# **Arthritis Alliance of Canada NEWSLETTER**

# **April 2019**

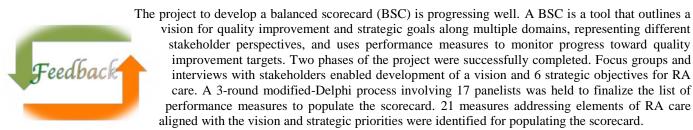
Table of Contents
ARTHRITIS ALLIANCE OF CANADA
Developing a patient-centered framework for measuring, monitoring and optimizing rheumatoid arthritis care – A Call
to Action!
The CRA-AAC-CIHR-CATCH Collaborative Project to Build an Economic Business Case for
AAC IA Models of Care
AAC 2019 Annual Meeting – SAVE THE DATE
AAC 2019 Research Awards Program: "Call for Applications" in progress!
MEMBER'S CORNER
ARTHRITIS HEALTH PROFESSIONS ASSOCIATION
AHPA Pre-Course and Award Recipients
ARTHRITIS CONSUMER EXPERTS
Election advocacy
Biosimilars education video series
ARTHRITIS RESEARCH CANADA
New Grant from CIHR
ARTHRITIS SOCIETY
National Office
Arthritis Talks symposium series launches May 4th
New online learning module: Eating well
New article series on women and arthritis
2019-20 Research competitions launched
Celebrating volunteers
British Columbia
Arthritis Society partners with Cassie & Friends to Stop Childhood Arthritis
Nova Scotia
Arthritis Society celebrates Maud Lewis for Heritage Day
CANADIAN ARTHRITIS PATIENT ALLIANCE
News from CAPA
COMMUNITY UPDATES
CANADIAN RHEUMATOLOGY ADMINISTRATIVE DATA NETWORK
McGill University Health Centre
ONTARIO RHEUMATOLOLGY ASSOCIATION
18 <sup>TH</sup> Annual Meeting on May 24, 2019
UNIVERSITY OF CALGARY
Congratulations to Dr. Deborah Marshall
Dr. Claire Barber's New Research Project
CALENDAR OF EVENTS

# **ARTHRITIS ALLIANCE OF CANADA**

ABOUT THE ARTHRITIS ALLIANCE OF CANADA ......8

#### **ONGOING PROJECTS**

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





When it comes to measuring the quality of rheumatoid arthritis (RA) care, **your feedback is important!** As part of the 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: <a href="https://rheum.ca/patient-centered-framework/">https://rheum.ca/patient-centered-framework/</a>. 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, is well underway. Conducting a Cost-Consequences Analysis of IA MOCs is in full swing with participation of 10 out 16 CATCH sites representing four provinces, Alberta, Manitoba, Ontario and Quebec. A survey of sites and phone interviews were conducted 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 and 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!

# **AAC 2019 Annual Meeting – SAVE THE DATE**



The Arthritis Alliance of Canada's 2019 Annual Meeting will be hosted on Friday, November 29<sup>th</sup> 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" in progress!

On April 5<sup>th</sup>, AAC has announced a "Call for Applications" for the 4th round of its successful Research Awards Program. Again, this year, AAC will provide eight awards, valued at \$750 CAD/award, including an Early Career Researcher award including two sub-categories: Basic Science/Clinical Science; and Health Science/Population Health, Master Student, PhD Student, Post-doctoral Fellow, Knowledge Translation in Research/Science, Knowledge Translation in Practice and most importantly, the Patient for Active Engagement in Arthritis Research.

We are pleased to confirm continued partnership of our sponsors for the **fourth** 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 in Basic/Clinical science
- 5) Arthritis Research Canada for the Early Career Researcher in Health Science/Population Health
- 6) Sponsor for the Knowledge Translation in Research/Science award is yet to be confirmed
- 7) Amgen Canada for the **Knowledge Translation in Practice**, and the
- 8) Arthritis Society for the Patient for Active Engagement in Arthritis Research.

We are expecting to receive complete application packages on Friday, May 31 at midnight EST, with no exceptions. We look forward to your participation in this important initiative!

