdeblevy

At SickKids the pediatric rheumatology group continues to be active with a large clinical service, research program, and pediatric rheumatology fellowship. We currently have 10 full- and part-time physicians as well as several cross-appointed community pediatric rheumatologists, six clinical fellows, three research fellows, two extended role practitioners, four nurses, plus a full-time physiotherapist and a social worker, and a part time dietician, as well as several research staff and administrative assistants. Whew!



#Everybodystandup #Toronto

### **Laurence Rubin** @drlaurencerubin

Almost thirty years in Timmins and counting. Our team (Dr. Simon Carette, Ms. Mary Ellen Marcon, and myself) delivering “the model of Northern Arthritis Care”. But who will follow in our footsteps? That is our greatest challenge—interested parties should contact SOON!

# Reflections on Rheumatoid Hands

By Catharine Dewar, PhD, MD, FRCPC



1922 - 2015

**To the Editor of *The Journal of Rheumatology* (JRheum):**

Last week I saw a patient for the first time since she started her biologic drug. She was very emotional as she described sitting down at the piano bench and picking out a favorite piece of music. She began to play and it was difficult for her, but she blamed that on lack of practice for more than five years. Hearing the piano come alive again, she was overwhelmed with emotion, and that is what she was trying to convey to me. I glanced at her hands and she was “wringing” them and abducting and flexing all her fingers, something she had not been able to do painlessly for a very long time. She was reliving the rebirth of her hands. It is no wonder she was close to tears as she thanked me for my clinical gifts. This brought to mind my mother’s hands, and her own love of classical music.

My mother was Helen Catherine Howard, and she died in 1999. She developed rheumatoid arthritis (RA) at age 66, and like many patients who have medical family members, she “didn’t read the textbook” when she challenged my diagnostic skills as a newly credentialed rheumatologist in 1990. She presented with Guyon’s canal syndrome and Achilles enthesopathy, a most unusual and definitely asymmetrical pairing. Discussions and examinations

ensued and eventually, after many months, it became painfully apparent that she had become “a rheumatoid.”

Her beautiful hands deteriorated in a shocking fashion in fewer than nine years. Even cutting an onion became impossibly painful for her. My brother said that she lamented, “I killed myself,” after overhearing a discussion about her chest radiograph. She blamed no one but herself for developing lung cancer after decades of smoking. I knew that cigarettes were also strongly linked to RA,<sup>1</sup> but I never shared that with her; she was already dealing with enough pain mentally and physically. She went on to survive lung cancer twice within nine years, sequentially in each upper lobe. She quit smoking the night of her first lobectomy, but this meant she gave up all rituals and behaviors associated with cigarettes including coffee, newspapers with crossword puzzles, and the piano. Like the *Polonaise* that I remember her playing,<sup>2</sup> she was heroic; she never complained even as she observed the destruction of her hands.

Sadly, she had begun smoking in her 20s and the cigarettes were a “gift” to her for working in a war factory, making powdered eggs for the troops. She had a marvelous sense of humor and I understood why she never liked eggs, after cracking open one too many “stinkers.” In the 1940s

cigarettes were just as addictive, but the US Surgeon General's warnings about the health risks were years in the future.<sup>3</sup>

I compare my mother's journey and the loss of her hands to the startling success stories I have had with "rheumatoids" treated with biologics. That is the saddest thought — that my own mother could have been spared the indignity of becoming housebound and disabled had she lived just a few months longer. She would have experienced "the biologic era." Ironically, I published my research in the field of cytokines and patients with RA a year before she developed her second lung tumor and a few years before her death.<sup>4</sup> Her remaining lower lobes were further compromised by prednisone and she rapidly succumbed to community-acquired pneumonia. All of the traditional RA remittive drugs had failed her, and her treating rheumatologist resorted to steroids to ease her suffering. She died far too young at age 74. Her husband, my father, carried on without her until he died, on August 19, 2015, at age 93. He was one of Western Canada's first certified rheumatologists.<sup>5</sup> He trained with Philip Hench at the Mayo Clinic in the early 1950s when cortisone was first discovered and promoted as the "cure" for RA.<sup>6</sup> Dad hated to see the problems prednisone caused his wife, but he understood the futility of her situation. My father lived his final years in his own heroic fashion and he too never complained... but he never had any problems with any of his joints.

