



March-ing into action

March is not just when spring break and Daylight Saving Time happen, it's also a time for new beginnings and new hope for people who live with arthritis. It follows quickly after a major conference, usually held at the end of February, where arthritis specialists from all over Canada come together to share their experience and expertise. And when they return to their practices they are re-energized and armed with new knowledge to help their patients. It's also a time to celebrate Childhood Arthritis Awareness Month, Pharmacist Awareness Month, and International Women's Day. For those of us at Arthritis Consumer Experts (ACE) and the Arthritis Broadcast Network, it's a time to "march" into action. Read on to get the highlights of the conference, to learn about current issues in juvenile arthritis, find out how the National Arthritis Awareness Program (NAAP) is working with pharmacists, and what ACE has been up to this month.



March is Childhood Arthritis Awareness Month

Children living with juvenile idiopathic arthritis (JIA) face many barriers to receiving certain "gold standard" medications. The reasons vary, but the result is the same: access to medications to treat arthritis in kids is routinely delayed or inadequate, and sometimes denied altogether. Here are the current key issues that require our collective attention:

For children who develop arthritis before the age of five, they need a liquid suspension medication to ease pain and inflammation. The most common non-steroidal anti-inflammatory drug (NSAID) used in Canada for children living with JIA is naproxen (Naprosyn®). The medication, approved by Health Canada for use in children, is manufactured by a third party supplier and provided by a Canadian pharmaceutical company. Recently, the third party supplier discontinued production of liquid medications, so pediatric rheumatologists can no longer provide naproxen in liquid form to their young patients. Now, families have to pay \$200 per month to have the pill form made into a liquid. The pharmaceutical company indicates that even

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if they can find a new supplier, it will take between three and five years to test and then get approval for a new formulation.

Methotrexate is the most commonly prescribed disease modifying medication for children living with arthritis. It comes in two tablet sizes: 10 mg and 2.5 mg. The larger tablet means parents only have to give one or two pills to their child each week, as opposed to between four and ten of the smaller pill. The less frequent, higher dose, means more children can take the medication. Unfortunately, often families are told by their local pharmacists that the larger formulation does not exist. The benefit of the 10 mg formulation extends to adults and the elderly, as well.

Intra-articular triamcinolone hexacetonide (TH) is a steroid that has been available for over fifty years, and used to treat children with arthritis for more than thirty years. Specifically, it treats oligoarticular arthritis, and sometimes polyarticular arthritis, in children. Early use of TH (commercial name: Aristospan® TH) means that serious complications and painful symptoms can be avoided. It is effective—more so than other intra-articular steroid formulations—safe, and inexpensive.

Currently, access to TH is restricted because the holder of the distribution rights in Canada no longer has access to the medication from its earlier manufacturing source. A Canadian pharmaceutical company manufactures and distributes TH to the United States, but does not hold rights to distribute it here in Canada. This means that the product must be obtained through Health Canada's Special Access Program (SAP), and the process is long and complicated. Each time rheumatologists want to administer TH to a patient, they have to file an application. When they do, they must provide full clinical details of the child's disease course, including previous treatments, and give specific references to support the use of TH.

At most, only six months worth of medication can be applied for at a time. For more medication, yet another application must be filed. Sometimes the applications are denied, so rheumatologists are told to use other treatments that are not

appropriate for their patients. The process, which has been in place for more than two years, has resulted in unacceptable delays in providing treatment. Furthermore, it is a waste of physician and healthcare staff resources, and takes time away from their patients.

