

# JointHealth<sup>TM</sup> monthly

Arthritis research, education and advocacy news : April 2012



## Arthritis: a lifelong disease requiring a long-term plan

**Generally, sicker Canadians** are more likely to have below-average income (they are also less likely to have post-secondary education, and tend to be older and live in a rural community), so often cannot pay for their medications. The medications, whether they are needed to reduce pain, prevent complications from their disease, or to treat the underlying disease process, contribute to a better quality of life, to greater economic productivity, and reduced healthcare costs. These are the people, more than anyone else, who need medications included on public formularies.

*“Sicker Canadians” — the term used in the Canadian Health Care Matters series to mean their sample of survey respondents with chronic conditions who reported being in fair or poor health.*

**Health Council of Canada** — An independent, nonprofit organization, funded by Health Canada, that reports on the progress of national healthcare reforms.

The Health Council of Canada recently published its findings from the 2011 *Commonwealth Fund International Health Policy Survey of Sicker Adults*, in the sixth bulletin of its *Canadian Health Care Matters* series. In it, they state:

*“The 33% of Canadians with one or more of seven chronic conditions account approximately for 51% of family physician/general practitioner consultations, 55% of specialist consultations, 66% of nursing consultations and 72% of nights spent in a hospital... It’s a significant number considering 90 per cent of these Canadians take at least one drug as part of their routine regimen.”*

Yet astoundingly, almost one-quarter of Canadians in fair to poor health reported not filling a prescription, or missing a dose, because they could not afford their medications... compared to one in ten from the general population.

Rheumatoid arthritis and osteoarthritis alone cost the Canadian economy approximately \$33 billion due to the direct expense of healthcare and the indirect costs of lost productivity. Higher numbers of hospital stays, surgeries, emergency department visits, and prescriptions are associated with chronic disease, making it expensive for Canada’s healthcare system.

Many provincial governments in

Canada have signaled that their health regions will be directed to move from an acute care model to a more diverse, chronic care management model.

Four pillars\* support effective chronic disease care:

- **Self-Management**
- **Community-Based Care**
- **Timely access to the right specialists**
- **“Access to and professionally monitored use of the right medication at the right time for the required length of time.”**

**Chronic disease management CANNOT be successful without ALL four pillars in place.**



\* A concept developed by the [Better Pharmacare Coalition](#)



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## The fourth pillar: Appropriate and timely access to medications

There are more than 100 different types of arthritis, including osteoarthritis, rheumatoid arthritis, lupus, gout, and ankylosing spondylitis. Arthritis can affect people very differently, ranging from mild to deadly, inconvenient to totally disabling, and merely uncomfortable to excruciating.

Physicians, working with their arthritis patients, are best suited to make treatment and medication decisions. Limited access to innovative medicines limits the ability to effectively manage chronic diseases such as rheumatoid arthritis. In some cases such limitation may be solely responsible for life altering, even life-threatening circumstances. Diseases are individual. So too must be patient treatment.

## Arthritis: an under-recognized disease

Arthritis is one of the most prevalent chronic diseases, yet it is not recognized as such. One of the challenges, Arthritis Consumer Experts (ACE) faces is undoing the public's misperceptions about arthritis. Many see it as strictly an "older person's disease". When we explain that children get arthritis too, most people are surprised. **The fact is that 60% of the nearly 4.5 million Canadians with arthritis are under the age of 65** and more Canadians are affected by arthritis than diabetes, heart disease, or cancer. It is without question, however, a women's disease: according to *Life with Arthritis in Canada*, nearly two-thirds (64%) of those affected with arthritis in Canada are women.

## A call to action

The next challenge for the arthritis community is determining an effective call to action for Canadian consumers and healthcare professionals, getting them involved in mobilizing the right community leadership and participation to profoundly change how arthritis is perceived and treated as a chronic disease in Canada.

For primary care practitioners, nurses and nurse practitioners, we offer tools that will improve their skills and enhance their ability to talk to patients about primary and secondary prevention and early detection of degenerative and inflammatory arthritis.

For physiotherapists and occupational therapists, we develop tools that provide relevant information they can incorporate into their practices and promote conversations with their patients about joint complaints and effective primary prevention, exercise and rehabilitation strategies.

For pharmacists, we help them expand their role as a partner in patient healthcare who can deliver key information to customers about the importance of sticking to prescribed treatment and encourage patients to learn about self-management strategies.



## Talkin' 'bout a (patient) revolution

At the public level, our call to action to consumers today occurs in the midst of a patient revolution. There is an increasing wave of consumers researching and looking to online materials for credible and accessible chronic disease identification, medical information and self-treatment strategies.



The traditional provider-centric healthcare model that focuses on the chronic disease, with the healthcare professional (HCP) viewed as the 'knowing' expert and the patient a 'passive' recipient, is becoming obsolete. Patients are taking a more active role in their disease management. Both arthritis patients and HCPs are experts: patients are experts on their lives and experiences of their disease, and HCPs are experts on the clinical side of the disease. ACE believes an arthritis patient is empowered when provided with sufficient knowledge to make informed decisions, given adequate control and resources to implement their choices, and is armed with the necessary experiences to evaluate the effectiveness and impact of the steps taken. A major impediment is that few HCPs are equipped with the medical training, skills, tools, or system support to encourage arthritis patients to consider outcomes, ask questions, and clarify preferences within a visit.

