Arthritis Alliance of Canada NEWSLETTER

October 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) Final Annual Meeting face-to-face meeting of its members and stakeholders, sadly enough, is fast approaching. We'll gather for the last time and celebrate AAC's contribution into improving the lives of Canadians for consecutive 17 years, from 2002 to 2019. Our concluding meeting program will be taking place on Friday, November 29th 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 in progress and we would like to encourage you to register here!!

We look forward to seeing you in Toronto soon!



Legacy Awards

As you know, in September 2019, AAC announced the <u>Call for Proposals for six (6) one-time Legacy Awards</u>, 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. The AAC Board of Directors will start the review of all submissions shortly and the winning projects will be announced at the Special Awards Ceremony on November 29th as part of the AAC Final Annual Meeting program. *We look forward to sharing exciting news in November!*

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) on October 30th, 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 completed the analysis of the qualitative data and are now preparing a report with findings from this qualitative work. An abstract with findings from the qualitative phase has been submitted to the Canadian Rheumatology Association Annual Scientific Meeting 2020. 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!*

"Talk to Your Doctor About Joint Pain" Handout

Dear Colleagues,

In the closing days of <u>Arthritis Alliance of Canada</u>, there is excellent opportunity for offering a small portion of kindness to 6 million Canadians living with Osteoarthritis (OA)! On September 12th, 2019, arthritis patient-led organizations launched the <u>Talk to Your Doctor About Joint Pain Handout</u>, developed 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.

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The working group prepared and shared with the arthritis community promotional resources, including: an Infogram (letter and foldable format), a social medical medical medical social medical medical social social medical social social social social medical social so

communication launch kit, <u>social media press release</u> and short video clips featuring Dr. Gillian Hawker addressing to: <u>Patients, Healthcare Professionals</u> and <u>Stakeholders</u>. Promoting this great tool takes seconds, and it would save those living with OA from unnecessary pain. Our colleagues at the Arthritis Society and Arthritis Consumer Experts are doing it-YOU SHOULD DO IT TOO!

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 each of the applicants for their efforts in presenting their research projects and all reviewers from the arthritis community 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

World Arthritis Day

On October 12, Arthritis Consumer Experts (ACE) celebrated World Arthritis Day by releasing the final issue of their three-part JointHealthTM insight series, featuring an interview with ACE's President, Cheryl Koehn, President of Arthritis Consumer Experts, two weeks after a total knee replacement, answering, questions about her personal recovery and rehabilitation process. This issue is a helpful resource for both patients and health care providers who wish to learn more about the experience of joint replacement and challenges faced by those who also



Twitter Chat for National Psoriatic Arthritis Day: #cdnPsADay

To kick-start National Psoriatic Arthritis Day, Arthritis Consumer Experts (ACE) co-hosted a Twitter Chat with Canadian Arthritis Patient Alliance (CAPA), Canadian Association of Psoriasis Patients (CAPP), Canadian Psoriasis Network (CPN), Canadian Spondylitis Association (CSA) and The Arthritis Society (TAS). The event was an opportunity to discuss effects and risk factors for psoriatic arthritis as well as for patients to ask questions about the disease. Dr. Melinda Gooderham, dermatologist from Peterborough and Dr. Jonathan Chan, rheumatologist from Vancouver, kindly answered patients' questions throughout the event. The Twitter Chat included 21 participants, 296 tweets and earned over 705K impressions (total tally of all the times tweets with the hashtag were seen). The program partners will soon be releasing a document that combines all of their top PsA patient resources and highlights from the event. Stay tuned!

ARTHRITIS RESEARCH CANADA

News from Arthritis Research Canada



have an autoimmune disease.

