

Leading Science: The latest advances in Canadian arthritis research

In this issue of JointHealthTM insight, ACE reviews key research takeaways from the annual Canadian Rheumatology Association and Arthritis Health Professions Association Annual Scientific Meeting. The Annual Scientific Meeting showcases the strengths of the extended Canadian arthritis community, including researchers, clinicians and patients, to engage with interactive programming and acquire insights from leading experts.

In this issue of JointHealthTM insight

Click the title of each section to go to the page it is on.

Note: This interactive feature is not available in Apple Preview.

[CRA/AHPA Annual Scientific Meeting: What did we learn](#) Pg. 2

[Alberta Indigenous Peoples in Alberta receive lower level of emergency care](#) Pg. 2

[Arthritis and Indigenous Peoples in Canada](#) Pg. 3

[Matters of the Heart: The connection between arthritis and heart disease](#) Pg. 4

[Patient preferences for managing sleep difficulties](#) Pg. 5


[Making the transition from paediatric to adult rheumatology care](#) Pg. 5

[List of Young Adult with Rheumatic Disease \(YARD\) Clinics in Canada](#) Pg. 6

[References](#) Pg. 7

ACE also looks at the challenges surrounding the transition patients experience when moving from care delivered by a paediatric rheumatology team to adult rheumatology care. A process that is that much more complicated for 18–25-year-old men and women who are dealing with other challenges at the same time around their emotional, physical, and sexual development.



A woman's profile is shown in a warm, orange-toned background. She is looking upwards and to the right. Her hair is dark and styled in a braid. She is wearing a necklace with large, light-colored beads.

CRA/AHPA Annual Scientific Meeting: What did we learn

This year's annual meeting was held virtually due to the pandemic and featured exciting sessions on the latest news and information in arthritis, as well as an online platform for arthritis leaders to learn, educate, and collaborate, with the goal of improving patient care.

Building on the success of its Facebook/Twitter Live Events at the past seven CRA/AHPA annual meetings (the largest arthritis stakeholder event in Canada), ACE hosted the #CRArthritis event to coincide with the CRA/AHPA annual meeting in February 2022. ACE conducted interviews during the annual meeting with keynote speakers, meeting attendees, patients living with arthritis – all of whom are leading disease experts. The interviews are available on the Arthritis Broadcast Network YouTube channel and Arthritis At Home program.

Here is a summary of some of the key research takeaways ACE discovered at the conference:

Alberta Indigenous Peoples in Alberta receive lower level of emergency care

Several events in 2020 and 2021 garnered national and worldwide media attention and shook the consciousness of Canadians. The death of Joyce Echaquan, and the discovery of the remains of 215 children on the grounds of the Kamloops Indian Residential School were tragic examples of the consequences of centuries long racism in Canada. Specific to Joyce Echaquan, the Quebec coroner's inquest report ruled that prejudice and racism were contributors to her death.

With these events of systemic racism in mind, researchers from the University of Alberta looked at more than 11 million emergency room visits between 2012 and 2017 in Alberta to determine if Indigenous Peoples received different levels of emergency care compared to non-Indigenous patients, even when those needs were the same.

The study found that emergency room staff consistently rated Indigenous Peoples' need for emergency care as less urgent than non-Indigenous patients. The researchers'

conclusion was that systemic racism and stereotyping, as well as communication challenges and the level of trust in the health care system were all contributing factors to the different assessments of the need for urgent care for Aboriginal Peoples.

