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ARTHRITIS ALLIANCE OF CANADA

ONGOING PROJECTS

Developing a patient-centered framework for measuring, monitoring and optimizing rheumatoid arthritis care - A Call to Action!

**** Survey open until Friday, June 7th, 5pm EST****



When it comes to measuring the quality of rheumatoid arthritis (RA) care, *your feedback is important!* 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. Now, the research team is reaching out to the public for feedback on the framework and the measures it includes. **To review the framework and submit comments please click [here](#).** This will redirect you to the Canadian Rheumatology Association website where the material is posted. *Thank you for your feedback!*

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

The 4-way partnership project, a study on building an economic business case for the AAC Inflammatory Arthritis Models of Care (MOCs), is well underway. Conducting a Cost-Consequences Analysis of IA MOCs is progress with participation of 10 out of 16 CATCH sites representing four provinces, Alberta, Manitoba, Ontario and Quebec. *All 10 sites involved in the study have completed the survey and phone interviews as part of this phase; data are being currently analyzed.*



This study will ultimately provide consistent and standardized description of IA MOCs at participating CATCH locations across Canada; list cost-categories associated with implementation of IA MOCs, determine key success and contextual factors relevant for the successful implementation and sustainability of IA MOCs, as well as inform a formal cost-effectiveness analysis of IA MOCs. *The working team is excited about this project's interim success and will continue updating you on its progress!*

The Osteoarthritis (OA) Information Handout for Patients



The Arthritis Alliance of Canada's project to create an Osteoarthritis (OA) Patient Information Handout is in its final stages. A draft of the Handout has been produced through an iterative process involving representatives from patient-led and patient-focused organizations, members of the AAC OA Models of Care Committee - scientific and clinical experts in OA. The Handout was designed with the goal of enhancing education and raising awareness in osteoarthritis care and prevention. Once completed, the Handout will serve as a resource to improve patients' self-management, self-advocacy and health literacy, as well as to facilitate meaningful and effective dialogue between patients and primary care practitioners.

The draft version of the Handout has undergone several rounds of content review and editing. Earlier this month, the Handout was sent to members of the AAC OA Models of Care Committee for feedback and an updated version will be circulated to the entire AAC membership and key stakeholders for additional input. *Stay tuned!*

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!*



AAC 2019 Research Awards Program -Call for Applications Closing

Dear readers! We would like to remind you that the fourth cycle of the AAC Research Awards program is closing at midnight, Friday, May 31st. The following **eight** research awards were announced in early April including: 1) Master's Student; 2) PhD Student; 3) Post-doctoral Fellow; 4) Early Career Researcher (Early Career Faculty Member/Investigator) in: Basic/Clinical Science; 5) Early Career Researcher (Early Career Faculty Member/Investigator) in: Health Science/Population Health; 6) Knowledge Translation Research/Science; 7) Knowledge Translation Practice; and 8) Patient for Active Engagement in Arthritis Research. *Hurry up and submit your applications for any of the eight awards by this Friday!*



Recipients of the AAC Research Awards will be announced during the Special Awards Ceremony on Friday, November 29th in Toronto.

MEMBER'S CORNER

ARTHRITIS RESEARCH CANADA

My Lupus Guide



As May is Lupus Awareness Month, Arthritis Research Canada is proud to announce that our Senior Scientist, Dr. Paul Fortin, launched a web-based app, *My Lupus Guide*, across Canada in both official languages, on World Lupus Day. The app provides a wide variety of information about lupus and addresses important lupus-related issues including pregnancy, dealing with work, explaining lupus to family and friends and much more. Its development took years and involved immense patient input. *My Lupus Guide* is truly a resource to help people with this disease.

Congratulations to Dr. Paul Fortin

We are excited to announce that Dr. Fortin has been awarded a renewal of his Tier 1 Canada Research Chair in Systemic Autoimmune Rheumatic Diseases. As you know, a Tier 1 Chair is the highest salary award available to a Canadian scientist. This award will provide funding to cover his salary and operating research money. We are excited to see what Dr. Fortin's research continues to do for individuals living with SARDs.



