

Arthritis Consumer Experts 2019 Year in Review



In 2019, Arthritis Consumer Experts (ACE) worked – everyday, all day – to improve the lives of people living with arthritis through education, (em)powerment and advocacy. With guidance from its members, the arthritis patient community, healthcare professionals, researchers and partner organizations, ACE continued to develop their JointHealth™ family of programs. This includes updating the JointHealth™ Report Card, creating JointHealth™ insight and JointHealth™ express newsletters, submitting patient inputs to CADTH and provincial drug plans, participating in conferences, workshops and webinars, as well as collaborating on exciting new patient resources and education tools.

In this issue of JointHealth™ insight, we provide highlights of ACE programming in 2019 and announce the winner of **Canada's Best Workplaces for Employees Living with Arthritis Award**. We also discuss two awards which were presented at the Arthritis Alliance of Canada's Annual Meeting in Toronto on November 29, 2019, including the **Qualman-Davies Consumer Community Leadership Award** and **The Arthritis Alliance of Canada (AAC): Legacy Award**. Thank you for making 2019 a year of progress, meaning and success!

JointHealth™ insight

JointHealth™ express


JointHealth™  Education

Biosim·Exchange

JointHealth™ Report Card

#Vote4Arthritis 

Arthritis Broadcast Network 

Multiple National and International
Conference Attendance and Presentations 



Winter



ACE released a **special issue of JointHealth™ insight**, which focused on the complex relationship between arthritis and mental health. This topic is particularly important because people with inflammatory arthritis (IA) are more likely to experience mental health conditions such as depression, anxiety and “brain fog” than the general population. The issue covered the latest research on the topic, management strategies and includes a section on sex and intimacy for people living with arthritis.

Tell us about your experience. How do you manage your mental health while living with arthritis? Share your response with us online.



Cheryl Koehn, Founder and President of Arthritis Consumer Experts, moderated the Women in Biz Network’s nationwide series called **RA Matters at Work** (supported by Lilly Canada). in Vancouver, Toronto and Montreal. Patient experts and leading health-care professionals, including Olympians Spencer O’Brien and Nathalie Lambert, doctors Diane Lacaille and Susan Bartlett, and patients Julia Chayko and Laurie Proulx shared their unique perspectives on the challenges RA presents on employees’ lives and how they overcame them.

What do you think? What are some ways to create a work environment that challenges the negative beliefs associated with living and working with arthritis? Share your response with us online.





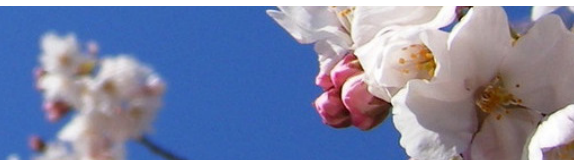
Together with patient partner organizations – the Canadian Spondylitis Association and the Arthritis Patient Advisory Board of Arthritis Research Canada – ACE hosted the fifth annual **#CRArthritis Facebook and Twitter Live** event at the 2019 Canadian Rheumatology Association and the Arthritis Health Professions Association Annual Scientific Meeting in Montreal. The event included a total of 36 interviews with conference presenters and attendees, informing and educating over 635,000 people on Twitter and 11,658 people on Facebook during the week of the meeting.

At the meeting, Cheryl Koehn also co-presented with Dr. John Esdaile and Dr. Sasha Bernatsky a workshop: “Having an Informed, Positive Biosimilar Transition Conversation with Your Inflammatory Arthritis Patient.”

The workshop looked at the “nocebo” effect associated with transitioning patients from biologic originators to biologic biosimilars, which can be attributed to a patient’s “subjective” perception that the biosimilar is inferior to its originator, a perception that may arise from negative suggestions from prescribers and clinical staff, even if such suggestions are unintended.

Want to learn more about how to have a good conversation with your rheumatologist about advanced therapies? [Click here](#) to enroll in JointHealth™ education: Advanced Therapies for Inflammatory Arthritis.

Spring



As part of its strategic, sustained advocacy program, during every provincial election and federal election in Canada, ACE sends an open letter to political parties and individual candidates outlining the impact of arthritis and asks how government can improve prevention, treatment and care.

In the Spring of 2019, Newfoundland and Labrador, Alberta and Prince Edward Island held provincial elections. ACE provided each Party with information on the impact of arthritis in their province and asked for their comments and promises on models of care, arthritis education, indigenous arthritis care, reimbursement for inflammatory arthritis medications, and flexible work arrangements. ACE published the party and candidate responses to help voters make their choice.