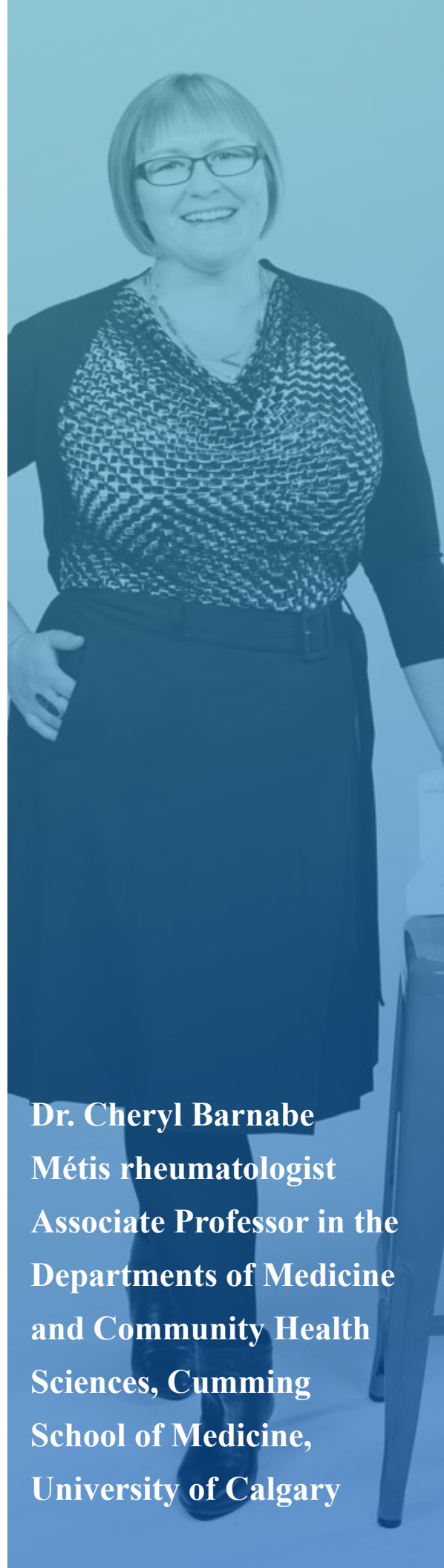
Dr. Cheryl Barnabe is a co-author of the study and a Métis rheumatologist with a graduate degree in Clinical Epidemiology. She is one of Canada's leading researchers focused on identifying and resolving health system care gaps for Indigenous patients. According to Dr. Barnabe: "I think many of us recognize that this is the daily experience in the emergency departments. But I think having the ability to show it in this large scale, with these large numbers, really puts it into perspective. This isn't just a one-time event or a bad day that one health-care professional has had. This is a daily experience of Indigenous Peoples that we see in our province."

For more information from Dr. Barnabe about discrimination against Indigenous patients in Alberta hospital emergency departments, please [click here](#).


Arthritis and Indigenous Peoples in Canada

Arthritis affects Indigenous Peoples more significantly and more severely than in non-Indigenous populations. The legacy of more than 140 years of colonization – the disregard for cultural values and failure to provide culturally relevant care - has created health inequities that have contributed to this higher prevalence and worse outcomes. Specifically, Indigenous Peoples in Canada experience:

- Higher rates of inflammatory arthritis such as lupus, rheumatoid arthritis and ankylosing spondylitis¹;
- Higher rates of death from lupus and its complications compared to non-Indigenous patients²;
- Worse disease outcomes in early rheumatoid arthritis compared to white patients. This means slower improvements in pain and swelling and less likelihood of achieving remission (i.e., getting the disease under control)³;
- Experience fewer visits to specialists than the non-Indigenous population as well as significantly more hospitalizations due to arthritis complications; and,
- Have lower rates of evidence-based inflammatory arthritis therapies being used among Indigenous people despite the disease being more severe.⁴



Dr. Cheryl Barnabe
Métis rheumatologist
Associate Professor in the
Departments of Medicine
and Community Health
Sciences, Cumming
School of Medicine,
University of Calgary



Matters of the Heart: The connection between arthritis and heart disease

Having arthritis – osteoarthritis, but especially inflammatory arthritis like rheumatoid arthritis, lupus, ankylosing spondylitis or psoriatic arthritis – puts people at increased risk for heart disease. That includes heart attack, stroke, atrial fibrillation (irregular heartbeat), high blood pressure, heart failure, and atherosclerosis (plaque in the arteries).

According to Dr. Bindee Kuriya, Assistant Professor, Department of Medicine, University of Toronto and Director, Rapid Access Rheumatology Clinic: “Inflammation, regardless of where it comes from, is a risk factor for heart disease. So, it’s not surprising that people with inflammatory arthritis have more cardiac events.”

At a workshop presentation at the CRA/AHPA annual meeting, Dr. Kuriya focused on the need for a multi-disciplinary approach, requiring multiple specialists, to screen and manage traditional risk factors for heart disease in a rheumatology setting as well as to target and manage inflammation. These risk factors – diabetes, hypertension, weight, smoking, abnormal cholesterol - are often not screened for in inflammatory arthritis patients and when they are identified, they are not aggressively treated.

