

Arthritis Alliance of Canada FINAL NEWSLETTER

December 2019

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ARTHRITIS ALLIANCE OF CANADA

Final Annual Meeting
Friday, November 29th, 2019, 12:30-5:00 pm EST

Sadly enough, but that day had come! On **Friday, November 29th, 2019** the [Arthritis Alliance of Canada's \(AAC\)](#) gathered for the last time as a unified organization at a face-to-face Final Annual Meeting in Toronto. As an umbrella organization of more than 30 [member organizations](#)-various arthritis stakeholders, including healthcare professionals, researchers, funding and voluntary sector agencies, governments, industry, and arthritis patient organizations and groups across Canada, AAC members and stakeholders celebrated organization's success in accomplishing a number of major initiatives and partnership projects including, but not limited to the frameworks for:

- ✚ [A Pan-Canadian Approach to an Inflammatory Arthritis Model of Care](#)
- ✚ [Performance Measurement Framework for IA Models of Care](#)
- ✚ [Canadian Rheumatoid Arthritis Core Clinical Data Set \(CAN-RACCD\)](#)
- ✚ Supporting online tools, such as [Inflammatory Arthritis Care Path Toolkit](#), [Osteoarthritis Tool for Family Physicians](#) and health care providers and its complementary version the [Talk to Your Doctor About Joint Pain Handout](#), designed to assist those with or at risk of OA, in having better conversations with their doctors or other health care professionals

- Two projects that are currently in progress and expected to complete in 2020: Cost-Consequences Analysis of Models of Care for Patients with Inflammatory Arthritis, led by Dr. Elena Lopatina PhD candidate in Health Economics at the University of Calgary (elopatina@ucalgary.ca); and Development of a Patient-Centered Framework for Measuring, Monitoring and Optimizing Rheumatoid Arthritis Care, led by Dr. Claire Barber (cehbarbe@ucalgary.ca) at the University of Calgary and Dr. Diane Lacaille (dlacaille@arthritisresearch.ca) at the University of British Columbia.

An Executive Summary [Arthritis Alliance of Canada: 2002-2019:17 Years of Success](#) and a pictographic overview of the [AAC historical milestones](#) highlight in a nutshell various remarkable contributions of each of the Alliance member organizations to the work of the AAC over the years!

November 29th was a truly remarkable day for AAC, as we have celebrated excellence in arthritis research and stakeholder collaboration! The Alliance recognized [recipients](#) of the fourth and final round of Research awards, a winner of the 2019 Qualman-Davies Consumer Community Leadership Award and AAC member organizations that received the one-time only Legacy Awards at the Luncheon and Special Awards Ceremony during the final meeting! **Congratulations to all awardees!**

Research Awards

Seven awards were presented to recognize contributions to arthritis research in Canada:

1. PhD Student Award, sponsored by Arthritis Consumer Experts, to **Ms. Daeria Lawson** (Toronto Western Hospital, University Health Network, Toronto)
2. Early Career Researcher in Basic/Clinical Science Award, sponsored by CIHR Institute of Musculoskeletal Health and Arthritis, to **Dr. Jackie Whittaker** (University of British Columbia, Vancouver)
3. Early Career Researcher in Health Science/Population Health Award, sponsored by Arthritis Research Canada, to **Dr. Glen Hazlewood** (University of Calgary, Calgary)
4. Post-Doctoral Fellow Award, sponsored by CIHR Institute of Musculoskeletal Health and Arthritis, to **Dr. Marina Amaral De Avila Machado** (McGill University, Montreal)
5. Master Student Award, sponsored by McCaig Institute for Bone and Joint Health, to **Kelsey Chomistek** (University of Calgary, Calgary)
6. Master Student Award, sponsored by the Arthritis Alliance of Canada, to **Yvonne Brandelli** (Dalhousie University, Halifax); and
7. Patient for Active Engagement in Arthritis Research Award, sponsored by the Arthritis Society, to **Ms. Maureen Sauve** (Co-Chair, SPIN Patient Advisory Board; VP Advocacy and Public Relations, Scleroderma Canada, Hamilton, ON)



Legacy Awards

The one-time AAC Legacy Award funding opportunity was designed to allow [AAC member organizations](#) to collaboratively advance the [work of the Alliance](#) and continue communication and dissemination of the developed tools and resources after the network ceases its activities at the end of December 2019. The following six AAC member organizations received the legacy grant, each valued at up to \$35,000 Canadian dollars:

