

Arthritis isn't a big deal until you get it.

This issue of JointHealthTM monthly highlights the report from the Summit on the Standards for Arthritis Prevention and Care. ACE is also pleased to announce the 2006 Free Educational Workshop Schedule.



Arthritis Consumer Expert's 2006 Free Research-based Education JointHealthTM Workshop Schedule



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Ask 4 million Canadians.

Four million Canadians have arthritis today. Arthritis knows no age limits. Children and adults of all ages get arthritis. Arthritis comprises over 100 different conditions and is the leading cause of deformity and long-term disability in Canada. It is one of the major reasons why people over 65 years of age visit their family physician. The burden of illness in the population due to arthritis is increasing due to increased longevity, reduced physical activity, increasing obesity and lack of access to timely health care to mitigate disability.

Arthritis is costly to society. The inability to work and/or live independently and lost opportunities have a devastating impact on the lives of four million Canadians. Strategies must be developed to reduce the burden due to arthritis in our population. Unless these strategies are developed immediately, it is anticipated that arthritis will place an even greater stress on the health care system over time and will continue to destroy lives.

Arthritis and MSK disorders are Canada's leading cause of physical disability, affecting millions of people and accounting for billions of dollars in direct and indirect costs. While the prevalence of arthritis in the Canadian population is quite high (16%), it is even higher among certain sub-populations such as off-reserve Aboriginal people (27%).

Across the country, Canadians with arthritis do not have consistent or equitable access

to the best evidence-based treatments available today. Where you live can be more important in determining treatment than how sick you are. Wait times for joint-replacement surgery are excessively long.

Alliance for the Canadian Arthritis Program

The report from the Summit on Standards for Arthritis Prevention and Care

November 1-2, 2005,
Ottawa, Ontario, Canada

To respond to these and other health-care issues, more than 30 stakeholder organizations came together to form the Alliance for the Canadian Arthritis Program (ACAP). The Summit on Standards for Arthritis Prevention and Care (Nov. 1-3, 2005) was the culmination of an eight-day campaign of high-level meetings in Ottawa by ACAP that sought to promote government action by transferring arthritis knowledge and expertise. The Summit Planning Committee brought together representatives from across the broad arthritis community, and for the first time in the history of national arthritis initiatives, the majority represented people living with arthritis. <

Turn to pages 2 and 3 to learn more about the Standards.

Education

Arthritis Consumer Expert's 2006 Free Research-based Education "JointHealth™" Workshop Schedule

Arthritis Consumer Experts is excited to tell you about its fifth annual research-based education workshop series.

In 2006, ACE will host 10 free workshops offering the latest research information on rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, osteoarthritis and osteoporosis.

As always, ACE workshops will be held in cities across Canada and co-led by a leading local rheumatologist and arthritis patient advocate. The focus of the JointHealth™ workshop series is to provide people with arthritis and their family members or friends the most up-to-date information available to help them "win" against or better manage their disease. They will provide research-based information and address participants' specific concerns and questions.

September 12	:	Halifax, NS
September 13	:	Fredericton, NB
September 14	:	St. John's, NL
September 19	:	Winnipeg, MB
September 20	:	Regina, SK
September 21	:	Edmonton, AB
September 21	:	Montreal (in French)
September 26	:	Ottawa, ON
September 28	:	Toronto, ON
October 4th	:	Victoria, BC

Please note all workshops will be held from 6-9pm to accommodate people who work during the day. Workshop venues will be announced in next issue of JointHealth™ monthly, and on ACE's website www.arthritisconsumerexperts.org



Pre-registration is required, but attendance and a detailed information package are FREE at all ACE workshops.

To register, visit ACE on the web at arthritisconsumerexperts.org or call us toll-free at 1-866-974-1366.

Advocacy

Standards for Arthritis Prevention and Care

The Summit generated consensus across the entire spectrum of the arthritis community: consensus on definitive standards that need to be implemented now. They are:

1. Every Canadian must be aware of arthritis.
2. Every Canadian with arthritis must have access to accurate information and education on arthritis that meets a defined set of criteria and are appropriate to their age and stage of disease.
3. Participation in social, leisure, education, community and work activities must be an integral measure used to evaluate outcomes by health professionals, educators, policy makers and researchers.
4. Every Canadian must be informed about the importance of achieving and maintaining a healthy body weight, and actively encouraged to engage in physical activity to prevent the onset and worsening of arthritis.
5. All relevant health professionals must be able to perform a valid, standardized, age appropriate musculoskeletal screening assessment.
6. Inflammatory arthritis must be identified and treated appropriately within four weeks of seeing a health-care professional.
7. Health-care professionals must recognize osteoarthritis as a significant health issue and treat it according to current treatment guidelines.
8. Bone mineral density testing must be offered free to all women > 65 years, all men and women with low-trauma fracture after age 40, and every Canadian of any age with risk factors for osteoporosis, according to current prevention and treatment guidelines.
9. Every Canadian with arthritis must have timely and equal access to appropriate medications.
10. Post-approval evaluation of arthritis medications must be part of drug approval.
11. Patient preferences, including risk-benefit trade-offs, must be incorporated into regulatory-decision making and prescribing of arthritis medications.
12. Every Canadian requiring joint surgery must wait no longer than six months from the time the decision to have surgery is made by the patient and physician. <

Priority standards for implementation

On January 24th 2006, the Steering Committee for the Alliance for the Canadian Arthritis Program met in Toronto to determine “next steps” for implementation of the standards. Each standard was reviewed and discussed with the respect to importance to people living with arthritis (i.e. potential to reduce the burden of arthritis in our population) and the feasibility of implementing the standard in Canada to make a discernible difference in their lives within one to two years.

Consideration was also made of the ongoing activities of each of the stakeholder arthritis organizations in terms of what was unlikely to happen without the collective energy of the entire arthritis community behind it.

Based on these day long discussions, the following three standards were identified as requiring our immediate attention.

1. Every Canadian must be aware of arthritis.

The ACAP, through its member organizations, will undertake a number of strategies to increase Canadians’ awareness

of arthritis. This will include a social marketing campaign directed to the Canadian public and the development and implementation of an “Arthritis 101” program directed at elected officials and government health policy makers.



2. All relevant health professionals must be able to perform a valid, standardized, age-appropriate musculoskeletal screening assessment.

The “Access to Diagnosis” Team will formally evaluate the reliability and validity of various arthritis screening tools in order to determine the optimal candidate tool or tools. Once the tool(s) is determined, key leaders within the arthritis community will liaise with medical and allied health professional schools to encourage training of relevant health professionals in performance of the screening assessment, and with the professional licensing bodies to encourage that evaluation of competency

in performance of the assessment is incorporated into the accreditation process. Continuing medical education strategies will be used to disseminate the tool(s) to relevant health providers in established practice. Links with the Canadian Medical Association to assist in this dissemination will be sought.

3. Every Canadian with arthritis must have timely and equal access to appropriate medication.

A sub-committee of ACAP will be established to examine the current situation in Canada with respect to access to medications currently recommended for the management of arthritis and osteoporosis. This sub-committee will also assess the scientific evidence to support the “life-saving” or “quality-of-life saving” effects of these medications. Once this information has been assembled, the sub-committee will make recommendations to ACAP regarding the next steps, including whether or not there is evidence to support the need for a federally funded drug plan for so-called life-saving medications for arthritis. <

Setting the research agenda for additional Standards for Arthritis Prevention and Care

Although there was an abundance of research available to confirm 12 definitive standards for arthritis prevention and care, several “provisional” standards were developed at the Summit with the recognition that additional research would be required to justify their implementation.

The three leading arthritis research funding organizations in Canada – the Institute of Musculoskeletal Health and Arthritis, the Canadian Arthritis Network, and The Arthritis Society will be looking at funding research into these and others in order to set definitive standards. “Provisional” standards identified at the Summit included:

- To prevent arthritis, every Canadian must understand and implement prevention strategies to reduce sport and recreation injuries.
- Every Canadian with arthritis must have timely access to appropriate integrated health care appropriate to their age and disease stage.
- Every Canadian with arthritis will be enabled to participate in life roles that are important to them.

Call to action

ACE encourages you to become a part of the “arthritis alliance” by writing a letter or email to your MLA/MPP and MP.

Please include a copy of the 2 page standards document; www.arthritisconsumerexperts.org/pdfs/ExecutiveE.pdf, by copying this link into your email. If you do not have internet access write or call ACE to get a print copy at: 1-866-974-1366.

Ask them to ensure that their government’s health care reform plan includes ways to implement these national arthritis standards.

MLA Finder/MP/MPP Finder

To find your Member of Parliament (MP) go to http://canada.gc.ca/directories/direct_e.html. This site provides you with both email and mail addresses for MPs. If you do not have internet access call:

1 800 O-Canada (1 800 622-6232)

To find your Member of the Legislative Assembly (MLA) or Member of the Provincial Parliament (MPP) go to your provincial government website and click on members and/or MLA or MPP finder. If you do not have internet access call the general number for your provincial government located in the government pages of your phone book.

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

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



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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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