JointHealth insight Arthritis research, education and advocacy news: April 2018

What's new in the science of arthritis?

#CRArthritis - Bringing the latest research and knowledge from the Canadian rheumatology community to the laptops and mobile devices of people living with arthritis. Arthritis Broadcast Network (ABN) hosted it's fourth year, the 2018 #CRArthritis Facebook and Twitter Live event at the 2018 Canadian Rheumatology Association (CRA) Annual Scientific Meeting and Arthritis Health Professions Association (AHPA) Annual Meeting. This year's 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. The bonus: Our team of patient interviewers effectively role modelled patient-provider communication and "demystified" who specialty physicians and care providers are and what they do.

In this issue of JointHealth™ insight, we explore what "personalized and precision medicine" – the theme to this year's CRA and AHPA Annual Meeting – means to arthritis patients and healthcare providers, and we present a curated guide to a selection of #CRArthritis interviews.



What is personalized and precision medicine?



The terms "precision medicine" and "personalized medicine" are used interchangeably but what do they mean for patients? The Canadian Institutes of Health Research (CIHR) defines personalized medicine as the transformation of the delivery of healthcare to patients from a reactive "one-size-fits-all" system towards a system of predictive, preventive, and precision care.

According to the CIHR: "Personalized medicine will not only focus on the identification of biomarkers and genetic signatures for prevention and prediction of therapeutic response, but will also enhance awareness about lifestyle and preventive lifestyle changes." Research shows that personalized approaches are beneficial to patients living with arthritis because it will minimize trial and error in treatment, deliver the right treatment in a timely manner, and help achieve disease remission.

Arthritis Broadcast Network explored with its guests what personalized and precision medicine means in their area of expertise, and most importantly, what it means to people living with arthritis:

- Interview 18 Ahmad Zbib: The CRA and AHPA annual meeting
- Interview 38 Dr. Tom Appleton: Personalized and precision medicine at the CRA conference



Communicating with your healthcare team about your goals and concerns is the first step to personalized and precision medicine.

Juvenile arthritis – A better world for future generations



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). JIA is one of the most common chronic diseases among children and can lead to significant morbidity and long-term disability. Rheumatic diseases in children are often more severe than in adults and may be presented in more unusual ways, creating challenges in diagnosis and treatment. Precision medicine using genome sequencing offers a great possibility for remission or control of the disease early on – which is the overall goal in pediatric rheumatology. Our guests also spoke about the unique social dimensions that exist in the field, such as caring for the family in addition to the child, and detecting symptoms when the patient may not be able to speak or describe them for him or her-self.

To learn more about juvenile arthritis, watch the following #CRArthritis interviews:

- Interview 4 Dr. Rae Yeung: Juvenile arthritis in Canada
- Interview 9 Dr. Lori Tucker: Pediatric rheumatology and juvenile arthritis
- Interview 11 Dr. Stuart Turvey: Immunology and pediatric rheumatology
- Interview 15 Dr. Earl Silverman: Juvenile arthritis (teenagers) and neonatal lupus



When should you take your child to see a pediatric rheumatologist?

- If you notice multiple swollen or painful joints lasting longer than an injury normally would
- If your child consistently has morning stiffness

Spondyloarthritis and Psoriatic Arthritis – Advancements in diagnosis and therapy



In the past decade, more clinical trials and medication are being developed specifically for psoriatic arthritis and spondyloarthritis. As a result, the gaps between the onset of symptoms, diagnosis and start of treatment are being shortened. Dr. Vinod Chandran, Co-Director of the Psoriatic Arthritis Clinic at Toronto Western Hospital on psoriatic arthritis and spondyloarthritis leads a team focusing on ways to predict and ultimately prevent co-morbidities associated with psoriasis and spondyloarthritis before they happen. Dr. Chandran was one of several Canadian experts who presented on spondyloarthritis at the CRA conference.

To learn more about spondyloarthritis, watch the following #CRArthritis interviews:

- Interview 3 Dr. Vinod Chandran: Psoriatic arthritis and spondyloarthritis
- Interview 8 Dr. Walter Maksymowych: Spondyloarthritis
- Interview 17 Dr. Jonathan Chan: Ankylosing spondylitis



For patients with spondyloarthritis, it is very important to maintain core muscle strength. Here are some tips for when you are at work:

- · take frequent stretch breaks
- · take the stairs
- · maintain good posture
- modify your work station accordingly (i.e., back cushion, keyboard tray)



For patients with psoriatic arthritis, properly caring for your skin will help manage your symptoms. Consider using a humidifier in your home to prevent dryness.

Giant Cell Arteritis and Vasculitis



Vasculitis is an inflammation of the wall of blood vessels, arteries, veins or capillaries. The inflammation causes a weakening and narrowing of the blood vessel which can progress to the point of blood vessel blockage or haemorrhage. Giant cell arteritis (GCA), or temporal arteritis, is an inflammatory disease affecting the large blood vessels of the scalp, neck and arms. Inflammation causes a narrowing or blockage of the blood vessels, which interrupts blood flow.

