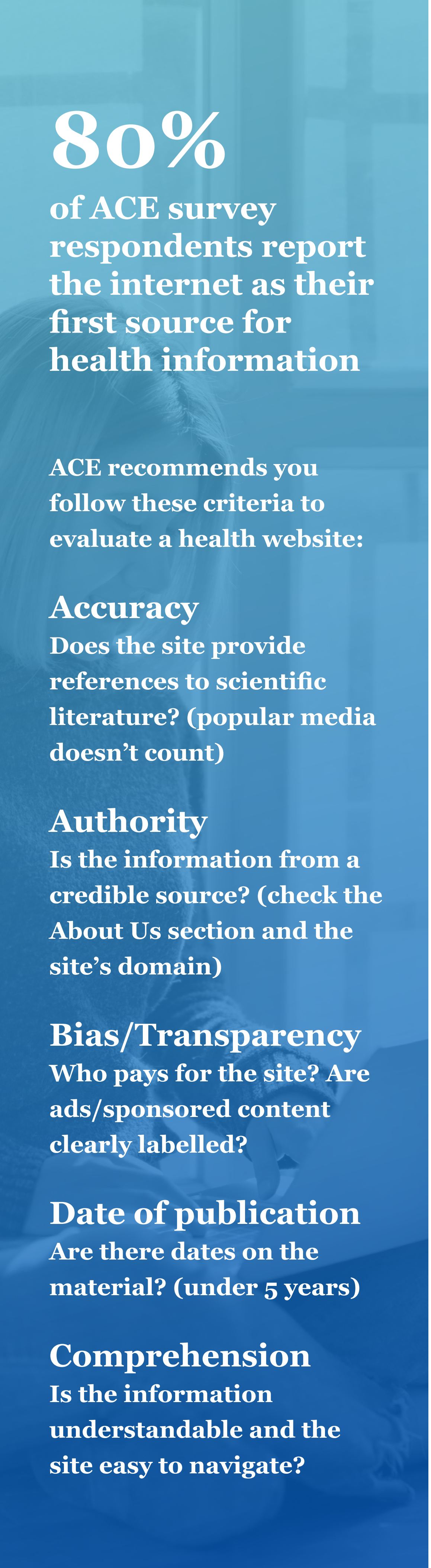
JointHealth™ insight
Arthritis research, education and advocacy news : Spring 2020

What's new in rheumatic disease research in the age of COVID-19?

In this issue of JointHealth™ insight, ACE provides tools to help you be an informed partner in your healthcare, including a criteria to evaluate the credibility of a health website as well as a summary of key video interviews ACE and its patient partners Arthritis Patient Advisory Board of Arthritis Research Canada and the Canadian Spondylitis Association conducted during the 2020 Canadian Rheumatology Association and Arthritis Health Professions Annual Scientific Meeting.



80%

of ACE survey respondents report the internet as their first source for health information

ACE recommends you follow these criteria to evaluate a health website:

Accuracy

Does the site provide references to scientific literature? (popular media doesn't count)

Authority

Is the information from a credible source? (check the About Us section and the site's domain)

Bias/Transparency

Who pays for the site? Are ads/sponsored content clearly labelled?

Date of publication

Are there dates on the material? (under 5 years)

Comprehension

Is the information understandable and the site easy to navigate?

Good or Bad? How to evaluate health information on the internet

During the COVID-19 pandemic the demand for health information has meant consumers are searching the internet for credible information but what criteria should they use?

A survey of ACE members and subscribers across Canada revealed over 80 per cent of respondents went to the Internet first for health information. The most commonly researched topics are specific arthritis disease information; treatments; and exercise.

According to a 2019 Canadian Medical Association study, most Canadians are already reporting a positive impact of technology in health care, whether it is improving the flow of information between them and their physician (68%) or improving their health care experience (63%). However, as we have all learned during the digital age, you cannot automatically trust the information found on the Web.