1. The [Arthritis Society](#) and [Canadian Arthritis Patient Alliance \(CAPA\)](#) for the project proposal on **Creation of an online Osteoarthritis Resource Hub**
2. The [Arthritis Society](#) and [Canadian Institutes of Health Research \(CIHR\)-Institute of Musculoskeletal Health and Disease \(IMHA\)](#)



AAC Consumer Coalition receiving legacy award

for the project proposal on *Publishing an updated arthritis research landscape report*

3. [Bone and Joint Canada](#) and [Canadian Orthopaedic Foundation](#) for the project proposal on *Development of a "Learning Network" to disseminate evidence-based information about the management of hip and knee OA*
4. AAC Consumer Coalition: [Arthritis Consumer Experts](#), [Canadian Arthritis Patient Alliance](#), [Canadian Spondylitis Association](#) and [Arthritis Patient Advisory Board of Arthritis Research Canada](#) for the project proposal on *Inflammatory Arthritis Models of Care Provincial Summits: Coast-to-coast advocacy for improved arthritis care*
5. [Canadian Rheumatology Association](#) and [Canadian Arthritis Patient Alliance \(CAPA\)](#) for the project proposal on building *Canadian RA Registry Network*
6. [McCaig Institute of Bone and Joint Health](#) and University of Calgary for the project proposal on *Biosimilar starts and switches, what we can learn from patients?*

2019 Qualman-Davies Consumer Community Leadership Award



This year, the arthritis community honored Anne Lyddiat, National Trainer at the Patient Partners in Arthritis Program in presenting the Qualman-Davies Arthritis Consumer Community Leadership Award was created in 2014 to recognize one person's contributions to helping Canadians living with the disease to be heard in decision-making processes that affect millions. That's what Ann Qualman and Jim Davies did as early pioneers in arthritis advocacy in Canada. Their tireless and selfless efforts helped millions of Canadians. ***Congratulations, Anne! So well deserved!***



Anne Lyddiat (in the centre) receiving an award



Anne Lyddiat (bottom row centre), surrounded by her colleagues and friends from Patient Partners in Arthritis Program and her daughter Karyn Benner (top row to the right between Jennifer Boyle and Cheryl Koehn)

Nice Memories to Keep!

A warm networking Reception completed the day of the Final Annual Meeting of the AAC members, stakeholders and our guests! We are delighted to share the online link with all the nice [photos](#) that were taken during the meeting for your long and lasting memories.





AAC Founders (left to right): Ms. Cheryl Koehn, Dr. John Esdaile, Dr. Dianne Mosher, Dr. Gillian Hawker, Mr. Denis Morrice



AAC Board Members (left to right): Ms. Jennifer Burt, Dr. Dianne Mosher, Dr. Deborah Marshall, Mr. Gerald Major



AAC members networking



AAC members networking



AAC members



Brainstorming on future collaborations



Brainstorming on future collaborations



AAC members networking



AAC members networking



Dr. Dianne Mosher, AAC Past-Chair, Advisor to the Board

Stay Connected!

Dear Readers! Please be informed that after the Alliance's closure at the end of December 2019, the website: www.arthritisalliance will be kept live as an archive of all AAC reports, publications and available tools until 2025. If you wish to contact any of the AAC member organizations, please visit the [membership page](#) to find the contact details and reach out to the member organization of your interest.

Appreciating Contributions and Wishing Happy Retirement!

Two weeks ago, the arthritis community was honoring Janet Yale, President & CEO of the Arthritis Society and Chair of Board, the Arthritis Alliance of Canada as Janet plans to embark on her retirement journey in early 2020. On behalf of the AAC members and the Board of Directors, we would like to thank Janet for seven years of service at the Alliance in the capacity of the Chair of Board and express deepest appreciation of her upbeat leadership skills, commitment and various tremendous contributions to improving the lives of Canadians with arthritis! *Good luck to you for the future, Janet!*



Left to right: Janet Yale, AAC Chair of Board, President & CEO, Arthritis Society, and Cheryl McClellan, Chief Operations Officer, Arthritis Society

Seasons Greetings for 2020 and a Huge Thank you!

On behalf of the Arthritis Alliance of Canada Board of Directors, we wish you and your families warmest greetings for a wonderful holiday season and successful dawn of the new decade!

