

# CAPA VOICES



## Arthritis Awareness Month

September is arthritis awareness month and like every year I was wondering what would be the most effective activity that all of us could do to change the public's awareness of arthritis. We tend to form opinions about our world by what we see in the media so it is no surprise that arthritis is perceived as a disease which we acquire as we grow older or that it is a disease which can be cured with a few pills. These are the images which bombard us constantly on our TV

## Research

CAPA members are involved in research as consultants, collaborators and even as co-principal investigators. Consumer involvement in research brings relevance and patient centered perspective to the research project. An example of a recent research project where two former CAPA Steering Committee members, Anne Dooley and Jean Legaré are collaborators is the recently published Canadian Rheumatology Association's Rheumatoid Arthritis Guidelines which you can access by selecting this link.

[CRA: Website Highlights](#)

screens, in magazines and the internet. Isn't it time that we let the media and advertisers know that they don't have it right? Isn't it time that they portray us the way we really are? I believe that this is one way to increase arthritis awareness. Voice your opinion by writing editors and advertisers to let them know how people with arthritis should be portrayed. Here is an article which inspired me and I hope it inspires you as well. [An Identity Crisis for RA: Article - The Rheumatologist](#)

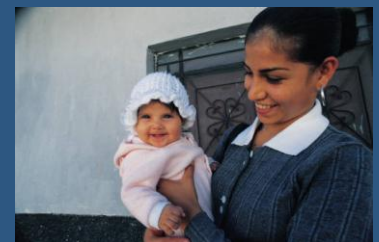
Louise Bergeron

One research project that you may be interested in participating in is "People Getting a Grip on arthritis (PGrip) an online program which consists of new educational material on self-management strategies which has proven to be effective in relieving arthritis if you have osteoarthritis or rheumatoid arthritis. The cost is free. Register before September 30th, 2011 by submitting your information (name, E-mail, and postal address) by fax 613-562-5428 or by e-mail: [pgriponline@gmail.com](mailto:pgriponline@gmail.com) For any questions please contact Dr. Lucie Brosseau: [lucie.brosseau@uottawa.ca](mailto:lucie.brosseau@uottawa.ca)

## Special events

- Canadian Arthritis Network's Annual Scientific Meeting  
Quebec City  
October 27-29, 2011  
[Canadian Arthritis Network - Today's Arthritis Research: Tomorrow's Cure](#)

***"We tend to form opinions about our world by what we see in the media so it is no surprise that arthritis is perceived as a disease which we acquire as we grow older or that it is a disease which can be cured with a few pills."***



Which one has arthritis? Most people would respond neither



September is Arthritis Month. What matters to you?

## The walls are crumbling down. Who will support infrastructure for arthritis research in Canada?

Two weeks ago I attended a meeting sponsored by the Canadian Arthritis Network for the newly formed working group, *Canadian Consortium of Rheumatology Cohorts (CANCoRC)*, which represents 15 different rheumatic disease groups. What struck me at this meeting and other arthritis research meetings that I've attended over the years is the lack of sustainable funding available for infrastructure expenses related to research. Examples of expenses include rental of office space, office supplies, lab supplies, equipment and personnel to keep these arthritis research groups operational. It is all nice and dandy to hand out individual research grants but how are researchers expected to carry out the research if there is no money to pay personnel or expenses for labs and equipment on an ongoing basis? Presently researchers are

depending on individual grants to finance these expenses so sometimes all is lost when one year they do not get funding for their individual grant application or they lose of donor funding. Unfortunately this is an all too familiar story which is not only impacting arthritis research but all research in Canada. We will continue to lose and have already lost researchers, databanks and research knowledge due to a shortsighted vision on the part of our present government. You can make a difference by contacting your MP's or government representatives and letting them know that arthritis research matters to you.

Follow this link to find your Federal MP

[Find your Member of Parliament using your Postal Code](#)

Louise Bergeron

## Canadian Rheumatology Meeting

Last February, I had the chance to attend the Canadian Rheumatology Association (CRA) congress... in Cancun! Representing CAPA, I was one of four consumers from different organizations across our country who attended this scientific congress that showcased new initiatives from both Canadian and Mexican researchers. We heard about the latest data on many types of arthritis including lupus, rheumatoid arthritis, ankylosing spondylitis and gout. The congress also gave us the opportunity to network and to underline the importance of consumer involvement in research. Indeed, CAPA strongly believes that consumers and investigators must work together to shape research that is relevant to people with arthritis. The full report will be available on our website soon.

Marie-Eve Veilleux



Consumers manning the consumer booth at the Canadian Rheumatology Associations 2011 Annual Meeting in Cancun

From left to right:  
Joyce Ma and Otto Kamensek Consumer Advisory Board of the Arthritis Research Centre  
Marie-Eve Veilleux Canadian Arthritis Patient Alliance  
Louise Bergeron Consumer Advisory Council of the Canadian Arthritis Network

## Canadian Arthritis Patient Alliance

### E-mail:

[info@arthritispatient.ca](mailto:info@arthritispatient.ca)

### Web Site:

[www.arthritispatient.ca](http://www.arthritispatient.ca)

[www.arthritiques.ca](http://www.arthritiques.ca)

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Share with us your  
stories or what matters  
to you by contacting  
us at  
[info@arthritispatient.ca](mailto:info@arthritispatient.ca)

## B.C. Healthcare Update

I attended a recent meeting with BC's Ministry of Health regarding consumer updates on BC's Drug Review. Several positive steps have been taken and the overall atmosphere was very positive and constructive.

In particular, Pharmanet is continuing to improve, keeping more information in one spot for health professionals. A project is underway to have pharmacists providing clients with a review of their medication with follow-ups happening up to 4 times a year. This provides feedback on both prescription drugs, over-the-counter drugs and even natural remedies, which should save lives annually.

Other reported progress included more client representation (i.e. a patient rep on the BC Health Literacy Network), better disposal of unused prescriptions and a new program to help people stop smoking which should be rolled out at the end of September.

Ted McNicol



## World Arthritis Day October 12<sup>th</sup>,

The European League against Arthritis and Rheumatism are promoting their World Arthritis Day with the theme **MOVE TO IMPROVE** which encourages people with arthritis to participate in physical activities to improve health outcomes. You can post a photo of yourself, engaged in a physical activity, on their website. Join them on Facebook or on their website.

[World Arthritis Day 2011 Homepage](#)

## Great Resource

CAPA's strength is it's involvement with like-minded organizations. One group we are involved with is the Canadian Pain Coalition.

[Canadian Pain Coalition: Home Page](#)

## Join us on Facebook

Keep in touch by joining our Facebook group. We have the latest news and updates from Canada and around the world to keep you informed.

[Canadian Arthritis Patient Alliance - Wall | Facebook](#)

**CAPA** Canadian Arthritis Patient Alliance  
experience · perspective · voice

**ACA** Alliance Canadienne des Arthritiques  
expérience · vision · voix