Dr. Kuriya’s message to inflammatory arthritis patients is to ask their rheumatologist and primary care provider what kinds of screening they need. For example, an evaluation of heart health should include regular tests of blood pressure, blood sugar and cholesterol. The European League Against Rheumatism (EULAR) recommends cardiovascular disease screening for inflammatory arthritis patients at least once every five years, and every time they change their medication. Patients may also want to speak to their specialists about doing a stress test, echocardiogram or electrocardiogram to check their heart health.

To learn more about the links between arthritis and heart disease, please view this [#CRArthritis interview](#) with Dr. Kuriya.

Patient preferences for managing sleep difficulties

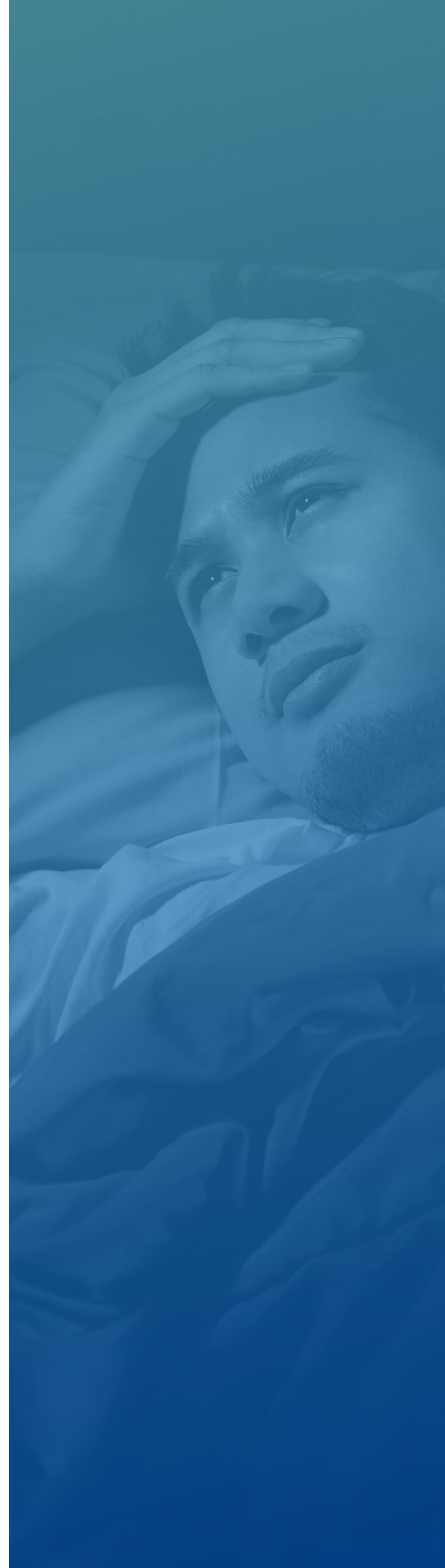
Sixty per cent of Canadians living with arthritis report having trouble sleeping. Getting to sleep, and staying that way, can be very difficult, especially for people who live with arthritis and experience chronic pain. Problems sleeping in persons with inflammatory arthritis have been shown to contribute to worsening of symptoms including fatigue, pain, and health related quality of life. To guide the creation of a personalized digital therapy program for persons with arthritis experiencing sleep difficulties, researchers at Arthritis Research Canada presented the **findings** (Page 9 of ASM Poster Presentation Abstract) of an on-line needs assessment identifying help-seeking behaviors, insomnia management strategies and treatment preferences for patients. The survey confirmed that people with insomnia are not getting the help they need and that people would be willing to use an internet program to improve sleep.

