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ARTHRITIS ALLIANCE OF CANADA

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 RA care and build a framework for measuring it. The research team is currently hard at work on analyzing the results of the public survey conducted in June and how it may impact the development of the scorecard. Preliminary findings of the Balanced Scorecard project for RA patients 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 4-way collaboration project, a study on building an economic business case for the AAC Inflammatory Arthritis Models of Care (IA MOCs), is well progressing. By present moment, 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 Canadian Early Arthritis Cohort (CATCH), representing four provinces, Alberta, Manitoba, Ontario and Quebec. Researchers are now working on the first draft of a report with the findings from this qualitative work. 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 interim success and will continue updating you on its progress!*

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

Arthritis patient-led organizations are preparing for the release of its [Talk to Your Doctor About Joint Pain Handout](#) in September during Arthritis Awareness month. The Handout is a patient version of the [Osteoarthritis Tool for Family Physicians](#) that was launched by the AAC and the College of Family Physicians of Canada in 2017 to provide primary care providers who are managing patients with new or recurrent joint pain from osteoarthritis in the hip, knee or hand, with a standardized guideline to assist with assessing and triaging patients with OA symptoms.

Talk to Your Doctor About Joint Pain Handout has been developed through a collaborative process involving representatives from patient-led and patient-focused organizations, in close consultation with members of the AAC Models of Care Committee and scientific and clinical experts in OA, with the goal of enhancing education and raising awareness in osteoarthritis care and prevention. This tool is also designed to 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. *Stay tuned for the upcoming launch of the Handout on September 12th!*

AAC 2019 Research Awards Program: Update

The review of the **forty-three (43) applications** for the AAC Research Awards 2019 is in full swing. **Twenty-one (21) reviewers** from the arthritis community-14 researchers and 7 patient representatives-with expertise in arthritis research are currently evaluating these applications. The review process is expected to complete on August 31st, at which point the selection process will start. Six research awards, including 1) Master Student, 2) PhD Student, 3) Post-doctoral Fellow, 4) Early Career Researcher in Basic/Clinical Science, 5) Early Career Researcher in Health Science/Population Health and 6) Patient for Active Engagement in Arthritis Research, will be presented to the winning applicants during 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 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 implementation of numerous nationwide programs and projects 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 and Qualman-Davies Consumer (Patient) Community Leadership Award. A formal registration process to attend the AAC Final Annual Meeting will start mid-September. *We look forward to your participation and engagement in Toronto!*

MEMBER'S CORNER

ARTHRITIS RESEARCH CANADA

Exciting Activities at ARC over the Summer



Arthritis Research Canada had an exciting summer, with scientists securing close to \$3 million in research grants from the Canadian Institutes of Health Research, the Canadian Rheumatology Association and the BC Support Unit. As you know, less than 10 per cent of all submitted grants to the CIHR receive funding, so this is a big accomplishment for arthritis research.

Studies include: a physiotherapist-led primary care model for low back pain, systemic sclerosis, fathers' engagement during pregnancy (when arthritis is involved), tumor necrosis factor inhibitors and the potential connection to multiple sclerosis, rheumatoid arthritis and the decision to continue treatment during pregnancy. Researchers will also study the effectiveness of the BC government fee code to support rheumatology nurses in treating inflammatory arthritis, the role of tools in rheumatoid arthritis patient outcomes, new statistical methods to permit better estimates of treatment interventions, and new techniques of measuring the antinuclear antibody test for lupus.

Arthritis Research Canada summer students secured almost \$20,000 in funding to examine Reddit forums, the experiences and information needs of individuals with arthritis and comorbid mental disorders, mental health complications in pregnant and postpartum women with rheumatoid arthritis, and Canadian Rheumatology Association rheumatoid arthritis guidelines. Researchers will also work to develop a reminder system to help physicians prevent inflammatory arthritis complications.

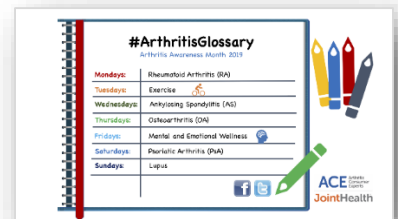
ARTHRITIS CONSUMER EXPERTS



Arthritis Consumer Experts is expanding patients' #ArthritisGlossary on social media



Arthritis Consumer Experts is preparing for Arthritis Awareness Month in Canada with the #ArthritisGlossary social media campaign. #ArthritisGlossary will provide a daily dose of information, definition, resource, or tip to help patients navigate life with arthritis. Every day from Sunday, September 1 to Monday, September 30, 2019, patients will find a #ArthritisGlossary social media post on ACE's Twitter (@ACEJointHealth) and Facebook (@ACEJointHealth) account, specifically themed by type of disease or wellness/lifestyle tips.