#CRArthritis2020 – Bringing the latest research and knowledge from the Canadian rheumatology community to people living with arthritis

Arthritis Consumer Experts (ACE) joined together with patient partners – the Canadian Spondylitis Association and the Arthritis Patient Advisory Board of Arthritis Research Canada – to host the sixth annual #CRArthritis Facebook and Twitter Live event (https://bit.ly/CRArthritis2020YouTube) at the 2020 Canadian Rheumatology Association (CRA) and the Arthritis Health Professions Association (AHPA) Annual Scientific Meeting in Victoria, British Columbia.

The event was showcased through the Arthritis Broadcast Network – a multi-media platform created by ACE 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 #CRArthritis event brings the latest research, knowledge and care initiatives from the Canadian rheumatology community to people living with arthritis.

In this section, we explore this year's meeting theme of "2020 Vision: A New Decade in Rheumatology" and present a curated guide to a selection of #CRArthritis interviews. These interviews include research highlights, news from patient organizations, and helpful lifestyle tips from healthcare providers.

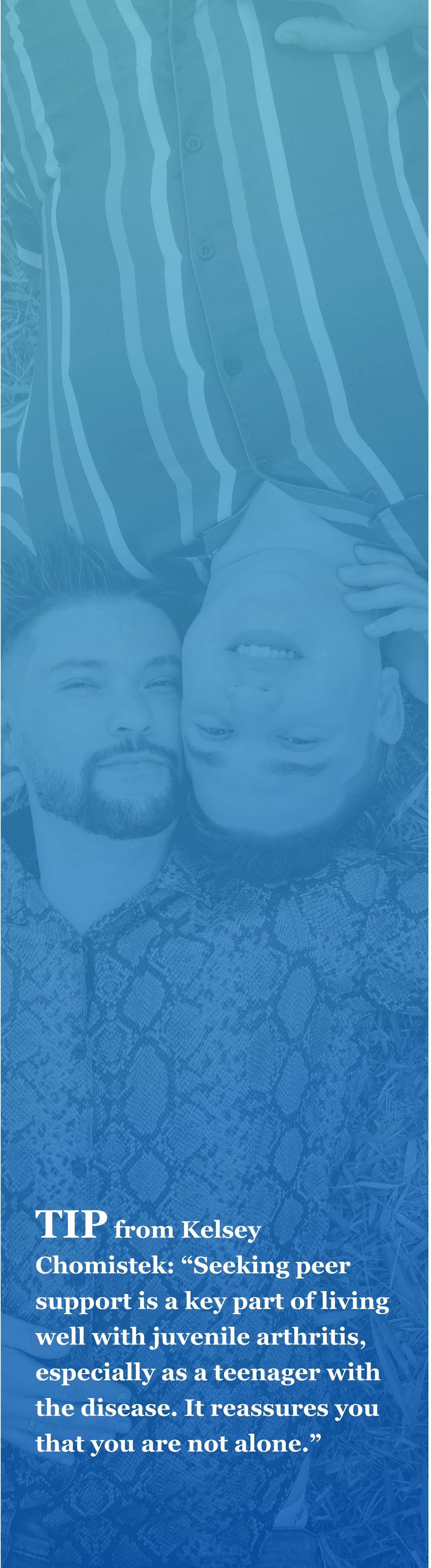
What's ahead for arthritis research?

The last few decades have seen incredible advancements in rheumatology – from the introduction of highly effective therapies and new models of care to more patient partnerships in research and interdisciplinary care teams. So, what's next? In **interview 1**, Dr. Tom Appleton, Program Director of the CRA Annual Scientific Meeting talks about the next renaissance in rheumatology and "how we can work together and bring new voices in to think about big ideas and new ideas in a way that we haven't in the past". Read on to learn about the exciting projects that could fuel the next "rheumatology renaissance."

