

Arthritis and Aboriginal peoples

Arthritis is, in many ways, an equal-opportunity disease; anyone from babies to the elderly is at some risk of developing the disease. That said, specific groups of people are at higher risk of developing certain types of arthritis—women are more likely to develop rheumatoid arthritis, young men have a higher likelihood of developing ankylosing spondylitis, and the risk of developing osteoarthritis increases with age.

Aboriginal Canadians are affected by arthritis at a rate significantly higher than those in non-aboriginal populations in Canada. Nineteen percent of Aboriginal people living off-reserve report having arthritis, and the Aboriginal population in Canada has a relatively young average age; if the Aboriginal population had the same age composition as the overall Canadian population, this rate would be 27%.

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JointHealth Monthly is available in print and online in English and français.


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Though data are not available for First Nations people living on-reserve, research indicates that for those living off-reserve the prevalence of serious inflammatory arthritis is about 5%. This compares to 1% of the total population of Canada.

Along with being much more common, arthritis occurring in Aboriginal people is also more debilitating, and more likely to be life-threatening than arthritis in non-aboriginals. The most serious forms of arthritis—the inflammatory, autoimmune types of the disease like rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis—are far more prevalent in aboriginal communities. These painful and debilitating diseases, if left untreated, can often make it impossible for people to work and care for their families.

Significantly higher rates of arthritis, combined with poverty and other health concerns facing many Aboriginal Canadians, are cause for great concern for many aboriginal people with arthritis, their families and communities, and health professionals who work in Aboriginal communities.

These concerns are compounded by the fact that many Aboriginal Canadians cannot access



In this special Canadian election issue of JointHealthTM monthly, we bring you timely information about the growing crisis of arthritis in Aboriginal communities in Canada, the failure of the Non-Insured Health Benefits medication plan to meet the needs of Aboriginals with arthritis, and some ideas about how people with arthritis can take action during this election campaign.

Please visit the special federal election section of the ACE website at www.jointhealth.org for more information about arthritis issues in this campaign.

reimbursement coverage for the medications their specialists are prescribing for their arthritis, because the coverage provided by the federal Non-Insured Health Benefit (NIHB) plan is some of the most restrictive in Canada. For more information about the NIHB, see the article entitled "Non-Insured Health Benefits plan—a failing safety net" in this issue of JointHealthTM monthly. ☺



Canadian federal electi

An election presents an excellent

opportunity for the voice of arthritis to be heard. At this time, we must make the candidates seeking to represent us aware of the growing arthritis crisis in Canada. For far too long, arthritis has lived in the shadows—misunderstood by the public and ignored by government after government. It is time to change this, and a federal election is the perfect time to start.

During an election campaign, voters often have the opportunity to ask questions of the candidates standing for election in their riding. These opportunities may include:

* Debates: The leaders of the major parties debate one or more times during an election campaign. Sometimes the opportunity exists for citizens to submit questions about issues that are important to themselves and their communities.

* Radio phone-in shows: these provide an excellent opportunity to ask candidates questions about party policy or personal opinion.

* All Candidates Meetings: in most ridings, these meetings are held at least once, and often more, to give members of the public the opportunity to see their candidates in person. All Candidates Meetings are presented in a question-and-answer format, and people attending are almost always encouraged to ask questions.

* Telephone calls from the campaign office or door-to-door visits: One of the primary components of most election campaigns is called “voter contact”. In most ridings, the campaigns will be organizing phone calls and/or visits to voters. When you are called or visited, it is important to ask questions about arthritis. Often, specific questions asked will be logged by the canvasser and forwarded to the candidate or campaign manager.

* Walking in to the campaign office: Campaigns set up offices in part to allow people to walk in and communicate with campaign staff and/or the candidate directly. Simply walk in during campaign office hours and ask to speak with someone about policy. Bring along your list of questions in print form, including your name and contact information, to leave behind in case no one is available.

Non-Insured Health Benefits plan —a failing safety net

The Non-Insured Health Benefits (NIHB) plan is a supplemental health benefits plan that was created to ensure that the health of First Nations and Inuit Canadians is up to the same standard as non-Aboriginal Canadians. To that end, the NIHB is supposed to provide coverage for necessary medication treatments when they are not covered by the province.

Research clearly shows that biologic response modifiers, used in combination with other medications, are the gold standard in treatment for moderate to severe inflammatory arthritis. First Nations and Inuit people covered under the NIHB do not have reimbursement access to the full range of biologic response modifiers, or have to fail more medications prior to accessing them compared to people with other drug coverage plans. This can result in delayed treatment, joint damage, and

irreversible joint damage causing permanent disability.

