Arthritis Alliance of Canada NEWSLETTER

September 2019

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ARTHRITIS ALLIANCE OF CANADA

Final Annual Meeting Friday, November 29th, 2019, 12:30-5:00 pm EST

The Arthritis Alliance of Canada's (AAC) Annual Meeting on Friday, November 29th will be the final face-to-face gathering of its members and stakeholders, devoted to celebration of the 16-year success of AAC's contribution into improving the lives of Canadians with arthritis through development and dissemination of numerous tools and programs in models of care, arthritis research, as well as advocacy and awareness initiatives. The meeting program will be a half-day event at the Delta Hotels Toronto that will highlight achievements and recognize recipients of the AAC six Research Awards, Qualman-Davies Consumer (Patient) Community Leadership Award and AAC Legacy Awards. A formal registration process to attend the AAC Final Annual Meeting is now open; and we are delighted to invite you to register, following the link to a registration page. We look forward to your participation and engagement in Toronto!





Legacy Awards

Early this week, AAC announced the Call for Proposals for six (6) <u>one-time</u> Legacy Awards, valued at up to \$35,000 CAD/award. The purpose of this funding opportunity is to allow <u>AAC member organizations</u> to collaboratively advance the <u>work of the Alliance</u> and continue communication and dissemination of available tools and resources. **Eligibility Criteria:**

- AAC Member organizations <u>must</u> apply <u>collaboratively</u>; individual applicants should represent <u>two or more</u> AAC member organizations.
- The <u>application form</u> is available online. The completed application should be submitted to the AAC office at <u>lgazizova@arthritisalliance.ca</u> by <u>midnight EST</u>, <u>Monday</u>, <u>October 28th</u>.
- The AAC Board will evaluate and decide on all applications received by the deadline.
- Decisions on the winners of the AAC Legacy Awards will be announced and awards presented on Friday,
 November 29th, 2019 at the AAC Annual Meeting Special Award Ceremony in Toronto, Ontario.

Please share this information with your colleagues!

ONGOING PROJECTS

Developing a Patient-Centered Framework for Measuring, Monitoring and Optimizing Rheumatoid Arthritis Care

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 of RA care and building a framework for measuring it. The research team completed analyzing the results of the public survey conducted in the early summer. Researchers are currently working with the Physician Learning Program through Alberta Medical Association and plan to present physician individualized reports on 5 measures addressing treat-to-target (T2T) in October 2019. The team is collaborating with Health Analytics Work Group (Department of Medicine,

University of Calgary) to develop a continuous reporting strategy. The study team is also conducting a follow-up project which aims to develop a patient survey for measuring quality of care. The team is preparing a series of manuscripts summarizing the work for all phases. Findings of the Balanced Scorecard for RA patients project will be presented at the AAC Annual Meeting on November 29, 2019 in Toronto. *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 study on building an economic business case for the AAC Inflammatory Arthritis Models of Care (IA MOCs) is well underway. This is 4-way collaboration (Canadian Rheumatology Association - Arthritis Alliance of Canada - Canadian Institutes of Health Research - Canadian Early Arthritis Cohort (CATCH)) project, led by Dr. Elena Lopatina, PhD candidate in Health Economics at the University of Calgary. Up-to-date, the research team had completed the first phase of the study - qualitative research, which included surveys and interviews with key representatives from 10 sites from the CATCH from four provinces, Alberta, Manitoba, Ontario and Quebec. The team has finalized the analysis of the qualitative DATA and are now preparing a report with findings from this qualitative work. The team has also started the second phase of the study, CATCH data analysis. Some results of this work will be presented at the AAC Annual Meeting on November 29, 2019 in Toronto. *The working team is excited about this project's success and will continue updating you on its progress!*

Arthritis Patient-led Groups Develop "Talk to Your Doctor About Joint Pain" Handout



