# **Arthritis Alliance of Canada NEWSLETTER**

## **June 2019**

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#### **ARTHRITIS ALLIANCE OF CANADA**

#### ONGOING PROJECTS

Developing a patient-centered framework for measuring, monitoring and optimizing rheumatoid arthritis care – Public Comment Phase Completed!



As part of the Balanced Scorecard (BSC) project, Dr. Claire Barber at the University of Calgary and Dr. Diane Lacaille at the University of British Columbia, have been leading a National CIHR-funded study to define quality RA care and build a framework for measuring it. The research team has just completed the public comment phase of the study, with the survey closed on June 7<sup>th</sup>, and a number of helpful comments received.

The research team is currently analyzing feedback from the survey and evaluating the ways in which it will impact the scorecard. *Stay tuned for more updates on this important project!* 



## The CRA-AAC-CIHR-CATCH Collaborative Project to Build an Economic Business Case for AAC IA Models of Care

The 4-way collaboration project, a study on building an economic business case for the AAC Inflammatory Arthritis Models of Care (IA MOCs), is progressing well. As part of the Cost-Consequences Analysis stage, the research team had completed analysis of qualitative data for 9 out of 10 participating CATCH sites and started analyzing and comparing these data across the sites. 10 out 16 CATCH sites representing four provinces, Alberta, Manitoba, Ontario and Quebec. The results of the qualitative analysis will be eventually shared with the project partners and their stakeholders. *The working team is excited about this project's interim success and will continue updating you on its progress!* 

#### AAC 2019 Research Awards Program – 43 Applications Received!



Dear readers! The Call for Applications for the 4<sup>th</sup> round of the AAC Research Awards Program completed on Monday, May 31<sup>st</sup>. This awards cycle identified a total of **fourty-three** (43) **applications** for six awards, valued at \$750 CAD/award.

AAC will commence review of the applications over the coming weeks. Awards are expected to be presented to the winning applicants during the Special Awards Ceremony on Friday, November 29th in Toronto.

Big "Thank You" to our sponsors-McCaig Institute for Bone and Joint Health, Arthritis Consumer Experts, CIHR Institute of Musculoskeletal Health and Arthritis, Arthritis Research Canada and the Arthritis Society!

#### **AAC 2019 Annual Meeting – SAVE THE DATE**

The Arthritis Alliance of Canada's 2019 Annual Meeting will be hosted on Friday, November 29th at the Delta Hotels Toronto. This meeting program will be a half-day event and run from 12:30 pm to 5:00 pm EST, concluded by a cocktail reception immediately after the meeting.

Stay tuned for more details on the program and the registration process to start mid-September. We look forward to your participation and engagement in Toronto!



## MEMBER'S CORNER

#### **ARTHRITIS RESEARCH CANADA**

#### **New Grant Received by ARC**



It has been an exciting month for Arthritis Research Canada! We are proud to be the recipient of a two-million grant, awarded by Health Minister, Adrian Dix. This funding will allow us to make significant advances in research aimed at arthritis prevention, early diagnosis, better treatment and improved quality of life.

#### Welcome Dr. Jackie Whittaker to ARC!

We are also pleased to announce that *Dr. Jackie Whittaker* (PT, PhD) has joined Arthritis Research Canada as a Research Scientist of Musculoskeletal Rehabilitation. Osteoarthritis is common, disabling and the number of joint replacements is rising dramatically. Injury is a major cause. In fact, it has been suggested that 25% of all knee osteoarthritis is caused by sports injuries from age 14 to 21. Dr. Whittaker believes many of these cases of knee osteoarthritis can and should be prevented. Her research has the potential to create a huge benefit for the Canadian population. Welcome to the team Dr. Whittaker!



#### Congratulations to Dr. Cheryl Barnabe!

We are also excited to announce that *Dr. Cheryl Barnabe*, Senior Research Scientist of Rheumatology, has received a 5-year Tier II Canada Research Chair for Rheumatoid Arthritis and Autoimmune Diseases. Her work will benefit indigenous people with arthritis in Canada and around the world. We would also like to congratulate *Dr. Linda Li*, Senior Scientist of Clinical Epidemiology, on her Tier II Canada Research Chair renewal for Patient-Oriented Knowledge Translation.

