

Arthritis science: What's new in the research zoo? #CRArthritis 2019

#CRArthritis2019 – Bringing the latest research and knowledge from the Canadian rheumatology community to people living with arthritis

Arthritis Consumer Experts (ACE) joined together with their patient partners – Canadian Spondylitis Association and the Arthritis Patient Advisory Board of Arthritis Research Canada – to host the fifth annual #CRArthritis Facebook and Twitter Live event at the 2019 Canadian Rheumatology Association (CRA) and the Arthritis Health Professions Association (AHPA) Annual Scientific Meeting. The event was carried live on ACE's [Arthritis Broadcast Network](#) – a multi-media platform for the arthritis community to share news, information and stories about living well with arthritis. Featuring live interviews with leading researchers, patient advocates and healthcare providers in Canada, the event highlights the deep knowledge and skills in the Canadian rheumatology community and the latest research relevant to arthritis patients, their families and even other care providers.

In this issue of JointHealthTM insight, we explore this year's theme of "building bridges" and present a curated guide to a selection of #CRArthritis interviews. This issue will include research highlights, news from the patient organizations, and helpful lifestyle tips from healthcare providers.

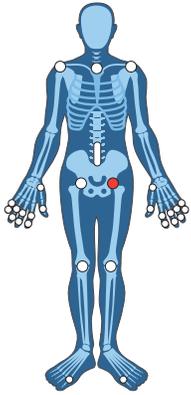


What does 'building bridges' mean at the CRA?

The CRA and AHPA Annual Scientific Meeting provide academics, clinicians and patients a space to discuss new concepts in arthritis diseases and review new treatment guidelines. The theme of this year's meeting was "Building Bridges": Bringing together different groups and perspectives to ensure the best care for patients with rheumatic diseases. Where do the bridges lead? To patients,

researchers across Canada, physio and occupational therapists, health psychologists among others. When building models of care, the building bridges theme help include the input of diverse patients groups, such as that of the indigenous communities. We hope you will be inspired by the building bridges theme throughout this issue, starting with [interview 28 – Ahmad Zbib: The CRA and Building Bridges.](#)

It's not "just" osteoarthritis



Osteoarthritis (OA) is by far the most common type of arthritis. It is estimated to affect more than 3.2 million Canadians – about 1 in 10. In [▶ interview 2](#), Dr. Tom Appleton speaks about advances in osteoarthritis treatment and care, including new non-opioid pain medication for people with OA. Dr. Appleton also explains the connection between OA and inflammation: “An important distinction to make is that osteoarthritis has always been called a non-inflammatory disease but really what we mean by that is that it’s not an autoimmune disease. There is still inflammation.”

In [▶ interview 5](#), Ed Ziesmann talks about the development of a new osteoarthritis patient tool developed by Arthritis Consumer Experts, the Arthritis Society and the Arthritis Alliance of Canada. The tool is intended to help people with OA self-advocate for better care, self-manage their disease, and increase health literacy. Health literacy refers to having a better understanding of the healthcare system and common medical language that may be used in your appointment with your family doctor. The OA patient tool is a companion piece to the [Physicians OA Tool](#), and will create an open patient-doctor dialogue. The new patient tool will be released in the coming year.

TIP

Weight management, regular physical activity and muscle strengthening exercises will help reduce OA pain and could prevent further joint damage.

Kids & Arthritis



Approximately 24,000 children in Canada, or every 3 in 1000, have some form of arthritis or pediatric rheumatic disease, the most common being juvenile idiopathic arthritis (JIA). Our guests on the #CRArthritis Facebook and Twitter Live event describe the innovative ways that they are working to improve the lives of children and youth with rheumatic diseases. In [▶ interview 7](#), Dr. Karine Toupin-April describes a web application she is developing that will help teens with arthritis make decisions about pain management based on their personal preferences. This application is a key element to ensure a smooth transition between paediatric and adult rheumatology care. The app will help patients self-manage their disease and should be released in the coming year.

In [▶ interview 21](#), Dr. Nicole Johnson explains a new project where children with JIA tell their stories on video. The project observed that children wanted to be seen as capable; they want people to focus on what they could do, not what they couldn't do. Johnson added: “What we [physicians] learnt from that project is they [the children] have wealth to teach us, no matter the age, no matter how long they've had their disease.”

In [▶ interview 33](#), Claire LeBlanc talks about the importance of physical activity for children that have JIA. Researchers have created YouTube videos to help children do their home exercise programs, as prescribed by their physiotherapist or occupational therapist. The videos will soon be accessible online and rolled out to paediatric rheumatology centres across Canada.

