Arthritis Alliance of Canada NEWSLETTER

February 2019

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ARTHRITIS ALLIANCE OF CANADA ONGOING PROJECTS

The Osteoarthritis (OA) Information Handout for Patients

The Arthritis Alliance of Canada (AAC) OA Information Handout for Patients is being developed through an iterative process with OA patients and patient-led organizations in partnership with OA content experts from the AAC Models of Care Committee and key stakeholders from member organizations. The Handout is intended to serve as a resource to improve patient self-management, self-advocacy and health literacy; and its design will complement the style and content of the OA Tool for primary care practitioners (PCP) to facilitate meaningful and effective patient-PCP dialogue.

The (AAC) OA Information Handout for Patients will: 1) assist those with or at risk of OA, in having better conversations with their doctors or other health care professionals, by informing them about the care they can expect



to receive-good communication between patients and doctors is important in reaching an accurate diagnosis and building effective treatment plans; 2) help patients identify the causes of their joint pain and loss of mobility; 3) inform them of the basics of primary prevention strategies and self-care methods; and 4) improve patients' quality of life through the successful implementation and adoption of this Handout.

The draft "Handout" Infogram will be circulated soon to the entire AAC membership and key stakeholders for a final round of feedback. *Stay tuned!*

Developing a Balanced Scorecard for Patients with Inflammatory Arthritis

Funded by the Canadian Institutes of Health Research (CIHR), the purpose of this project is to develop a Patient-Centered Balanced Scorecard for Rheumatoid Arthritis (RA). This reporting tool will be a framework for improving quality of care for RA that is defined by stakeholder priorities, and is national in scope. Commencing in June 2017, it is being led by a clinicians and researchers from the University of Calgary, the University of British Columbia, the University of Alberta and Arthritis Research Canada (ARC). The project is supported, as well, through ongoing collaboration with the Arthritis Alliance of Canada (AAC) and the Canadian Rheumatology Association (CRA) Quality of Care Committee.

Phases I and II of the project are complete. Results are being presented at the Canadian Rheumatology Association Annual Scientific Meeting, February 2019, in the following posters: Phase I: "Developing a Patient-Centered Balanced Scorecard for Quality of Care in Rheumatoid Arthritis: Vision and Strategic Objectives" and Phase II: "A Patient-Centered Balanced Scorecard for Rheumatoid Arthritis: Selecting the Performance Measures"

Currently, the research team is building an electronic version of the scorecard for testing and evaluation in a rheumatology clinic setting during 2019. A phase of public comment on the scorecard is set to commence in March 2019. Please stay tuned for more updates on this great project!

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

"Building an Economic Business Case for AAC IA Models of Care ", a collaborative initiative, which embarked on in 2017 by the Arthritis Alliance of Canada, Canadian Rheumatology Association, Canadian Institutes of Health Research and Canadian Early Arthritis Cohort (CATCH) National study, is well on track with the first phase of this study being currently underway.

The project explores characteristics of examples of models of care for patients with Inflammatory Arthritis and assesses the associated quality of care and costs in order to identify factors that contribute to a successful model of care in the Canadian environment. The Working Committee has engaged 8 CATCH sites to participate in the study.

Conducting a mix of survey and phone interviews with the investigative sites is part of the qualitative phase of the study. An update on the study progress will be presented during the National Update Session at the Canadian Rheumatology Association (CRA) Annual Scientific Meeting on Thursday, February 27th in Montreal.

During this meeting, an interactive workshop on this project will be hosted on Saturday, March 2nd, 2019, from 10:00 -11:00 am, at Fairmont the Queen Elizabeth Hotel in Montreal. The objectives of the workshop are to: 1) present to the meeting participants the purpose for the economic business case for AAC Inflammatory Arthritis Models of Care (IA MOCs) in Canada; 2) explore the role of collaborative projects on the cost-consequence analysis of IA MOCs and the value and strength of collaborative research; and 3) determine how the cost-consequence analysis of IA MOCs cam identify opportunities to improve access to care, and ultimately patient outcomes. During the second part of the workshop, participants will have the opportunity to engage in a facilitated discussion about improving access to care for patients with Inflammatory Arthritis and increasing the uptake of MOCs. *We look forward to your participation at the workshop!*

AAC Research Awards 2019: Timelines

Dear readers! We are delighted to announce the timelines of the 2019 AAC Research Awards cycle below:

Call for Applications:	Monday, April 1st, 2019	
Application Deadline:	Wednesday, May 15th, 2019	
Applications Review Process:	June - September 2019	
Announcement of Award Recipients:	End of November 2019	



Stay tuned for an official "Call for Applications" launch in April!