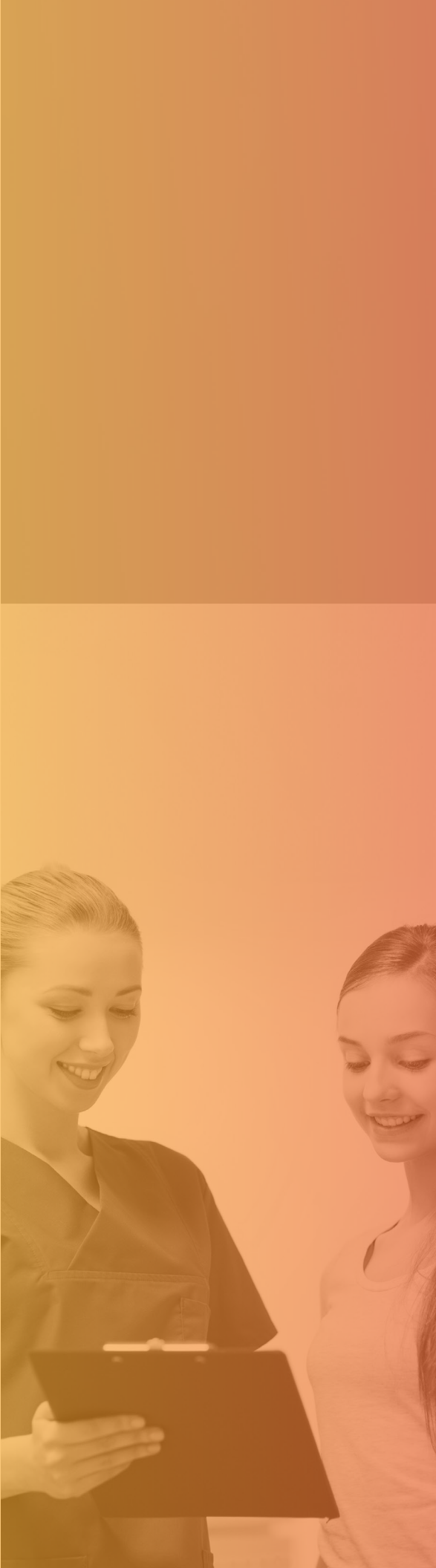
Making the transition from paediatric to adult rheumatology care

Approximately 6,200 (0.10%) Canadians aged 15 years and younger live with diagnosed juvenile arthritis and more than 1,000 (17.1 per 100,000 persons per year) are newly diagnosed each year.

While there is no cure for juvenile arthritis, early diagnosis followed by an effective management strategy can help improve an individual's functional ability and productivity in daily life. Medication treatment plans aimed at reducing pain and inflammation are key to controlling the disease and improving function. The treatment plan also often includes physiotherapy and occupational therapy along with regular exercise. Children diagnosed with juvenile arthritis benefit from a multidisciplinary team, including paediatric rheumatologists, rheumatology nurses, pharmacists, physiotherapists and occupational therapists, optometrists and ophthalmologists, in addition to their primary care physician. Dietitians and social workers may also be part of the team.

At the age of 18, adolescents living with inflammatory arthritis (IA) are required to change their medical care from a pediatric to adult health care. According to Dr. Elizabeth Hazel, Associate Professor of Medicine at McGill University, this is challenging for all juvenile arthritis patients but particularly





for those who were diagnosed closer to 18 years old and who have less experience and knowledge about the self-management of their inflammatory arthritis. For all juvenile IA patients, they must also confront the challenge of changing the delivery of their much-needed care at the same time as they may be moving out of their family home, starting a job, beginning post-secondary education or entering a relationship.

Dr. Hazel points to research **studies** conducted by both American and Canadian pediatric rheumatologists that report the lack of self-management skills among juvenile arthritis patients and the lack of sufficient time arthritis professionals have to provide adequate transition services for their young patients. The studies also found both juvenile patients and their healthcare providers were not fully aware about the community resources that support patients making the transition to adult care.

Canadian studies also show that 25%-75% of juvenile arthritis patients experience gaps in or, in extreme cases, lose access to their standard of care when they transfer to the adult healthcare system. To address these challenges, Canadian researchers have proposed a national **standard** of rheumatology transition care for youth in Canada.

To help address the gaps in the transitional care of adolescents and young adults with IA in Canada, Dr. Hazel founded and leads the Young Adult with Rheumatic Disease (YARD) Clinic out of the McGill University Health Centre, which provides multidisciplinary care to patients with juvenile arthritis. To learn more about Dr. Hazel's experience and the YARD Clinic, view this **#CRArthritis interview**.