#### **ARTHRITIS CONSUMER EXPERTS**

#### Canada's Best Workplaces for Employess Living with Arthritis



Canadian employers, working with their private health insurers, are increasingly looking for ways to promote patient-focused prevention, treatment and management of arthritis as part of a health and wellness program for employees. To recognize these best arthritis practices, Arthritis Consumer Experts (ACE) is searching for Canada's Best Workplaces for Employees Living with Arthritis.

ACE analyzes company practices and programs compared to other candidate companies based on criteria such as arthritis literacy, physical workplace adaptability, flexible hours and extended health benefit plans.

For more information on Canada's Best Workplaces for Employees Living with Arthritis award, please <u>click here</u>. The deadline to apply is August 9, 2019.

#### ARTHRITIS SOCIETY

#### **National Office**

#### **New Workplace Resources**

Working with arthritis can make some things more challenging, but many of those challenges can be made easier through simple accommodations that can help maximize employee well-being and effectiveness. Employers can improve productivity and increase retention of valuable skills and experience by creating a framework to support employees living and working with arthritis. We have built an expanded library of resources and guidance for employers and employees - check them out at <a href="https://www.arthritis.ca/work">www.arthritis.ca/work</a>.



#### **Summer camps**

With the warm weather finally upon us, our summer camps are already in full swing. Across the country, nearly 400 children and youth living with arthritis are gearing up to attend one of our seven camps, taking place from the Atlantic region to British Columbia and points in between. Campers will be on the go every day enjoying new adventures, making friends, and filing away so many happy memories. This includes participating in activities such as canoeing, kayaking, archery, wilderness camping skills, waterskiing, high ropes, horseback riding, rock climbing and campfires. It's amazing what kids with arthritis can do given the opportunity – but the best part of camp is the connections they make, and the confidence they gain from knowing they're not alone. We are thrilled to provide a space for children and youth living with arthritis to feel the joy of the community of campers just like them, including our first camper from Newfoundland and Labrador. It's a place where everyone understands you, and each camper is supported to grow in big and small ways. In the words of a former camper, "I finally found people who I could be myself around. Thank you."

#### Leading the way in OA research

In May, the Osteoarthritis Research Society International (OARSI) held its annual world congress in Toronto, the leading international conference focused on cutting-edge clinical and basic biomedical research on osteoarthritis (OA). The congress was attended by over 1,200 research scientists, rheumatologists, surgeons, radiologists, allied health professionals, and others. This was the highest attendance that the congress has ever had in North America.

At the congress, the OARSI Basic Science Research Award was presented to *Dr. Frank Beier* from Western University for his pioneering work in studying the genetics and molecular biology of OA in rodent models. We are proud to have funded Dr. Beier's research over the years, and have had the pleasure of working with him as a volunteer expert reviewer and advisor for our research program. Listen to Dr. Beier talk about his research in this video from Western University (English only).

#### **Atlantic Division**

#### **New Executive Director**

Susan Tilley-Russell, Executive Director of the Atlantic region, has decided to retire as of the end of June 2019. Susan has been with the Arthritis Society for 9 years, leading the work of our four Atlantic provinces and engaging a dedicated team of staff and volunteers. Susan has worked tirelessly to support people with arthritis in the Atlantic communities. We thank Susan for all her years of work on behalf of the arthritis community. Jone Mitchell, previously our Director of Development for Nova Scotia, has been named the new Executive Director, Atlantic Division, effective July 1st. Congratulations Jone!