# MEMBER'S CORNER

# ARTHRITIS HEALTH PROFESSIONS ASSOCIATION

#### **AHPA Pre-Course and Award Recipients**

The Arthritis Health Professions Association (AHPA) was pleased to once again join CRA at the 2019 Annual Scientific Meeting held in Montreal QC. Our 11<sup>th</sup> Annual Pre-Course was a successful day with presentations from rheumatologists, an orthopaedic surgeon, an Advanced Clinician Practitioner in Arthritis Care, an Arthritis Society physiotherapist and a representative from CAPA.



At the Gala Dinner, we were pleased to present the Lifetime Achievement Award to *Mary Ellen Marcon*, an ACPAC trained physiotherapist with the Arthritis Society for more than 35 years and a loyal AHPA member who has made a difference to people living with arthritis, especially those in Northern Ontario. The AHPA Extraordinary Service Award was presented to *Leslie Soever* for her years of dedicated service on the AHPA Board of Directors, first as Career and Professional Development Chair and then as President (for an extraordinary 4 years!).

## Congratulations to Mary Ellen and Leslie!



Leslie Soever (left) receiving the AHPA Extraodinary Service Award from Sue MacQueen, AHPA President



Mary Ellen Marcon (left) receiving the Lifetime Achievement Award from Sue MacQueen, AHPA President

# **ARTHRITIS CONSUMER EXPERTS**

#### **Election advocacy**

ACE sent open letters and surveys to political parties and candidates running in the <u>Alberta</u> and <u>Prince Edward Island</u> provincial elections. 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 model of care and improve patient outcomes in their province.



#### Biosimilars education video series

In a special series of <u>JointHealth<sup>TM</sup> Biosimilars Education videos</u>, Arthritis Consumer Experts speaks to medical experts, including Dr. Susan Bartlett and Dr. John Esdaile, about key patient issues on transitioning between similar biologic medications. In the five-part video series, ACE examines biosimilars, the latest research and real world experience on transitioning, and a role-play demonstration of a rheumatologist-patient biosimilars transition conversation.

# ARTHRITIS RESEARCH CANADA

#### **New Grant from CIHR**



Arthritis Research Canada's exciting start to the year continues into February and March with another \$1 million plus in grant funding from the Canadian Institutes of Health Research (CIHR). This is excellent news for our research teams and for the millions of Canadians living with arthritis.

These grants will be used to research a new way to measure disease activity in people with systemic lupus erythematosus, to determine whether those with osteoarthritis can keep running as they age, and to develop a mobile educational app that will contain the most recent information on diagnosis, clinical photos, and treatment on topics such as systemic lupus erythematosus, systemic sclerosis (scleroderma), psoriasis and psoriatic arthritis. We are proud of our researchers and the amazing work they do for people with arthritis!

# **ARTHRITIS SOCIETY**

#### **National Office**

# Arthrite Arthritis

#### Arthritis Talks symposium series launches May 4th

The Arthritis Society is launching a new national symposium series, Arthritis Talks. Our inaugural event is *Arthritis Talks: Nourish and Flourish*, which will provide people living across the country with access to arthritis experts in the fields of nutrition, physical exercise and medical cannabis. Speakers include registered dietitian Lalitha Taylor, physiotherapist Brenda Tittlemier and Rattan Panesar, MD. Participate in the live events in Calgary or Winnipeg, in viewing parties near you or via the interactive webcast presentation. Find out more and register at www.arthritis.ca/arthritistalks, and stay tuned for announcements about future Talks.

#### New online learning module: Eating well

In March, as part of National Nutrition Month, we released a new online learning module, *Eating Well*. While a balanced diet can't cure arthritis, it can help maintain a healthy weight, protect joints and preserve energy levels to help manage arthritis symptoms. Check it out at our online learning hub, www.arthritis.ca/education.

#### New article series on women and arthritis

Women are disproportionately affected by arthritis. On International Women's Day we launched the first article in a six-part series for health consumers about arthritis and women's health. Check it out on our digital arthritis magazine, *flourish* (www.arthritis.ca/flourish), and stay tuned for more.