On September 12th, 2019, arthritis patient-led organizations launched the <u>Talk to Your Doctor About Joint Pain Handout</u>, which is a patient version of the <u>Osteoarthritis Tool for Family Physicians</u> that was released by the AAC and the College of Family Physicians of Canada in 2017. The Talk to Your Doctor About Joint Pain Handout has been developed through a collaborative process involving multiple stakeholders, in consultation with members of the AAC Models of Care Committee and scientific and clinical experts in OA. A key objective of

this resource is to provide assistance to 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. The working group prepared and shared with the arthritis community promotional resources, including: an Infogram (letter and foldable format), a social media communication launch kit, social media press release and short video clips featuring Dr. Gillian Hawker promoting the Handout to: Patients, Healthcare Professionals and Stakeholders. We encourage you to continue promoting and disseminating this important tool with your communities – PLEASE ACT NOW!

AAC 2019 Research Awards Program: Update

The review of the **forty-three** (43) applications for the AAC Research Awards 2019 has completed. We would like to thank **twenty-one** (21) **reviewers** from the arthritis community-14 researchers and 7 patient representatives-who volunteered their time and shared expertise in arthritis research evaluating these applications. Award winners will be announced and awards will be presented at the *Special Awards Ceremony on Friday, November 29th in Toronto.*Thank you all for your great support in making this AAC program a successful effort once again!



ARTHRITIS CONSUMER EXPERTS

Arthritis Consumer Experts launches three-part series of JointHealthTM insight

During Arthritis Awareness Month in Canada, ACE published two issues of JointHealthTM insight with a focus on osteoarthritis and joint surgery. Part one (1) of the series covered important new research about osteoarthritis and increased risk of cardiovascular deaths. Part two (2) focused on evidence-based strategies for improving heart health and osteoarthritis. Part three (3) will be published during World Arthritis Day on October 12. We will take an in-depth look at recovering from joint replacement surgery – from a patient's perspective.



Election Advocacy

For the upcoming federal election, ACE sent open letters and surveys to the Conservative Party of Canada, the Green Party of Canada, the Liberal Party of Canada, and the New Democratic Party of Canada to help ACE members and subscribers compare newly emerging healthcare platforms. ACE outlines for the parties the impact of arthritis and asks them to share how government can contribute to implementing arthritis models of care and improving patient outcomes. Any responses received by ACE will be catalogued and posted on the Vote for Arthritis Federal Election 2019 page as they arrive.

ACE social media campaign

During Arthritis Awareness Month, ACE conducted a social media campaign - #ArthritisGlossary. The campaign reached more than 15,000 people on Facebook and had over 55,000 impressions on Twitter. Thank you to everyone who participated in our campaign.

ARTHRITIS RESEARCH CANADA

News from ARC



In connection with Arthritis Awareness Month, Arthritis Research Canada announced Olympic snowboarder, Spencer O'Brien as our spokesperson. Spencer was diagnosed with rheumatoid arthritis at the age of 25, prior to the 2014 Winter Olympic Games in Sochi. By openly sharing her story and being the face of Arthritis Research Canada, Spencer hopes to inspire others, dispel some of the more prevailing myths about arthritis

and promote that only through arthritis research can we find answers and save lives.

Arthritis Research Canada congratulates Christina Le and Darren Mazzei on receiving Arthritis Society doctoral salary awards. Ms. Le is a physiotherapist and Arthritis Research Canada trainee at the Glen Sather Sports Medicine Clinic, whose research focuses on youth sport-related knee injury. Her work seeks to inform rehabilitation strategies aimed at optimizing quality of life, preventing osteoarthritis, and ensuring the long-term health of youth that suffer from sport-related injuries. Mr. Mazzei is comparing the health benefits and economic costs of a pilot exercise education program that is currently running at rehabilitation clinics across Alberta, with programs that take the usual approach to osteoarthritis care. Osteoarthritis is one of the most common forms of arthritis and focusing on these initiatives to further research is a very worthwhile goal.