My mother was a great role model for a rheumatologist husband and daughter. This poem is dedicated to my mother and all "rheumatoids" who suffered with painful hand disability and deformity before the biologic era.



Dr. Catharine Dewar.

### My Mother's Hands

*I see the tendons bounce and dance  
then disappear,  
floating across the metacarpals  
whose heads sway in gentle rhythm.  
I'm spellbound by your loving hands  
as I watch you play Chopin's Heroic Polonaise.*

*Your fingers come alive  
stretching and yawning  
across the octaves,  
mocking the demands of the notes.*

*I see your hands floating lightly  
embracing the blacks and the whites,  
allowing for the differences  
of all participants.  
Essential elements  
to the composition,  
the music,  
and the gifts  
of your life.*

### References

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2. Chopin's Polonaise in A-flat Major, Op. 53, the "Heroic" Polonaise. To hear this 1842 composition by Chopin, visit [www.chopinproject.com](http://www.chopinproject.com).
3. Winkelstein W Jr. From the editor: the surgeon general's report on smoking and health (sic). *Am J Epidemiol* 2002; 155:1142.
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6. Lloyd M. Philip Showalter Hench 1896-1965. *Rheumatology* 2002; 41:582-4.

### Acknowledgement

I am forever indebted to my father, the late Dr. David Lloyd George "Red" Howard, who was my first rheumatology mentor.

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Head,  
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North Vancouver, British Columbia*

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# Dis-jointed?

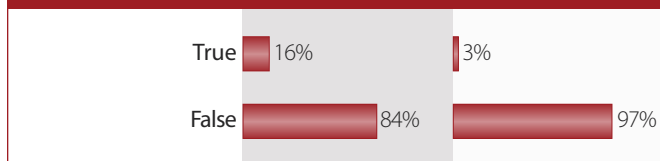
This issue's Joint Count is going up in smoke! The CRA featured *A Smokin' Panel* as the 2016 *Controversies in Rheumatology* session at the Annual Scientific Meeting (ASM). The CRA surveyed members who attended the session, as well as those members who were unable to attend the ASM. Here's what came out from amid the smoke and mirrors. The left sides of the tables report results from non-attendees, while the results on the right sides are those collected onsite at the ASM through the *Sli.do* app.

As a primer, Dr. Andy Thompson and his *RheumReporters* noted that the endocannabinoid system is important for the maintenance of homeostasis. This endocannabinoid system down regulates the sympathetic nervous system's "fight vs. flight" system. Endocannabinoids reduce stress, and improve appetite, sleep, and pain.<sup>1</sup>

Chronic pain is prevalent. In Canada, about one in five individuals suffer from chronic pain; this figure translates into about six million individuals nationally.<sup>1</sup> Chronic pain is a constellation of symptoms that can include pain, insomnia, nausea, cognitive difficulties, depression, and anxiety. Opioids are frequently used in the management of chronic pain but a Cochrane Collaboration review concluded that opioids have only a small effect on pain and physical function.<sup>1</sup>

Dr. John Pereira opened the *Controversies in Rheumatology* session, offering perspectives from a prescriber and challenging the audience to consider whether medical marijuana is riskier than standard opioids currently used

**Table 1. Medical marijuana is riskier than standard opioids currently used for chronic pain management from the perspective of tolerance, addiction, and overdose?**

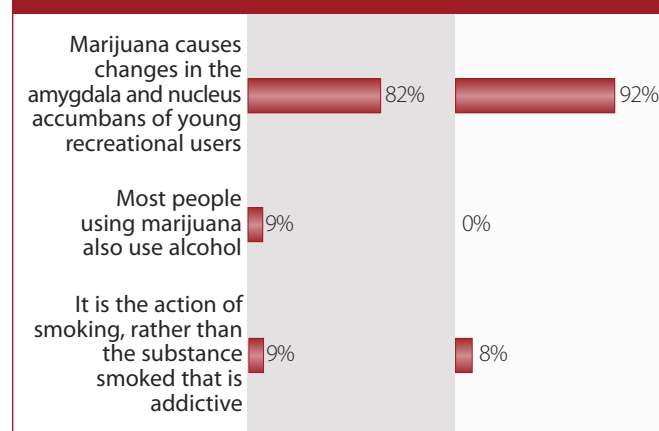


for chronic pain management, from the perspective of tolerance, addiction, and overdose (Table 1). Of those surveyed, 84% of respondents outside the ASM and 97% of those who attended the *Controversies in Rheumatology* session noted that this statement was false. Dr. Pereira urged the audience to keep their minds open and to consider medical marijuana, including strains that are minimally psychoactive. Physicians should acknowledge that we generally lack great treatment possibilities for chronic pain and we should consider alternatives.<sup>1</sup>

