

Education



The ACE 2005 Research-based Education Workshop Schedule

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This issue of JointHealthTM monthly highlights the results of ACE's survey on NSAID use in Canada. Also this issue highlights one more of the thousands of topics presented at the American College of Rheumatology (ACR) 2004 Annual Scientific Meeting. The topics covered in this issue are:

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What is Important to Canadians with Arthritis Taking NSAIDS?

People with arthritis want to know about the medication they are taking, like NSAIDs (non-steroidal anti-inflammatory drugs). Over 100 people with arthritis responded to **ACE's Consumer/Patient Survey on NSAID Use in Canada**.

We would like to say thank you to everyone who participated in this survey. The survey was conducted, in English and French, through ACE's newsletter, JointhealthTM monthly, both online and print versions.

ACE is happy to report the results were presented recently at the 3rd Canadian Consensus Conference on the use of NSAIDs (non-steroidal anti-inflammatory drugs) in Canada.

Prior to the ACE survey, no Canadian research, gathering the consumer perspective, had been done on what consumers think about the NSAIDs they take.

In the United States, two studies looked at the topic of NSAID use from the consumer perspective. One study, by Fraenkel et al (2004), looked at older adults and their use of anti-inflammatory drugs. In this study older adults chose safety over effectiveness. However, in a sample of 80 older adults, 90% did not know about the NSAID side effects of GI bleed/ulcer, or

renal toxicity and 54% were unaware about the possibility of stomach upset or heartburn as an adverse effect.

Another study, recently presented at the American College of Rheumatology meeting, suggested that information exchanged between a doctor and his/her patient can be improved using patient-centered communication. For example, with NSAIDs, consumers would get to learn about this type of medication, ask questions and be apart of the decision-process in their treatment plan.

ACE's study looked at what is important to its community members who take NSAIDs. ACE was not only interested in what its community members thought about NSAIDs, but also who the respondents were.

Who responded to the survey?

- 68% reported having rheumatoid arthritis (RA)
- 81% were under the age of 65 years of age
- 81% were female
- 33% responded from Ontario, 30% from BC and 13% from Quebec
- 99% have been diagnosed by a doctor with arthritis.


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Depression and rheumatoid arthritis

At the American College of Rheumatology Annual 2004 Scientific Meeting there was a presentation by Patricia P. Katz, PhD on Depression and Rheumatoid Arthritis: Function, Disability and Psychological Well-Being. This study is important because depression appears to be more prevalent among individuals with RA than among the general population.

Depression is something that is clinically diagnosed by a doctor. The main symptoms of depression are sad mood, loss of interest in activities, and physical changes such as loss of appetite, decrease in activity, weight loss or gain, sleep disturbances and agitation.

“...depression appears to be more prevalent among individuals with RA than among the general population.”

If depression is not diagnosed and properly treated it can result in death, an increase in illness and disease, and a decrease in one’s quality of life.

Dr. Katz wanted to find out if there was a relationship between chronic diseases like rheumatoid arthritis and depression by looking at how people valued a wide-range of their activities.

Dr. Katz asked two questions. The first was, **“How did people with rheumatoid arthritis value their life activities?”** The results suggested there is a wide-range of life activities that individuals find meaningful and self-fulfilling. Examples include: socializing with friends,

traveling, creative activities such as crafts, and recreational activities along with taking care of family, household maintenance, sleep and work.

The study showed that over a five year period there was a 10% loss of valued activities. The greatest losses were noted in work, nurturing, culture and leisure, volunteering and social participation.

The second question researchers looked at was, **“What is the link between disability and depression in RA?”** The study looked at whether depression was a result of difficulty with one’s activities of daily living or, whether a loss of valued activities such as participation in social events, hobbies or leisure activities led to feelings of depression. The results suggest that:

- a loss of valued life activities and not just difficulty with basic activities can lead to the development of depression
- the loss of some activities appears to be more important than others in the onset of depression. An example of three activities include: inability to participate in recreational activities, socializing and get around the community where one lives.

Dr. Katz suggested that if treatment is received at these two points the possible outcomes might either reduce the chances of disability, or after the disability is present, reduce the potential for the development of depression in persons with rheumatoid arthritis.

For more information on rheumatoid arthritis and early diagnosis, go to www.arthritisconsumerexperts.org/news/. Click on October/November and on the article: **Rheumatoid arthritis should be considered a medical emergency**. Also click on September and on the article: **Treatment of Rheumatoid Arthritis - The Earlier the Better**. <

Survey *continued from page 1*

What respondents who are taking NSAIDs said

- 84% of respondents are currently taking NSAIDs
- Overall 80% reported they had a great deal of say(41%) or some say(39%) in their prescribed medication
- 78% feel the NSAIDs they are taking are effective in controlling their arthritis
- 55% take non-selective NSAIDs (like naproxen (Naprosyn®), diclofenac (Voltaren®), indomethacin (Indocin®), Arthrotec® and meloxicam (Mobicox®), among others)
- 45% take selective NSAIDs (like valdecoxib (Bextra®), celecoxib (Celebrex®), and rofecoxib (Vioxx® - prior to its removal from the market September 30, 2004)
- 75% knew the benefits and risks of taking NSAIDs. The majority received NSAID information from their doctor (41%) or the internet or arthritis groups (32%)
- Overall 87% of respondents reported either being very satisfied (32%) or satisfied (55%) with the information they received about NSAIDs.