Improving Access and Equity

Today, more than 6 million Canadians live with some form of arthritis but not everyone has the same experience when it comes to accessing care. In **interview 16**, Dr. Cheryl Barnabe explains how she is working with Emilie Pianarosa to address this issue by incorporating equity into Canada's Rheumatology Care Guidelines. This is important because health inequalities may increase if guidelines and interventions focus only on the general population. Through their research, they've identified 6 groups that should be prioritized when addressing issues of equity in rheumatology:

- people living in rural/remote locations
- Indigenous peoples
- minorities/refugees
- the frail and elderly
- people with low socioeconomic status
- sex and gender groups



TIP **from Kelsey Chomistek: “Seeking peer support is a key part of living well with juvenile arthritis, especially as a teenager with the disease. It reassures you that you are not alone.”**

Dr. Barnabe and Pianarosa have worked with healthcare providers within these populations to learn about what types of care work best in these groups, and what should be incorporated into the new guidelines. To learn more about how different population groups are impacted by arthritis, watch **interview 34** with Dr. Deborah Marshall on the prevalence of rheumatoid arthritis (RA) in Alberta – some rural and remote regions experience a rate five times higher than the provincial average.

One way that rheumatologists are working to improve access to care is through the clinical support of nurses, physios and occupational therapists. In **interview 10**, Dr. Vandana Ahluwalia talks about how extended role providers who receive special training to work in rheumatology clinics in Ontario help increase the capacity of these clinics. The following interview with Ross Duncan explores outcomes from a similar program in British Columbia with nursing support in rheumatology clinics:

> **Interview 5** - Ross Duncan: access to care and health economics (en anglais)

In **interview 40**, Dr. Betty Diamond describes ways that the equity and quality of care for women’s health may be improved if there are more women healthcare professionals.

ACE is a co-authour of Leveling the Field in Canada: Reimbursement Equality in Biologic Therapy for Canadians with Rheumatoid Arthritis. **Click here** (**https://bit.ly/LevellingTheFieldEN**) to see the report that highlights the lack of equitable access and patient/physician choice in treating RA with the biologics.

Advancements in Pediatric Rheumatology

In Canada, there are approximately 24,000 children living with arthritis. Models of care (referring to how healthcare providers organize care for patients) are often developed in the realm of adult rheumatology and then applied to pediatric rheumatology. In **interview 31**, Dr. Lori Tucker explains how she wants to ensure doctors like herself are able to deliver the best care for patients and their families by developing a model of care that is specific to children with rheumatic diseases. To address this, Dr. Tucker led a special session at this year's meeting alongside experts in models of care for inflammatory arthritis and pediatric rheumatologists to find out what practices were happening across the country, what barriers there are to providing care and what changes should be made moving forward. The session created a conversation around the future of pediatric rheumatology and developing models of care that are specific to their patient population. In the next decade, Dr. Tucker says it should be all about multidisciplinary care to ensure families can find all the support they need in one setting. The interviews listed below explain other projects that are focused on providing care for adolescents and children:

Interview 22 - Kelsey Chomistek: Self-management program for adolescents with juvenile arthritis

Interview 24 - Katherine McGuire: Medication and quality of life in juvenile arthritis

Interview 45 - Dr. Ann Yeh: Neuroinflammatory diseases in the field of pediatrics

Living Well with Arthritis

Since patients began to be involved in rheumatology research, they've advocated for the inclusion of things that matter to them in their everyday lives with arthritis. One of these things is living with fatigue, a topic which is explored in **interview 32** with Dr. Susan Bartlett. Using data from the Canadian Early Arthritis Cohort, Dr. Bartlett found that 70% of people with inflammatory arthritis reported severe fatigue around the time of diagnosis. Interestingly, 30% of patients who are in remission still report persistent fatigue. One risk factor for fatigue that was identified is being overweight; evidence has shown this can lead to more disease activity and make medication therapies less effective. "Patients have reported that even losing five pounds improves their wellbeing," said Dr. Bartlett.