MEMBER'S CORNER

ARTHRITIS RESEARCH CANADA

Exciting Research Projects in 2019



Arthritis Research Canada has had a great start to 2019! We are excited to announce that Dr. Diane Lacaille, our Associate Scientific Director, will receive the Distinguished Investigator Award from the Canadian Rheumatology Association. Our scientists have also secured a significant amount of funding to research automated

electronic medical record reminders, the cost benefit of new biologic agents in treating children with inflammatory arthritis, use of advanced multi-modal imaging to predict early inflammatory arthritis progression, and mental health complications in individuals with inflammatory arthritis. We look forward to the life-changing findings this research will bring.

2019 Arthritis Soirée

The 2019 ARThritis Soirée will be held on **May 22 at The Roof, Hotel Vancouver at 7pm PDT**. Mike Reno, lead singer of Loverboy, along with an all-star band, will give an up close and personal performance that will include some of Loverboy's greatest hits. A fabulous evening, co-hosted by Fred Lee and Sonia Deol, will present a choice of gourmet hors d'oeuvres, BC wines, champagne, the legendary oyster and caviar bars compliments, an exclusive raffle, and live and silent auctions.

For more information about the event, please visit <u>arthritissoiree.ca</u> and join us in supporting life-changing arthritis research!

ARTHRITIS CONSUMER EXPERTS

Arthritis and Mental Health

In the latest <u>issue of JointHealthTM insight</u>, Arthritis Consumer Experts (ACE) reports on the important relationship between mental health and arthritis. The issue also covers the burden of depression on love, and recognizing, preventing, and managing depression and anxiety. <u>Click here</u> to read the latest issue.



#CRArthritis Facebook and Twitter Live event

Interviews will take place from Wednesday, February 27th until Saturday, March 2nd in the Arobase room on the third floor above the main conference area. Interview sign-up sheets will be posted outside of the room. We look forward to your participation!

CANADIAN RHEUMATOLOGY ASSOCIATION

CIORA Online Grant Application System is now open!



Canadian Initiative for Outcomes in Rheumatology cAre (CIORA) is a unique granting division of the CRA committed to being a catalyst for improving the care of Canadians living with all rheumatic diseases. CIORA's grant program supports sustainable projects related to rheumatic diseases that promote:

- Awareness/Advocacy/Education
 - Health Economics/Sustainability of Health Care/Quality Improvement
- Early Access for rheumatic disease patients
- Multi-Disciplinary Care Teams

CIORA is issuing another call for grants in 2019!

CIORA Online Grant Application System to open: January 28, 2019 Letter of Intent must be submitted by: February 25, 2019

CIORA Online Grant Application submission deadline: April 1, 2019 at 17:00 (Pacific Time)

Grant notifications to be sent out: June 2019

ARTHRITIS SOCIETY: NATIONAL OFFICE



New Online Education Module

The Arthritis Society is excited to announce its newest online education tool, Overcoming Fatigue. This free program teaches about arthritis-related fatigue and empowers the user to make positive changes to find more energy in day-to-day life.

More online learning modules will be released throughout the year, visit the Arthritis Society education website to learn more: https://arthritis.ca/support-education/online-learning.

Arthritis Society 70th Anniversary Gala

The Arthritis Society 70th Anniversary Gala will be held on March 7, 2019 at Arcadian Court in Toronto. The Gala will focus on celebrating and recognizing the achievements of trailblazing women who have had an impact on the research and science surrounding Arthritis. This includes a tribute to Dr. Claire Bombardier and her research as well as the many other women who have contributed to Arthritis research. For more information and to purchase tickets, please contact Amy Burstyn at amy@burstyninc.com or at 647.272.3776.



McCAIG INSTITUTE FOR BONE AND JOINT HEALTH

Congratulations to McCaig Institute members

Congratulations to McCaig Institute members Steven Boyd and Deborah Marshall for their successful CIHR project grants:



- Steven Boyd: Advanced multi-modal imaging to monitor progressive joint adaptation in the knee following an acute ligament injury
- **Deborah Marshall:** Towards a patient-centered system: Integrating preferences of patients with osteoarthritis into evaluation of health services interventions to improve patient outcomes and health system efficiency.