What is Important to Canadians with Arthritis Taking NSAIDs?

ACE asked respondents to rate the importance of effectiveness, side effects and medical coverage, as these areas are the most commonly studied by researchers. The following results showed that all three areas are important to the respondents:

- Effectiveness: 100% of respondents report either very important(92%) or important(8%)
- Side Effects: 99% report either very important (68%) or important (31%)
- Medical Plan Coverage: 82% report either very important(45%) or important(37%)

In summary, the survey showed that Canadians with arthritis want to be able to make informed choices about their health care treatment plan with:

- Accessibility of accurate information about arthritis and NSAIDs
- Effective patient-centered communication, especially for older adults
- Medical coverage is important which means that non-coverage unfairly penalizes people with arthritis.

Thank you again to all the respondents to this survey. It is your participation and responses that will make a difference for everyone living with arthritis. <

Listening to You

We hope you find this information of use. Please tell us what you think by writing to us or emailing us at:

info@arthritisconsumerexperts.org.

Through your ongoing and active participation, ACE can make its work more relevant to all Canadians living with arthritis.

Update your email or postal address

Please let us know of any changes by contacting ACE at:

info@arthritisconsumerexperts.org.

This will ensure that you continue to receive your free email or print copy of JointHealth™ monthly.



2005 Free Education Workshop Schedule

We are pleased to announce the ACE 2005 research-based education workshop schedule. This year's schedule includes:

- **Plan to Win with Rheumatoid Arthritis**
- **Plan to Win with Ankylosing Spondylitis**
- **JointHealth™**

ACE's workshops will be held in urban and rural cities across Canada. These innovative workshops will be led by a leading rheumatologist and arthritis patient advocate. They will provide research-based information and address participants' specific concerns and questions.

Visit the ACE web site

www.arthritisconsumerexperts.org

to register **now** – workshops begin in April and will fill up quickly. If you prefer to register by phone, please call 1.866.974.1366.

Please note the workshop locations will be announced in future issues of JointHealth™ and on the ACE website as they become available.

Plan to Win with Rheumatoid Arthritis (RA) workshops

These workshops provide you with the critical information you need to know to take control of **rheumatoid arthritis**, one of the most common forms of inflammatory arthritis. Topics covered include:

- What rheumatoid arthritis is and about its effects
- Developing your own customized treatment plan (health care team, medications, exercises, work)
- Healthy living strategies
- Access to treatment and services in your community
- Latest arthritis research news
- "Question and Answer" session

Spring 2005

Saskatoon, SK	April 6
Sherbrooke, QC	April 19 (F)
Lethbridge, AB	May 4
Abbotsford, BC	May 10
Prince George, BC	May 18
Kelowna, BC	May 19

Fall 2005

Charlottetown, PEI	September 13
Saint. John, NB	September 14
Halifax, NS	September 15
Ottawa, ON	September 19
Sudbury, ON	September 20
Victoria, BC	September 27
Trois-Rivières, QC	September 28 (F)
Thunder Bay, ON	October 13
Windsor, ON	October 27
Yellowknife	TBA

(F) = workshops conducted in French

Plan to Win with Ankylosing Spondylitis (AS) workshops

new

New for 2005, this workshop will focus on **ankylosing spondylitis**, another type of inflammatory arthritis that commonly affects the spine and other large joints in the body.

Spring 2005

Burnaby, BC	April 20
Quebec City, QC	May 19 (F)
Edmonton, AB	May 25

Fall 2005

Montreal, QC	September 22
Toronto, ON	September 29
Calgary, AB	October 11
Winnipeg, MB	October 12
St. John's, NF	October 18
Hamilton, ON	October 19
Regina, SK	October 26

(F) = workshops conducted in French

JointHealth™ workshops

JointHealth™ workshops will focus on two of the most common chronic diseases in Canada – **osteoarthritis and osteoporosis**. These diseases affect millions of Canadians making this a very popular workshop.

Taking an integrated approach to managing these two health challenges requires a whole-body perspective. More than ever, people need to develop a strong health care team to take advantage of all the opportunities to manage their health. These workshops will help you learn about prevention strategies and focus on what you can do to live well with osteoarthritis and osteoporosis.

Spring 2005

Nanaimo, BC	April 21
Calgary, AB	May 3
Montreal, QC	May 10 (F)

Fall 2005

Halifax, NS	September 17
Coquitlam, BC	October 6

(F) = workshops conducted in French

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 health care 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.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, 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 health care 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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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 health care related questions or concerns, you should contact your physician. You never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.


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