More highlights from important research about life with arthritis can be found in the interviews listed below:

Interview 21 - Nevena Rebic: Pregnancy and RA

Interview 26 - Nicole Anderson: Stress, pain and arthritis

Interview 28 - Roxanne Bennett: Nutritional risk in arthritis and barriers to healthy eating behaviours

To connect with other teens living with a rheumatic disease, check out Cassie and Friend's Teen Arthritis +Autoinflammatory Group (TAG).

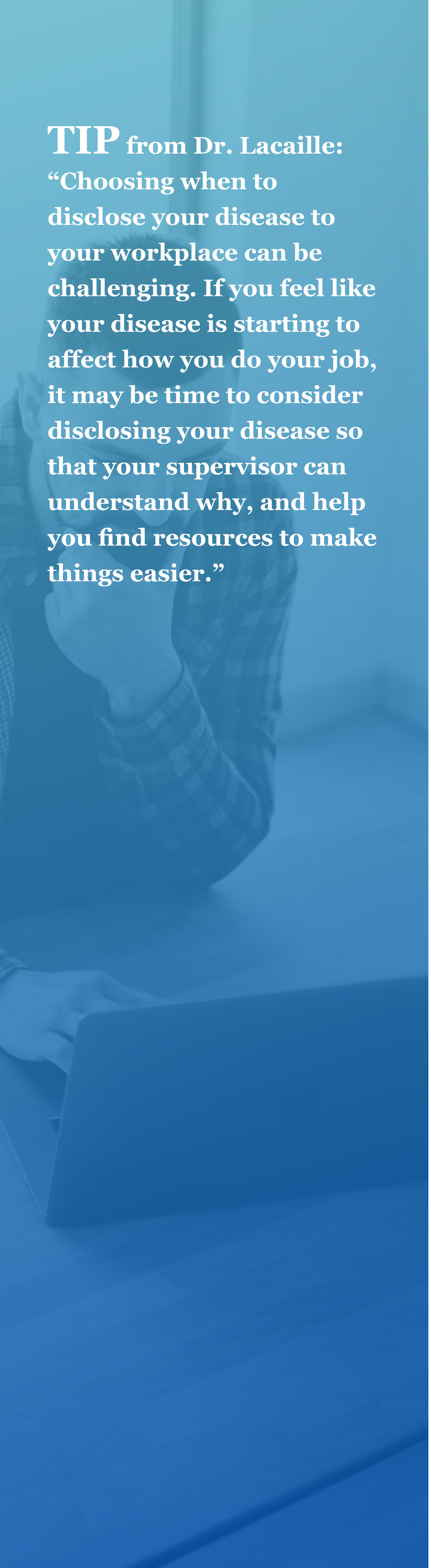
Want to learn more? Click here (https://bit.ly/JHIExerciseEN) to see a special edition JointHealth™ insight on exercise and nutrition.

TIP from Cheryl Koehn on starting exercise: "Start slow if you haven't exercised in a while and work your way up to more exercise. You can start with walking and range of motion exercises (such as stretching). It's important you don't start with too much or you may get discouraged. And don't forget to love yourself."

Arthritis in the Workplace

Another challenge for people living with arthritis is maintaining work with the disease. In **interview 24** with Dr. Diane Lacaille and **interview 12** with her trainee Dr. André Luquini, they discuss Making it Work with Arthritis, their self-management program for rheumatoid arthritis patients. It includes five online modules on topics such as effective communication and how to ask for accommodations followed by online meetings with a vocational counselor and occupational therapist. They presented findings from their program trial which included 564 people. Results from the trial showed that the program was effective at improving productivity at work and helping people with inflammatory arthritis continue to work. They found there to be significant difference at six months in terms of productivity with increasing improvement for two years after.

In its efforts to raise awareness about arthritis in the workplace, ACE runs an annual program: Canada's Best Workplaces for Employees Living with Arthritis. The program has extensive information people living with arthritis need to know. **Click here** (**https://bit.ly/BestArthritisWorkplacesEN**) to learn more.