Continuing the discussion, Dr. Mary-Ann Fitzcharles asked whether the option to *Smoke those Joints Away* is the best course of action for patients with chronic pain.<sup>2</sup> She asked about the most compelling evidence for addiction to marijuana. There was no dis-joint in the answers given (Table 2), with 82% of those who did not attend the ASM and 92% of attendees responding that marijuana causes changes in the amygdala and nucleus accumbens of young recreational users when using daily cannabis. Addiction occurs in 9% of all users.<sup>1</sup>

Dr. Steven Bellemare ended the session with an overview of medical-legal considerations for prescribing cannabinoids for rheumatic-related conditions. He set up a scenario where

**Table 2. What is the most compelling evidence for addiction to marijuana?**





## Locum Opportunity: Saint John Regional Hospital

Looking for a great opportunity? Consider a rheumatology locum at the Saint John Regional Hospital in Saint John, New Brunswick. A maternity leave locum in a rheumatology practice will be available from June 3 to December 3, 2016. You would be joining a group of two rheumatologists, a rheumatology nurse, an MSK physiotherapist, and an occupational therapist.

You would be participating in outpatient rheumatology clinics and weekday inpatient consults. There is an opportunity to provide support to our internal medicine teaching unit as well as call coverage for internal medicine.

The Saint John Regional Hospital is a tertiary care hospital associated with Dalhousie University and Halifax. Tertiary care medical and allied health departments fully support the department of rheumatology in management of IA, connective tissue diseases, and vasculitis.

There are excellent medical education opportunities available; medical students, clinical clerks, and family medicine and internal medicine residents regularly rotate through our department. In addition, Saint John Regional Hospital is a satellite of Dalhousie University campus at the University of New Brunswick, providing abundant opportunities to be involved in undergraduate and post-graduate training.

The department of rheumatology is actively involved in research trials and registries. We have funding to support research initiatives.

Horizon Health Network is the largest healthcare organization in Atlantic Canada, operating 12 hospitals and more than 100 medical facilities, clinics, and offices providing medical services ranging from acute care to community-based health services to New Brunswick, northern Nova Scotia, and Prince Edward Island. With 1,000 physicians, an annual budget exceeding \$1 billion, and approximately 13,000 employees, Horizon Health Network's strategic vision focuses on research, innovation, and education.

Candidates must be eligible for licensure with the College of Physicians and Surgeons of New Brunswick, possess privileges with Horizon Health Network, and be members of the Royal College of Physicians and Surgeons of Canada, as well as hold adequate liability insurance.

If you are intrigued by this opportunity, please contact us for further details.

Carol Clark, Physician Recruitment Coordinator  
Saint John, New Brunswick  
(506) 648-6286  
[RecruitMD2@HorizonNB.ca](mailto:RecruitMD2@HorizonNB.ca)  
[www.HorizonNB.ca](http://www.HorizonNB.ca)

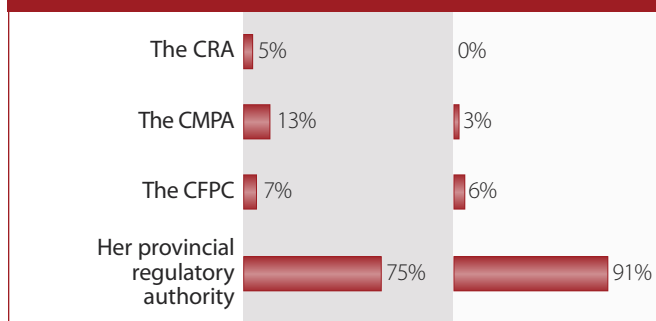
a physician is considering signing the medical document to provide access to medical marijuana for one of her patients. In the scenario, the physician consults a number of resources in order to ensure her practice falls within the acceptable standard of care. He then asked the audience which body's guidelines or advice is it most important to align one's practice with (Table 3). Of those surveyed outside the ASM, 75% reported that the provincial regulatory body should guide practice. The vast majority (91%) of those who attended the session selected the same response. Again, no dis-joint in understanding there!

