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### ARTHRITIS ALLIANCE OF CANADA

#### AAC Member/Stakeholder Survey Results: Planning for the Future!

The results are in! The Arthritis Alliance of Canada (AAC), we are currently reflecting on our accomplishments and achievements from the past 16 years; looking ahead to determine what our future might look like, determining the focus, shape and form in which we could be moving forward.

We received good response and feedback from our members and stakeholders to the AAC Members/Stakeholder survey that was conducted throughout the month of May until June 4th. A total of 35 responses were received: 83% came from AAC member organizations and 17% from individual respondents. We would like to thank all our member organizations, individual members and community representatives for the valuable input, comments and suggestions!

At this moment, the input is being analyzed to assist the AAC Board with making necessary decisions for the AAC's future direction. The upcoming AAC Annual Meeting in November 2018 will be devoted to celebrating our successes, discussing the results of the survey in more detail and planning for the future!



## AAC 2018 Research Awards Program: “Call for Applications” Deadline Extended!

We are extending the “Call for Applications” for the 3<sup>rd</sup> round of the AAC Research Awards until **Tuesday, July 31<sup>st</sup>, 2018**. The **eight** awards, valued at **\$750 CAD/award**, will be presented to the winning applicants at the AAC 2018 Annual Meeting, on Wednesday, November 21<sup>st</sup> in Toronto. We would like to thank the sponsors of the awards for the continued partnership for the 3<sup>rd</sup> consecutive year:

- 1) [McCaig Institute for Bone and Joint Health](#) for the **Master Student** award
- 2) [Arthritis Consumer Experts](#) for the **PhD Student** award
- 3) [CIHR Institute of Musculoskeletal Health and Arthritis](#) for the **Post-doctoral Fellow** and
- 4) **Early Career Researcher (Early Career Faculty Member/Investigator) in Basic/Clinical science**
- 5) [Arthritis Research Canada](#) for the **Early Career Researcher (Early Career Faculty Member/Investigator) in Health Science/Population Health**
- 6) [Bone and Joint Institute of the University of Western Ontario](#) for the **Knowledge Translation** award
- 7) Sponsor TBD for the **Knowledge Translation Practice** award; and
- 8) [Arthritis Society](#) for the **Patient for Active Engagement in Arthritis Research**.

### ARTHRITIS ALLIANCE OF CANADA 2018 Annual Meeting: November 21-22 at the Sheraton Center Downtown Toronto Hotel

The AAC 2018 Annual Meeting, entitled “*Arthritis Alliance of Canada: Celebrating Our Successes and Planning for the Future*”, will be hosted in partnership with Arthritis Society and CIHR Institute of Musculoskeletal Health and Arthritis.

It will kick-start with a Gala Dinner on **Wednesday, November 21<sup>st</sup>** at 7:00 pm EST, followed by a full-day program on **Thursday, November 22<sup>nd</sup>** until 5:00 pm EST. The registration process will be open soon; stay tuned for a registration link to follow!

*We look forward to meeting you in Toronto!*



## MEMBER'S CORNER

### ARTHRITIS CONSUMER EXPERTS

**ACE** Arthritis  
Consumer  
Experts

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

The [Qualman-Davies Arthritis Consumer Community Leadership award](#) was created in 2014 to recognize the pioneering arthritis advocacy efforts of Ann Qualman and Jim Davies who were two of the first people striving to bring awareness to arthritis across Canada.

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. The application deadline is September 20th, 2018. Please submit completed nominations to [feedback@jointhealth.org](mailto:feedback@jointhealth.org). The winner will be announced at the Arthritis Alliance of Canada's 2018 Annual Meeting Gala dinner taking place on Wednesday, November 21st in Toronto, Ontario.

#### Arthritis Broadcast Network (ABN)

On June 7 and 8 at the KT Canada scientific meeting, Arthritis Broadcast Network hosted its inaugural online [#Greek2Street](#) event. Consumer-patient “reporters” interviewed conference presenters and attendees over live Facebook and twitter broadcasts. The aim of the event was to de-mystify the world of knowledge translation, and to bring current KT research to the broad online patient community, in an engaging and accessible way. Thanks to KT Canada and our wonderful guests, the two-day event was a huge success, informing and educating over 1,000 people on Facebook and over 200,000 people on Twitter. All interviews remain online and can be found on Arthritis Broadcast Network's [Twitter](#), [Facebook](#) and [YouTube](#). Please note the *KT Canada Scientific Meeting* was presented in English.