TIP from Dr. Lacaille: "Choosing when to disclose your disease to your workplace can be challenging. If you feel like your disease is starting to affect how you do your job, it may be time to consider disclosing your disease so that your supervisor can understand why, and help you find resources to make things easier."

The Future of Clinical Trials in Rheumatology

Before any new medicines can be introduced to the patient community, they must go through a process of **clinical trials** to determine their safety, efficacy and how they compare to existing treatments. In **interview 11**, Dr. Sasha Bernatsky explains how she is working to improve clinical trials. Currently, most trials consist of patient participants who are enrolled on a strict criterion, which often do not resemble the real arthritis patient population. For example, they usually don't include seniors or people who have multiple chronic conditions. Dr. Bernatsky is working with Dr. Glen Hazlewood to set up a network within Canada that could build capacity for more pragmatic trials in rheumatology. Pragmatic trials are a type of clinical trial that have less strict inclusion criteria and therefore, more closely resemble the real-world.

Many of our interviewees expressed their excitement over the possibility that stem cell treatment may be effective for people living with scleroderma. In **interview 6**, Dr. Mark Harrison highlights his study to ensure patient perspectives and priorities are included in clinical trials for stem cell treatment. Dr. Harrison emphasizes the importance of addressing what matters to patients in making decisions about stem cell treatment for sceleroderma and not making assumptions, which are well intentioned but often do not align with patient perspectives.

Medications

Over the last year, provincial and private drug benefit plans have begun implementing biosimilar transition policy requiring patients to move from their current biologic originator to its Health Canada approved biologic biosimilar, an equally safe and effective but less costly version of the originator medicine. In **interview 20**, Dr. Cathy Flanagan speaks about the 'Biosimilar Initiative Policy' in British Columbia. She describes an ongoing study involving real world data to evaluate the outcomes of the policy. For example, data is being collected on medication refills, medication switch's, physician visits, hospital and emergency room visits before and after implementation of the policy. So far, less than 2% of patients and their doctors have requested to be exempt from the biosimilar transition policy.

Watch the following interviews for more information related to medications for arthritis:

Interview 33 - Hsin Yen Lui: Eye toxicity and hydroxychloroquine in arthritis

Interview 35 - Alexandra Charlton: Addressing patient concerns about medication therapies and biosimilars

Interview 37 - Tom Hahn: Adherence to statin therapy in rheumatoid arthritis

Alternative Therapies for Pain Reduction

In **interview 4**, Lindsay Knazan talks about her practice as a yoga therapist and how yoga changed her experience living with ankylosing spondylitis. The goal of yoga therapy is to reduce inflammation and pain, regulate the nervous system and ultimately improve day to day life with arthritis. Lindsay says that many of these outcomes can even be achieved through simple breathing techniques.

TIP **Visit Biosim•Exchange (https://biosim.jointhealth.org/) to find out more about biosimilar facts, research and drug plan policies across Canada.**