The takeaway message from the *Controversies in Rheumatology* session was that there is some smoke and mirrors at play when discussing medical marijuana usage in chronic pain patients. The general consensus was that physicians should be wary of risks to patients and society when considering alternative treatment options with data available thus far.

### Reference

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**Table 3. Which body's guidelines or advice is it most important for the physician to align her practice with?**





# WHEN METHOTREXATE ALONE IS NO LONGER ENOUGH, CONSIDER

<sup>PR</sup>  
**XELJANZ®.**



**Simple, twice-daily oral dosing**

XELJANZ (tofacitinib) in combination with methotrexate (MTX) is indicated for reducing the signs and symptoms of rheumatoid arthritis (RA) in adult patients with moderately-to-severely active RA who have had an inadequate response to MTX. In cases of intolerance to MTX, physicians may consider the use of XELJANZ as monotherapy.

Use of XELJANZ in combination with biological disease modifying anti-rheumatic drugs (DMARDs) or potent immunosuppressants such as azathioprine and cyclosporine is not recommended.

## **Most serious warnings and precautions:**

**Risk of Serious Infections:** Patients treated with XELJANZ are at increased risk for developing serious infections that may lead to hospitalization or death. Most patients who developed these infections were taking concomitant immunosuppressants such as methotrexate or corticosteroids. If a serious infection develops, interrupt XELJANZ until the infection is controlled. Reported infections include: active tuberculosis, invasive fungal infections, bacterial, viral, and other infections due to opportunistic pathogens.

Treatment with XELJANZ should not be initiated in patients with active infections including chronic or localized infection.

Patients should be closely monitored for the development of signs and symptoms of infection during and after treatment with XELJANZ, including the possible development of tuberculosis in patients who tested negative for latent tuberculosis infection prior to initiating therapy.

**Malignancies:** Lymphoma and other malignancies have been observed in patients treated with XELJANZ. Epstein Barr Virus-associated post-transplant lymphoproliferative disorder has been observed at an increased rate in renal transplant patients treated with XELJANZ and concomitant immunosuppressive medications.

## **Other relevant warnings and precautions:**

- Risk of gastrointestinal perforation. Use with caution in patients who may be at increased risk for gastrointestinal perforation.

- Risk of viral reactivation, including herpes zoster.
- Risk of malignancies, lymphoproliferative disorder, and nonmelanoma skin cancer.
- Risk of lymphopenia, neutropenia, anemia, and lipid elevations.
- XELJANZ should not be used in patients with severe hepatic impairment, or in patients with positive hepatitis B or C virus serology.
- Use with caution in patients with a risk or history of interstitial lung disease (ILD).
- XELJANZ can increase the risk of immunosuppression. Concurrent use with potent immunosuppressive drugs is not recommended.
- Concurrent use with live vaccines is not recommended.
- Use with caution in patients with impaired renal function (i.e., CrCl <40 mL/min).
- XELJANZ should not be used during pregnancy.
- Women should not breastfeed while being treated with XELJANZ.
- The safety and effectiveness of XELJANZ in pediatric patients have not been established.
- Caution should be used when treating the elderly because of an increased risk of serious infection.
- Use with caution in Asian patients because of an increased risk of events including: herpes zoster, opportunistic infections and ILD.
- Treatment with XELJANZ was associated with increases in creatine kinase.



