

This issue of JointHealth™ monthly is dedicated to rheumatoid arthritis (RA) and aboriginal people in Canada. This issue includes an article from an aboriginal person and her experiences with RA.

The topics covered in this issue of JointHealth™ monthly are:

#### Education

- Rheumatoid arthritis and the aboriginal population – what the research says
- Rheumatoid arthritis and unmet needs for aboriginal people
- ACE 2006 workshop schedule

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- Call to action: a voice from the Summit, November 2005
- I am a First Nation Canadian and have lived with rheumatoid arthritis since I was 33 years old
- Update your email or postal address

#### Arthritis Consumer Experts (ACE)

- Who we are
- Guiding principles and acknowledgement



#### JointHealth™ Workshop Schedule on page 2

Ace is pleased to offer this issue on-line, both in English and français. You can also download a PDF printable version, both in English and French.

  
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## Listening to you

### Call to action:

a voice from the Summit, November 2005

#### We can and we must change this NOW!

I am a second generation First Nation Canadian living with severe rheumatoid arthritis since I was 33 years old. My family, including 4 siblings, my mother and an uncle all have known firsthand how severe, debilitating and mind numbing the pain of arthritis can be.

Poor living conditions, lack of education, contribute to the 27% of all Canadian aboriginal people having to live with arthritis. Timely access to awareness, education, treatment and information to this forgotten segment of Canadians living with arthritis must be addressed now.

I am honoured to be a voice for those, who do not know they have one. Pain is pain, for all aboriginal people living with arthritis, no matter where they live in our country.

#### We can and we must change this NOW.

Joyce Greene  
Speaker at the Summit for Standards for  
Arthritis Prevention and Care, November 2005  
Aboriginal Rep for  
The Consumer Advisory Council  
of the Canadian Arthritis Network

I am Joyce Greene and I live with severe rheumatoid arthritis everyday. Some days are better than others and I celebrate those days and appreciate them and say, "Today is a good day!" I am a mother, wife, friend, volunteer as well as a person living with rheumatoid arthritis (RA).

Rheumatoid arthritis affected me and my family in a big way. I woke one morning over 15 years ago unable to move my body. My joints were so swollen all over my body I walked into the doctor's office much like the Tin man from the Wizard of Oz, when

he needed oil for his joints. The doctor gave me 9 non-steroidal anti-inflammatory pills (NSAIDs) and told that would be enough until I saw a rheumatologist. It was two months until I was able to get into see the rheumatologist so the nine pills did not help much.

My body was so swollen my rheumatologist later referred to me like a giant marshmallow. It took three visits to even find the bones in my feet due to the inflammation. I was treated with prednisone right away but it

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## Listening to you

Call to action: *continued*

took years to get my disease under control.

Before I was diagnosed and during the beginning of my disease I didn't know much, if anything, about RA or what to do about. I didn't know to take the NSAIDs regularly not just when my pain was unbearable. I also didn't know to go back and get a prescription for more NSAIDs when the wait to get into see a rheumatologist was longer than expected.

My disease was out of control for about five years. During that time not only was each movement painful and tiring and simple tasks seemed almost impossible with or without help, the joints in my hands and feet were

*"My disease was out of control for about five years."*

permanently disfigured. I tried many of the traditional arthritis prescription medications but nothing worked for long until 1999.

Five years after I was diagnosed I was fortunate to be apart of a study using adalimumab (Humira®) in combination with methotrexate. Humira® is a biologic response modifier that is used to treat rheumatoid arthritis. This treatment gave me my life back. The day after just the first injection I was able to get up and dressed and get my son ready for school. To this point I could not do any of this without help from my homecare worker. It was such an elating feeling to be able to do something all by myself and for my son. Dependency is not a nice feeling.

Two of the major problems with getting

RA was not recognizing the symptoms in the beginning as something more than 'normal' stiffness and seeing a rheumatologist right away. The research suggests that getting diagnosed and treated within the first three months of symptoms showing up makes a huge difference in decreasing joint damage and deformity. I know this now but I did not know this when my symptoms began.

I have learned a great deal from my experience with RA. I grew up in foster care from the age of 6 months and did not meet my birth family until six years ago. My arthritis had damaged my neck and I needed surgery that if not successful could cause paralysis or death. This prompted me to seek out my roots. I found out my entire birth family has RA and/or osteoarthritis (OA). I may have never met them if I didn't have arthritis and for that I'm grateful.

I am now an advocate for aboriginal people with arthritis where more people get RA than in the non-aboriginal community, 27% to 16%. The disease also is more aggressive for aboriginal people. Educating people to know what arthritis is and how to recognize early symptoms and knowing what to do next are the important issues for all Canadians. Access to a doctor, especially a rheumatologist, is difficult in the major cities, let alone in the more remote areas and for on-reserve aboriginals.

Today, I try to live in the moment. I know first hand how isolating and painful arthritis is. If I am able to convince one person to get early treatment from a doctor and not have to go through what I did, then it's worth it.

Joyce Greene

## Education

### Rheumatoid arthritis and unmet needs for aboriginal people

**There is a lack of research** looking at arthritis and aboriginal health, especially for on-reserve aboriginals. About 29% of aboriginals live on-reserve in Canada. Of those, who live off-reserve, 49% live in rural areas. Access to rheumatologists is difficult in large urban cities across Canada and this difficulty increases in smaller urban areas and rural areas. There are less than 300 rheumatologists practicing full-time in Canada to help over 300,000 Canadians with rheumatoid arthritis.

