# **Arthritis Alliance of Canada NEWSLETTER**

## September 2018

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# ARTHRITIS ALLIANCE OF CANADA AAC 2018 Research Awards Program: Update

<u>Twenty-five (25) reviewers</u> are diligently working to complete evaluations of the <u>fifty-two (52)</u> applications received for the AAC's 2018 Research Awards round. The review of the applications is expected to be completed, with evaluation scores finalized, in the beginning of October. The winners of the AAC 2018 Research Awards will be announced at the Annual Meeting Gala Dinner on Wednesday, November 21<sup>st</sup>, Toronto.

We would like to thank our reviewers again for putting their time and efforts in identifying the recipients of the AAC Research Awards!



## 2018 Annual Meeting in Toronto, November 21-22: Annual Meeting Program "Arthritis Alliance of Canada: Celebrating Our Successes and Planning for the Future"

The registration process for the AAC 2018 Annual Meeting and Arthritis Society & CIHR-IMHA Trainee Workshop is now open.

We invite you to register here!

Our Annual Meeting program this year will present:

- Wednesday, November 21<sup>st</sup>, *Gala Dinner "AAC: Celebrating our Successes"* at 7:00-9:00 pm EST, featuring Welcome Remarks by AAC Chair of Board Janet Yale, and a keynote speech by our guest speaker, <a href="Professor Anthony Woolf">Professor Anthony Woolf</a>, from the Royal Cornwall Hospital, Truro, UK. Professor Anthony Woolf is a Musculoskeletal Health and Wellbeing Specialist and the Chair of Arthritis and Musculoskeletal Alliance; and
- A Special 2018 Awards Ceremony to recognize recipients of the:
  - **❖** AAC Research Awards
  - ❖ The Qualman-Davies Arthritis Consumer (Patient) Community Leadership Award; and
  - Arthritis Society Trainee Awards



Thursday, November 22nd, will commence with the AAC Members Annual General Meeting, at 9:00 am EST, continued with a full day of facilitated breakout group discussions with AAC members, stakeholders and arthritis community, as we review all the many achievements that the AAC had accomplished over the years and determine direction of the Alliance going forward. The discussions will be facilitated/conducted by an external consultant Robin Cory, Partner at Colbeck Strategic Advisors, Centre for Social Innovation. The meeting is expected to adjourn at 5:00 pm EST.

# We look forward to your engagement in the program in Toronto in November!

#### Developing a Patient-Centered Balanced Scorecard for Rheumatoid Arthritis (RA)

To further improve the quality of care for people living with arthritis, and to continue building AAC's quality framework, the AAC and the Canadian Rheumatology Association's Quality of Care Committee are key partners in the development of a Patient-centered Balanced Scorecard for Rheumatoid Arthritis. As the most common type of Inflammatory Arthritis, Rheumatoid Arthritis is one of the leading causes of physical disability and has profound economic impact through high medical costs and lost labour force participation. Despite its significant impact, the quality of care for RA is currently not monitored in Canada. Hence, the development of a Balanced Scorecard aims to provide a framework to improve the efficiency and performance of care for RA.

Funded by the Canadian Institutes of Health Research (CIHR), this study commenced in June 2017. With input from a wide range of stakeholders, including people living with arthritis, physicians, allied health providers, healthcare managers and policy-makers, a research team led by Dr. Claire Barber and Dr. Diane Lacaille will finalize measures to be included in the balanced scorecard for RA. It is expected that in early 2019 the Balanced Scorecard will be implemented in Alberta to test its acceptability and feasibility.

## **MEMBER'S CORNER**

#### ARTHRITIS CONSUMER EXPERTS

#### **Quebec Election**

In anticipation of Quebec's provincial election on October 1, 2018, ACE sent an open letter and a survey to candidates running in the Quebec election. Arthritis





affects more than one million Quebec residents and is an important healthcare issue for candidates. ACE is archiving responses and posting them on the Quebec Election page.