To learn more about pediatric rheumatology, watch the following interviews:

- [▶ Interview 4 – Dr. Adam Huber: Juvenile dermatomyositis and building global networks with researchers and physicians](#)
- [▶ Interview 17 – Dr. Mercedes Chan: Juvenile arthritis and mentoring pediatric rheumatologists](#)

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Learn more about JIA? Visit:
<http://bit.ly/JHJuvenileArthritis>

Working with arthritis



Work can present considerable challenges for people living with arthritis. According to an estimate of the economic burden of illness by Statistics Canada, work disability from arthritis costs \$13.6 billion per year. In [▶ interview 3](#), Dr. Diane Lacaille introduces us to “Making it Work with Arthritis”, a self-management program she developed to help people with inflammatory arthritis lead healthy and productive lives at work, and ultimately, prevent work disability. Currently, the research team is analysing data from a study with 565 Canadian patients to see the effectiveness of the program. “We know that work is an issue for people with arthritis, but we also know that given the right resources, people can be very successful at work. Often there’s not a lot out there for people to access, so this program fills an important need in our healthcare system,” said Lacaille. In [▶ interview 15](#), Kiran Dhiman talks about the relevance of the “Making it Work” program for patients with osteoarthritis. She found that the osteoarthritis population generally needs more attention to pain management in the workplace than those living with inflammatory arthritis.

Another important dimension of working with arthritis is presenteeism, defined as when a person is physically present at work but has a decrease in work productivity due to sickness or disease symptoms. This impacts the company, the employer and the employee themselves. In [▶ interview 24](#), Andre Luquini explains the research he is doing to determine which factors impact presenteeism, such as pain, stiffness, stress, commute times, etc.



[Click here](#) to learn about Canadian companies who apply the best arthritis strategies and practices in the workplace.

Targeted specific research



There are more than 100 different types of arthritis, that fall into two major groups: osteoarthritis and inflammatory arthritis. Several interviewees shared with us important advancements targeted at specific types of arthritis..

Scleroderma is a rare autoimmune connective tissue disease in which skin of the extremities, chest, abdomen, and/or face becomes thick and hard. It can cause issues in the blood vessels, scarring of organs, Raynaud’s and gastrointestinal tract complications. In [▶ interview 9](#), Dr. Janet Pope shares information about the development of **SPIN (The Scleroderma Patient-centered Intervention Network)** – a global organization of researchers, healthcare providers and patients aimed at developing, adapting and testing programs that help improve the lives of patients.

In [▶ interview 23](#), Alexandria Legge shares the findings of a case study on vasculitis, and a new prognostic tool for patients with systemic lupus. The tool is known as a frailty index. “What we found was that frailty index scores early in disease were predictive of future mortality, as well as other important outcomes like organ damage and hospitalization,” said Legge. Systemic lupus can be challenging to predict because the presentations and outcomes of the disease are so variable. Prognostic tools can help identify patients that are particularly vulnerable to certain outcomes and prevent further damage.

To learn more about research in disease specific areas, watch the following interviews:

- [▶ Interview 19 – Timothy Kwok: Osteoporosis](#)
- [▶ Interview 22 – Dr. Roberto Mendoza: Joint hypermobility and Ehlers Danlos Syndrome \(EDS\)](#)
- [▶ Interview 35 – Dr. Michel Zummer: Hot topics in spondyloarthritis \(French\)](#)

TIP

[Click here](#) to read about the different forms of arthritis, symptoms and treatment options.

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What's up with arthritis medication?



In the last 20 years, the big advancement in rheumatology has been the development of biologic drugs; drugs that have powerful influence on inflammatory forms of arthritis. As some of the patents for biologics have started to expire, companies have developed generic forms of the drugs called biosimilars. Evidence has shown that biosimilars are the same as biologics in safety and efficacy, and since being approved by Health Canada, many doctors are now beginning to prescribe them.

In [▶ Interview 32](#), Dr. John Esdaile talks about transitioning from biologics to biosimilars and the doctor's role in the process. The way doctors talk about medications can impact a patient's decision about what medications to take. When a doctor or pharmacist create doubts in the patient's mind about the efficacy of the drug, then the patient may feel that the drug doesn't work as well for them, this is called the "nocebo effect". To learn more about biosimilars, visit <https://biosim.jointhehealth.org>

To learn more about medications in rheumatology, watch [▶ interview 26](#) with Dr. Clifton Bingham on checkpoint inhibitors for cancer treatment, and how they are associated with rheumatic diseases. In [▶ interview 30 \(French\)](#), Dr. Maria Fernandez talks about developing an anti-inflammatory medication for gout that is less toxic than what is currently available.

TIP

If you are exploring complementary therapies in addition to your medication, such as cannabis, don't be afraid to tell your rheumatologist or nurse. It is important that they know the different pain management strategies you are trying and how they are working for you.



Looking for more information about arthritis medications? Check out the JointHealth™ [Medications Guide](#).

