

JointHealthTM insight

Arthritis research, education and advocacy news : May 2020

“By, For, and With” People With Arthritis For 20 Years

2000

2020

ACE Arthritis
Consumer
Experts

Arthritis Consumer Experts (ACE) is celebrating its 20th anniversary in 2020. Over the past 20 years, our team of dedicated staff – who live with arthritis – are guided by you, our members and subscribers, and our advisory board of leading scientists, medical professionals and informed arthritis patients. Every day, all day, we work and volunteer to serve our arthritis community and the public.



Since ACE’s founding in 1999, we’ve come a long way. So much has changed in 20 years. Our hairstyles, what we wear, the music we listen to, the phones we carry. But one thing has been constant. A group of people who understand exactly what you face daily, living with arthritis.

And today, that support community numbers more than 50,000 members of the ACE community across Canada and almost 20,000 followers and fans on social media. As our membership has grown, so has our reach. Each month, ACE now reaches more than 240,000.

Who ACE Serves Today

Our community today trusts us to provide the latest in research through our education and information programs to people who need it, when and where they need it. Our advocacy work, such as the JointHealth™ Arthritis Medications Report Card, has been integral to developing and implementing new arthritis health policy these past two decades, making the best treatments more accessible and affordable. We've partnered with the research community to ensure they look for answers to questions that are most important to people like us – over 6 million Canadians living with arthritis.

ACE members often tell us how they count on us for support and how we get what they are going through. There's no need to hide or minimize their experiences living with arthritis. Members also tell us how ACE has “changed their outlook and life and powered them to ‘come out of the disease closet’ and become more comfortable to be open about their disease.”

ACE has also powered arthritis patients to make a lasting impact and difference for models of arthritis care. A staggering six million Canadians live with arthritis. ACE continues to provide education from the medical world and practical information on how to get involved in advocacy for our members. That is how one becomes a (em)powered patient. It starts by helping you feel stronger and more confident. ACE does this through our education programs like [JointHealth™ Education](#) and by arming you with the tools and knowledge you need to become an advocate for your health and for arthritis. ACE's digital presence has grown dramatically the past decade and is successfully connecting people living with arthritis in Canada and around the world. To be in a community full of people that truly “get it” is a very special and empowering feeling.

Reach & Influence:

Approximately

240,000
each month

8,250
members

41,000
subscribers

17,000
followers & fans

Another of ACE's missions has been to encourage our members to take action. Each of us has the power to change arthritis—together, we can change the way arthritis is perceived by the public, portrayed in the media, and understood by government.

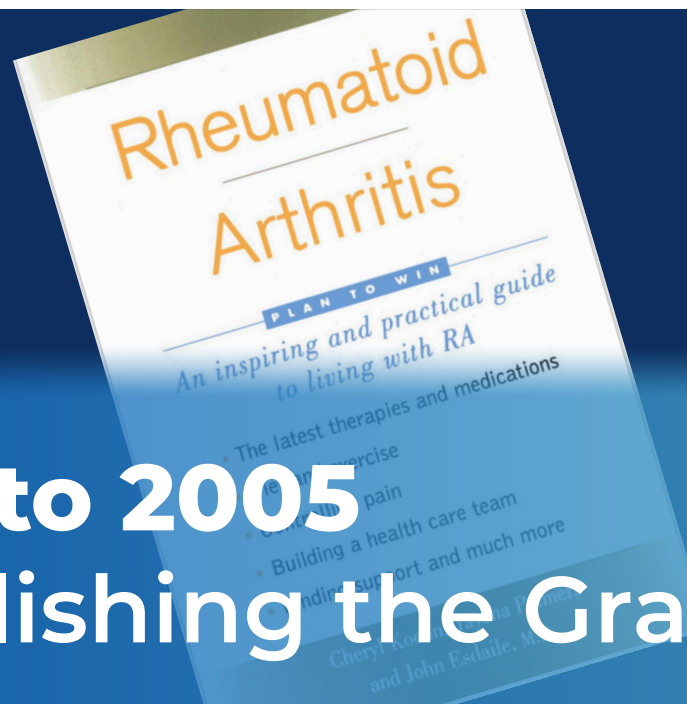
As people with arthritis, and their family members and friends, our arthritis community is in an unique position to provide media, government, and healthcare decision makers with the real story of arthritis. ACE leads numerous programs to raise awareness and advocate for arthritis patients with government and in the workplace, including the annual recognition of **Canada's Best Workplace for Employees Living with Arthritis.**

But none of us can do this alone. One or two voices may be easy to ignore, but by speaking together, we are powerful. The voice of arthritis—the voices of all of the people who live with the disease, or care about someone who does—is strong and getting stronger every day.

To mark the 20th anniversary of ACE and the work we have done and continue to do on behalf of people living with arthritis, we would like to share a timeline of some of our milestones over the past two decades “changing arthritis” in Canada.