ARThritis Soirée a Huge Success

ARC's annual event, the ARThritis Soirée, took place on May 22 at The Roof, Hotel Vancouver, and it was a huge success. We are truly grateful for everyone who made the evening possible and contributed to life-saving arthritis research.

ARTHRITIS CONSUMER EXPERTS

Election Advocacy



ACE sent open letters and surveys to political parties and candidates running in the [Newfoundland and Labrador](#) provincial election. Based on the AAC's IA and OA Models of Care work, ACE outlines for the parties and candidates the impact of arthritis and asks each candidate to share how government can contribute to implementing the models of care and improve patient outcomes in their province.

Biosimilars in Canada – What Inflammatory Arthritis Patients Need to Know

ACE has produced a new guide – “Biosimilars in Canada: What inflammatory arthritis patients need to know” – to address the needs of patients who want information on biosimilar medications. The guide provides answers to questions patients may have on biosimilars and provide them the tools they need to support their conversations with their rheumatologists and other health care providers and ensure science-based continuity of care. ACE thanks Arthritis Research Canada for its review of the content in this guide to ensure scientific and clinical accuracy.

CANADIAN SPONDYLITIS ASSOCIATION

The Comorbidity Awareness Campaign

As part of our comorbidity/complications awareness campaign, the CSA and Crohn's and Colitis Canada partnered and held a twitter chat on May 15. The one-hour chat was to share with patients living with AS and IBD the link between Inflammatory Bowel Disease (IBD) and Spondyloarthritis (SpA). Joining members from both the CSA and SpA was gastroenterologist Dr. Mark Silverberg. This was an excellent opportunity to engage patients



in the discussion around the prevalence, symptoms and importance of early diagnosis and treatment of both conditions.

The CSA will be presenting a poster on the 2018 comorbidity survey results at EULAR in June. The poster speaks to the importance of educating patients on the complications they are at risk of experiencing and the importance of managing symptoms earlier and how preventing or treating earlier impacts the healthcare system. Results also confirmed that by educating allied healthcare professionals on SpA conditions can lead to earlier diagnosis. A similar poster was presented at CADTH in April. In addition to Facebook and twitter, you can now follow the CSA on Instagram and Pinterest!

ARTHRITIS SOCIETY: NATIONAL OFFICE

Arthritis Talks symposium series has successful kick-off



Our first Arthritis Talks national symposium was a great success, with over 2,200 registrants coming together live and via interactive webinar on May 4th to hear from arthritis experts in the fields of nutrition, physical exercise and medical cannabis. Content from the event will be available online soon for those who were unable to attend, so stay tuned. To get on the notification list for future talks in the series, visit www.arthritis.ca/arthritis Talks, and click on “Upcoming Talks”.

Two new online learning modules: *Staying Active and Daily Living*.

Staying active and making the most of daily life: the newest additions to our suite of online learning modules are now available. Keeping your joints moving is one of the most important things you can do to help manage your arthritis: *Staying Active* offers guidance on ways people with arthritis can incorporate safe activities into their lives that can help them retain – and even regain – their mobility. *Daily Living*, meanwhile, is designed to provide self-management strategies to help people with arthritis keep doing both the things they need to do and the things they love to do. Check them both out at our online learning hub, www.arthritis.ca/education.

New patient articles on Osteoarthritis

We are expanding the resources we have available for people living with or at risk from osteoarthritis. Two new patient-focused articles look at the link between sports injuries and OA (featuring insights from renowned sports medicine specialist Dr. Julia Alleyne), and an examination of assistive devices that can help people with OA cope with some of the challenges they may encounter in daily life. Check them out on our digital arthritis magazine, *flourish* (www.arthritis.ca/flourish) and stay tuned for more.



2019-20 Research competitions

We are still accepting submissions to the following research grant programs for the 2019-20 funding year:

- Strategic Operating Grants (focused this year on improving our understanding of arthritis and finding a cure)
- Stars Career Development Awards

Results of these competitions will be announced in December. Find out more by visiting www.arthritis.ca/researchers.