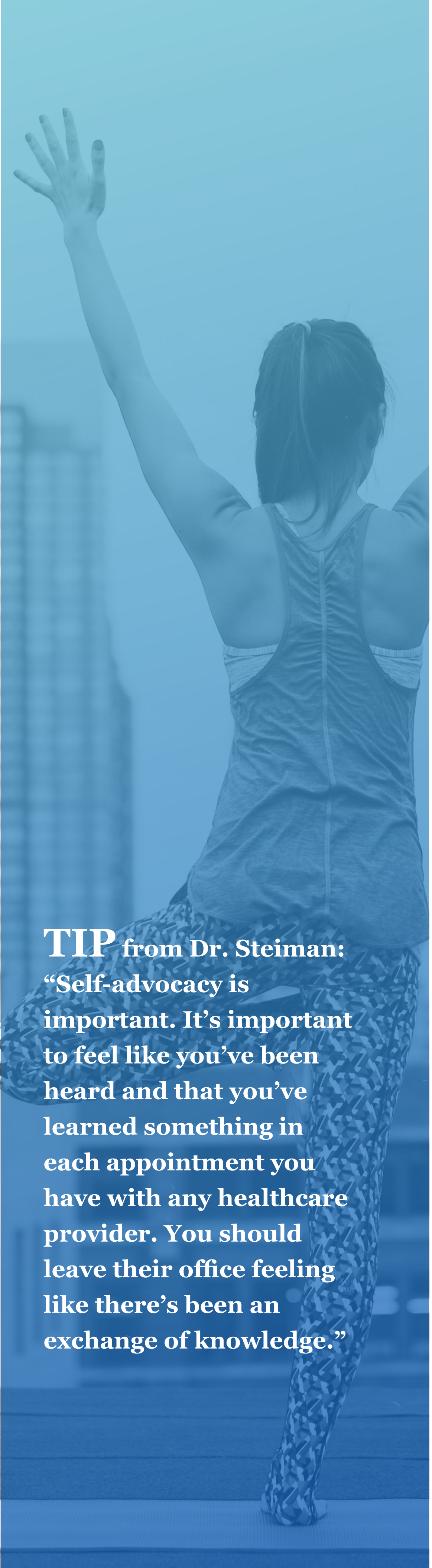
TIP **from Lindsay: "If you're looking on YouTube or online for breathing techniques, try any practice that doesn't require retention (i.e. holding the breath). If a specific technique doesn't feel soothing for you, try another one."**

The CRA's position statement on medical cannabis use in rheumatic diseases states: "The CRA recognizes the need for improved pain relief in patients with rheumatic diseases. With the legalization of cannabis, Canadians are increasingly turning to their physicians for guidance regarding medical cannabis use, which has already entered mainstream medicine. Medical cannabis has not been subject to the standard review required for drug approval by Health Canada. In the absence of studies examing the effects of medical cannabis in patients with rheumatic diseases, rheumatologists should be prepared to offer pragmatic advice in a caring and empathetic way to ensure harm reduction." In **interview 43**, Dr. Mary-Ann Fitzcharles looks at the use of medical marijuana for arthritis pain management and answers some frequently asked questions about medical marijuana.

Delivering the Best Care to Patients

The rheumatology community is always looking for ways to improve patient care. One evidence-based approach is providing patients with multidisciplinary care – this means ensuring that patients receive support from a variety of healthcare professionals such as pharmacists, social workers, physiotherapists, nurses and occupational therapists. In **interview 41**, Dr. Carter Thorne shares information about **The Arthritis Program (TAP)**, which he founded in Newmarket, Ontario. TAP delivers a team-based approach to the assessment, treatment, and education of individuals with arthritis. Dr. Thorne's clinic has a 50% remission rate, patients experience fewer medication changes and most are on only one medication to manage their disease (monotherapy). Dr. Throne believes this is largely due to the collaboration, communication and trust that is built between providers and patients at his clinic. He shares his clinical research with other sites to support clinicians in developing their own multidisciplinary clinics.

One sure way to deliver effective care is to start with great rheumatology training! In **interview 2**, Dr. Marie Clements-Baker explains a new method of teaching that is being implemented in some universities in Canada: Competency Based Medical Education (CBME). CBME is a teaching method that ensures residents can demonstrate and show their capabilities - residents are more closely evaluated and receive more feedback compared to traditional teaching methods.



TIP from Dr. Steiman: "Self-advocacy is important. It's important to feel like you've been heard and that you've learned something in each appointment you have with any healthcare provider. You should leave their office feeling like there's been an exchange of knowledge."

In interview 38, Drs. Kam Shojania and Nima Shojania also talk about CBME and other changes to teaching frameworks. Dr. Kam Shojania says that in the past, education consisted mainly of lectures and marks. Today, patients and nurses help with teaching and there is a greater focus on collaboration, communication and diversity within students and instructors. All of these factors significantly improve quality of care for patients.