ARTHRITIS SOCIETY: NATIONAL OFFICE

Thank you to everyone who engaged in our Arthritis Awareness Month focus on women's health



We saw tremendous online engagement and interest in arthritis and women's health this month. Thank you to our arthritis community friends and colleagues for helping to amplify the message and get our resources in front of more people. Thousands of people have shared our posts, read our stories at www.arthritis.ca/flourish, and/or visited our new resources page at www.arthritis.ca/women. This important

conversation is just beginning – we look forward to generating more awareness and providing more support and engagement for women living with arthritis throughout the year.

NEW: Interactive Risk Assessment tool

Arthritis prevalence in Canada is expected to grow from 6 million today to 9 million by 2040, which means millions of Canadians are at risk of developing the disease. Our new Risk Assessment tool, developed with financial support from UCB, helps people identify whether they are at risk for arthritis by evaluating their health background, lifestyle and other factors. The tool provides customized guidance and links to resources to help mitigate against controllable factors, and it encourages people at higher levels of risk to discuss it with their doctor. Try out the tool at https://arthritis.ca/about-arthritis/arthritis-risk-factors/arthritis-risk-factor-assessment.

Federal election – Take Action!

Make arthritis matter this election: let the leaders and their parties know you expect them to put forward arthritis-friendly platforms. Visit www.arthritis.ca/fedvote2019, and in just a few short clicks you can support our recommendations around national pharmacare, medical cannabis and wait times for joint replacement by sending emails to the editors of your local papers, and to the party leaders. It is quick and easy to share your activity with your social networks as well, and ask them to lend their voice to this call for real action to support people living with arthritis.

Education Events- Education events

Fall is event season! We have a number of educational and other events scheduled throughout the month of October, in various regions across the country. To find out about events coming up in your area, visit www.arthritis.ca/events.

CANADIAN ARTHRITIS PATIENT ALLIANCE

SAVE THE DATA for CAPA Twitter Chat on October 12

Save the date for the next CAPA Twitter chat on #arthritisatwork! The event will be held on October 12 at 1 p.m. in support of World Arthritis Day. Please consider participating and sharing the event details with anyone interested in arthritis in the workplace.



We also recently published our fall newsletter where you can learn about our CADTH and Health Canada submissions, and read an article on rheumatology leader Dr. Karine Toupin-April to see what she is doing to support kids with arthritis and their families. You can also stay informed about CAPA activities by subscribing to our newsletter on the CAPA website.

McCAIG INSTITUTE FOR BONE AND JOINT HEALTH

Changing the narrative: Progress and challenges of improving osteoarthritis (OA) care



"In rich countries, costs of health care are rising faster than economic growth. We need to eliminate low-value interventions and practices," said Dr. Stefan Lohmander, MD, PhD, at the recent Cy Frank Legacy Lecture in Calgary. Lohmander, an orthopaedic surgeon from Lund University, Sweden, and a

world leader in using patient reported outcomes to evaluate care, delivered his lecture to an audience in Calgary, before traveling to Edmonton, Ottawa and London, ON for similar presentations.

Swimming upstream

Lohmander's provocative talk focused on how OA care needs to change. Stressing the importance of exercise as an effective OA drug, Lohmander raised concerns about prescribing opioids for pain relief in OA patients. "The evidence shows that NSAIDS (non-steroidal anti-inflammatory drugs, such as ibuprofen) and opioids offer similar pain relief in OA. Why, then, are doctors prescribing opioids for OA? This has to stop." Lohmander also discussed the overuse of arthroscopic surgery for knee pain in middle-aged and older patients. "There are a series of studies that show that lifestyle modifications and exercise are as effective as arthroscopic surgery in the management of the painful knee in middle aged patients," said Lohmander. "Given this, why would we prescribe surgery, which is costly and carries some risk?"