# 2019-20 Research competitions launched

Our research grant and award competitions for 2019-20 have been launched! We are looking forward to these new opportunities to support cutting-edge research by funding:

- Strategic Operating Grants (focused this year on improving our understanding of arthritis and finding a cure)
- Stars Career Development Awards
- Graduate PhD Studentship Awards
- Postdoctoral Fellowship Awards
- Arthritis Centre Grants (focused this year on capacity building or research training in rheumatology).

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

#### **Celebrating volunteers**

National Volunteer Week was observed this April, which celebrates the millions of Canadians who volunteer their time and skills to improve lives. We thank and celebrate dedication of our 2,500 active volunteers in roles ranging from leadership to event management, education to administrative support, all of whom work alongside us to increase our reach and impact. Learn more about volunteering at the Arthritis Society: <a href="www.arthritis.ca/volunteer">www.arthritis.ca/volunteer</a>.

# **British Columbia**

## Arthritis Society partners with Cassie & Friends to Stop Childhood Arthritis

Announced at the All-In For Arthritis Gala in Vancouver, this partnership brings together Canada's largest charitable funder of arthritis research investment and programming with the only charity in Canada 100% focussed on childhood arthritis. Goals of the partnership include collaborating to bring more programming to children living with JIA and other childhood forms of arthritis, and raising the profile, reach and impact of <a href="Stop Childhood Arthritis">Stop Childhood Arthritis</a> (<a href="www.stopchildhoodarthritis.ca">www.stopchildhoodarthritis.ca</a>), the Arthritis Society's five-year, \$5-million initiative that is funding research into personalized medicine aimed at stopping childhood arthritis in its tracks.

## **Nova Scotia**

# **Arthritis Society celebrates Maud Lewis for Heritage Day**

The Arthritis Society partnered with Canada Post and the Art Gallery of Nova Scotia to celebrate 2019 Heritage Day honouree Maud Lewis. Events brought members of the public and busloads of school children to the AGNS to learn about the renowned folk artist, who lived with crippling rheumatoid arthritis. They heard from art experts as well as members of the rheumatology community. The day was commemorated with a limited-run Maud Lewis postage stamp.

## CANADIAN ARTHRITIS PATIENT ALLIANCE

# **News from CAPA**



The Canadian Arthritis Patient Alliance is proud of our President, Linda Wilhelm, for her appointment to the <u>Canadian Pain Task Force</u>, and know she will represent the arthritis community and people who live with chronic pain passionately in this role.

Laurie Proulx attended the PARE conference, sharing CAPA's <u>workplace resources</u>, and Dawn Richards attended the CADTH symposium, presenting a poster on how opioid policy has affected people who live with chronic pain and co-hosting a session with Zal Press (aka Patient Commando) on <u>patient partner compensation in research and healthcare</u>.

# **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. Evelyne 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. Our Lupus Clinic celebrated 40 years of research this fall! Team members of the Montreal General Hospital Lupus Clinic will take part in the Scotia Bank Charity Challenge 5K run on April 27 to raise 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 <a href="mailto:autumn.neville@rimuhc.ca">autumn.neville@rimuhc.ca</a>.



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 was held April 15, 2019, and we were happy to have Dr. Cynthia Crowson to present on *Prognostic risk score development and validation*. For more information pertaining to our meetings, upcoming webinars or all other information concerning the CANRAD Network, please contact at <a href="mailto:autumn.neville@rimuhc.ca">autumn.neville@rimuhc.ca</a> or visit our website <a href="http://www.canradnetwork.ca/">http://www.canradnetwork.ca/</a>.



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 <a href="mailto:autumn.neville@rimuhc.ca">autumn.neville@rimuhc.ca</a> or visit our website <a href="http://canaim.ca/">http://canaim.ca/</a>.