Education around arthritis and access to treatment and care is important for all Canadians whether living in urban or remote areas. Arthritis such as rheumatoid arthritis is hereditary and being able to recognize symptoms and what to do about it is important for optimal health outcomes. If one family member has rheumatoid arthritis, the other family members are 3-4 times more likely to develop rheumatoid arthritis. Failure to diagnose rheumatoid arthritis early can lead damage that could have been prevented and perhaps premature death.

More research is needed around arthritis and aboriginal health in Canada. With one-third of the aboriginal population under the age of 15, this is the fastest growing population group in Canada. The majority of aboriginals live in remote areas making access to diagnosis and treatment in a timely manner difficult, if not impossible. Recognizing early symptoms of rheumatoid arthritis is important and education can help, especially in the remote and on-reserve areas where aboriginals reside. <

## 2006 FREE Research-based Education JointHealth™ Workshop Schedule



Pre-registration is required, but attendance and a detailed information package are FREE at all ACE workshops. All workshops will be held from 6-9pm.

**For more information and registration visit ACE at:**  
[arthritisconsumerexperts.org](http://arthritisconsumerexperts.org)  
or call us at 1-866-974-1366.

- September 12** : **Halifax, NS.** Halifax Radisson, 1649 Hollis St.
- September 13** : **Fredericton, NB.** Delta Fredericton, 225 Woodstock Rd.
- September 14** : **Montreal (in French).** Best Western Ville Marie, 3407 rue Peel.
- September 14** : **St. John's, NL.** Fairmont Newfoundland, 115 Cavendish Square.
- September 19** : **Winnipeg, MB.** Radisson Winnipeg Downtown, 288 Portage Ave.
- September 20** : **Regina, SK.** Delta Regina, 1919 Saskatchewan Dr.
- September 21** : **Edmonton, AB.** Westin Edmonton, 10135 100th St.
- September 26** : **Ottawa, ON.** Cartier Place, 180 Cooper St.
- September 27** : **Toronto, ON.** Best Western Primrose, 111 Carlton St.
- October 3** : **Victoria, BC.** Empress Hotel, 721 Government Street, Victoria.

# Rheumatoid arthritis and aboriginal people – what the research says

**Rheumatoid arthritis affects about 1% of the Canadian population or 1 out of every 100 people. This increases to 5% for aboriginal Canadians. This population not only is at greater risk for getting RA but the disease is more severe than with other populations. For aboriginal people rheumatoid arthritis is one of the top five chronic diseases reported. More Canadian women get RA than men (3:1), however, this figure almost doubles for aboriginal women.**

*“More Canadian women get RA than men (3:1), however, this figure almost doubles for aboriginal women.”*

The following information is from two studies. The first one was conducted by Health Canada in 2001. It compares arthritis among non-aboriginal people and off-reserve aboriginal people. This was a cross-sectional study so looked at various age groups at one point in time. The second study was conducted by the National Aboriginal Health Organization (NAHO) 2002, by First Nations people for First Nations people. This study is a longitudinal study that looks at the same group of people over time, in this case, every four years. This type of study shows changes over time as the results can be compared to the previous study.

According to the Health Canada study using 2001 Census data, 3% of the Canadian population is made up of aboriginal people. Approximately one-third of the aboriginal population is under the age of 15 years making them a much younger and growing group. The over 65 age is about 4%. Approximately 29% of aboriginals live on reserve and were not included in this study. Of the remainder, slightly more than half lived in urban areas and the rest in rural areas in Canada. There are an unusually high proportion of aboriginal people living in non-urban areas of Canada compared to non-aboriginals making access to health care a barrier for those living with chronic diseases like arthritis.

In the study aboriginal people reported arthritis as the most common chronic disease. Like in the non-aboriginal population arthritis increased with age and more females reported having arthritis than males. The study also reported that aboriginal people with arthritis experienced higher rates of disability than non-aboriginal people with arthritis. But like in non-aboriginals, arthritis affected their quality of life in all aspects, from home and work life to leisure activities. The study did not conclude why disability among aboriginals with arthritis was reported at a higher rate but suggested that it was perhaps because there is a higher rate of inflammatory arthritis such as rheumatoid arthritis and ankylosing spondylitis in aboriginal populations compared to non-aboriginal populations.

A second study conducted by the National Aboriginal Health Organization (NAHO) 2002, by First Nations people for First Nations people, showed similar results to the 2001 study by Health Canada. There were approximately 22,000 participants making up 238 communities, both on-reserve and off-reserve First Nations people across Canada.

The following highlights some of the results of the study:

- arthritis is one of the five top conditions to affect the First Nations population
- more than half (52%) of First Nations adults with disabilities reported having arthritis compared to 14.6% without disabilities
- 25.3% of First Nations adults have arthritis compared to 19.1% of the general Canadian population
- there is a higher rate of arthritis among First Nations women compared to other women in Canada, except for women over 60 years of age. The following chart shows the range of difference between these two groups with more than double the First Nations women with arthritis compared to other Canadian women up to age 39 years.

Age	First Nations Women	Other Canadian Women
Under 30	6.4%	2.5%
30–39 years	16.2%	7.6%
40–49 years	24.7%	15.8%
50–59 years	43.3%	32.9%
60 + years	54.1%	51.6%

Arthritis is the number one reported chronic disease in Canada and the biggest burden on the Canadian healthcare system, however, less than 1% of the federal health research budget goes towards arthritis research. This is an important issue for all Canadians, but particularly for aboriginals for the reasons outlined in this article. It is vitally important that government, arthritis researchers and arthritis education groups partner with the aboriginal community around arthritis issues to increase awareness, education and access to treatment and care for their community. <

## 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.

## 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.

## 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™.



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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. ◀

  
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