Published research in North America and Europe is increasingly corroborating a key role of interleukin-6 (IL-6) in the development of GCA with the potential to deliver a new standard of care to people living with GCA.

In Interview 16 Dr. Nader Khalidi, Associate Professor, Division of Rheumatology, McMaster University, shares insights from his CRA conference presentation on giant cell arteritis and vasculitis and advancements in care.



Like with all forms of arthritis, maintaining a healthy lifestyle with proper exercise, rest and nutrition is important for managing GCA and vasculitis.

Nutrition



In the field of nutrition, balance is key. Understanding what constitutes as "good food" can help you improve your overall health, obtain proper nutrients, and promote disease wellness. In ▶ Interview 19, Ms. Inez Martincevic, a clinical dietician from the Hospital for Sick Children in Toronto, introduces us to the "Dirty Dozen" and "Clean 15" list from the EWG's 2018 Shopper's Guide to Pesticides in Produce™.



Frozen vegetables have the same nutrients content as fresh vegetables and can be a more convenient and affordable alternative!

Exercise is Medicine



In her Keynote presentation at the CRA conference, Dr. Linda Li, Professor at the Department of Physical Therapy at the University of British Columbia (UBC) and Senior Scientist at Arthritis Research Canada, explained how exercise is medicine for someone living with arthritis. Physical activity can reduce pain, inflammation and joint damage. Exercise prescriptions should be personalized just like other aspects of care. In Interview 20, Dr. Li explores the role of electronic health, research, and the use of wearable fitness devices (i.e., FitBit) for setting and achieving personalized goals related to physical activity. To learn more about exercise as medicine, please visit Exercise is Medicine® Canada (EIMC), a global health initiative that is focused on encouraging primary care physicians and other healthcare providers to include physical activity when designing treatment plans for patients and referring their patients to recognized Exercise Professionals.



Group exercise classes are great for motivation, adherence and forming social connections, but we must not forget the individualized approach that cannot be maintained through a group setting. It is important to develop a personalized exercise plan with a physiotherapist or other healthcare team member, tailored specifically to you and your disease.

Pregnancy



Having arthritis does not exclude you from starting a family. It is important to communicate with your rheumatologist on your planned pregnancy and work together to develop an adjusted treatment plan. Researchers are working to alleviate fear associated with medication use during pregnancy. For example, in Interview 28, Nicole Tsao, PhD student at UBC and practicing pharmacist, explains that biologic use during pregnancy does not cause malformations in the baby. In Interview 7, Dr. Neda Amiri, Clinical Instructor at the UBC's Division of Rheumatology, shares her expertise on pregnancy and arthritis.



An open conversation with your rheumatologist before you try getting pregnant is an important first step for developing a treatment plan that accommodates your preferences and most importantly focuses on the safety of you and your baby.

Medication



It is common for patients to struggle to "stick with" their medication (taking it as prescribed) for various reasons. Several researchers at the CRA conference spoke about the importance of medication adherence and the profound positive effects proper medication use can have on disease outcomes. In Interview 23, Dr. Mary de Vera, Assistant Professor in medication adherence at the Faculty of Pharmaceutical Sciences at UBC and research scientist at Arthritis Research Canada, explains how lupus patients that stick to their treatment plan have a 40% lower risk of developing diabetes. Similarly, gout can be completely cured if medication is taken as prescribed.

For more on medications, watch the following #CRArthritis interviews:



Interview 26 – Dr. Alan Low: The Role of the Pharmacist



Medication concerns? Talk to your pharmacist. They are often more accessible than a rheumatologist and will be able to answer most medication related questions you have.

Medical marijuana and pain management



Medical marijuana, when used correctly and in consultation with your rheumatologist, has the potential of promoting sleep, relaxation and appetite while reducing levels of pain and inflammation. More research needs to be done on the impacts of cannabis and rheumatic diseases before physicians can confidently and accurately prescribe cannabis to patients. In laterview 5, Dr. Mary-Ann Fitzcharles, Associate Professor of medicine in the Division of Rheumatology at McGill University and Consultant Rheumatologist to the McGill Pain Centre at the Montreal General Hospital, explains the benefits and risks associated with cannabis use for pain management.



If you use cannabis, it is important to buy from a licensed producer. Read Health Canada's Proposed Approach to the Regulation of Cannabis to learn more.

Improving Access to and Quality of Care



There are major disparities in Canada when it comes to quality of arthritis care. Tools are being developed to measure and improve these disparities to ensure a standardized, comprehensive quality of care, nation-wide.

- Interview 35 Dr. Claire Barber: Quality of Arthritis Care in Canada
- Interview 36 Dr. Marie Westby: Quality of Care for Hip and Knee Replacements

Different models have been suggested to improve access to care in rural and remote communities: "Telemedicine" and "e-health" (i.e. communicating with a health care provider online or over the telephone) can act as supplements to care in these communities but will not replace in-person contact with rheumatologists. Another effective solution is sharing patient care among different members of a healthcare team (physiotherapist, occupational therapist, nurse, etc.).