From our experience as a leading national advocate and as the founder of the *Arthritis is cured! (if you want it)* **National Arthritis Awareness Program**, we have identified technology as the key driver behind the rise and adoption of healthcare partnership into practice. The emergence of a patient revolution, catalyzed by new technology and characterized by the patient/physician/caregiver/pharmacist partnership is under way. Patients are seeking and sharing more healthcare information online and using mobile health such as medical Smartphone apps.

Through its JointHealth™ family of programs, which includes weekly and monthly online and print publications, video and audio web workshops, and robust social media communications, Arthritis Consumer Experts (ACE) provides free education and information programs to inform, educate and empower people with arthritis to help them take control of their disease and improve their quality of life. With 6,500 members and 35,000 JointHealth™ program readers and subscribers, ACE is the largest provider of arthritis information, by and for Canadians living with, or interested in, arthritis.



The *Arthritis is cured! (if you want it)* program is Canada's **National Arthritis Awareness Program (NAAP)** and the leading source of the newest arthritis information, programs and tools. The co-leaders of the NAAP, Arthritis Consumer Experts (ACE) and the Arthritis Research Centre of Canada (ARC), believe if Canadians start talking about arthritis, a cure can and will be found. Now in its third year of promoting interest, activity and conversations about arthritis and its impact on Canadians, the NAAP has created a new way to broadcast the arthritis story.

## Enter the Arthritis Broadcast Network:

Your daily source for arthritis news and information



**Arthritis Consumer Experts is pleased to announce the launch of this “go-to” source of arthritis news, education, and inspirational lifestyle stories for consumers and healthcare professionals alike, updated every day.**

With guidance from its Expert Advisory Panel, the NAAP designed ABN as a multimedia platform to entertain, inform, and inspire people with arthritis to live their best lives.

Featured ABN programs include:

- **News:** Arthritis news. Anytime. Anywhere.
- **Life:** Living your best life with arthritis
- **Arthritis Intel:** Helping you detect, treat, and manage arthritis
- **A-Team:** Partnering with your healthcare team
- **Women:** Exploring women’s arthritis issues and needs

But it’s more than just a place that informs and entertains you. Here you can join the conversation. ABN is an ever evolving project: a place where you are a part of the community – and it is a social, interactive, and informative place shaped by its participants.

We hear you, now let the world hear you. Share your experience of living with arthritis by sending us your stories, videos and photographs, and we will share them with the world. Please email us at [feedback@arthritiscured.org](mailto:feedback@arthritiscured.org).

To find out more about the NAAP, you can go to [www.arthritiscured.org](http://www.arthritiscured.org) or visit our **Facebook** page, follow us on **Twitter**, or join us on **LinkedIn**.

By building relationships, enabling conversations and sharing stories through the ABN, we will not only engage our public, but also mobilize it to advocate for us at a critical time for arthritis in Canada. In 2012, the **Arthritis Alliance of Canada** will contribute to the ongoing national healthcare debate by developing and releasing a National Framework for Arthritis. And ACE, through special projects like the **Arthritis Broadcast Network**, will be there to cover the stories around the making of the Framework and Canada’s implementation of the four pillars for effective chronic disease management. For information about the Framework, please read our December 2011 issue of **JointHealth™ monthly**.

### **Become an ABN Insider.**

**Sign up** for the latest ABN updates, exclusive feature stories, and more!

### **Become an ABN Contributor.**

If you belong to an arthritis group or related organization, you can become an **ABN Contributor** by:

- Sending us your newsletter, Facebook post, tweet, e-mail or other publication to [feedback@arthritiscured.org](mailto:feedback@arthritiscured.org)
- Emailing links to your videos
- Making a direct link from your home page. Ask for details.



# Get involved...

Arthritis is a debilitating and sometimes life threatening disease that affects too many people to go unnoticed and untreated. Let's work together!

Refuse to accept "no cure" for an answer.

Help change the face of arthritis with the *Arthritis is cured! (if you want it)* – Canada's leading National Arthritis Awareness Program (NAAP). Join the conversation. Here's how you can make a difference:

- Be a star and a part of our community: **submit** your arthritis stories, photos and videos to ABN
- Get the app! Download **ArthritisID** and **ArthritisID PRO** at the iTunes Store
- Like us on **Facebook**
- Follow us on Twitter: **@ArthritisCured / @Guerirlarthritis**
- Visit us on **YouTube** (Did you know you can email our videos to friends, family and colleagues?)
- Speak to your doctor and healthcare team: share the resources available on the Healthcare Professionals Resources section of our **website**.
- Healthcare professionals: network with NAAP on **LinkedIn**.
- Help find a cure by **donating to arthritis research**.

## 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](http://www.jointhehealth.org)

### Guiding principles and acknowledgement

#### 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 the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



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ACE thanks these private and public organizations and individuals.

### Disclaimer

The material contained in this newsletter 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. Should you have any healthcare related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.