For children who do not respond well to standard therapies (NSAIDs, corticosteroids, and DMARDs), biologic response modifiers ("biologics") may provide another hope—and help these children avoid joint damage, physical limitations, and improve their chances of having a normal childhood. However, access to biologics for children with arthritis is limited and varies from province to province. For example, four biologics in Saskatchewan and five in Quebec are available to kids, that is, reimbursed by the provincial formulary, while in the Yukon, none is available. The non-insured health benefits (NIHB) formulary only covers two biologics, which means First Nations and Inuit children have fewer options than other Canadians. One of the findings of a study called, "Access to Biologic Therapies in Canada for Children with Juvenile Idiopathic Arthritis" found that "overall, the application process was believed to be acceptable, but approval took one week to one year and many application forms were designed for adult rheumatic diseases, making the pediatric applications challenging."

Like in adults,
treating the inflammation of
auto-immune forms of arthritis
as early as possible
to avoid damage to joints
and disability,
is the key to successful disease management.
That cannot be done
if situations like those described above exist.



March Forth: A Call to Action

Write to your provincial and federal representatives to share your concerns about the need to address the medication access issues covered in this month's JointHealth™ monthly. For tips on how to communicate with elected officials or key decision-makers, please visit our **"What You Can Do"** page within the **"Taking Action"** section of the JointHealth™ website.

What can you do
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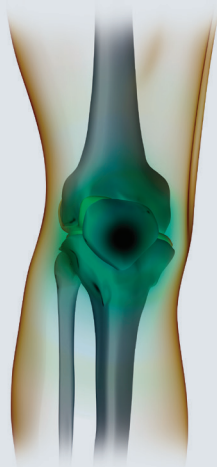
For information about JIA, including the medications that are used to treat it, please watch the JointHealth™ workshop titled, **"Children and Arthritis"** and visit **Cassie and Friends**, a Vancouver-based organization focused solely on helping kids with arthritis.



Pharmacist Awareness Month is about letting people know that the role of the pharmacists in primary healthcare is **expanding**. They do more than simply dispense prescribed medications; depending on the province and sometimes with limitations, they can also:

- Administer vaccinations and injection medications
- Provide chronic disease counseling
- Help with smoking cessation
- Prescribe for minor ailments and/or conditions
- Provide emergency prescription refills
- Order and interpret lab tests
- Make a therapeutic substitution
- Renew or extend prescriptions
- Change medication dosage or formulation
- Initiate a prescription medication therapy

At a time when it can take months to get an appointment with a doctor, those needing advice can usually find their pharmacists conveniently nearby and available. Help spread the good news and share what you have learned with friends and family, so they may benefit from the changes too.



Here's what Arthritis Consumer Experts and the Arthritis Research Centre of Canada are doing as co-leaders of the National Arthritis Awareness Program to help pharmacists help Canadians with arthritis:

On March 18, Drs. John Esdaile and Carlo Marra delivered the 4th continuing education session to Shoppers Drug Mart pharmacists across Canada as part of the three year Arthritis Consumer Experts/ Arthritis Research Centre of Canada/Shoppers Drug Mart Arthritis Program. The session featured an evidence-based osteoarthritis of the knee screening tool developed from Dr. Marra's research work in pharmacy. His research showed that a simple, easy-to-administer questionnaire was as accurate as an MRI at detecting osteoarthritis of the knee, without the high cost to the healthcare system.

As scientific director of the Arthritis Research Centre of Canada (ARC), Dr. John Esdaile is one of Canada's leading clinical arthritis researchers.

The mastermind behind the screening tool, Dr. Carlo Marra has a Bachelor of Science in Pharmacy, a Doctor of Pharmacy, a PhD. in Epidemiology, and is a Fellow of the Canadian Society of Hospital Pharmacists (FCSHP). His many roles include:

- Research Scientist in Pharmacoepidemiology with the Arthritis Research Centre of Canada
- Assistant Professor, Pharmacy Practice, with the Department of Pharmaceutical Sciences at the University of British Columbia (UBC)



Dr. John Esdaile



Dr. Carlo Marra

- Director with UBC's Collaboration for Outcomes Research Evaluation (CORE) group for the Faculty of Pharmaceutical Sciences
- Research scientist with the Centre for Health Evaluation and Outcome Sciences (CHEOS) of the Providence Health Research Institute at UBC's Vancouver campus

His groundbreaking research on arthritis and pharmacy led to the development of the Osteoarthritis of the Knee Questionnaire being reviewed in the education session. Together, Drs. Esdaile and Marra gave Shoppers Drug Mart pharmacists and associates information about the most important aspects of osteoarthritis disease and illustrated how to use the Questionnaire with patients and customers.