### **COMMUNITY UPDATES**

#### CANADIAN RHEUMATOLOGY ADMINISTRATIVE DATA NETWORK

#### **McGill University Health Centre**



Interesting research projects are underway at the Research Institute of the McGill University Health Centre (RI MUHC), led by rheumatologist *Dr. Évelyne Vinet*. To improve strategies for health professionals counselling pregnant women with rheumatic disease, her team conducted a focus group

study assessing the clinical and psychosocial needs, barriers, and facilitators to pregnancy counselling in women with RA and SLE. Abstracts for this study were presented at the 2018 ACR and at the 2019 CRA. She is also building the Lupus prEGnAnCY (LEGACY) cohort, a large, multi-centre, international prospective cohort of SLE pregnancies, to evaluate adverse pregnancy outcomes, their predictors, and potential preventive therapies. A Canadian Initiative for Outcomes Research in Arthritis (CIORA) funded randomized controlled trial is underway assessing an educational tool for improving preeclampsia knowledge in pregnant women with SLE. Dr. Vinet was the recipient of the Laurentian Rheumatology Conference 50th Anniversary Award (\$1,000) where she also presented Lupus: a case of female discrimination. Team members of the Montreal General Hospital Lupus Clinic took part in the Scotia Bank Charity Challenge 5K run on April 27 to support the Singer Family Fund for Lupus Research. For more information, pertaining to our RI MUHC activities, fundraising efforts and our Lupus Clinic, please contact autumn.neville@rimuhc.ca.

The CANRAD Network team includes a variety of decision makers, epidemiologists, clinicians and researchers interested in the use of administrative data for rheumatic disease research. We held our annual CANRAD Network Meeting during the 2019 CRA Annual Scientific Meeting & AHPA Annual Meeting in Montreal, QC. We discussed the validation of administrative data algorithms to study chronic conditions as well as



pediatric outcomes in chronic illness. Our spring webinar will be held April 15, 2019, and we are happy to have the presentation *Prognostic risk score development and validation* by Dr. Cynthia Crowson. For more information pertaining to our meetings, upcoming webinars or all other information concerning the CANRAD Network, please contact at <u>autumn.neville@rimuhc.ca</u> or visit our website <a href="http://www.canradnetwork.ca/">http://www.canradnetwork.ca/</a>.



The CAnadian Network for Advanced Interdisciplinary Methods for comparative effectiveness research (CAN-AIM) objective is to respond to key knowledge gaps regarding drug safety and effectiveness by answering queries which arise from Health Canada and other regulatory parties. We are currently working with several enhanced cohorts, including PiMS, CATCH, CanHepC and GENESIS-PRAXY, as well as

responding to a number of queries from Health Canada using other clinical and administrative databases. Our team has collaborated with DSECT's webinar series; we encourage you to participate in the very informative sessions. We were recently funded to build a biologic registry to provide real-world information comparing the safety and effectiveness of biosimilar drugs versus their originator biologic drugs. Our five-year study includes adults (aged 18 years and older) with inflammatory rheumatic disease or inflammatory bowel disease who are initiating therapy with a biosimilar or the originator biologic drug. The primary outcome is simply maintenance of treatment, but we will also collect information on start/stop/changes in systemic steroids and immunosuppressive drugs, disease control, and adverse effects, particularly infection. For information on our queries, on our upcoming webinars or for more information on our team, please contact at autumn.neville@rimuhc.ca or visit our website http://canaim.ca/.

#### MCCAIG INSTITUTE FOR BONE AND JOINT HEALTH

#### The Mobility for Life Project

The McCaig Institute for Bone and Joint Health is about to launch *The Mobility for Life Project* – a longitudinal cohort study that expands existing research studies and includes exciting new research initiatives. The *Mobility for Life Project*, which will begin recruiting study participants in late 2019,



will follow a large cohort of people with and without bone and joint conditions over many years. *The Project* will encompass both existing and new studies in four key areas; healthy living, inflammatory arthritis, osteoarthritis and osteoporosis. Much of the data will be collected in the McCaig Institute's Centre for Mobility and Joint Health.

The McCaig Institute is currently inviting applications for a Program Manager for the *Mobility for Life Project*. If you are interested, see the full job profile for more information, or visit this <u>URL</u>.