- Interview 27 Dr. Karen Beattie and Hannah Zou: Telemedicine
- Interview 30 Dr. Michelle Teo: arthritis care in interior BC

To learn more about access to care, watch the following #CRArthritis interviews:

- Interview 2 Janet Yale: The Arthritis Society, spreading awareness and resources
- Interview 13 Sujay Nagaraj: Improving care in indigenous communities
- Interview 24 Dr. Vandana Ahluwaila: arthritis priorities in Canada

TIP

If your community does not have access to a publically funded arthritis program, we encourage you to take advantage of all the credible tools and resources available to arthritis patients through online platforms.

Preventing Rheumatoid Arthritis: New Research



Rheumatoid arthritis (RA) is caused by a combination of genetics and environmental circumstances. There are various events that can "trigger" RA (pregnancy, periods of stress, infections, etc.) and although researchers can't predict these events, they can develop ways to reduce the chances of these events triggering the disease.

Click the links below to learn more about current research on the prevention of RA:

- Interview 6 Dr. Mark Harrison: Patient preferences on preventive medication for RA
- Interview 29 Dr. Hani El-Gabalawy: Identifying individuals at risk of RA and exploring preventative measures

TIP

It is vitally important that patients inform arthritis research. To learn more about the roles people living with diseases or illness play in research and how to get involved, visit Arthritis Research Canada and have a look at this IAP2 spectrum infographic.

Discussions with your doctor





Many of ACE's members who live with an inflammatory arthritis have told us they lack the communications expertise to have full, satisfying conversations with their rheumatologists on topics such as treatment options during their clinical visits. In response, ACE created JointHealth™ Education - North America's first on-line classroom designed to educate, empower and graduate today's modern arthritis patient.

This program is informed by ACE's participation on a global advisory panel that conducted a survey in 16 countries of rheumatoid arthritis patients and their health care providers. The results illuminate the discord between the needs, concerns and fears of patients compared to the views of their health care providers.

Watch the following #CRArthritis interviews to learn more from several presentations at the CRA conference about strategies and tips for communicating with your rheumatologist:

Interview 10 – Dr. Dafna Gladman: Rheumatology care

Interview 12 – Dr. Barry Koehler: Evolution of rheumatology care



Sometimes it can be difficult to identify your own symptoms and explain to your doctor how you have been doing since your last appointment; ask the people you live with for their observations. For example, they may notice patterns about your pain or fatigue that you are not aware of yourself.

Teamwork and patient-centred care in arthritis Models of Care



For a comprehensive model of care, many "team members" must be involved in a patient's treatment plan (i.e. occupational therapist, physiotherapist, nurse, pharmacist, family doctor, social worker). Each team member can provide valuable information to the patient, and the division of care amongst several providers will ultimately streamline care and reduce waiting periods. Currently, models are being developed to make shared-care more convenient for both patients and providers.

An important aspect of teamwork is ensuring that the patient is an equal partner in their own care. For best disease outcomes, treatment plans must be built around the patient's individual disease and their personal preferences. This is known as patient-centred care and is a key dimension of personalized medicine.

For more on teamwork and patient-centred care, watch the following #CRArthritis interviews:

- Interview 14 Dr. Deborah Marshall: research on patient preferences
- Interview 21 Leslie Soever: Your full arthritis healthcare team
- Interview 25 Dr. Alison Kydd: patient-centred care as personalized medicine
- Interview 31 Dr. Jennifer Reynolds: patient-centred care
- Interview 32 Dr. Jason Kur: improvements in arthritis models of care
- Interview 33 Dr. Trudy Taylor: Importance of patient doctor relationships
- Interview 34 Dr. Glen Hazlewood: Patient preferences
- Interview 39 Dr. Carter Throne: Inter-professional model of care
- Feature post on Arthritis Broadcast Network- Dr. Laura Nimmon: Teamwork and power dynamics

Another aspect of patient-centred care is ensuring patients are partners in research teams, advisory boards and grant review panels. This ensures that research is relevant and meaningful to patients. The topic is discussed in

Interview 37, with Dr. Clayon Hamilton, a postdoctoral fellow at UBC.



Speak to your doctor about the members of your healthcare team outside of medical professionals (such as your spouse, family, or close friends). Consider bringing one of these "teammates" into your appointment so that they can be a more direct part of your care.

Share #CRArthritis to help others understand arthritis

This year's #CRArthritis event taught us that there is an incredible community of researchers, healthcare professionals and patient leaders who are working hard to address gaps in the field of rheumatology and provide patients with the best care possible. Please share, like, and comment on the interviews in "#CRArthritis Facebook and Twitter Live 2018" to continue the conversation online.







Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower 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, leading medical professionals and 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 profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities, and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.

- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and healthcare providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- 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.

Thanks

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



Acknowledgements

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

ACE also receives 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. ACE assures its members, academic and healthcare professional collaborators, government and the public that the work of ACE is free from influence of its funders.

Disclaimer

The material contained in this or any other ACE publication is provided for general information only. It 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. If you have any healthcare related questions or concerns, you should contact your physician. Never disregard medical advice or delay in seeking it because of something you have read in any ACE publication.



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