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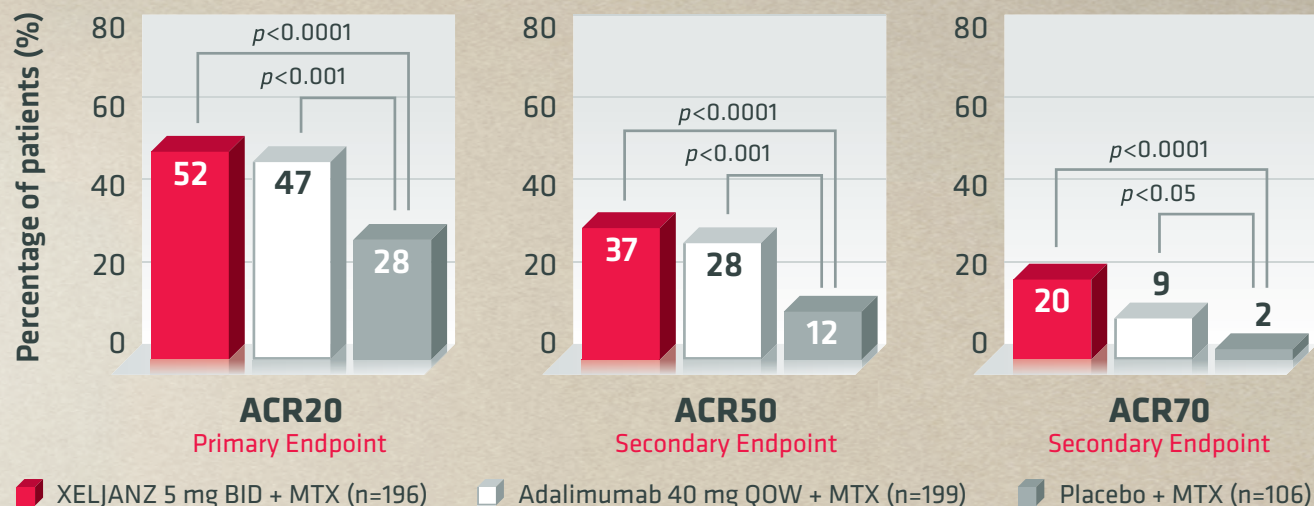


## Demonstrated powerful efficacy where response to methotrexate was inadequate

Significant symptom reduction was shown at 6 months in MTX-IR patients treated with XELJANZ + MTX vs. placebo + MTX.<sup>1\*</sup>

This study was not designed to compare XELJANZ to adalimumab.

### ACR response rates at 6 months



Significant improvement in physical functioning at 3 months was achieved in MTX-IR patients treated with XELJANZ + MTX vs. placebo + MTX.<sup>1\*</sup>

Mean HAQ-DI decrease from baseline at 3 months: -0.56 XELJANZ 5 mg BID or -0.51 adalimumab 40 mg QOW vs. -0.25 placebo ( $p < 0.0001$ ).

This study was not designed to compare XELJANZ to adalimumab.

- XELJANZ causes a decrease in heart rate and a prolongation of the PR interval. Caution should be observed in patients with a low heart rate at baseline (<60 beats per minute), a history of syncope or arrhythmia, sick sinus syndrome, sinoatrial block, atrioventricular (AV) block, ischemic heart disease, or congestive heart failure.
- Treatment with XELJANZ was associated with increased incidence of liver enzyme elevations.

#### For more information:

Please consult the product monograph at [http://www.pfizer.ca/en/our\\_products/products/monograph/342](http://www.pfizer.ca/en/our_products/products/monograph/342) for important information relating to adverse reactions, interactions, and dosing information which have not been discussed in this piece. The product monograph is also available by calling us at 1-800-463-6001.

**Reference:** 1. Pfizer Canada Inc. XELJANZ Product Monograph. April 16, 2014. 2. Arthritis Society. June 2014 Impact - Ease of Use. Available at <http://www.arthritis.ca/page.aspx?pid=7650>. Accessed July 22, 2014.

BID = Twice daily; QOW = Every other week; MTX-IR = Methotrexate Inadequate Responders

\*Multicentre, randomized, double-blind, placebo-controlled study in patients  $\geq 18$  years with active RA according to ACR criteria. Patients received MTX and were randomized to receive XELJANZ 5 mg BID (n=196), adalimumab 40 mg QOW (n=199), or placebo (n=106). The primary endpoints were the proportion of patients who achieved an ACR20 response at month 6, mean change from baseline in HAQ-DI at month 3, and the proportion of patients who achieved DAS28-4 (ESR)  $< 2.6$  at month 6.

†The Arthritis Society's Ease-of-Use Commendation recognizes products, like the XELJANZ bottle cap, that have been independently tested for easy use and handling for people living with arthritis. The Arthritis Society does not determine the therapeutic value of products and the designation is not intended as a general product endorsement that are designed for ease of use in patients with arthritis.



The XELJANZ bottle cap was awarded The Arthritis Society's Ease-of-Use Commendation.<sup>2†</sup>



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