#### RESEARCH INSTITUTE OF THE McGILL UNIVERSITY HEALTH CENTRE (RI-MUHC)

#### **Congratulations to Dr. Vinet!**

Dr. Vinet received the Laurentian Rheumatology Conference 50th Anniversary Young Investigator Award. She was presented the award after she gave a talk called "State-of-the-art – Lupus: A case of female discrimination" at the 50<sup>th</sup> Edition of the Laurentian Conference of Rheumatology in Estérel, Québec, Canada.

#### **Abstracts at the Laurentian Conference**

The following abstracts were presented at the 50<sup>th</sup> Edition of the Laurentian Conference of Rheumatology:

- 1) Challenges to Optimal Rheumatology: A Focus Group Study. Dollinger J, Neville C, Pineau CA, Vinet E, Hazel E, Lee J, Bernatsky S. The aim of this study was to assess challenges to optimal rheumatology care, from the point of view of patients attending a tertiary care rheumatology clinic. This study provides insights into the barriers and facilitators that patients experience related to quality rheumatology care, confirming results from earlier work. Communication between providers, as well as between patients and providers, is important. Self-management is a key component of rheumatology care, but requires knowledge about the disease and coping skills to withstand daily challenges.
- 2) Clinical Significance of Raynaud Phenomenon in Systemic Lupus Erythematous. Nour Rached-d'Astous, Christian Pineau, Evelyne Vinet, Louis-Pierre Grenier, Fares Kalache, Sabrina Fallavollita, Sasha Bernatsky. We conducted a cross-sectional study amongst the patients in our lupus cohort to look at whether or not Raynaud's phenomenon was associated with particular clinical manifestations in Systemic Lupus Erythematosus. We found a positive association between Raynaud's phenomenon and anti-RNP antibody, anti-Smith antibody and female gender.



### **Calendar of Events**

Juvenile Arthritis Conference, Arthritis Foundation	July 18 – 21, 2019	Houston, Texas, USA
13 <sup>th</sup> International Conference on Orthopedics, Arthroplasty and Rheumatology	July 25 – 26, 2019	London, UK
International Federation on Ageing, 14 <sup>th</sup> Global Conference	August 8-10, 2019	Toronto, ON
Association of Women in Rheumatology National Conference	August 15, 2019	Hilton Head, South Carolina, USA
International Conference on Arthritis: Global Challenges and Future Perspectives	August 19 – 29, 2019	Vancouver, BC
Lupus Academy 8 <sup>th</sup> Annual Meeting	September 6 -8, 2019	Warsaw, Poland
46 <sup>th</sup> Annual Meeting and Refresher Course, The International Skeletal Society	September 7 – 13, 2019	Vancouver, BC
Discrete Choice Experiment Short Course	September 8-11, 2019	Banff, Alberta
14th World Congress on Inflammation	September 15 -19, 2019	Sydney, Australia
World Congress on Rheumatology and Orthopedics, Scientific Federation	September 24-25, 2019	Madrid, Spain
13 <sup>th</sup> Annual Conference Pain Society of Alberta	October 17 – 20, 2019	Lake Louise, Alberta
17 <sup>th</sup> International Congress of Immunology (IUIS)	October 18 -22, 2019	Beijing, China
The International Hand and Wrist Congress (IHWC)	November 14 – 16, 2019	Dubai, UAE
Arthritis Alliance of Canada 7th Annual Meeting	November 29, 2019	Toronto, Ontario

#### ABOUT THE ARTHRITIS ALLIANCE OF CANADA

With more than 35 member organizations, the Arthritis Alliance brings together arthritis health care professionals, researchers, funding agencies, governments, voluntary sector agencies, industry and, most importantly, representatives from arthritis consumer organizations from across Canada. While each member organization continues its own work, the Alliance provides a central focus for national arthritis-related initiatives.

For more information about the Arthritis Alliance, please contact: Lina Gazizova at <a href="mailto:lgazizova@arthritisalliance.ca">lgazizova@arthritisalliance.ca</a> or visit our website: <a href="www.arthritisalliance.ca">www.arthritisalliance.ca</a>