

September is National Arthritis Awareness Month in Canada . . .



To see the app features please visit
bit.ly/ArthritisIDfeatures

The Power of Celebrity Disease Endorsement P3



Jayne MacAuley tells ACE what she has learned about arthritis through her role as a senior editor with Zoomer Magazine. P2



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and the *Arthritis is cured!* (if you want it)

National Arthritis Awareness Program (NAAP)
is in full force!

In honour of Arthritis Awareness Month, the NAAP's co-leaders, the Arthritis Research Centre of Canada (ARC) and Arthritis Consumer Experts (ACE) are excited to announce the launch of ArthritisID and ArthritisID PRO.

ArthritisID and ArthritisID PRO are iPhone and iPod touch applications that help you detect, treat and manage arthritis.

Eighty percent of Internet users look online for health information and treatment advice. Our research has shown a corresponding desire from primary care providers. The NAAP's new arthritis apps are valuable mobile health tools developed in response to this demand.

The apps, which can be downloaded for free at the iTunes store, bring the most current and accurate arthritis research together in one single place. You no longer have to spend hours online wading through endless websites, wondering if the information they contain is reliable.

In ArthritisID, you may appreciate the "Doc Talk" section, which gives tips for speaking to your doctor or pharmacist about arthritis, joint pain, and arthritis prevention. And, from the "Arthritis Community" section you can link directly to online arthritis organizations and find ways to get involved.

ArthritisID PRO extends the reach of the NAAP's information and tools beyond the desktop, to the mobile devices that healthcare professionals are using in a variety of clinical settings, whenever they need them. Resources include:

- Continuing Medical Education (CME) activity accredited by the College of Family Physicians of Canada providing Mainpro[®] M2 Credits. Arthritis ID PRO is the only mobile arthritis app to include this feature.

September is turning out to be a transformative month for arthritis in Canada. The NAAP and its co-leaders, ARC and ACE, are excited to be key players in helping elevate arthritis awareness and the need to support Canada's world-leading arthritis research efforts.

- Five detailed, but short, videos that demonstrate appropriate techniques for conducting joint exams. They are performed by ARC rheumatologists Dr. John Esdaile (in English) and Dr. Diane Lacaille (in French).

A unique feature of both apps is an interactive screening tool that asks several questions, and from the responses can suggest a type of arthritis. The raw material for the screening tool comes from the arthritis point-of-practice tool created in the first year of the NAAP. The point-of-practice tool incorporates the most recent classification criteria for rheumatoid arthritis (RA) by the American College of Rheumatology and new osteoarthritis knowledge from Osteoarthritis Research Society International (OARSI). To round out the research, we consulted with the Canadian Rheumatology Association, The Arthritis Society, and Dr. Gillian Hawker who provided input from OARSI.

Following the screening result, the apps connect you to the "Arthritis Types" section to read "Spotlights" and "Red Flag" indicators of each of the seven types of arthritis covered in the apps. Here, you will also find detailed information about treatment strategies. This section lists medications typically used to treat a form of arthritis, and





Jayne MacAuley tells ACE what she has learned about arthritis through her role as a senior editor with Zoomer Magazine.

Jayne doesn't have arthritis. Before she started working for Zoomer Magazine, all she knew about the disease was through her work as a lab technologist years ago, where she did blood tests for rheumatoid factor. Rheumatoid factor, an antibody produced by the immune system, can attack healthy tissue. She did not realize until she started doing research for Zoomer, that arthritis encompasses so many diseases beyond rheumatoid arthritis and osteoarthritis, such as lupus and gout. She certainly had no idea how painful arthritis is and how it can lower the quality of someone's life.

Through its coverage of health and wellness issues, Zoomer reaches out to people with arthritis, as they do with other diseases like cancer, by conducting interviews with doctors about specific disease types and then providing a patient profile to offer its readers different perspectives. Jayne finds that readers are particularly engaged by personal stories of successfully living with disease because it helps them to relate better to the topic. As part of its outreach, Zoomer will discuss arthritis in the context of other subjects like joints and joint health, exercise, nutrition or lifestyle, and, says Jayne, "As important discoveries are made and new treatments developed that improve the quality of life for people with arthritis,

Zoomer will be sure to deliver the encouraging news to our readers."