CRA SCR Marching Together: Representing Arthritis and You



Arthritis Consumer Experts (ACE) was in Whistler, BC for the 2014 Canadian Rheumatology Association (CRA) Annual Scientific Meeting & Arthritis Health Professions Association (AHPA) Annual Meeting. The meetings, which ran from February 26 to March 1, brought rheumatologists and arthritis health professionals (like physiotherapists) from all over Canada together to learn about and share the latest advances in arthritis research and care.

ACE founder and President, Cheryl Koehn, and Kelly Lendvoy, Vice President, Communications and Public Affairs, shared their advocacy knowledge and experience with presentations to both Associations. Topics covered included the latest on ACE's initiatives on subsequent entry biologics (or "SEBs"), private insurance reimbursement challenges, and the role of pharmacy and social media in better serving the needs of people with arthritis.

ACE and representatives from the Canadian Arthritis Patient Alliance, the Consumer Advisory Board of the Arthritis Research Centre of Canada, the BC Lupus Society, the Canadian Spondylitis Association and Patient Partners were there to share the arthritis consumer perspective and "make arthritis news".



Interviews at the CRA

While there, consumer "reporters" from several arthritis patient groups interviewed rheumatologists (doctors who specialize in treating arthritis) and other arthritis-health related topic presenters about their views on the state of arthritis in Canada. The issues we spoke to meeting participants about included:

- Highlights of the conference and exciting developments in arthritis research
- The use of social media in patient care and medical research
- Other important topics related to arthritis

We encourage you to visit and watch the videos on Arthritis Broadcast Network or on our YouTube channel:

<https://bit.ly/ABNYouTube>

Thank you to interviewers:

- **Anita Chan:** JointHealth™ Program Coordinator
- **Chris DeBow:** Project Consultant for the Canadian Arthritis Patient Alliance (CAPA)
- **Kelly English:** Member of the Consumer Advisory Board of ARC
- **Cheryl Koehn:** Founder and President of Arthritis Consumer Experts and the JointHealth™ family of programs
- **Dr. Janis McCaffrey:** General practitioner and person living with lupus
- **Marilyn Muldoon:** Member of the Consumer Advisory Board of the Arthritis Research Centre of Canada (ARC)
- **Manon Roberge:** Representative from the Canadian Spondylitis Association

Highlights of the CRA meeting

As they do every year, the CRA took a time during the meeting to recognize individuals for their work that has advanced arthritis research and improved patients' lives. We were honoured to have a chance to interview two of them and share what we learned with you.

Dr. Brian Feldman, won the Distinguished Investigator award for more than twenty years of contributions to the field of rheumatology, which include:

- Designing clinical trials and developing new ways to study patients with rare disorders.
- Playing a key role in developing tools to measure disease activity in children with juvenile dermatomyositis and in the treatment and prevention of the complications of hemophilia (which can lead to arthritis if bleeds into the joints are not properly or adequately treated).
- Improving care for children with juvenile dermatomyositis by improving the understanding of how the disease shows up in kids and how it progresses, and by finding new approaches to treating it.



This is only one of many awards he has received for his work in pediatric rheumatology.

His current responsibilities include being the Head of the Division of Rheumatology at the Hospital for Sick Children in Toronto, Ontario and chairing The Arthritis Society's Medical Advisory Council. Also, he is an advocate for children having better access to medications to treat their arthritis.