Arthritis Research Canada congratulates Senior Research Scientist, Dr. Linda Li - who was announced as a Fellow of the Canadian Academy of Health Sciences, one of the highest honours within Canada's academic community. The induction ceremony was held in Ottawa on September 19, 2019. Dr. Li's research and academic activ

ities focus in two areas: models of care in the management of arthritis, and the development and evaluation of knowledge translation strategies. Her research centers on assessing health service delivery models, and understanding and facilitating the use of evidence by health professionals and patients. Dr. Li's areas of expertise include clinical epidemiology, knowledge translation, clinical trials, and survey design. She currently holds a Canada Research Chair in Patient-oriented Knowledge Translation.

ARTHRITIS SOCIETY: NATIONAL OFFICE

NEW: Arthritis & Work Portal



We are proud to have launched several new resources and tools to support employees living with arthritis and their employers who accommodate them. On our revamped arthritis.ca/work portal, you'll find a wealth of resources for each audience, including videos, an interactive accommodations tool, information on disclosing arthritis in the workplace, and much more. For an overview, check out our new Welcome video.

UPDATE: Canadian Arthritis Statistics

Our statistics on arthritis prevalence and impact have been updated, drawn from the latest Canadian Community Health Survey and evaluated by the Arthritis Community Research Evaluation Unit (ACREU). Among other changes, we have updated provincial prevalence estimates and added in a new section on troubles with mobility. See all of the latest statistics, including some handy infographics, at www.arthritis.ca/facts.

UPDATE: Federal election advocacy

Canadians seized upon this past election season to show their support for the Arthritis Society's advocacy on key issues affecting people with arthritis. More than a thousand Canadians sent emails to the party leaders to highlight pharmacare, medical cannabis and joint replacement wait times. Hundreds more submitted letters to the editor or shared on social media, prompting official responses from two of the parties. This activity is crucial in our endeavour to achieve policy changes that help people with arthritis live better. We can't thank these supporters enough.

Our election push may be over, but the advocacy work continues: we will be holding several meetings with representatives from all parties to ensure that arthritis priorities are heard. To stay in the loop with our ongoing advocacy efforts, visit www.arthrtiis.ca/advocacy.

6th annual Quebec Arthritis Forum a tremendous success!

The Arthritis Society presented its day of conferences dedicated to the disease on October 26 with its 6th annual Arthritis Forum, held at the Québec City Convention Center. More than 900 participants took part in the event, whether in Quebec City, in one of the seven satellite cities across the province, or in a webcast across Canada. With 17 lectures given by health experts, five workshops and a 20-exhibitor show, the Forum allowed participants to find solutions to better live with arthritis.

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 has recently submitted an grant application to the Department of Defense, Military Medical Research and Development, United States Army (Lowdose aspiring use, placenta-mediated complications, and cardiovascular events in a multi-national SLE inception cohort).

CANRAD Network team includes a variety of decision makers, epidemiologists, clinicians and researchers interested in the use of administrative data for rheumatic disease research. For more information pertaining to our meetings, upcoming webinars or all other information concerning the CANRAD Network, please contact Jessica Wang at 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, via CIHR's Drug Safety and Effectiveness Network (DSEN). The team's renewal grant application to CIHR was successful,

representing \$2.55M over three years (September 2019 to March 2022). CAN-AIM continues to build a 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 with RA, AS, or inflammatory bowel disease, who are initiating therapy with a biosimilar or 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, our upcoming webinars or more information on our team, please contact Jessica Wang at lifang.wang@rimuhc.ca or visit our website http://canaim.ca/.

Calendar of Events

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
2019 CRA Canada Night in Atlanta	November 11, 2019	Atlanta, Georgia, USA
Arthritis Alliance of Canada Final Annual Meeting	November 29, 2019	Toronto, Ontario
The Canadian Arthritis Research Conference: Taking Collaborative Action	February 25 - 26, 2020	Victoria, British Columbia
2020 CRA & AHPA Annual Scientific Meeting	February 26 - 29, 2020	Victoria, British Columbia
CRUS Advanced MSK US Hand and Foot Course	February 29 - March 1, 2020	Victoria, British Columbia
British Society for Rheumatology Annual Conference	April 20 - 22, 2020	Glasgow, United Kingdom

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