Changing Arthritis For 20 Years



2000 to 2005 Establishing the Grassroots

2000

The need of an authentic arthritis voice was the impetus for the founding of ACE; governments had low or no awareness of rheumatoid arthritis and how it should be treated. Our first Work Plan was solely focused on advocating for Health Canada to complete its review of etanercept and infliximab, then for reimbursement access on provincial and private drug formularies.

2002-2005

ACE “toured” across-Canada holding “Plan to Win” [patient education forums](#) focusing on rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, and osteoarthritis.

In 2002, with co-authors John Esdaile, MD, and science writer Taysha Palmer, Cheryl Koehn, Founder and President of ACE, published “[Rheumatoid Arthritis: Plan to Win](#)”. The book offers an inspiring, scientifically based game plan for minimizing the effects of chronic illness and achieving optimal health.

JointHealthTM Report Card

2006 to 2010 Pioneering Arthritis Advocacy

2005-2006

ACE co-founds the [Summit on Standards for Arthritis Prevention & Care](#). The Summit brought together, for the first time in our community, representatives from Canada's arthritis community — including formal and informal care givers, health care providers, government representatives (federal and provincial), arthritis researchers and clinicians, voluntary associations, the pharmaceutical industry, and people with arthritis — to develop definitive national standards for arthritis prevention and care.

2007

ACE launches the first issue of ACE's Medication Guide and JointHealthTM [Arthritis Medications Report Card](#) — Canada's first independent patient organization evaluation of public reimbursement access to arthritis medications.

2009

The development and roll out of the [National Arthritis Awareness Program \(NAAP\)](#) across Canada to inform the public about arthritis. As part of the NAAP, the arthritis community “hit the streets” in Vancouver, Calgary, Ottawa, Toronto, Montreal and Halifax to share information about arthritis. Over 100,000 Canadians were met on the street and provided information aimed to debunk myths and change Canadian's perceptions of the effects arthritis has on our communities, our families and our lives.

2010

The premiere of the [Arthritis Broadcast Network \(ABN\)](#), the legacy channel of the National Arthritis Awareness Program. The ABN is a multi-media platform for the arthritis community to share news, information and stories about living well with arthritis. It conducts the #CRArthritis Facebook and Twitter Live event at the Canadian Rheumatology Association Annual Scientific Meeting and Arthritis Health Professions Association Annual Meeting.



2011 to 2015 Raising Arthritis Awareness Across Canada

2011

ACE launches **ArthritisID** and **ArthritisIDPRO** (for healthcare professionals) apps — the most comprehensive free arthritis apps for consumers, featuring current, evidence-based arthritis information to help detect, treat and manage arthritis.

2013

ACE announces a three year partnership with Shoppers Drug Mart Corporation – where Shoppers Drug Mart launched the Shoppers Health Care Portal, a website designed to provide Canadian health care professionals with access to drug reimbursement information and clinical tools with the goal of improving patient care. [Click here](#) to screen yourself for arthritis.

2014

The introduction of **Canada's Best Workplaces for Employees living with Arthritis** — a national campaign to help employers better understand arthritis in the workplace and recognize companies who offer exceptional work environments for their employees living with arthritis. Some of the notable award winners over the past five years: TELUS, City of Ottawa, Simon Fraser University, L'Oréal Canada, Aboriginal Peoples Television Network, Government of Yukon, and Université de Montréal.



2016 to 2020 Serving More Than 240,000 Canadians Every Month

2016

ACE launches the [JointHealth™ Education](#) and [Biosim•Exchange](#).

JointHealth™ Ed is an easy-to-use, online “classroom” that offers disease specific courses featuring lessons that are interactive and evidence-based. Each course gives you the key facts or “speaking points” to cover during your appointments with your rheumatologist and in your daily life with family, friends and co-workers.

The JointHealth™ Education program now includes five on-line courses:

1. JHEd: Rheumatoid Arthritis
2. JHEd: Advanced therapies for Inflammatory Arthritis
3. JHEd: Biosimilars Education Video Series
4. JHEd: Psoriatic Arthritis
5. JHEd: Ankylosing Spondylitis

As part of its work in Canada and the United States helping lead biosimilars discussions since 2009 and sharing information with stakeholders, ACE launches [The Biosim•Exchange](#) — an information hub that provides timely, balanced information for consumers-patients and reports on public and private health insurance formulary policy, biosimilars news and background analysis or listing decisions specific to biosimilars.

ACE co-founds and serves as Secretariat of the [Global RA Network](#) with rheumatoid arthritis (RA) patient organizations and leaders from 18 countries (and growing). The Global RA Network builds international relationships and identifies and works on common goals and initiatives to improve the lives of people living with RA around the world. The Global RA Network’s first initiative was to conduct a survey on patient experiences of RA models of care.

