

I am Métis and I have Lyme disease. Before I was finally diagnosed with this disease I had not known anything about it. I did not know that it existed, let alone what it was, how one would contract it, what the symptoms were or how to treat it. I wanted to know if others were more aware. I decided to research the awareness and impact of Lyme disease within First Nations communities. I wanted to know if the government is adequately warning people who are deemed at higher risk of the dangers of contracting Lyme, what the symptoms were and how to receive proper treatment.

Even before researching this project, I knew that Lyme is a highly controversial and politicized issue. There are issues with the guidelines in which the government uses in order to evaluate the Lyme patients; however there are concerns about the method of testing, specifically the ELISA and Western Blot test. They are known to be very unreliable. The government uses the guidelines which were created from the Infectious Disease of America, not only are these guidelines greatly debated, the creators of those guidelines are being currently being investigated. Daniel J Cameron MD (current International Lyme and Associated Diseases Society President) stated at the LDA and ILADS 2008 conference, “the CDC acknowledges that reported cases may represent less than 10% of the true incidence” (<http://www.canlyme.com>). The controversy continues about how one can actually contract the infection. Some believe, including Dr. Murakami, that it is “spread by birds, rodents and primarily Deer Ticks” and possibly can be carried “by mosquitoes, fleas and other biting insects” (<http://www.drerniemurakami>).

I had begun my research with an appointment with Jenna LaFrance at the First Nations Student Centre (LaFrance, 2008). Although she had heard of Lyme disease she was aware of the risks, symptoms or treatment. She was very helpful in suggesting many websites; I found the

most useful site to be the Health Canada. If you selected the First Nations, Inuit, and Aboriginal Health link, you would find the *Animals and Your Health* poster and the *June 2007 Animals and Your Health Calendar* (<http://www.hc-sc.gc.ca>). I used both of those in my presentation. On one hand the government is admitting that those within these communities are at greater risk, hence the warnings, yet at the same time they are repeatedly stating that Lyme is not a concern within Canada.

I wanted to point out some of the inconsistencies, omissions and lies that I believed have been fed to the unsuspecting public as the “truth”. It makes no sense to me how the government and the medical community can post warnings that are directly aimed at a specific group of people they believe at higher risk (First Nations), than the general public yet the this information is not readily available. This topic is so vast I have barely scratched the surface.

First Nations people have historically and repeatedly been lied to (at a minimum) by the government. This is yet one more example where this continues to happen to this day. I was able to discuss the awareness and impact on First Nations communities with a Métis woman through the internet. She was finally diagnosed with Lyme disease after a 10 year battle with doctors, in which she came away with several different diagnosis's, such as Fibromyalgia, Chronic Fatigue Syndrome, Rheumatoid Arthritis, Lupus, and M.S (name withheld, 2008). This woman felt so stigmatized and was so afraid of repercussions if she came out publicly that she requested that I withhold her real name. Sadly, this is not a rarity but rather the norm. Patients have a legitimate fear about saying they have Lyme disease. A doctor will most likely tell you that Lyme is so rare that you wouldn't have contracted it. They also say that wherever you are from is not known to have Lyme. And quite honestly, they do not even know what symptoms they should be looking for, other than the greatly contested bull's eye rash.

Lyme disease has been a hotly contested issue between Lyme literate physicians, Lyme groups and the Canadian government, specifically the British Columbia Centre of Disease Control (CDC) which is under the umbrella of Public Health Agency of Canada. The following was taken from the CDC website, “Most tick bites will not result in illness, but a small fraction of ticks in the province carry bacteria that cause disease,” explains Dr. Murray Fyfe . Yet within this same advisory “The bacteria that causes Lyme disease has been found in western black-legged ticks (*Ixodes pacificus*) in many regions of the province including Vancouver Island, the Lower Mainland, the Sunshine Coast, the Fraser Valley and the Kootenays,” notes Dr. Muhammad Morshed (<http://www.bccdc.org>). Even with this advisory the CDC believes that most tick bites will *not* result in contracting Lyme but they continue by saying that Lyme has been found in *many* regions of the province. One again CDC contradicts their own information. They are admitting that the specific ticks which are well documented to carry the borrelia spirochete are found in many places within the province. According to Dr. Murakami’s website, the CDC is only reporting 4-6 people on average which has contracted Lyme per province (<http://www.drerniemurakami.com>). Along this same thinking, the United States are reporting thousands of cases right up to the Canadian border, as Dr. Murakami states “An explanation is in order” (<http://www.drerniemurakami.com>).