We would like to reiterate our sincere appreciation of the tremendous support of each of the [AAC member organizations](#) and every of our industry partners, including [Abbvie](#), [Amgen Canada](#), [Eli Lilly Canada](#), [Merck Canada](#), [Novartis Canada](#), [Pfizer Canada](#) and [Sandoz Canada](#) for tremendous contribution to the Alliance's 17 years of success in improving the lives of Canadians with arthritis! Without you, your commitment and support, the important work that had been done over these years, would not be possible!



Wishing you all a very Happy New Year 2020 and best wishes for the future!

MEMBER'S CORNER

ARTHRITIS HEALTH PROFESSIONS ASSOCIATION (AHPA)

News from AHPA

The 2020 membership drive for the [Arthritis Health Professions Association \(AHPA\)](#) officially launched in November 2019. AHPA is a dedicated group of health professionals from across Canada who are passionate about improving the care of people with rheumatic disease and collaborate with other professionals and patient organizations to promote public awareness of the needs of people living with arthritis. Upcoming events for the AHPA include the 12th AHPA Pre-course being held on Wednesday, February 26th during the 2020 Canadian Rheumatology Association and Arthritis Health Professions Association Annual Scientific Meeting at the Fairmont Empress Victoria in Victoria, British Columbia. The AHPA Annual General Meeting will also be held during the meeting in Victoria on Friday February 28, 2020.



Left to right: Jennifer Burt, Sue MacQueen, Jennifer Boyle

AHPA will continue to work with the national arthritis community to promote our vision of “optimal care and quality of life for every Canadian living with Arthritis”.

ALBERTA BONE AND JOINT HEALTH INSTITUTE

Map to Motion

The Alberta Bone and Joint Health Institute has undertaken an important new initiative that will be an avenue for innovation in the musculoskeletal clinical and research communities. MAP to MOTION will capture and evaluate patients' musculoskeletal care journey in Alberta, providing improved access to information for patients, physicians, and other community providers such as physiotherapists, chiropractors, exercise therapists, and seniors care. The opportunity for researchers to conduct advanced analytics (i.e. dynamic modelling, machine learning, and artificial intelligence) will guide more personalized treatment plans and help reshape the healthcare landscape in Alberta towards sustainable value-based care. For more details visit: albertaboneandjoint.com/maptomotion.

ARTHRITIS CONSUMER EXPERTS

Greetings of the season

Season greetings of the season from Arthritis Consumer Experts (ACE). It's hard to believe this is the 20th year in a row I've had the privilege of saying that to you, our members, subscribers, followers, colleagues and friends. Over the past 20 years, our team of dedicated staff, expert scientific, clinical and informed consumers/patients have worked every day, all day, to serve our national community of 50,000 and the public. As ACE enters 2020, there is a lot to be excited about and look forward to. We will continue to bring a credible, research-based arthritis patient community voice to the forefront in provincial, territorial and federal government consultations on arthritis treatments and models of care. [Click here](#) to view Cheryl's message. To learn more about ACE's activities in 2019, read our latest issue of [JointHealth™ insight](#).



The #Arthritis2019 list

ACE is wrapping up the year by curating a #Arthritis2019 list for you. From December 17, 2019 to January 5, 2020, we will be highlighting arthritis news, research findings, resource tools, or updated clinical recommendations and guidelines from this year on our Facebook and Twitter channels. We invite you to participate in the #Arthritis2019 campaign by sharing your own arthritis highlights from 2019:

- Send us an [email](#) to share your arthritis highlights
- Share your arthritis highlights on our [Facebook](#) or [Twitter](#) pages and include the hashtag #Arthritis2019
- Share, like, and comment on #Arthritis2019 posts.

ARTHRITIS RESEARCH CANADA

News from Arthritis Research Canada

Arthritis Research Canada's research scientists, trainees, and representatives of the Patient Advisory Board, recently attended the American College of Rheumatology Annual Meeting in Atlanta, Georgia. The Arthritis Research Canada team presented a total of 87 abstracts including 2 oral presentations.



One highlight was a poster on strength training in rheumatoid arthritis co-presented by Arthritis Research Canada trainee Jasmin Ma, and one of her co-authors, Patient Advisory Board member Eileen Davidson. Although much research has been done on exercise and arthritis, there is almost no research on weight training in arthritis. Jasmin, along with her co-investigators and patient collaborators are trying to remedy that.