"Mind" your arthritis



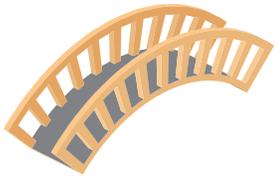
People living with inflammatory arthritis (IA), such as rheumatoid arthritis (RA), spondyloarthritis, psoriatic arthritis and lupus experience physical and emotional challenges. In [▶ interview 13](#), Dr. Gilles Boire shares his research on psychosocial determinants of disease activity such as depression and anxiety in patients with early IA. He found that there is a link between depressive states and overall disease outcomes, but it is unclear what comes first. The research team tested an Intervention of mindfulness-based stress reduction. Initial results show that management techniques need to be built specifically for each patient, rather than having a "one size fits all method".

In [▶ interview 6](#), Teresa Szlachetza explains her master's thesis, a systematic review on cognitive function in RA compared to the general population. Six out of eight articles reported that patients with RA had lower cognitive function in certain domains than people without RA. This cognitive function does not refer to intellect but to things such as fluency (flow of thoughts), memory processing, and speed of processing information. This research relates to what many patients describe as "brain fog", where patients report not being able to think clearly, concentrate and have problems with memory. The second part of Szlachetza's thesis is to use new data to see what factors impact the cognitive functions explained above such as sleep or anxiety.

TIP

If you are experiencing mental health challenges, do your best to tell your doctor. It is important for them to be aware of these symptoms (like anxiety or depression) so they can provide the proper help or refer you to resources and specialists who can help. This [special addition of JointHealth™ insight](#) gives information about arthritis and mental health.

Hot topics from arthritis patient organizations



Patient organizations play an important role in the rheumatology community. They often act as a bridge between researchers and healthcare providers and patients and their families. Our guests tell us about the arthritis patient-consumer organizations they are involved with and what projects they are working on.

- ▶ **Interview 1 – Shannon McQuitty: Introduction to #CRArthritis and being a member of the Arthritis Patient Advisory Board of Arthritis Research Canada**
- ▶ **Interview 10 – Janet Yale: The Arthritis Society 70th Year Anniversary**
- ▶ **Interview 25 – Wendy Gerhart: Canadian Spondylitis Association and public education forums**
- ▶ **Interview 29 – Ken Gagnon: Quebec chapter of the Arthritis Society (English)**
- ▶ **Interview 31 – Ken Gagnon: Quebec chapter of the Arthritis Society (French)**

Models of arthritis care



The Arthritis Alliance of Canada states that a Pan-Canadian Approach to Inflammatory Arthritis (IA) Model of Care establishes a framework for the development of high quality models of IA care that are evidence formed and reinforced by best practices. For a comprehensive model of care, many “team members” should be involved in a patient’s treatment plan (i.e. occupational therapist, physiotherapist, nurse, pharmacist, family doctor, social worker). “What we are trying to do is build interprofessional team-based care, because really patients need much more than just a drug,” says Dr. Vandana Ahluwaila in ▶ **Interview 36**. Each team member can provide valuable information to the patient, and the division of care amongst several providers will ultimately streamline care and reduce wait times. Our guests shared how they are providing effective and efficient models of care:

- ▶ **Interview 11 – Dr. Amanda Steiman: Project ECHO rheumatology in Ontario**
- ▶ **Interview 14 – Sue MacQueen: Advanced clinician practitioner in arthritis care**
- ▶ **Interview 16 – Dr. Carter Thorne: IA models of care**
- ▶ **Interview 18 – Dr. Deborah Marshall: Models of care in Alberta**
- ▶ **Interview 27 – Dr. Marie Claude Beaulieu: State of the art family practices for IA**



Learn more about modern models of arthritis care [here](#).

Another important aspect of care is ensuring that treatment plans are meaningful to patients and align with their preferences and values, “because it’s not just a matter of knowing the disease, it’s a matter of knowing the patient as well” says Dr. Beth Hazel in **interview 34 (French)**. Hazel talks about patient-centered care and new ways of training rheumatologists. Building bridges between patients and their healthcare team as well as the broader healthcare system is integral to providing the best care. To learn more about this, watch the following interviews:

- ▶ **Interview 3 – Dr. Diane Lacaille: Meaningful arthritis services in indigenous communities**
- ▶ **Interview 8 – Dr. Mark Harrison: Making health economics patient centered**
- ▶ **Interview 12 – Dr. Sasha Bernatsky: Patient-centred care and making informed choices**

TIP

To learn about different patient resources in Canada, check out this helpful [infographic](#) from the Arthritis Alliance of Canada.

TIP

In order to receive the best care, patients should learn strategies for getting the most from their medical appointments. In ▶ **interview 20**, rheumatology nurse Denise Jupp shares “insider tips” on how to do it. “Have a place (in a notebook or on your smartphone) to document when you have flares, what joints are affected, for how long and any other details about how they start. If possible, take photos of any swelling, or skin rashes that are present. This allows your nurse to get a better understanding of your disease activity since your last appointment,” said Jupp.

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, Canadian Biosimilars Forum, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Hoffman-La Roche Canada Ltd., KT Canada, Merck Canada, Novartis, 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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