Advocating for people with arthritis

This year has been a busy one on the advocacy front, as the recent spate of provincial elections in PEI, Alberta and Newfoundland & Labrador has generated a lot of discussion and engagement around critical issues like joint replacement wait times, rheumatologist shortages and rural care. You can find out more about the work the Arthritis Society is doing to raise these policy issues by visiting www.arthritis.ca/advocacy.



National Meeting on the Management of OA

On May1, 2019, Bone and Joint Canada hosted a meeting with representatives from across the country on the activities that are being undertaken in the provinces to improve the management of individuals with hip and knee osteoarthritis (OA). The day was divided into 4 sections: Current status of OA care – updated research, Successful programs, Tools for success and Evaluation during which there were presentations from across the country providing a spectrum of idea and opportunities on improving care. The day finished with an interactive discussion resulting in a number of recommendations which will be released later in the summer. Thank you to all who participated.

COMMUNITY UPDATES

UNIVERSITY OF CALGARY

Dr. Deborah Marshall’s Interviews with CBC Radio

On April 29th and 30th, Dr. Deborah Marshall sat down with CBC Calgary and CBC Edmonton to talk about increasing wait times for hip and knee replacements in Canada. In the interviews, Dr. Deborah Marshall highlighted the fact that only 70% of hip patients and 66% of knee patients in Alberta are meeting the 26 week wait time benchmark. She emphasized the need for a blended solution to this problem, which includes additional funding, improved referral processes, better triaging of patients for surgery, and better management of osteoarthritis with conservative approaches to medically manage the disease. For more information, you can listen to the interviews by clicking on the links below:



CBC Calgary: <https://www.cbc.ca/news/canada/calgary/programs/eyeopener/growing-wait-times-for-surgery-1.5115325>

CBC Edmonton: <https://www.cbc.ca/listen/live-radio/1-17-edmonton-am/clip/15694110-alberta-wait-times-for-surgeries-are-getting-longer>

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

Congratulations to Dr. Celine Brasil’s on Her New Fellowship

Dr. Celine Brasil was recently awarded a 2-year FRSQ (Le Fonds de recherche du Quebec- Sante) post-doctoral fellowship under the supervision of Dr. Sasha Bernatsky. Dr. Brasil’s research project, which studies thousands of lupus patients across North America, aims to improve predictive models related to outcomes after hydroxychloroquine, a cornerstone treatment for systemic lupus. This will ultimately result in more personalized medicine for patients with this chronic and often life-threatening autoimmune disease.

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 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 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/>.



Calendar of Events

The Arthritis Society: Walk for Arthritis	June 1 – 2, 2019	Canada nationwide
Scleroderma Society of Ontario Walk/Run	June 1 – 22, 2019	Hamilton, London, Ottawa and Toronto, Ontario
13 th International Society of Physical and Rehabilitation Medicine World Congress (ISPRM)	June 9 – 13, 2019	Kobe, Japan
2019 EULAR – The European Congress of Rheumatology	June 12 - 15, 2019	Madrid, Spain
2 nd International Combined Meeting of Orthopedic Research Societies	June 19 – 22, 2019	Montreal, Quebec
Rheumatology Research Workshop, American College of Rheumatology	June 22 – 23, 2019	Washington, DC, USA
9 th International Conference on Children's Bone Health	June 22 – 25, 2019	Salzburg, Austria

International Workshop on Osteoarthritis Imaging (IWOAI)	June 26 – 29, 2019	Charlottetown, Prince Edward Island
Juvenile Arthritis Conference, Arthritis Foundation	July 18 – 21, 2019	Houston, Texas, USA
13 th International Conference on Orthopedics, Arthroplasty and Rheumatology	July 25 – 26, 2019	London, UK
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
46 th 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
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
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 lgazizova@arthritisalliance.ca or visit our website: www.arthritisalliance.ca.