ARTHRITIS SOCIETY: NATIONAL OFFICE

New medical cannabis resources

This month we're launching several new educational resources focused on medical cannabis. Highlights include:

- [An updated medical cannabis resource hub](#)
- [Medical cannabis online learning module](#)
- [Medical cannabis infographic](#)
- [Medical cannabis FAQs video](#)

New research grants and awards

We announced [14 new research grants and awards](#) that start January 1st, 2020. Between these new commitments and our ongoing funding of existing projects, it brings the Arthritis Society's 2019-20 research funding commitment to nearly \$4 million, along with additional commitments from partners.

The new investments include:

- 5 new Stars Career Development Awards for early-career researchers (including two co-funded by CIHR-IMHA)
- 3 new Stars Career Development Awards for mid-career researchers (fully funded by CIHR-IMHA)
- 6 new Strategic Operating Grants

Top 10 research impacts of 2019

As 2019 comes to a close, our [Top 10 Research Advances 2019 highlights](#) many of the year's published discoveries made possible through the generosity of our donors and partners – from innovative therapies in development for osteoarthritis to preventing life-threatening complications.

Save the Date! Arthritis Talks – February 19, 2020

Our next Arthritis Talks symposium will take place on Wednesday February 19th 2020, and will focus on healthy aging. Watch for details soon at www.arthritis.ca/arthritis Talks.

PUBLIC HEALTH AGENCY OF CANADA

Coming in 2020 - New Fact Sheets on Arthritis from the Canadian Chronic Disease Surveillance System

The Public Health Agency of Canada (PHAC) is pleased to announce that beginning in spring 2020, new data from the [Canadian Chronic Disease Surveillance System \(CCDSS\)](#) will be released in a series of four publications on arthritis. The fact sheets will provide highlights of Canadian surveillance data on: Osteoarthritis, Rheumatoid Arthritis, Gout and Other Crystal Arthropathies and Juvenile Idiopathic Arthritis. They will be found on <http://www.canada.ca> by searching "Arthritis". More detailed CCDSS data on arthritis, as well as other chronic diseases, can also currently be found on PHAC's Public Health Infobase, a user-friendly tool for accessing public health surveillance data: <https://health-infobase.canada.ca/ccdss/data-tool/>.

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 a grant application to the Department of Defense, Military Medical Research and Development, United States Army (Low-dose aspirin 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/>.

ONTARIO RHEUMATOLOGY ASSOCIATION

19th ORA Annual Scientific Meeting

Don't forget to mark your calendars for the 19th ORA Annual Scientific Meeting, April 17-19, 2020 at the Kingbridge Conference Centre in King City. Dr. Janet Pope has recruited a series of expert speakers including Dr. Joseph Smolen, Dr. Michelle Petri, Dr. Maya Buch and more! To review the agenda and complete line-up of speakers, please visit this link: (<https://ontariorheum.ca/event/19th-annual-meeting>). We look forward to seeing you there!

SCLERODERMA CANADA

News from Scleroderma Canada

[Scleroderma Canada](http://scleroderma.ca) is a national, charitable organization whose vision is – A world free from scleroderma. We work collaboratively with provincial organizations to plan, promote, facilitate and support events. Recently, Advocacy Days were held in Alberta and Ontario, with Members of the Legislative Assembly and representatives. In Ontario, we were privileged to meet the Premier himself, to share personal stories and advocate on behalf of patients. Scleroderma Canada was able to help decision-makers understand the importance of raising awareness, the need for improved access to and subsidization of unaffordable medications and the need for improved education, throughout the medical community. We are happy to announce our 19th Bi-Annual, National Scleroderma Conference will be held in Niagara Falls, Ontario in September 2020.



Calendar of Events

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 (AAC)

With more than 30 member organizations, the Arthritis Alliance brought 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 continued its own work, the Alliance provided a central focus for national arthritis-related initiatives.

Please note the Arthritis Alliance of Canada (AAC) is ceasing its operations at the end of December 2019. The [AAC website](#) will be kept live as an archive of all AAC reports, publications and tools until February 2025; however, its content won't be updated. If you wish to contact any of the AAC member organizations, please visit the [membership page](#) to connect with the member organization of your interest.