As a senior editor researching health articles for Zoomer, Jayne has become more attuned to a world with arthritis. Now she sees arthritis all around her. She has a friend who was diagnosed with rheumatoid arthritis when he was 39. As she got to know him, she discovered how tough it has been on him. When he was diagnosed, he had two young children and his wife had to go back to school so she could work . . . because he could not. He's had both hips replaced and has been taking prednisone for many years. Prednisone treats the symptoms, but is less effective than disease modifying antirheumatic drugs (DMARDs) or biologics for slowing joint damage.

She admires her friend, who is almost 80 now, for his "remarkable courage."

Prednisone is fast acting, so it is often used as a therapy while a patient waits for DMARDs, which act more slowly, to work. Low doses may slow joint damage, especially used in combination with other DMARDs, but more than five months of continuous prednisone therapy may increase the risk of osteoporosis.



Zoomer Magazine partnered with ACE and the Arthritis Research Centre of Canada (ARC) for Year Two of the Arthritis is cured! (if you want it) National Arthritis Awareness Program, to help raise awareness with its readership. Its readers are active people over 45, often referred to as the "boomer" generation.

His determination has served him well; however, if he had received his diagnosis today, he would have more treatment options and might have avoided hip replacement surgeries. And, through arthritis awareness programs like the **National Arthritis Awareness Program**, *Arthritis is cured! (if you want it)*, he would find more up-to-date information about arthritis and a greater sense of empowerment. All of these things lead to better outcomes for people living with the disease.

Jayne also sees how the pain and discomfort of rheumatoid arthritis interfere with a music teacher's ability to play instruments and do her job. Likewise, Jayne has witnessed the suffering her mother-in-law went through due to the pain of osteoarthritis in her shoulders.

The hardest thing, she says, is watching arthritis slow people down, and not being able to help. Seeing what her friends and family go through, she feels blindsided by the disease.

From observation, she has learned the best thing people with arthritis can do is to keep themselves comfortable . . . and to keep moving.

ACE has one thing to add: learn all you can about your disease because knowledge is power . . . and empowerment.



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provides self-care and prevention strategies to support healthcare professionals and patients in making decisions about what to do to maintain or improve health and manage living with osteoarthritis, ankylosing spondylitis, psoriatic arthritis, lupus, gout, RA, and juvenile idiopathic arthritis.

From organizing educational lectures and public forums to producing webcasts and YouTube videos and developing digital "games", and now Smartphone apps, ACE and ARC are committed to delivering patients, the public, and healthcare providers the information they need in ways they want.

Tell people about the apps! Your friends and

family can learn a lot too, and perhaps understand more what you are going through.

Here are easy-to-remember short URL's to help find the app:

- ArthritisID bit.ly/GetArthritisID
- ArthritisID PRO bit.ly/GetArthritisIDPRO
- ArthritisID (Fr) bit.ly/ArthritisIDFr
- ArthritisID PRO (Fr) bit.ly/ArthritisIDPROFr

In its first two years, the NAAP grew to become a leading source for trusted, timely arthritis knowledge through exciting new communication channels. To learn more about the NAAP, please visit www.arthritisiscured.org.

The demand for information parallels the need for arthritis research in Canada. Approximately 4.5 million Canadians live with one of the more than 100 types of arthritis — in less than 20 years, the number will be 7 million. Today arthritis accounts for one in ten doctor visits and one in 16 hospital stays. In stark contrast to the need, arthritis only receives three percent of research dollars in Canada.

The Power of Celebrity Disease Endorsement

A celebrity endorsement of a disease or serious public health issue can be a powerful and positive tool for raising awareness and funds. Consider what Michael J. Fox has achieved for Parkinson's awareness and research funding.

Another hope is that the celebrities will inspire people, who may be reluctant to seek diagnosis or treatment, to get more screenings and checkups for common and often treatable medical conditions.

The early diagnosis message is an extremely relevant one for arthritis and other diseases to slow or prevent long-term damage. What we know from reports like The Public Health Agency of Canada's "Life with Arthritis in Canada" is there are thousands of Canadians who go untreated for arthritis because they lack information.