We are hoping you can help us drive arthritis awareness in September:

- like, retweet, and reply on Twitter using #ArthritisGlossary; or,
- like, comment, and share on Facebook using #ArthritisGlossary; or,
- Would you like to contribute to the #ArthritisGlossary? Email your word(s) and definition(s) to feedback@jointhealth.org.

Election Advocacy

ACE sent open letters and surveys to political parties and candidates running in the Manitoba 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.

The Qualman-Davies Arthritis Consumer Community Leadership Award

A reminder that the application deadline for the Qualman-Davies Arthritis Consumer Community Leadership is September 27, 2019. The award is given to anyone with arthritis who displays, or has displayed, selfless actions

through volunteer work in their community. If you would like to nominate someone, please fill out the nomination form for them to be considered. Please submit completed nominations to feedback@jointhealth.org.

ARTHRITIS SOCIETY: NATIONAL OFFICE

September is Arthritis Awareness Month – focus on women’s health



This year we’re exploring the relationship between arthritis and women – the impact, the research and the opportunity. Our goal, as always, is to live in a world where people are free from the devastating effects that arthritis has on lives – this month we’re giving special focus to what that means for women. Highlights from the month will include a new Arthritis & Women webpage collecting relevant links and resources, sharing of key awareness facts and figures, and a variety of flourish articles including research updates, educational content and inspiring profiles. Watch for our updates throughout the month at www.arthritis.ca/women (launches in September).

New research grant and award recipients announced

Our latest research grant and award competitions have been announced, representing almost \$700,000 in new commitments to arthritis research, including:

- 7 Graduate PhD Salary Awards
- 7 Postdoctoral Fellowship Awards
- Arthritis Centres across the country

As Canada’s largest charitable funder of arthritis research, this investment reflects the Arthritis Society’s ongoing commitment to advance knowledge and develop greater capacity in the medical and research communities serving the needs of Canadians living with or at risk of developing arthritis. For more information about these awards, visit <https://arthritis.ca/researchers/competition-results>. Note that this year’s Strategic Operating Grants and Stars Career Development Award recipients will be announced in December.

New resources for managing arthritis at work

We have released several new and updated resources to assist employees and employers in addressing the challenges of arthritis at work. These resources include a new PDF guide on Ontario’s AODA employment standards (a good model for other jurisdictions), a video and podcast to help employees understand their rights and communicate their needs, and a video and podcast to help employers recognize the benefits of accommodating employees with arthritis. We have also significantly updated our online learning module, Arthritis & Work. Find out more at www.arthritis.ca/work.

Updates to mental health and arthritis online learning program

We have brought fresh new updates to our online learning resource addressing Mental Health and Wellbeing for people living with arthritis. These updates reflect the latest developments in understanding, coping and thriving with arthritis and its impact on overall wellbeing, and can be an invaluable resource for patients and caregivers alike. Find out more at www.arthritis.ca/education.

Federal election

Canada’s general election will take place on Monday October 21, 2019. While health care is primarily considered to be a provincial issue, there are many ways in which the needs of Canadians living with arthritis can be helped through federal policies. The Arthritis Society will be calling on all parties and candidates to support our recommendations in the areas of national pharmacare, medical cannabis and wait times for joint replacements – recommendations that, if implemented, will help improve health outcomes and quality of life for people living with arthritis. Find out more about our positions on these issues by visiting www.arthritis.ca/advocacy.

ARTHRITIS TALKS: Registration open for Arthritis and Work, Saturday Sept. 21

The Arthritis Society is holding the second in its series of Arthritis Talks educational symposia on Saturday, September 21. The theme is Arthritis at Work and will include a presentation by Dave Turner, a specialist in employment law. Participants will learn about working with arthritis, including workplace accommodations, strategies to manage their pain at work, and what to consider if they are thinking about medicinal cannabis as a treatment option. You can attend in-person at Kamloops and Victoria, BC, at viewing events in Cranbrook BC and Edmonton AB, or online via live interactive webinar anywhere in Canada. For details or to sign up to participate in-person or via webinar, visit arthritis.ca/arthritis Talks.

McCAIG INSTITUTE FOR BONE AND JOINT HEALTH

The 2019 Cy Frank Legacy Lectureship



Our 2019 Cy Frank Legacy Lecturer will be Dr. Stefan Lohmander, MD, PhD, Professor, Department of Clinical Sciences, Lund University, Sweden. Dr. Lohmander will be giving four presentations across Canada: Sept. 16th in Calgary, September 17th in Edmonton, September 19th in London, Ontario, and September 20th in Ottawa. Here are all the details:



September 16, 2019 in Calgary

- 4:00 p.m., Theatre 4 Health Sciences Centre, reception to follow
- Register at: cyfranklecture2019.eventbrite.ca

September 17, 2019 in Edmonton

- 4:00 p.m., 2-39 Corbet Hall, University of Alberta, reception to follow
- Register at: bit.ly/cyfrankveg2019

September 19, 2019 in London, Ontario

- 1:45 p.m., London Health Sciences Centre, University Hospital (B3-246), Auditorium A

September 20, 2019 in Ottawa, Ontario

- Canadian Academy of Health Sciences Forum and Annual General meeting
- 8:40 a.m., Fairmont Chateau Laurier

The Cy Frank Legacy Lectureship honours and commemorates the late Dr. Cy Frank, an internationally acclaimed visionary who championed the application of research to create solutions for patients. The lectureship showcases individuals who reflect the passion of Dr. Frank. For more information, please contact: mccaig@ucalgary.ca.



