

# JointHealth™ monthly

Arthritis research, education and advocacy news : May 2005

## Summit on Standards for Arthritis Prevention and Care Ottawa, November 1-3, 2005



### "ROCK THIS JOINT" 2005

Bringing together arthritis knowledge and action

#### **This issue of JointHealth™ monthly**

highlights the upcoming Summit on Standards for Arthritis Prevention and Care, November 1-3, 2005. We not only explain what the Summit is about but also talk about how you can get involved as a person living with arthritis or osteoporosis.

#### **Education**

- Summit on the Standards for Arthritis Prevention and Care, November 1-3, 2005
- Spring 2005 workshop update
- Fall workshop schedule

#### **Advocacy**

- Have your voice heard at the Summit

#### **Feedback**

- Listening to You
- Update your email or postal address

#### **Arthritis Consumer Experts (ACE)**

- Who we are
- Guiding principles and acknowledgement
- Disclaimer



#### **Arthritis Consumer Experts™**

910B Richards Street, Vancouver BC V6B 3C1  
t: 604.974.1366 f: 604.974.1377  
tf: 1.866.974.1366

e: [info@arthritisconsumerexperts.org](mailto:info@arthritisconsumerexperts.org)

[www.arthritisconsumerexperts.org](http://www.arthritisconsumerexperts.org)

© ACE Planning & Consulting Inc. 2004

**This year will be remembered as a significant milestone for Canadians with arthritis**, as decades of research and evidence are translated into a definitive plan of action.

This fall, the Summit on Standards for Arthritis Prevention and Care (SAPC) will bring together representatives from throughout Canada's arthritis community – including formal and informal care givers, health care providers, government (federal and provincial), arthritis researchers and clinicians, voluntary associations, the pharmaceutical industry, and people with arthritis – to develop definitive national standards for arthritis prevention and care.

The Summit will take place November 1-3, 2005, at the Chateau Laurier in Ottawa.

Approximately 250 participants will take part, bringing together the collective knowledge and commitment of the arthritis community, to consolidate thoughts and ideas and to move forward cohesively and effectively.

The overall objective of the Summit is to come up with concrete, clear and definitive recommendations for government – pragmatic, actionable, evidence-based standards for arthritis prevention and care.

A Planning Committee, made up of representatives from a wide cross-section of arthritis groups in Canada,

has been formed to develop the format, structure and content for the Summit, and to determine the Summit's participants. More than ever before, people with arthritis will be strongly represented, in planning, attending and promoting the Summit, and in helping to shape its recommendations.

SAPC will be the culmination of "Rock This Joint 2005 – Bringing Together Arthritis Knowledge and Action," an initiative that will see eight days of high-level arthritis meetings in Ottawa this fall. In addition to the Summit, "Rock This Joint" includes the Bone and Joint Decade World Network Conference (October 27-29) and the Canadian Arthritis Network's 5th Annual Scientific Conference (October 29-31).

"Rock This Joint" is an initiative of the Alliance for the Canadian Arthritis Program (ACAP). ACAP was formed two years ago, when the organizations working to help people with arthritis live better lives joined together. More than 30 organizations are involved, and while each group continues its own work, ACAP provides a central focus for all arthritis-related initiatives.

While "Rock This Joint" will culminate with the Summit, it will be no means end there. ACAP is committed to following through on the standards – continuing to work with government to ensure their implementation in the months and years ahead. ◀

## The "facts" about the Summit on Standards of Arthritis Prevention and Care

### Date:

November 1-3, 2005

### Location:

Ottawa (Chateau Laurier)

### Number of Summit Participants:

Approximately 250

### Representation:

A broad cross-section of groups and organizations that make up the arthritis community, including:

- people with arthritis
- formal and informal care givers
- health care providers
- government – federal and provincial
- arthritis researchers and clinicians
- voluntary associations
- pharmaceutical industry

### Purpose of the Summit:

Through consensus involving all stakeholders, set evidence-based national health system standards for arthritis prevention and care, to ensure optimal arthritis care for all Canadians.

### Summit Goals:

The Summit will bring together the broadest possible group of arthritis stakeholders to:

- review and present the evidence for care at all levels, including access, costs and quality of care;
- make evidence-based recommendations to federal, territorial and provincial governments;
- identify barriers to care and develop strategies to overcome them; and
- where evidence is inadequate, establish an agenda to drive development of additional standards, and to guide priorities in arthritis research in Canada.

### Summit Planners:

The Summit on Standards for Arthritis Prevention and Care is an initiative of the Alliance for the Canadian Arthritis Program (ACAP). ACAP was formed in 2003, when the organizations working to help people with arthritis live better lives joined together. More than 30 organizations are involved, and while each group continues its own work, ACAP provides a central focus for all arthritis-related initiatives.

## Have your voice heard at the Summit

To prepare for the Summit on Standards for Arthritis Prevention and Care, the Planning Committee identified nine priority standards for development. These fall into three themes: Prevention, management and models of care, and awareness.