In our interview, we spoke with him about his CRA workshop titled, "Measuring Stuff: What's Right? What's Wrong? We Can't Manage What We Don't Measure." It was about reducing bias when it comes to understanding whether a treatment is working for a patient. He explained that it is easy for the doctor to see what they want to see, which is the best outcome for their patients. For this reason, it is important that there are ways to make objective (unbiased) measurements.

To watch the interview and learn more about his research, click here: <http://bit.ly/BrianFeldman>

Dr. Cheryl Barnabe, was the winner of this year's Young Investigator's award for her accomplishments in the first few years of an academic position, which included:

- Establishing a successful program in epidemiology* and health services research on the topic of arthritis in indigenous populations.
- Initiating the adoption of new imaging technology for monitoring bone damage in rheumatoid arthritis.
- Winning eight peer-reviewed grants as the principal investigator and being the co-investigator on six other grants.
- Developing faculty-wide national and international research collaborations.
- Writing thirty-one publications, mostly as first author.
- If that doesn't seem like much (we jest), she also supervises several undergraduate students and PhD. candidates and is on the executive committee of the Indigenous Physicians Association of Canada and the Royal College of Physicians Surgeons of Canada Indigenous Health Advisory Committee. Plus, she has developed research collaborations with Chiefs and Elders of several Alberta communities and provides clinical rheumatology services in rural and urban First Nation communities.



Dr. Barnabe went to medical school in Manitoba. In 2006, she moved to Calgary to do her training in rheumatology, and then did her Masters degree in clinical epidemiology. As a member of the Manitoba Metis population and because of her own family history of arthritis, she has a personal interest in finding out why arthritis is more common in aboriginal populations and also why they are less likely to seek healthcare.

In our interview with Dr. Barnabe, we spoke to her about the findings she presented in a talk she gave at the CRA meeting called "Investigating Access to Arthritis Health Services for Aboriginal People: A Framework for System Reform." One major reason individuals may not seek out care when they start to have arthritis symptoms comes from misconceptions and stereotypes that people in healthcare often have about aboriginal people. Another reason is that in the context of social or psychological trauma, or other diseases, their coping strategy has become "toughing it out". Finally, since arthritis is common—everyone in their family may have it—it is normal to have arthritis, so it may seem to some people that medical care is unnecessary.

To watch the interview and learn more about this astounding woman and her research, click here: <http://bit.ly/CherylBarnabe>

* **Epidemiology:** The study of the distribution of illness in a population that sets out to answer, "Why is this disease so prevalent in this group of people in this area?"



International Women's Day

As you may know, March 8 was International Women's Day.

It's a day to celebrate women's achievements and challenge inequality.

You may also know that arthritis occurs unequally between the sexes: nearly two-thirds of those affected with arthritis are women. But here are some little known facts about arthritis that women (and men) should know:

The individual woman with arthritis will be more disabled than a man with arthritis.

Why? The reasons for these differences between men and women are not completely understood. Possible reasons may have to do with physiological and anatomical differences between the two genders.

Women get more knee injuries.

Why? Women tend to favour their quadriceps muscles in the front of the thigh to stabilize the knee, rather than the stronger hamstring and gluteal muscles that support the back of the thigh.

Women with arthritis have significantly greater difficulty than men with climbing stairs, standing for twenty minutes, moving room-to-room or walking ½ km, reaching, and with grasping or carrying.

Why? This is unknown, but may be related to hormones.

Though ankylosing spondylitis (AS) is an exception to the rule—it affects 2 to 3 times more men—it takes, on average, three years longer for a woman to be diagnosed with AS than it does a man (7 years vs. 10 years).

9 out of 10 people living with systemic lupus erythematosus are women.

Why? There are a few possible reasons, but basically the disease can affect women and men differently. Doctors may be looking for symptoms that are typical in men and expecting them to be the same for women.

About Arthritis Consumer Experts

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.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 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

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Arthritis Research Centre of Canada
Arthrite-recherche Canada

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