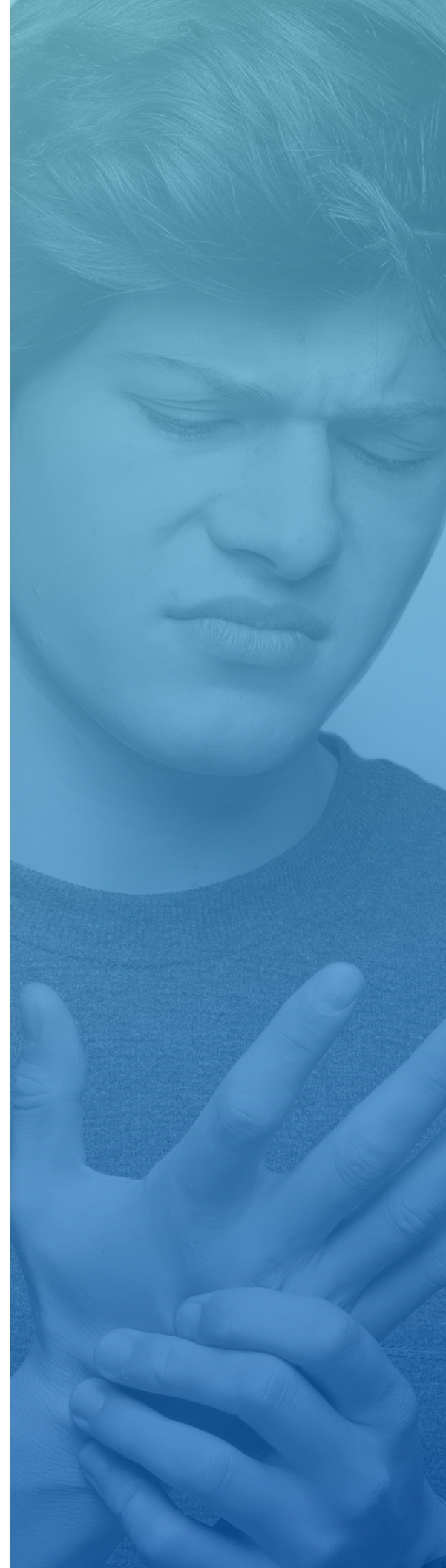
List of Young Adult with Rheumatic Disease (YARD) Clinics in Canada

- **Alberta Health Services – University of Calgary: Young Adults With Rheumatic Diseases (YARD) Clinic**
- **IWK Health Centre**
- **McGill University Health Centre**
- **The Boris Clinic**
- **Vancouver Coastal Health: Young Adult Rheumatic Disease Program**

For more information about juvenile arthritis care, please visit Cassie + Friends - the only charity in Canada dedicated 100% to the pediatric rheumatic disease community. **Cassie + Friends** offers a special '**Taking the Reins**' webinar that looks at transitioning to adult care and educates families on when the best time might be to get children more involved with managing their juvenile arthritis.

References

1. C. McDougall, K. Hurd, C. Barnabe. Systematic review of rheumatic disease epidemiology in the indigenous populations of Canada, the United States, Australia, and New Zealand. *Semin Arthritis Rheum*, 46 (5) (2017), pp. 675-686
2. K. Hurd, C. Barnabe. Mortality causes and outcomes in Indigenous populations of Canada, the United States, and Australia with rheumatic disease: a systematic review. *Semin Arthritis Rheum*, 47 (4) (2018), pp. 586-592
3. Nagaraj, S., Barnabe, C., Schieir, O., Pope, J., Bartlett, S. J., Boire, G., Keystone, E., Tin, D., Haraoui, B., Thorne, J. C., Bykerk, V. P., & Hitchon, C. Early rheumatoid arthritis presentation, treatment, and outcomes in Aboriginal patients in Canada: A Canadian early arthritis cohort study analysis. *Arthritis Care & Research*, 70(8) (2018). 1245-1250. <https://doi.org/10.1002/acr.23470>
4. Healthcare utilization for arthritis by Indigenous populations of Australia, Canada, New Zealand, and the United States: A systematic review
<https://www.sciencedirect.com/science/article/pii/S0049017216301664?via%3Dihub>



Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) and its team members acknowledge that they gather and work on the traditional, ancestral and unceded territory of the Coast Salish peoples - xʷməθkʷəy̓əm (Musqueam), Skwx-wú7mesh (Squamish), and Səlilwətaʔ Selilwitulh (Tsleil-Waututh) Nations.

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: Amgen Canada, Arthritis Research Canada, Canadian Biosimilars Forum, Canadian Rheumatology Association, Eli Lilly Canada, Fresenius Kabi Canada, Merck Canada, Novartis Canada, Organon Canada, Pfizer Canada, Sandoz Canada, Teva Canada, UCB Canada and the University of British Columbia.

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 2022