"We need to change the message, change the treatment focus and put the patient in charge. It's not about decreasing OA, it's about decreasing the burden of OA." A podcast of Dr. Lohmander's Calgary presentation is available at: mccaig.ucalgary.ca.

COMMUNITY UPDATES

CENTRE FOR HIP HEALTH AND MOBILITY

Survey Assessing the Quality of Rehab Care

Researchers (Lead: Dr. Marie Westby) at the Centre for Hip Health and Mobility in Vancouver, BC are conducting a Canada-wide survey to assess the feasibility and reliability of an online questionnaire on the quality of rehab care you routinely provide to patients after total hip and knee replacement surgery.



This questionnaire is one of many resources included in the QUICK-TJR toolkit that you can use to:

- Implement best practice recommendations for TJR rehab
- Track the quality of rehab you are providing
- Communicate rehab goals and expectations with your patients

Your responses will help to refine the questionnaire and capture a 'snap shot' of current rehab practices across Canada. Link to the 15-20 minute survey: https://tinyurl.com/TJR-questionnaire.

Survey closes October 30th. **Two \$25 Indigo gift cards offered as prize draws!** Participation in this survey is voluntary and by completing the survey, you are consenting to participate in the study. Additional information about your eligibility to participate in the study and how your responses will be kept confidential are described at the start of the questionnaire.

If you have any questions, please contact the Principal Investigator Dr. Westby <u>marie.westby@vch.ca</u> 604-875-4111/68834. Funding provided through an Arthritis Society/Arthritis Health Professions Association Research Award.

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

Health Canada Raises Concerns about Unproven Cell Therapies

RI-MUHC would like to share the information regarding the safety and effectiveness of cell therapies. Recently, Health Canada has raised concerns relating to Canadian health care practitioners who transmit unproven information regarding the safety and effectiveness of cell therapies (e.g., stem cell therapy). Some of these physicians have even started offering unauthorized cell therapies to patients, potentially exposing them to life-threatening or life-altering risks (e.g., serious infections). Since all cell therapies fall under the category of drugs according to the Food and Drugs Act, these treatments must be authorized and regimented by Health Canada. To date, only three therapies (Prochymal, Kymriah and Yescarta) have been granted market authorization by Health Canada. Apart from these therapies, some treatments can be administered to patients under the conditions of a Health Canada-approved clinical trial, which can be found on Canada's Clinical Trials Database. At the moment, most known cell therapies are in their experimental phases.

Health Canada encourages Canadians to report the potential sale or promotion of unauthorized therapies online (http://healthycanadians.gc.ca/apps/radar/MD-IM-0005.08.html), by calling a toll-free number (1-866-234-2345) or by reporting the issue by mail/fax (https://www.canada.ca/en/health-canada/services/drugs-health-products/medeffect-canada/adverse-reaction-reporting.html).

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. For more information, pertaining to our RI MUHC activities, fundraising efforts and our Lupus Clinic, please contact at lifang.wang@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 are currently organizing a CANRAD webinar for the fall. For more information pertaining to our meetings, upcoming webinars or all other information concerning the CANRAD Network, please contact lifang.wang@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 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 lifang.wang@rimuhc.ca or visit our website http://canaim.ca/.



Calendar of Events

3 rd World Congress of Sports Physical Therapy	October 4 -5, 2019	Vancouver, BC
13 th Annual Conference Pain Society of Alberta	October 17 – 20, 2019	Lake Louise, Alberta
17 th International Congress of Immunology (IUIS)	October 18 -22, 2019	Beijing, China
12 th World Congress on Rheumatology, Orthopedics &Sports Medicine	October 21 -22, 2019	Hong Kong
The International Hand and Wrist Congress (IHWC)	November 14 – 16, 2019	Dubai, UAE
2019 American College of Rheumatology (ACR) & Association of Rheumatology Professionals (ARP) Annual Meeting	November 8-13, 2019	Atlanta, Georgia, USA
Arthritis Alliance of Canada Final 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.