For First Nations and Inuit people with rheumatoid arthritis, the NIHB dictates which biologic response modifier a person is first able to obtain coverage for, rather than allowing the physician and patient to choose the best of the five available based on the patient’s disease, ability to self-administer the medication, cultural beliefs, and other considerations.

The situation is more dire still for those living with other forms of inflammatory arthritis. For example, Aboriginal NIHB clients living with ankylosing spondylitis and psoriatic arthritis are left totally in the cold. Contrary to the advice of the federal/provincial/territorial Common Drug Review, the NIHB has neglected to place any of the three biologics approved for use in these indications on the list for reimbursement at all.

What is happening to Aboriginal Canadians with arthritis is a tragedy that must be addressed immediately. It is the right of every Canadian, regardless of their culture or place of residence, to access our universal public healthcare system. To read the ACE background document on the NIHB, please visit the special election section of www.jointhehealth.org.

As part of our work involving the current Canadian federal election campaign, ACE is asking the major parties about their opinions and priorities as they relate to the NIHB. You can visit our website to view the questionnaire and results as we receive them. Following the federal election, ACE will be working hard to educate the newly-minted MPs about all arthritis issues, and especially the failure of the NIHB to meet its mandate where arthritis medications are concerned. ☞

on 2008

Whenever possible, it is vitally important that people who care about arthritis issues take this campaign period to ask questions about arthritis and to express a strong interest in health care issues. If candidates understand that people with arthritis are watching to see which politicians care about their issues, change will begin to occur at the government level.

It is important to frame your questions with a small amount of information at the beginning, so that candidates have some background on the issue. Arthritis Consumer Experts has prepared a list of question that people with arthritis may wish to ask candidates running for election. You may wish to have a copy of JointHealth™ monthly on hand when you meet with candidates, at an All Candidates meeting or forum, or at their office.

Some examples of questions you can ask candidates, or their authorized representatives:

* Currently, the cost of arthritis and related musculoskeletal diseases in Canada is estimated at \$16.4 billion each year, the second highest cost after heart disease, with long term disability accounting for almost 80% of the economic cost of arthritis.

? **What measures will your government establish to address the detrimental impacts of arthritis and related conditions?**

* Despite the enormous impact on the economy and society, arthritis receives much less research funding than other diseases, with only \$0.94 for every person living with arthritis compared to \$731 for every person living with HIV and \$4.98 for every person living with diabetes.

? **What will your government do to address this discrepancy in research funding?**

* While there is no known cure for arthritis, excellent treatments exist. Unfortunately, many Canadians are unable to access these medications, due to prohibitive cost and a wide disparity between publically funded medication plans.

? **How will your government ensure that evidence-based treatments are made available to all Canadians regardless of province of residence or ability to pay?**

* In HIV/AIDS and cancer, national and provincial centres of excellence have shown to significantly improve the care and treatment of patients while at the same time reducing the burden of disease on the health system and communities and serving as a driving force internationally in groundbreaking research.

? **Would your government support the creation of a national centre of excellence for the prevention and treatment of arthritis?**

* Aboriginal Canadians have much higher rates of inflammatory arthritis (19%), and the arthritis they face is more debilitating and more likely to be life-threatening than arthritis in non-aboriginals.

? **What measures would you take to improve the lives of Aboriginal Canadians with arthritis?**

? **How would you ensure that Aboriginal Canadians are able to access a timely diagnosis and appropriate treatment?**

* Despite the high rates of inflammatory arthritis, First Nations and Inuit people covered under the Non-Insured Health Benefit plan (NIHB) have some of the worst, most restrictive reimbursement coverage for medications in the country.

? **What would your government do to ensure that First Nation and Inuit Canadians have care equal to that received by non-Aboriginal Canadians?**

? **How would you go about reforming the NIHB to ensure that First Nation and Inuit Canadians have care equal to that received by non-Aboriginal Canadians?**

? **What is your personal opinion about the medication coverage provided by the NIHB drug benefits plan for First Nation and Inuit Canadians?**

* Aboriginal Canadians dependent on the NIHB drug reimbursement plan who live with psoriatic arthritis and ankylosing spondylitis have no coverage at all for biologic response modifiers, the gold standard treatment medications for inflammatory arthritis.

? **What steps will you take to reform the NIHB to ensure that First Nation and Inuit peoples with these types of arthritis will have the same health care coverage as other Canadians?**

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.jointhehealth.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 / Wyeth Pharmaceuticals, Bristol-Myers Squibb Canada, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck Frosst Canada, Pfizer Canada, Schering-Plough Canada, and UCB Pharma Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada. ACE thanks these private and public organizations and individuals.

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 should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter. ☞


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