## ONTARIO RHEUMATOLOLGY ASSOCIATION

# 18<sup>TH</sup> Annual Meeting on May 24, 2019



The ORA is pleased to be hosting its 18th Annual Meeting in a new venue; the Kingbridge Conference Centre in King City, located just north of Toronto. With a theme of "Looking to the Future in Rheumatology" featuring outstanding roster of renowned international and home-grown Canadian presenters (Art Kavanaugh, Iain McInnes, Denis McGonagle, Raashid Luqmani and Edward

Keystone to name a handful), the 2019 Annual meeting is poised to be the best yet!

The format of our meeting this year is also freshened with more robust plenary sessions, interactive workshops, our ever-popular Friday night poster session and even a fireside chat with Art Kavanaugh looking at the rheumatology road ahead. We hope you can join us for this exciting event and an opportunity to connect with rheumatology colleagues and experts alike. Find out more <a href="here">here</a>.

## UNIVERSITY OF CALGARY



#### Congratulations to Dr. Deborah Marshall

Dr. Deborah Marshall has been awarded the CADTH 2019 Dr. Jill M Sanders Award of Excellence in Health Technology Assessment. Established in 2010 and awarded annually, this

award recognizes individuals whose outstanding achievements have significantly advanced the fields of health technology assessment, evidence-based drug reviews, or optimal technology utilization in Canada.



# Dr. Claire Barber's New Research Project

Dr. Claire Barber's new research project, "Development of a Patient-Centered Rheumatoid Arthritis (RA) Quality of Care Survey and Testing Continuous Reporting of Established RA Quality Measures," is funded by the Cumming School of Medicine, Department of Medicine Clinical Analytics Award. This recently funded project builds on key findings emerging from the RA Balanced Scorecard Study that is being co-led by Drs. Claire Barber and Diane Lacaille. The project aims to develop an RA Quality of Care Survey (RQCS) for patients to complete. This will be a data source for patient-valued elements of high quality of care not captured easily in existing data sources, filling the gaps identified through the ongoing Balanced Scorecard Study. As well, the RQCS will provide an opportunity to enhance data collection for validated existing quality of care measures that are assumed to be poorly documented in the medical record (i.e., smoking cessation counselling, exercise and lifestyle counselling).

Finally, the survey will provide an alternative method of monitoring quality of care for rheumatologists who do not participate in prospective data collection using the divisional Rheum4U electronic data platform (i.e., community rheumatologists who are divisional members). For more information, please contact the study coordinator, Victoria Bohm (victoria.bohm@ucalgary.ca).



# **Calendar of Events**

Osteoarthritis Research Society International (OARSI 2019) World Congress	May 2 - 5, 2019	Toronto, Ontario
50 <sup>th</sup> Edition of the Laurentian Conference of Rheumatology	May 9 - 11, 2019	Esterel, Quebec, Canada
2019 ARThritis Soirée	May 22, 2019	Vancouver, British Columbia
5 <sup>th</sup> Annual Mayo Clinic Rheumatology Review for Primary Care 2019	May 23-25, 2019	Amelia Island, Florida, USA
The Arthritis Society: Walk for Arthritis	June 1 − 2, 2019	Canada
Scleroderma Society of Ontario Walk/Run	June 1 – 22, 2019	Hamilton, London, Ottawa and Toronto, Ontario
13 <sup>th</sup> International Society of Physical and Rehabilitation Medicine World Congress (ISPRM 2019)	June 9 - 13, 2019	Kobe, Japan
2019 EULAR – The European Congress of Rheumatology	June 12 - 15, 2019	Madrid, Spain
2 <sup>nd</sup> International Combined meeting of Orthopedic Research Societies	June 19 – 22, 2019	Montreal, Quebec
9 <sup>th</sup> 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
Discrete Choice Experiment Short Course	September 8-11, 2019	Banff, Alberta
13 <sup>th</sup> Annual Conference, Pain Society of Alberta	October 17 – 20, 2019	Lake Louise, Alberta
17 <sup>th</sup> International Congress of Immunology (IUIS)	October 18 -23, 2019	Beijing, China
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 <a href="mailto:lgazizova@arthritisalliance.ca">lgazizova@arthritisalliance.ca</a> or visit our website: <a href="www.arthritisalliance.ca">www.arthritisalliance.ca</a>