"The severity of the disease and the pace of joint damage are variable, but it is usually progressive," said Dr. John Esdaille, Scientific Director at the Arthritis Research Centre of Canada. "Once joint damage occurs, it is irreversible, so it does not make any sense to wait until things get really bad to seek medical help. If the disease is treated early, damage can be limited or even avoided in some cases."

In the past 6 months, a number of high profile athletes have gone public about living with arthritis. Their stories have led to an increase in public discussion and in media coverage of one of the most prevalent but lower profile diseases in North America.

In the spring of 2011, golf pro Phil Mickelson helped launch a public awareness campaign for inflammatory arthritis. It was created in collaboration with Amgen, Pfizer, and the Joint Smart Coalition, which includes the Arthritis Foundation and the National Psoriasis Foundation.

ACE contacted Mr. Mickelson, whose representatives shared his story, a familiar sounding one for many people living with arthritis. A few weeks before the 2010 U.S. Open, Mickelson began to experience severe joint pain. Even his regular practice routine suddenly became difficult to endure. Mickelson's aches and pains got so excruciating that he could barely get out of bed, never mind swing a golf club.

"I got really scared," said Mickelson. "I started wondering what it was, and if it was even treatable."

Mickelson immediately went to see a rheumatologist, who diagnosed him with psoriatic

arthritis, a chronic, inflammatory arthritis caused by an overactive immune system. Symptoms and signs include stiffness, pain and swelling of joints, reduced physical function and reduced quality of life. It usually hits those in their 30s and 40s.

Mickelson's endorsed program "On Course with Phil" is meant to educate people about chronic inflammatory conditions and encourage people to get checked if they have any symptoms.

"This is meant to give people who have similar symptoms the tools and resources that will help them get questions of their own answered," said Mickelson. "I was so lucky, because I got on it right away,



What do you think?

ACE would like to hear your opinion about celebrity endorsement of disease and health issues, including arthritis. Is there a well-known Canadian living with arthritis who would serve as a positive role model for others? What message would you like to hear from a celebrity spokesperson? Please send your comments to info@jointhealth.org

so I was able to slow or stop any further damage."

During this year's U.S. Open in September, seven-time tennis Grand Slam winner Venus Williams announced her withdrawal due to the effects of Sjögren's syndrome. Sjögren's is a disease in which immune cells destroy the glands that lubricate mucous membranes. This may cause dry eyes, mouth and throat; half of people with this syndrome will develop arthritis.

At the same time that Williams withdrew from the tournament, a national arthritis awareness campaign was launched in New York at the US Tennis Open. Featuring Billie Jean King, the ads show middle-aged men and women participating in sports like swimming, biking, boxing and walking. The campaign focuses on activities the ad creator, the Arthritis Foundation, said could help relieve arthritis pain and sometimes even delay the onset of symptoms. The copy says, "In the fight against arthritis, you need a weapon," and asks, "What's yours?"

Billie Jean King, the 12-time Grand Slam singles winner and cofounder of World Team Tennis, is 67 year of age and has been living with osteoarthritis since she was in her 20s. Both her knees were replaced last year.

The new campaign wants people to refuse to accept pain and the limitations of arthritis on their lives. The program, in an urgent and hard-hitting way, encourages baby boomers 55 and older to take action now to prevent the progression of arthritis.

Research conducted last November among adults age 40 and older by Harris Interactive for the US Ad Council found that only 16 percent of those with arthritis were very confident they could manage their pain. The research also found that while 58 percent believed taking medication is the most effective way to relieve arthritis pain, only 45 percent thought regular exercise was an effective way to reduce this pain.

The voiceover on new television commercials — with middle-aged adults doing sports — says, "The pain will not control us. It will never break us, define us, or keep us still. Because arthritis can't beat us, if we beat it first."

Television ads featuring Ms. King depict her playing tennis, with arthritis as her opponent. In one, Ms. King says, "Tennis is a weapon for me with arthritis. There's nothing like it for me to hit a ball, run to the ball; any time, on any court. I'm ready, let's go."

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 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 web site, or during any of its educational programs or activities.

Thanks

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ACE thanks these private and public organizations and individuals.

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