#### Arthritis Awareness Month - #WhereIsArthritis

ACE is celebrating Arthritis Awareness Month in Canada with the #WhereIsArthritis social media campaign to share with the arthritis community ACE's current online resources designed to help people live a better life with arthritis. To participate, please follow #WhereIsArthritis on our Twitter account @ACEJointHealth and Facebook account Arthritis Consumer Experts.

#### Qualman-Davies Arthritis Consumer Community Leadership Award

Do you know a person living with arthritis in Canada who has, or is, providing leadership in the community and deserves recognition for their valuable volunteer work? Help us celebrate their contributions by nominating them for the Qualman-Davies Arthritis Community Leadership Award! The deadline to submit nominations has been extended to September 30, 2018.

#### ARTHRITIS RESEARCH CANADA



#### Arthritis Research Canada's Dr. Cheryl Barnabe appointment

Arthritis Research Canada (ARC) senior scientist, Dr. Cheryl Barnabe, has been appointed a member of the Royal Society of Canada. As you know, recognition by the RSC is the highest honour a person can achieve in the arts, social sciences, and sciences. An individual is only elected for outstanding scholarly, scientific and artistic achievement. We are extremely proud of Dr. Barnabe's accomplishment.

#### **Arthritis Awareness Month**

Arthritis Research Canada had a very successful Arthritis Awareness Month Campaign. Some highlights include our Reddit AMA or "Ask Me Anything" with Dr. John Esdaile. This online Q&A forum generated 1,000 comments and questions about a variety of arthritis topics – demonstrating that arthritis patients are turning to online communities for support. To view the conversation, click here.

ARC's campaign also included a Facebook contest, arthritis fact videos, a social media campaign and our annual Reaching Out with Arthritis Research public education forum (on September 29<sup>th</sup> at the Ismaili Centre in Burnaby). We'd like to take this opportunity to thank everyone in the arthritis research community who participated in our campaign. Together, we can make a difference!

#### **Annual Report**

Arthritis Research Canada is proud to announce that our 2017-2018 Annual Report is now available online. If you want to find out what we've been up to over the past year, click here to read the report.

#### ARTHRITIS SOCIETY: NATIONAL OFFICE



#### **Research Training Awards**

New research is vital to understanding the causes of arthritis and focuses on developing new treatment methods, with the hopes of one day finding a cure. The Arthritis Society honours

and provides funding to the best and brightest young minds currently working towards becoming the next generation of arthritis researchers in Canada. Arthritis Society Research Training Awards were presented earlier in September to these highly deserving individuals. The Arthritis Society would like to congratulate its 2018 recipients.

#### **Self-Advocacy Guides**

Effectively managing the symptoms of arthritis and their impact on life can be a challenge. Learning to advocate for yourself and your needs is an essential skill for people who want to manage their disease and live the best life possible despite their arthritis. The Arthritis Society is please to announce the release of a new <u>Self-Advocacy Guide</u>, which provides information and strategies to help you become an empowered advocate for your needs, and for the needs of others.

#### **Upcoming Pain Symposium**

Registration is now open for the Arthritis Society Prairie Region's fall symposium entitled Pain: Relief is Within Reach on Sat. Nov. 3, 2018. This comprehensive tri-city event will be held in Winnipeg, Saskatoon and Edmonton with expert speakers presenting in-person and via live stream. Guest include noted rheumatologist and arthritis researcher Dr. Hani El-Gabalawy and Dr. Sana-Ara Ahmed MD, FRCPC, Anesthesiologist, Chronic Pain & Cannabinoid Medicine Specialist. The two-hour webcast begins at 11:30 AM EDT. Register for all three events or the webcast today at arthritis.ca/prairiesymposium.

#### **CANADIAN ARTHRITIS PATIENT ALLIANCE**

#### **CAPA's Latest Newsletter**

Our latest newsletter is out highlighting what CAPA Board members have been up to the past few months! We encourage everyone to go to <a href="https://www.arthritispatient.ca">www.arthritispatient.ca</a> to sign up and receive it. Coming soon our new website launch and branding.