Themes	Priority Standards Areas
PREVENTION	1. Physical activity 2. Injury Prevention
MANAGEMENT AND MODELS OF CARE	3. Access to a Diagnosis 4. Manpower and Models of Care 5. Access to Medications 6. Access to Surgery
AWARENESS (information, education, communication)	7. Participation 8. General Public and Arthritis Consumer 9. Health Professionals Education

Each standard developed at the Summit will consider the needs of different arthritis population groups across Canada.

To help Summit planners understand what is actually happening to people with arthritis and osteoporosis out in the community, ACE asks you to think about the priority standards outlined above and tell us your thoughts on the following:

- What do you want to know about preventing arthritis and osteoporosis;
- How long you waited to be referred to a rheumatologist or other medical specialist;
- What was your experience getting medical information about your disease once you were diagnosed;
- What challenges did you face getting access to the medication prescribed to you;
- How long you waited for joint surgery.

By sharing your personal experience, consumers and patients, health care providers and government who attend the Summit will be able to consider what happens in "real life" when developing standards for arthritis prevention and care.

To share your story, email to [info@arthritisconsumerexperts.org](mailto:info@arthritisconsumerexperts.org) and type in the subject bar "My thoughts about the Summit".

**Thank you for taking the time to have your voice heard at the Summit. <**

### Update your email or postal address

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

[info@arthritisconsumerexperts.org](mailto:info@arthritisconsumerexperts.org).

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

### 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](mailto:info@arthritisconsumerexperts.org).

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

# Spring 2005 Workshop Update

Thanks to your great participation, the ACE Spring 2005 Workshops have been a huge success.

Approximately 700 people with arthritis and their family members attended workshops. The workshops focused on rheumatoid arthritis, ankylosing spondylitis, osteoarthritis and osteoporosis and were held in the following cities:

- Saskatoon (SK)
- Burnaby (BC)
- Sherbrooke (QC)
- Nanaimo (BC)
- Calgary (BC)
- Lethbridge (AB)
- Abbotsford (BC)
- Montreal (QC)
- Kelowna (BC)
- Quebec City (QC)
- Edmonton (AB).

At the end of each workshop, a complete evaluation of the presenters, as well as the workshop content and venue was completed. We also asked participants to tell us in their own words what they most valued about the workshop, and invited them to offer suggestions on ways to improve future workshops.

Over ninety five percent of ACE participants said they “agreed” or “strongly agreed” that the workshop presentations and content were excellent. Even participants with arthritis for over 20 years said they learned something new. People with arthritis for just a short time appreciated the depth of information provided in the three-hour workshops. One hundred percent of workshop participants found the hour long question and answer session of highest value, and that this part of the workshop included the views and experiences of a fellow person with arthritis.

*“One hundred percent of workshop participants found the hour long question and answer session of highest value, and that this part of the workshop included the views and experiences of a fellow person with arthritis.”*

About ninety-five percent of participants rated both the medical and patient advocate speakers as “excellent”. In particular, you liked hearing about the non-medical aspects of living with arthritis from a fellow person living with the disease.

The areas that workshop participants said they wanted more information on include:

- Arthritis research
- Specific types of arthritis and osteoporosis “friendly” exercises
- Diet and nutrition
- Experimental treatments
- Complimentary and alternative treatments

As promised, ACE will provide more information on these topics in future workshops, as well as include articles on these in upcoming issues of JointHealth™ monthly.

We want to thank all Spring 2005 Workshop participants for providing us with their feedback. It is very important for ACE to hear what you think in order to provide you with the highest quality workshop program possible.

If you attended an ACE workshop this Spring and would like to give us additional feedback, please email us. Thank you, and we hope to see you at a future workshop. ◀

## Free Workshops : Fall Schedule



### Every Spring and Fall, ACE offers free workshops in communities across Canada.

These researched-based education workshops are conducted by leading rheumatologists (arthritis specialists) and patient advocates. The workshops are held at times which are convenient for people with commitments during the work week.

For further information or to register, please go to [www.arthritisconsumerexperts.org](http://www.arthritisconsumerexperts.org) or call 1-866-974-1366.

ACE does not endorse any companies or products.

### Plan to Win with Ankylosing Spondylitis (AS)

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

new

Register now at [www.arthritisconsumerexperts.org](http://www.arthritisconsumerexperts.org) or call 1.866.974.1366.

### JointHealth™

Halifax, NS	September 17
Coquitlam, BC	October 6

### Plan to Win with Rheumatoid Arthritis (RA)

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
Yellowknife	TBA

(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](http://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

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



### Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada, Arthritis Foundation, Arthritis Research Centre of Canada, AstraZeneca Canada Inc., GlaxoSmithKline, Merck Frosst Canada, Northwest Rheumatism Society, Pfizer Canada, Sanofi-Aventis, Schering Canada, Sto:lo Nation Health Services and the University of Alberta.

ACE thanks these private and public organizations.

### 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. <

  
Arthritis Consumer Experts™  
910B Richards Street, Vancouver BC V6B 3C1