CANADIAN RHEUMATOLOGY ASSOCIATION

Submission for 2020 CRA & AHPA Annual Scientific Meeting

You are invited to submit abstracts for presentation during the 2020 CRA & AHPA Annual Scientific Meeting! Deadline for submissions is **October 11, 2019**. Details will be available at rheum.ca.

COMMUNITY UPDATES

ADVANCED CLINICIAN PRACTITIONER IN ARTHRITIS CARE (ACPAC)

Congratulations to Our Graduates

The Advanced Clinician Practitioner in Arthritis Care (ACPAC) Program (www.acpacprogram.ca) congratulates the following 11 graduates of the 2018-2019 program: Aksa Ahmed, Toronto, Ontario; Manasa Black, Vaughan, Ontario; Michelle Bridge, LaSalle, Ontario; Julie Chung, North York, Ontario; Andrew Courchene, Toronto, Ontario; Gargi Singh, Toronto, Ontario; Tamara Gotal, Toronto, Ontario; Julie Herrington, Hamilton, Ontario; Osk Jenkins, Peterborough, Ontario; Maria Luccisano, Richmond Hill, Ontario; and Jennifer Martin, Vaughan, Ontario.



Welcome New Trainees

The Arthritis Program (UHN) is funding the ACPAC program for the upcoming academic year. New this year is the expansion of the orthopaedic component in addition to the core rheumatology curriculum. The Advanced Clinician Practitioner in Arthritis Care (ACPAC) Program (www.acpacprogram.ca) welcomes the following 12 new trainees into the 2019-2020 program on Monday October 21, 2019: Sharon Armstrong, Toronto, Ontario; Andrew Bigness, LaSalle, Ontario; Marie-Hélène Brown, Saint-François-de-l'Île-d'Orléans, Quebec; Jonathon Burak, Dundas, Ontario; Gillian Grant, Toronto, Ontario; Joanne Hill, Toronto, Ontario; Karim Hussein, Aurora, Ontario; Michaela McGuire, Toronto, Ontario; Ania Roszkowski, Toronto, Ontario; Andrea Ruby, Toronto, Ontario; Gareth Sneath, Scarborough, Ontario; Rajiv Vase, Toronto, Ontario.

CANADIAN EARLY ARTHRITIS COHORT (CATCH)

Resources to Share

The Canadian Early Arthritis Cohort (aka CATCH, www.earlyarthritis.ca) has a brand new [YouTube channel](#) where we've loaded over 30 short videos to help people learn more about the CATCH research study and what it has taught us about rheumatoid arthritis, share the experiences of people who live with RA (some of whom are participants in CATCH), and share other topics about RA in general (for example, pain, fatigue, flare, and preparing for appointments). Feel free to share the channel and videos with your communities. For September's Arthritis Month, we will be launching [@earlyarthritis](#) and appreciate your follows and shares.



ONTARIO RHEUMATOLOGY ASSOCIATION (ORA)

Digital Health Technology Day



The Ontario Rheumatology Association will be hosting a Digital Health Technology Day on September 27, 2019 at the Delta Hotel Toronto. This event is available to ORA members and their staff. To learn more and to register, please visit this link: <https://ontariorheum.ca/event/ora-digital-health-technology-day>.

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
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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://healthy Canadians.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 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

International Conference on Arthritis: Global Challenges and Future Perspectives	August 19 – 29, 2019	Vancouver, BC
Lupus Academy 8 th Annual Meeting	September 6 -8, 2019	Warsaw, Poland
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
The 2 nd Cardio-Rheumatology Symposium	September 13, 2019	Toronto, ON
14 th World Congress on Inflammation	September 15 -19, 2019	Sydney, Australia
12 th Annual Perspectives in Rheumatic Diseases, Global Academy of Medical Education	September 20 – 21, 2019	Las Vegas, Nevada, USA
World Congress on Rheumatology and Orthopedics, Scientific Federation	September 24-25, 2019	Madrid, Spain
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
Arthritis Alliance of Canada Final Annual Meeting	November 29, 2019	Toronto, Ontario
2019 American College of Rheumatology (ACR) & Association of Rheumatology Professionals (ARP) Annual Meeting	November 8-13, 2019	Atlanta, Georgia, USA

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.