#### **CANADIAN RHEUMATOLOGY ASSOCIATION**

#### **CRA Announces New SLE Recommendations**

As an initiative of the Canadian Rheumatology Association, the Canadian Systemic Lupus Erythematosus (SLE) Working Group has developed novel recommendations for the assessment and monitoring of Systemic Lupus Erythematosus (SLE).

Read the new SLE recommendations here

#### CANADIAN SPONDYLITIS ASSOCIATION

#### CSA at the 2018 Cochrane Colloquium



Preliminary results from our comorbidity survey launched in the late spring to better understand the different comorbidities and prevalence members of our community live with and if other specialists assisted in the diagnosis of their SpA condition. There were over 400 people who participated from across Canada. The six most common comorbidities reported included: chronic pain, mental health (anxiety, depression), IBD (Crohn's and colitis), uveitis/iritis, sleep and chronic fatigue. These were followed by psoriasis, fibromyalgia, hypertension and lung disease. There were only 13 people (3.7%) who reported to not have any comorbidities and on average people experience 4 comorbidities.

The poster was recently presented at the Cochrane Colloquium in Edinburgh and sparked engaging conversations and positive comments from researchers who were intrigued by the topic and concept with much needed education on this topic. The full report will be posted on our website

once the analysis is complete. The poster is posted on our website <a href="http://www.spondylitis.ca/">http://www.spondylitis.ca/</a>.

#### **Arthritis Awareness Month**

During the month of September, to support Arthritis Awareness, the CSA has been active with social media to promote and support those living with all arthritic conditions. We hope to reach beyond those who have a diagnosis including family & friends, the undiagnosed and Canadians in general.

#### Save the Date for Our Twitter-Chat Event

Save the Date for a multi-organization-hosted Twitter-chat on Psoriatic Arthritis to in recognition of the National Psoriatic Arthritis Day newly recognized by Health Canada for October 19<sup>th</sup>. The Twitter-chat event will be held on October 18 at 7 p.m. EST in support of people living with or affected by PsA and its impact on people of all ages and genders. We invite you to share the event details with anyone interested in this important topic.

#### Information Session on Ankylosing Spondylitis

On the evening of November 13, in partnership with SPARCC, we will be holding an information session on Ankylosing Spondylitis. We have a great line-up including rheumatologists, a pain specialist, a psychologist and a physiotherapist. The event will take place in Toronto for those to attend in person and will be available for people to join via live webcast. Full event detail is listed on our website @ http://www.spondylitis.ca.

## **Community Updates**

#### CANADIAN RHEUMATOLOGY ADMINISTRATIVE DATA NETWORK



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 a CANRAD Network Meeting during the 2018 CRA Annual Scientific Meeting & AHPA Annual Meeting in Vancouver, BC and we will be organizing a CANRAD Network Webinar this fall! For more information pertaining to our 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/.

#### 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. She is also building the Lupus prEGnAnCY (LEGACY) cohort, a large, multicentre, 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

#### **UNIVERSITY OF CALGARY**

Please join us in congratulating Luiza Grazziotin Lago, University of Calgary (Supervisor, Deborah Marshall), McCaig Bone and Joint Health Institute, on her PhD Salary Award from the Arthritis Society on "Cost-effectiveness of early and aggressive treatment for children with juvenile idiopathic arthritis including the spillover effects on quality of life and productivity of children and their parents". She is one of 9 across Canada to receive this award!



# 272017

## **Calendar of Events**

Bromont, Quebec
Gent, Belgium
Toronto, Ontario
Ottawa, Ontario
Warsaw, Poland
Chicago, Illinois
Chicago, Illinois
Calgary, Alberta
Li Ka Shing Knowledge Institute, University of Toronto, Ontario
Montreal, Quebec
Bangkok, Thailand
Palais des congrès de Montréal, Montréal, Quebec
8 Tokyo, Japan
8 Toronto, Ontario
, 2019 Montreal, Quebec
Paris, France
Louisville, Kentucky
Madrid, Spain

#### 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 <a href="mailto:lgazizova@arthritisalliance.ca">lgazizova@arthritisalliance.ca</a> or visit our website: <a href="www.arthritisalliance.">www.arthritisalliance</a>.