The following interviews also discuss initiatives that are related to improving patient care:

Interview 15 - Derin Karacabeyli: Helping healthcare providers address weight management & smoking cessation in RA

Interview 25 - Dr. Amanda Steiman: Under-Diagnosing vs Over-Diagnosing in Rheumatology and Quality Improvement Initiatives

Interview 30 - Safoora Fatima: Health Assessment Questionnaire (HAQ) and mortality

ACE has worked closely with other leaders in the Canadian arthritis community to promote models of care. ACE has consistently identified gaps in models of care and solutions to provincial governments across Canada. Click here (https://bit.ly/JHIModelsofCareEN) to learn more about models of care.

Lupus and the Brain

Dr. Betty Diamond is considered one of the world's experts on lupus. Throughout her career, she has uncovered landmark findings related to lupus. In interview 40, Dr. Diamond explains that patients may experience Invisible cognitive impairments and mood disturbances as a part of their disease process. This is validating for many lupus patients, especially young women, who may have been told in the past that it was an imagined symptom.

In interview 8, Dr. Paul Fortin also covers psychosocial impacts of lupus. He notes that living well with lupus requires more than medication treatment as patients between 40-50 years old with about ten years of disease are scoring very low in quality of life measures.

How can lupus patients have a better sleep, maintain their job, and have access to exercise? MyLupusGuide is a helpful Canadian resource that addresses some of these questions.

ACE published a two-part special edition of JointHealth™ insight focusing on Joint Replacement surgery. Click here to read the issue.

Osteoarthritis

Each year, more than 130,000 Canadians have a total hip or knee replacement, in most cases, for arthritis. In **interview 17**, Marie Westby emphasizes the importance of rehabilitation after joint replacement and prehabilitation to gain muscle before surgery occurs. Marie is working to equip and engage patients in their own care both before and after joint replacement through implementation of the EQUIP tool kit.

Learn more about programs that are available to help you prevent or treat osteoarthritis in the following interviews:

Interview 3 – Dr. Jackie Whittaker: Osteoarthritis prevention

Interview 13 - Christopher Hawk: Advanced practice physiotherapy + helping patients access osteoarthritis care

Research in Other Types of Arthritis

There are over 100 types of arthritis and related rheumatic diseases. To learn more about exciting research happening in specific disease areas, watch the interviews listed below:

Interview 7 - Dr. Lihi Eder: Enthesis, psoriatic arthritis and cardiology

Interview 19 - Dr. Gilles Boire: Refractory monoarthritis

Interview 27 - Mathew Jessome: Clinical prediction tools in giant cell arteritis

Interview 29 - Alex Adrian-Hamazaki: Rheumatoid arthritis as risk factor for venous thromboembolism

Interview 36 - Dr. Jonathan Chan: Spondyloarthritis

Latest News from the Arthritis Patient Community

One source of knowledge whose importance cannot be overstated is that of the arthritis patient community. Patient partners and advocates work tirelessly to ensure that the patient voice is included in research, decision making, and the development of new care initiatives across Canada. Patient organizations also cultivate important spaces for patients by providing education, support and a sense of community for those living with the disease. Thank you to our patient interviewers who made this year's #CRArthritis event a great success!

Below are interviews with patient experts and patient organization leaders:

Interview 14 - Don Bindon: Living with ankylosing spondylitis and work at the Canadian Spondylitis Association

Interview 18 - Kelly English: New and upcoming events at Arthritis Research Canada

Interview 23 - Jennifer Wilson & Kelsey Chomistek: updates from Cassie and Friends Society for juvenile arthritis and other rheumatic diseases

Interview 39 - Trish Barbato: What's new and upcoming at the Arthritis Society

Interview 42 - Maya Joshi: School, work and personal life with rheumatoid arthritis

Interview 44 - Eileen Davidson: Patient advocacy and parenting with arthritis

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 JointHealthTM materials.

ARC
ARTHRITIS RESEARCH CANADA
Leading research. Finding answers. Saving lives.

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@jointhealth.org
www.jointhealth.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