Arthritis Broadcast Network
All your arthritis news and information. All the time.
www.ArthritisBroadcastNetwork.org



#Greek2Street
Dr. Jasmin Ma
Post-Doctoral Fellow
Arthritis Research Canada
University of British Columbia

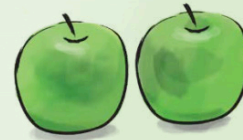
Knowledge Translation (KT) is the umbrella term for all of the activities involved in moving knowledge and findings from the laboratory, research journal, and the academic conference into the minds of organizations and people who can put it to practical use in the clinical office to improve health outcomes.

ACE hosted its second annual **#Greek2Street** social media event during this year's KT Canada Scientific Meeting. The aim of the event was to de-mystify the world of KT through video and/or audio interviews with attendees and presenters of the conference. You can watch or listen to the recorded interviews [here](#).

Summer



On May 27, 2019, the Government of British Columbia launched the Biosimilars Initiative, which implemented new reimbursement coverage for patients on infliximab or etanercept for rheumatoid arthritis, ankylosing spondylitis, or psoriatic arthritis. In preparation for this change, ACE published **The Biosimilars in Canada Guide: What Inflammatory Arthritis Patients Need to Know** – to address those needs of patients who want information on biosimilar medicines. The Guide provides answers to questions patients may have on biosimilars and the information tools they need to power and support their conversations with their rheumatologists and other health care providers and ensure science-based continuity of care. The guides were sent to rheumatology offices in British Columbia. In addition, ACE released a special **biosimilars JointHealth™ insight** which outlines and explains the latest provincial policies on biosimilar transitioning.



Biosimilars in Canada – What inflammatory arthritis patients need to know



eular

EUROPEAN
CONGRESS OF
RHEUMATOLOGY
2019 | 12 – 15 JUNE

ACE shared the latest research news from the 20th annual European League Against Arthritis (EULAR) Annual European Congress of Rheumatology in Madrid, Spain. Read more about ACE's live reports from EULAR 2019:

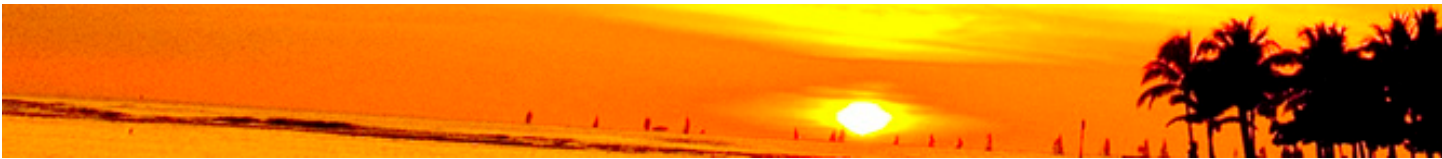
- [EULAR News – June 14: Weight loss benefits for psoriatic arthritis patients and treat to target in axial spondyloarthritis](#)
- [EULAR News – June 15: Optimizing e-health resources and tools for arthritis patients](#)
- [EULAR News – June 16: Fatigue and rheumatoid arthritis](#)



Also at EULAR, ACE led a meeting of the Global RA Network. Conceived by ACE in 2016 and co-founded by RA patient organization leaders from 18 countries, the Global RA Network is an international patient-led network mandated to identify and work on common goals and initiatives to improve the lives of people living with RA around the world. At the meeting, ACE shared the development of new features for members to use in their respective countries, including a **Models of Care Pathway Toolkit** and a new blog space where important news can be shared with the global RA community. The Global RA Network members also agreed to begin development of a 2020 public awareness campaign focused on “time to referral/ time to RA diagnosis” – one of the first gaps on the patient care journey.

We want to hear from you. What are your ideas about what a “time to referral” or “time to RA diagnosis” public awareness campaign should include to be successful? Share your response with us online.





JointHealth™ Education

Graduating Today's Modern Arthritis Patient



Select a course

Rheumatoid arthritis (RA)
JHed **RA**

Advanced therapies for IA
JHed
 Advanced Therapies

New!
 Psoriatic arthritis (PsA)
JHed **PsA**

New!
 Ankylosing spondylitis (AS)
JHed **AS**

Biosimilars
 Education Video Series
JHed **Biosimilars**

Take the lessons

Read the lessons

Pass the quizzes

Watch the videos

Graduate

ACE launched three new **JointHealth™ Education** (<http://bitly.com/ACE-JHed>) courses: Ankylosing Spondylitis, Psoriatic Arthritis and Biosimilars Education Video Series. Since 2016, JointHealth™ Education has graduated over a thousand arthritis patients and equipped them with the skills necessary to succeed as equal partners in their own care.