According to the Métis woman I was able to interview via email, she believes that a skin condition caused by borreliosis is showing up in reservations, on forestry workers, and even people which lead an outdoor lifestyle. It presents as “loose dark weather beaten skin on hands and feet, sudden arthritis that tends to come and go in intensity, and incredible fatigue”. She continues by stating that she has known many First Nations people that have had this condition “so bad they have lost fingers and toes”. This is a late stage only symptom of Lyme. It has been

recognized since 1883 in other countries but not once has Canada acknowledged its existence. She also believed that there are striking similarities between known Lyme symptoms and other health issues facing First Nations communities. For example: “Mental fog and irrational behavior, including violence. Exaggerated response to alcohol. Fatigue and all other unwellness in general, unusually high diabetes rate and an unusually high rate of arthritis”. She concluded our interview by stating “Imagine solving the education, social and other problems on reserves with a huge bottle of antibiotics” (name withheld, 2008).

My next interview was with the recently retired Dr. Ernie Murakami. He is the Lyme patient's greatest advocate within not only British Columbia but all of Canada. This opinion is shared by many within the Lyme community. I was previously his patient (he diagnosed me with Lyme in August of 2007, after a 20 years battle to find answers) and I was able to contact him through the telephone. We had discussed why he had retired and he claims it was because of the continued and escalating pressure from the BC College of Physicians and Surgeons. With his own health rapidly declining, he finally relented and retired, this devastated the Lyme patients worldwide. Our discussion then turned specifically towards Lyme and First Nations. His main practice was located in Hope, BC. He had many in several First Nations communities as his patients. He had noticed a higher amount of Lyme cases within those communities than the general public. He felt it was due to their exposure to the outdoors, specifically where deer ticks are known to be. Dr. Murakami believes many, many more First Nations have Lyme disease and simply have not been properly diagnosed yet. Not only does he believe the government fails to educate the public about Lyme, he feels there have been even less of an effort to inform the First Nations communities about their elevated risk, the symptoms, also how, when, and where to receive treatment (Murakami, 2008).

Dr. Murakami is a strong advocate for long term antibiotic therapy and if the case is severe enough, he will recommend IV antibiotic therapy. Although this method has met with resistance, criticism and outright opposition, there is scientific evidence available to support his position. The *Prolonged Lyme Disease Treatment: Enough is Enough* article by Patricia Ricks “confirms the experience of every patient with long-term Lyme disease in every patient advocacy group in the United States that antibiotic treatment relieves symptoms, discontinuation of it leads to their return, and that more research is needed to find a permanent solution to this disease. Dr. Halperin and others should concentrate on ascertaining the maintenance level of antibiotics that could allow patients to function normally.” (Ricks, 2008).

Through this project I have learned several things. One, there is an enormous **lack** of research in regards to First Nations and Lyme disease in any area. There needs to be research funding made available for people to actually conduct the research. I think there will be a much higher rate of positive Lyme cases within those communities than with the general population. I also believe that many of the health issues facing the First Nations people will be connected with Lyme disease and co-infections. Once we have the data we can then move towards healing people, families, and communities. I have also learned that there needs to be accountability for the government to accept, recognize, diagnose, treat, prevent and research Lyme disease. And lastly that the First Nations people need to better understand their health issues in order to better treat and hopefully cure them. There needs to be much more accessibility to the research that is available and that much more research must be conducted. I simply can not stress that point enough, research is the only way to have a chance to conquer this horrific illness.

## References

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