My name is Joyce Greene, and I am a second-generation First Nation Lax Kw’alaams mother, living with severe rheumatoid arthritis (RA). My birth mother, uncle, two sisters, and two brothers all have lived with either RA or osteoarthritis (OA). I was diagnosed in 1993; all my joints, from my jaw to my toes, are affected.

To offer some background information, Lax-Kw’alaams (alternately known as Port Simpson) is an Indigenous village community on the northwestern coast of British Columbia. Lax-Kw’alaams is home to the Nine Tribes, which make up part of the Tsimshian nation. Our land is known as “place of the wild roses”; it was in Port Simpson that the Hudson’s Bay Company established a trading post in 1834. Historically, this was the first Aboriginal community in British Columbia to officially revert its English name back to its Aboriginal one, from Port Simpson to Lax Kw’alaams. Today, Lax Kw’alaams is the largest of the seven Tsimshian village communities in Canada, with a population of 3,219 members in 2009. The Allied Tsimshian Tribes Association represents the legal and political interests of the people of the Lax Kw’alaams to the provincial and federal governments.1,2

I am an Emeritus Member of The Consumer Advisory Council of the Canadian Arthritis Network (CAN), and acted as the Aboriginal Representative between 2004 and 2008.3 We recognized that arthritis research was greatly needed within the Aboriginal community. Collaborating with consumers, researchers across Canada and internationally, together we have started to identify the ongoing issues, and assess the needs of the Aboriginal arthritis community through research.

I was an Arthritis Consumer Advocate, Manitoba/Nunavut Division, for The Arthritis Society (TAS) between 1994 and 2005.4 I am also a retired member of Patient Partners in Arthritis, where I served from 1998 to 2008. This hands-on program demonstrated a standardized musculoskeletal exam to a variety of medical students and healthcare professionals, and showed first-hand the difficulties of living with RA. Presently, I am a member of numerous advisory boards, and participate in on-going arthritis research projects.5

Health in Aboriginal People

According to the 2006 Aboriginal Peoples Survey (APS),6 the most commonly reported chronic health conditions among Métis aged 15 years and older were arthritis/rheumatism (21%), followed by high blood pressure (16%) and asthma (14%).

- Arthritis is one of the most prevalent chronic diseases in all three Aboriginal populations: First Nations, both on- and off-reserve (19% and 18% respectively), Inuit (15%), and Métis (21%).
- The arthritis prevalence estimate for First Nations adults living on-reserve, First Nations adults living off-reserve, and Métis adults was 1.3 to 1.6 times higher than the national estimate for arthritis in the Canadian adult population, after adjusting for differences in the age distribution in these populations.
- The prevalence estimate of arthritis/rheumatism in the Inuit population was similar to the total Canadian population, after age standardization.
- In all three Aboriginal populations, the prevalence of arthritis was higher among women compared to men.
- Close to two-thirds of First Nations individuals living on- and off-reserve who reported arthritis were between 30 to 59 years of age (64% and 61%, respectively).

Improving RA Care for Aboriginal Peoples

RA runs rampant both on- and off-reserve. Research has shown that detecting arthritis as early as possible will impact the whole disease process and the costs involved.7-11 Access to the full range of RA treatments on public formularies is sub-standard compared to that of non-First Nations people.

What training incentives are there for First Nations physicians and allied health professionals to better deal
with early detection, diagnosis, and treatment? Existing research literature describes how moderate-to-severe RA needs to be diagnosed, and treatment initiated, within six weeks or almost certain permanent damage will be done to the joints and their supporting structures.

Musculoskeletal disease is the disease category with the highest cost due to illness, with particularly high indirect costs to society. Within this category, arthritis accounts for 53% of the direct costs and 29% of the indirect costs. The Canadian Institutes of Health Research (CIHR) spent $19 million on arthritis-related research in 2005-2006, representing $4.30 for every person with arthritis. By comparison, diabetes research received three times as much funding (or about $12.85 per person), while cancer research received 52 times as much funding (or about $138.60 per person). Although it is difficult to directly compare the burden and costs of diverse diseases, these findings warrant greater attention in funding and policy decisions.

Training nurses, nurse practitioners, occupational and physical therapists, as well as providing financial incentives for First Nations medical students to return to their villages to support and educate the nursing staff and community members would be a huge boon to the people. Educational awareness programs need to be created by the communities from the ground up, not the top down, to be able to utilize the communities’ first-hand knowledge, and develop better understanding about their unmet needs and requirements.

A National Aboriginal Arthritis Strategy needs to be implemented, using a multi-pronged approach from the communities across our country; efforts towards integrating awareness, education, and research, starting at the school level, can lead to knowledge transfer and exchange.

Healthcare, Personified

I am an urban aboriginal mother, and thus extremely fortunate to have access to my healthcare team, and support for my ever-changing needs met with usually only a phone call. I have always believed that educating my family and myself, creating awareness about the first-hand effects of arthritis, would bring real change.

Over the past 20 years, I have experienced treatments through ongoing blood work, physiotherapy, and occupational therapy appointments. There have been numerous splints to support the swelling and inflammation of various joints, including ACL braces for my knees. I wore a brace on my neck for four months after my C1-2 surgery, without which I would have been paralyzed within six weeks. These issues are all due to the severity of my arthritis. As a result of my arthritic condition, I have:

- Had countless CT scans, X-rays, and MRI scans.
- Had home-care on a daily basis for six months prior to starting on a biologic agent study in 1999.
- Participated in that life-altering treatment-agent study for eight years, before treatment became ineffective.
- Been on my second biologic for the past four-and-a-half years.
- Been on ever-changing combination disease-modifying anti-rheumatic drug (DMARD) therapy over the past 20 years.
- Been hospitalized on numerous occasions, including having both hips replaced.

Prior to the treatment agent-study, my RA was completely out of control; I was unable to function without home-care, use of a wheelchair, and my family’s support and assistance. I will be having both my knees replaced simultaneously, in the summer of 2013.

My birth-mother was one of the first Aboriginal women in British Columbia to participate in a study in the 1960s involving methotrexate. She was incredibly proud to make a difference and help others. I have personally benefitted from using methotrexate in my combination therapy for almost 20 years. It is because of women like my birth-mother that real change happens. Even so many years later, there is no standardized holistic model of care to help First Nations peoples understand, accept and deal with their arthritis diagnosis. We can work together to change this.

Supporting Aboriginals with arthritis needs to become front and center of the discussion about healthcare.

Thank you.

Resources and Recommended Readings:
1. Lax Kw’alaams Band: First Nation Community of Lax Kw’alaams. www.laxkwalaams.ca
2. Lax Kw’alaams, British Columbia. en.wikipedia.org/wiki/Lax_Kw’alaams_British_Columbia
catno=89-637-X&chroppg=1&lang=eng
10. Arthritis Alliance of Canada. www.arthritisalliance.ca
12. Canadian Arthritis Funding Landscape Review. www.arthritisnetwork.ca/about_can/downloads/Arthritis%20Funding%20Analysis%20Final.pdf

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