Fall



In celebration of **Arthritis Awareness Month in September**, ACE released a three-part series of JointHealth™ insight with a focus on osteoarthritis and joint replacement surgery. The series covers important new research on osteoarthritis, an in-depth look at joint surgery including decisions about surgery and preparation for surgery, and what to expect in the recovery process. The series is available in three parts:



<http://bit.ly/TKRJHIPart1EN>



<http://bit.ly/TKRJHIPart2EN>



<http://bit.ly/TKRJHIPart3EN>



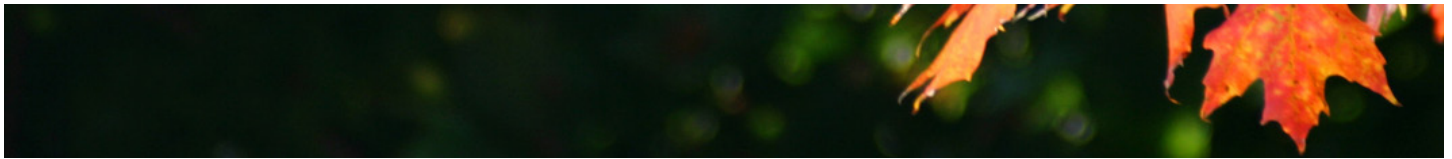
ACE created the **#ArthritisGlossary** social media campaign, providing a daily dose of information to help our members and followers navigate life with different types of arthritis. The glossary included definitions, resources, latest research findings or daily-living tips.

#ArthritisGlossary

Arthritis Awareness Month 2019

Mondays:	Rheumatoid Arthritis (RA)
Tuesdays:	Exercise
Wednesdays:	Ankylosing Spondylitis (AS)
Thursdays:	Osteoarthritis (OA)
Fridays:	Mental and Emotional Wellness
Saturdays:	Psoriatic Arthritis (PsA)
Sundays:	Lupus

ACE Arthritis Consumer Experts
JointHealth™



ACE continued its advocacy efforts for better arthritis prevention, treatment and care by reaching out to Parties running in the Manitoba provincial election and sharing their responses to the ACE Election Questionnaire with ACE Manitoba members and subscribers.

During the recent Canadian federal election, ACE asked the Conservative Party of Canada, the Green Party of Canada, the Liberal Party of Canada, and the New Democratic Party of Canada the same five questions about top health care issues for Canadians living with arthritis.

ACE collected Party responses and posted them on a Federal Election 2019 page to help our members and subscribers compare the Parties' healthcare platforms.



What did you think was the most important health issue during the Federal Election? Share your response online with the hashtag #Vote4Arthritis.

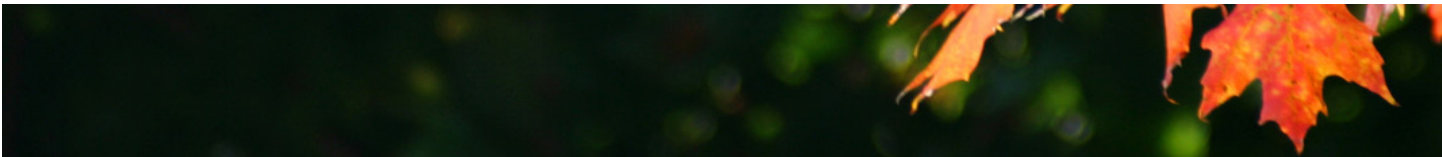


In September, the Arthritis Alliance of Canada (AAC) launched the **Talk to Your Doctor About Joint Pain Handout** (<http://bit.ly/JointPainTalkLetterFormatEN>), a patient version of the Osteoarthritis Tool for Family Physicians that was launched by the AAC and the College of Family Physicians of Canada in 2017. The new tool was developed through a collaborative process involving representatives from patient-led and patient-focused organizations, such as ACE, in close consultation with members of the AAC Models of Care Committee and scientific and clinical experts in osteoarthritis. The #JointPainTalk program aims to improve patient self-care, self-advocacy and health literacy for people living with osteoarthritis or at risk of developing it.