### New Workbook For Collaboration and Research

Arthritis Research Canada (ARC) is excited to announce that a new workbook is now available to help research teams of academics and patients plan how they will work together on a project. Patient engagement, including family members and caregivers, is becoming central to how health research is conducted in Canada. This engagement is essential to shaping research that reflects patients' priorities.



ARC studied the experiences and views of ARC's Arthritis Patient Advisory Board members and determined the key elements to a meaningful working relationship with researchers. The findings showed a lack of practical resources available to help guide their partnership. Without proper direction, these partnerships may leave patients feeling that their involvement is tokenism and not reflective of their rich experiential perspectives.

This framework is the foundation for a workbook to help research teams plan patient engagement activities. The workbook takes research teams through the eight components of the framework. Within each component, key questions are provided to guide the team discussion to generate dialogue on how each component will be addressed in the partnership. Towards the end of the workbook, team members are directed to select the key components that will form their work plan.

This workbook was created within a research project lead by Clayton Hamilton and co-researchers to develop metric to evaluate the quality of patient engagement in research. For more information click on the [PEIR Plan Workbook](#).

## ARTHRITIS SOCIETY: NATIONAL OFFICE

### Thank You!

Canadians in over 40 communities took part in the 9th annual Walk for Arthritis on June 2<sup>nd</sup> and 3<sup>rd</sup>, with over 8000 people coming together in a show of support for the over 6 million people who are living with arthritis.

"I want to express a heartfelt thank-you to our volunteers, participants, donors, and sponsors," said Janet Yale, President and CEO of the Arthritis Society. "Every year, we strengthen the arthritis community across Canada. It is inspiring to see so many people coming together in 45 communities to support one another, fundraise, and raise awareness about this disease that affects so many Canadians."



## CANADIAN ARTHRITIS PATIENT ALLIANCE

### New Tool



CAPA has launched a tool for patients by patients to help people successfully cope with taking methotrexate - find it on our [website](#) and share as well. You can view the tool and other things we've been up in our recent [CAPA newsletter](#).

CAPA was also proud to have 3 posters at EULAR meeting (see them [here](#)):

- Development & dissemination of a resource about methotrexate use for and by patients with inflammatory arthritis
- Getting the pulse on workplace experiences and accommodations
- Canadian arthritis patient alliance: understanding member profiles and needs.

## CANADIAN ORTHOPAEDIC FOUNDATION AND BONE AND JOINT CANADA

### GLA:D™ Program Report on Implementation and Outcomes

GLA:D™ Canada is pleased to announce the release of the 2017 Annual Report on the Implementation and Outcomes of the GLA:D® Program in Canada. The report summarizes the highlights from inception to December 2017 of the community-based education and exercise program for people with hip and knee osteoarthritis. Highlights include:

Training and Implementation:

- 14 courses for Health Care Providers (HCPs)
- 61 sites implemented the program by December 2017 in 5 provinces

Patient outcomes:

- 28% reduction in pain intensity
- 35% of participants increased their physical activity



These results show that the GLA:D® program is successfully helping individuals with hip and knee OA manage their symptoms, improve their function and quality of life, and increase their physical activity. The report can be accessed at the GLA:D™ Canada website: <http://gladcanada.ca/wp-content/uploads/2018/06/2017-GLAD-Canada-Report-Final.pdf>.

If you have any questions about the GLA:D™ Canada program please email us at [gladcanada.info@gmail.com](mailto:gladcanada.info@gmail.com).