We'd also like to congratulate Dr. Glen Hazlewood on receiving the Canadian Rheumatology Association's Emerging Investigator Award.

<u>CANADIAN ARTHRITIS PATIENT ALLIANCE</u>

Survey on Arthritis in Children

CAPA has partnered with the Ireland Children's Arthritis Network to understanding tips and tricks that parents and their kids use to deal with methotrexate - feel free to respond to our survey or pass it on! surveymonkey.com/r/QXVCJYM.



CAPA at the CRA ASM



Laurie Proulx will be presenting at the CRA - visit her posters 12 & 13: "Supporting Improved Patient Care: Developing Educational Resources for Patients and by Patients" and "#ArthritisParent: Evaluating Outcomes of a Twitter Chat on Issues regarding Arthritis, Pregnancy, and Parenting" on February 28 at 3.15 pm.

COMMUNITY UPDATES

INSTITUTE OF MUSCULOSKELETAL HEALTH AND ARTHRITIS

CIHR-IMHA Priority Announcement Urgent Reminder

Application Deadline: March 6, 2019

Increase your chance to receive funding in the upcoming Priority Announcement by selecting 1 of the 4 IMHA related funding pools (Musculoskeletal Health, Skin Health, Oral Health, or recently added Arthritis).

Priority Announcements (PAs) offer additional sources of funding (\$100,000) for highly rated applications that are relevant to specific research areas. Applications are submitted through the "201809PJT" competition of the Project Grant: Spring 2019 funding opportunity. Frequently Asked Questions provide additional information on the PA program. Remember to clearly indicate which of the funding pools listed above you are applying for on the Relevance Form. More information on research priorities of CIHR-IMHA can be found on our website.

UNIVERSITY OF CALGARY

New CIHR Porject Grant for OA study at University of Calgary

The University of Calgary has recently won a CIHR Project Grant for the study titled "Towards a patient-centered system: integrating preferences of patients with osteoarthritis into evaluation of health services interventions to

improve patient outcomes and health system efficiency." The study will look at two different policies aimed at addressing wait times for surgery. The first is a referral management policy which would give patients information about wait times for different surgeons and allows them to choose their preferred surgeon or the surgeon with the shortest wait time. The second policy offers patients the choice of an evidence-based conservative medical management program. Our study will look at whether patients would take up this alternative program and how this varies by characteristics of the program such as its cost. Depending on patient choices, both policies may shorten overall wait times, improve outcomes and reduce costs.

The Discrete Experiment Short Course

Dr. Deborah Marshall from University of Calgary, and Professor Mandy Ryan from the University of Aberdeen, will be presenting the Discrete Choice Experiment Short Course to be held at the Banff Centre for Learning, September 8-11, 2019. The registration deadline is August 1, 2019. Details can be found here: https://www.eiseverywhere.com/392142.

OBESITY CANADA

The 6th Canadian Obesity Summit



Obesity Canada is gearing up for the **6th Canadian Obesity Summit** April 23 to 26, 2019 in Ottawa, ON. The Summit is a multi-disciplinary scientific conference and networking event that takes a sweeping look at the latest research and best practices around obesity treatment and prevention. Be sure to check out the free workshops organized by some of the top organizations and professionals working in obesity today. Early-bird registration deadline: March 14, 2019. Link to the event at: obesitycanada.ca/summit-2019.

THE RESEARCH INSTITUTE OF THE McGILL UNIVERSITY HEALTH CENTRE

Exciting Research led by Dr. Sasha Bernatsky

Several exciting studies are currently being conducted at the RIMUHC by Dr. Sasha Bernatsky:

- 1. Comparative Effectiveness and Safety of Biosimilar and Legacy Drugs: The aim of this 5-year study is to compare the safety and effectiveness of biosimilar drugs versus their originator biologic drugs. Our study includes adults (18 years and older) with inflammatory rheumatic disease or inflammatory bowel disease who are initiating therapy with a biosimilar or the originator biologic drug. There are no disease activity criteria for entry. The primary outcome measure is simply maintenance of treatment, but we will also collect information on start/stop/changes systemic steroids and immunosuppressive drugs, disease control, and adverse effects, particularly infection.
- 2. Hydroxycholoroquine in Systemic Lupus: Hydroxychloroquine (HCQ) is a key drug which can reduce the risk of serious disease flares in Systemic lupus (SLE). However, there are increasing concerns about eye damage, the main side effect with long-term use of this drug. At present, we cannot precisely predict which SLE patient is most likely to flare once HCQ is tapered. Similarly, it is not clear what drives risk of eye damage. Our study will fill these knowledge gaps, and add information about patient preferences for HCQ use.
- 3. Air Pollution and Systemic Autoimmune Rheumatic Diseases: There is a growing interest in the role of air pollution on inflammation and disease. Our team has shown an association between road-traffic density and rheumatic disease onset in Montreal, found links between PM2.5 levels and rheumatic disease activity, and suggested PM2.5 and industrial emissions as triggers of rheumatic disease. The key areas that remain unknown are what types of pollution exposures might be most important, for both risk of antibody development and rheumatic disease risk. Our study will fill these remaining important knowledge gaps.

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. Evelyne Vinet. To improve strategies for health professionals counselling pregnant women with rheumatic disease, her team is conducting a focus group study assessing the clinical and

psychosocial needs, barriers, and facilitators to pregnancy counselling in women with RA and SLE. The first abstract for this study was presented at the 2018 ACR, and an abstract will be presented 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. Our Lupus Clinic celebrated 40 years of research this fall! Team members of the Montreal General Hospital Lupus Clinic will take part in the Scotia Bank Charity Challenge 5K run on April 27 to raise funds to support the Singer Family Fund for Lupus Research, funding that is instrumental to funding research activities at the clinic. 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 will hold our annual CANRAD Network Meeting during the 2019 CRA Annual Scientific Meeting & AHPA Annual Meeting in Montreal, QC on Thursday, February 28! For more information pertaining to our upcoming meeting, webinars or all other information concerning the CANRAD Network, please contact at autumn.neville@rimuhc.ca or visit our website http://www.canradnetwork.ca/.





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. Our team has collaborated with DSECT's webinar series; we encourage you to participate in the

very informative sessions. 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/.

Calendar of Events

CRA Annual Scientific Meeting and AHPA Annual Meeting	February 27 – March 2, 2019	Montreal, Quebec
CORA 2019: The 5 th International Congress on Controversies in Rheumatology and Autoimmunity	March 14 - 16, 2019	Florence, Italy
Canadian Rheumatology Ultrasound Society (CRUS) Basic Course	March 23 - 24, 2019	Toronto, Ontario
World Congress on Osteoporosis, Osteoarthritis and Musculoskeletal Diseases (WCO IOF-ESCEO)	April 4 - 7, 2019	Paris, France
Clinical Immunology Society (CIS), Immune Deficiency & Dysregulation North American Conference	April 4 - 7, 2019	Atlanta, Georgia, USA

13 th International Congress on Systemic Lupus Erythematosus	April 5-8, 2019	San Francisco, California, USA
Childhood Arthritis and Rheumatology Research Alliance (CARRA) Annual Scientific Meeting	April 10 - 14, 2019	Louisville, Kentucky, USA
32 nd Annual Spring Meeting, Canadian Society for Immunology (CSI)	April 12-15, 2019	Banff, Alberta
Childhood Arthritis & Beyond Meeting	April 23 – 26, 2019	Lake Louise, Alberta
14 th International Society on Scoliosis Orthopaedic and Rehabilitation Treatment (SOSORT) Meeting	April 25 - 27, 2019	San Francisco, California, USA
Osteoarthritis Research Society International (OARSI 2019) World Congress	May 2 - 5, 2019	Toronto, Ontario
50 th Edition of the Laurentian Conference of Rheumatology	May 9 - 11, 2019	Esterel, Quebec, Canada
5 th Annual Mayo Clinic Rheumatology Review for Primary Care 2019	May 23-25, 2019	Amelia Island, Florida, USA
2019 EULAR – The European Congress of Rheumatology	June 12 - 15, 2019	Madrid, Spain
Discrete Choice Experiment Short Course	September 8-11, 2019	Banff, Alberta
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 lgazizova@arthritisalliance.ca or visit our website: www.arthritisalliance.ca