Are you experiencing new or recurrent joint pain in the hip, knee or hand? Share your symptoms and talk to your family physician about your pain. Share your response with us online.





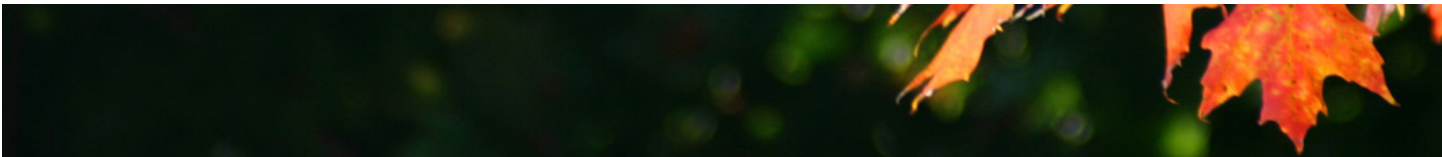
The **Arthritis Alliance of Canada: Legacy Award** is a funding opportunity to allow AAC member organizations to collaboratively advance the work of the Alliance through ongoing communication and dissemination of available tools and resources. A partnership of patient organizations that includes ACE, the Canadian Arthritis Patient Alliance, the Arthritis Patient Advisory Board of Arthritis Research Canada and the Canadian Spondylitis Association were selected as one of the recipients of the AAC Legacy Award. The proposed project – “Inflammatory Arthritis Models of Care Provincial Summits: Coast-to-coast advocacy for improved arthritis care” (“Summits”) – will address Ministry of Health awareness gaps in each province, and between provinces, of the Arthritis Alliance of Canada’s Inflammatory Arthritis Models of Care (IA MoC) “tools” and “tool kits” and work with them to assess and address their arthritis health services delivery models in the context of the AAC’s recommendations.



To help employers better understand arthritis in the workplace and recognize companies who offer exceptional work environments for their employees living with arthritis, ACE runs an annual national advocacy and awareness campaign: **Canada’s Best Workplaces for Employees Living with Arthritis**. Through a rigorous selection process using wide-ranging criteria, ACE evaluates Canadian companies that apply best arthritis practices.

ACE announced Providence Health Care of British Columbia as the winner of this year’s Canada’s Best Workplaces for Employees Living with Arthritis award. Based on workplace insights shared by employees and company managers, Providence Health Care stood out for their supportive work environments highlighted by chronic disease awareness, high quality benefits, wellness programs and prevention practices.

To learn more arthritis in the workplace, please visit the Canada’s Best Workplaces for Employees Living with Arthritis Program page: <http://bit.ly/BestArthritisWorkplacesE>



Conceived in 2014 by ACE and developed in partnership with our community partners – the Canadian Spondylitis Association, Arthritis Patient Advisory Board of Arthritis Research Canada and Canadian Arthritis Patient Alliance - **The Qualman-Davies Arthritis Consumer Community Leadership Award** recognizes 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.

The 2019 winner, Anne Lyddiatt, has been an active member of the arthritis community for over 20 years having been diagnosed with rheumatoid arthritis over 30 years ago. Anne was a nurse by training and worked primarily in the areas of administration, education and community health. Some of these activities include being one of the founding members of the Canadian Arthritis Patient Alliance, core faculty member of the Getting a Grip Program, advocate and canvasser for the Arthritis Society, co-chair for the Joint Effort Conference in Markham in 2005 and leader of the ASMP Program in London, Ontario. Anne was also involved with the Ontario Best Practices Research Initiative (formerly the Ontario Biologics Research Initiative) since its inception and was instrumental in helping them develop the protocol and early research platform. She is currently the National Trainer for the Patient Partners in Arthritis Program, where she trains volunteer patients to demonstrate a standardized musculoskeletal examination, leading educational sessions with medical students, residents and health care professionals within the medical school curriculum and continuing medical education events. Thank you, Anne, for your years of dedication to the arthritis community!

Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit www.jointhealth.org

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional

colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Thanks

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.



Disclosures

Over the past 12 months, ACE received grants-in-aid from: Arthritis Research Canada, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Hoffman-La Roche Canada Ltd., Knowledge Translation Canada, Merck Canada, Novartis Canada, Pfizer Canada, Sandoz Canada, Sanofi Canada, St. Paul's Hospital (Vancouver), UCB Canada, and the University of British Columbia.

ACE also received unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks funders for their support to help the nearly 6 million Canadians living with osteoarthritis, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and the many other forms of the disease.

Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

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ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.

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