## CANADIAN RHEUMATOLOGY ASSOCIATION

### Annual Report

The Canadian Rheumatology Association is proud to present our inaugural Annual Report. We encourage you to read the report to reflect on our achievements this past year and look forward to what we will accomplish in the future. [Read the 2017-2018 CRA Annual Report.](#)



## 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 summer! For more information pertaining to our webinars or all other information concerning the CANRAD Network, please contact at [autumn.neville@rimuhc.ca](mailto: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](mailto: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 for 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, 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. Of note, team members of the Montreal General Hospital Lupus Clinic took part in the Scotia Bank Charity Challenge 5K run on April 21. The event raised funds to support the Singer Family Fund for Lupus Research, funding that is instrumental to funding research activities at the clinic. For more information pertaining to our RI MUHC activities, fundraising efforts and our Lupus Clinic, please contact [autumn.neville@rimuhc.ca](mailto:autumn.neville@rimuhc.ca).

## UNIVERSITY OF LAVAL

### Call For Participants to Complete Survey



**Project: Expectations and educational needs of Canadian rheumatologists, rheumatology fellows and patients in the field of precision medicine.** You are invited to participate in an anonymous survey for a research project on precision medicine, a personalized medicine based on biomarkers, among patients with rheumatic diseases, with the intent to develop educational tools that meet their needs.



By completing this survey for an average duration of 10 minutes, there will be no direct benefit to you from participating to this research study. Participation to this project does not involve any particular risk. We have taken all reasonable measures to protect your identity and answers.

You will find the web survey link attached: <https://www.limesurvey.cifss.ulaval.ca/index.php/513128/lang-en>.  
If you have any questions, you can contact me by email [sophie.ruel-gagne.1@ulaval.ca](mailto:sophie.ruel-gagne.1@ulaval.ca). Thank you!



## Calendar of Events

Applying Precision Medicine to Psoriatic Disease	July 12, 2018	Toronto, Ontario
11 <sup>th</sup> World Congress on Orthopedics, Rheumatology and Sports Medicine	July 18-19, 2018	Sydney, Australia
Juvenile Arthritis Conference	August 2-5, 2018	Washington, DC
10 <sup>th</sup> Orthopedics, Orthopedic Nursing, Rheumatology Annual Meeting and Expo	August 31-September 1, 2018	Toronto, Ontario
Course on Sonoguided Interventions and Procedures in Musculoskeletal Diseases CAOT Conference 2018	September 12-14, 2018	Barcelona, Spain
Cardio-Rheumatology Scientific Day	September 14, 2018	Toronto, Ontario
2018 Cochrane Colloquium	September 16-18, 2018	Edinburgh, UK
BRIESE: British Columbia Rheumatology Invitational Education Series	September 28-29, 2018	Vancouver, British Columbia
Reaching Out with Arthritis Research (ROAR)	September 29, 2018	Burnaby, British Columbia
9 <sup>th</sup> European Congress on Rheumatology, Autoimmunity and Orthopedics	October 16-17, 2018	Warsaw Poland
ACR/ARHP Annual Meeting 2018	October 19-24, 2018	Chicago, Illinois
CRA Canada Night in Chicago	October 22, 2018	Chicago, Illinois
Canadian Obesity Network 7th Conference on Recent Advances in the Prevention and Treatment of Childhood and Adolescent Obesity	October 24-26, 2018	Calgary, Alberta
Arthritis Day for Primary Care Clinicians	October 27, 2018	Li Ka Shing Knowledge Institute, University of Toronto, Ontario
Canadian Physiotherapy Association Congress, Palais des congrès de Montréal	November 1-3, 2018	Montreal, Quebec
World Congress on Controversies, Debates and Consensus in Bone, Muscle and Joint Diseases (BMJD)	November 8-10, 2018	Bangkok, Thailand
Arthritis Forum	November 10, 2018	Palais des congrès de Montréal, Montréal, Quebec
World Congress on Osteoporosis, Osteoarthritis, and Musculoskeletal Diseases	November 14-15, 2018	Tokyo, Japan
<b>Arthritis Alliance of Canada (AAC) 2018 Annual Meeting</b>	<b>November 21-22, 2018</b>	<b>Toronto, Ontario</b>
CRA Annual Scientific Meeting and AHPA Annual Meeting	February 27- March 2, 2019	Montreal, Quebec
CARRA Annual Meeting	April 10-14, 2019	Louisville, Kentucky

### **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](mailto:lgazizova@arthritisalliance.ca) or visit our website: [www.arthritisalliance.ca](http://www.arthritisalliance.ca).