2017

On stage at the American College of Rheumatology Annual Meeting, ACE presented an abstract on [Patient Experiences of rheumatoid arthritis models of care: An international survey](#) – the first crowd-sourced research of its kind designed by RA patients, for patients, to better learn what their care experiences are in 14 countries in Europe, the Middle East, and North and South America. The survey highlights self-reported gaps and delays in all five key elements of a standardized RA models of care, including significant delays to diagnosis and specialist access.



2018

ACE launched its first-in-class series of fact-based videos on biosimilars in Canada. The videos feature Dr. John Esdaile (University of British Columbia) and Dr. Susan Bartlett (McGill University) and cover the latest biosimilars research, patient education information, the “nocebo effect”, and public drug plan reimbursement policy development. Click on the Biosimilars Education Videos tab [here](#) to view the videos.

ACE hosted its inaugural Arthritis Broadcast Network #Greek2Street Facebook and Twitter Live event at the KT Canada Scientific Meeting. The aim of the campaign is to get language and ideas that sound like “Greek” out to the “street” so people can put scientific knowledge into action in everyday life. [Click here](#) to learn more and view the series of interviews.

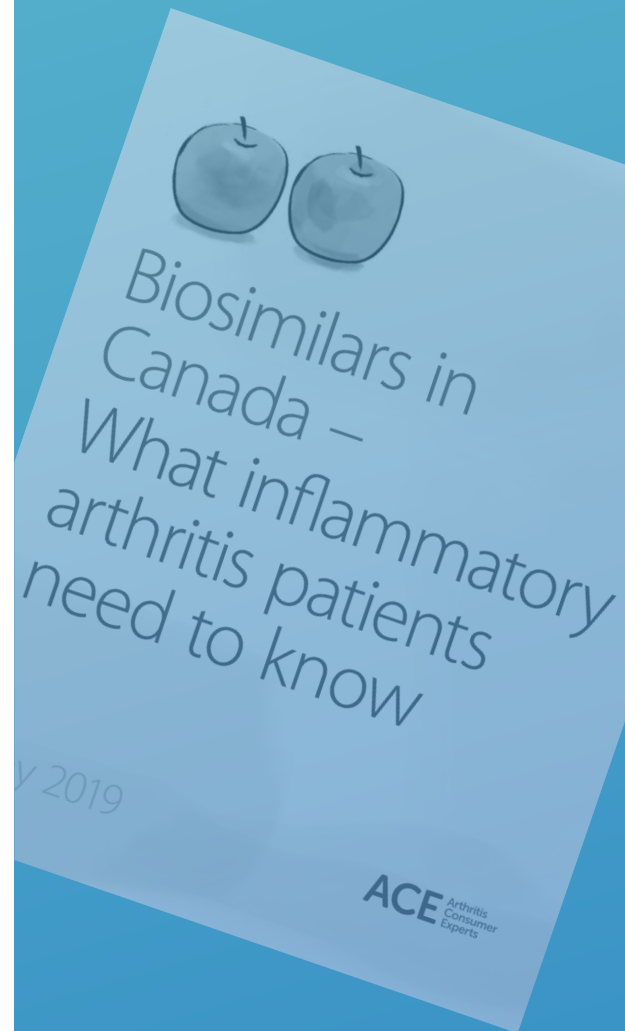
The Women in Biz Network: RA Matters at Work Event (held in Vancouver, Toronto, and Montreal) helped illuminate the accessibility of career progression for people with chronic diseases like rheumatoid arthritis. Moderated by ACE president, Cheryl Koehn, event speakers included: Drs. Diane Lacaille, Susan Bartlett, and Sara Ahmed, Canadian Olympic snowboarder Spencer O’Brien and Canadian Olympic medalist in short-track speed skating Nathalie Lambert, and allied health professionals and arthritis patients, volunteers, and advocates Alexandra Sirois, Alison Stewart, Dawn Richards, Flora To-Miles, Julia Chayko, Karen Tsui, Laurie Proulx, Leigh Mitchell, Maya Joshi, and Rachel Dei-Amoah.

2019

ACE published an information guide – “Biosimilars in Canada: 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 provide them 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. Click on the following link to view the guide: https://jointhealth.org/pdfs/BiosimilarsInCanadaGuide_EN.pdf

2020

Over the past 20 years, the delivery of healthcare and information has changed. ACE’s new program “Arthritis At Home” builds on that experience and brings arthritis experts into patients’ homes through ACE’s social media channels. ACE launched Arthritis At Home during the coronavirus pandemic crisis, when most of ACE’s members are confined to home, facing even more challenges in their daily lives than they normally would. As Arthritis at Home evolves over time, it will focus on speaking to experts on issues that matter most to patients: improving models of care and powering patient access.



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.jointhehealth.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, Amgen 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.

ACE Arthritis
Consumer
Experts

#210 - 1529 West 6th Avenue
Vancouver BC V6J 1R1
t: 604.974.1366

feedback@jointhehealth.org
www.jointhehealth.org

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.

© Arthritis Consumer Experts 2020