



Canadian Lyme Disease Foundation

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Canadian Lyme Disease Foundation withdraws endorsement of the Complex Chronic Disease Program at the BC Women's Hospital.

The Canadian Lyme Disease Foundation (CanLyme) today announced it is withdrawing its support for the BC Complex Chronic Disease Clinic. The Clinic was initially proposed to address inadequate diagnostics and treatment for Lyme disease patients.

"After much consideration, CanLyme is regretfully withdrawing from the advisory committee and removing its endorsement of the clinic's operations," said CanLyme President Jim Wilson.

"The provincial government promised to create a clinic that would provide better treatment for neglected chronic Lyme disease patients; people who couldn't get adequate treatment in BC; but, sadly, that mandate has not been met.

In spring 2011, immediately after an internal government report was made public, the BC government mandated a provincial clinic to address gaps in diagnosis and treatment of people with acute and chronic Lyme disease. The report revealed that the BC Lyme test was inadequate and that people with chronic Lyme were being refused treatment.

"CanLyme was recently shocked to hear from Lyme Disease patients that the Clinic would be restricted to the same inadequate guidelines that prompted the establishment of the Clinic in the first place," said Wilson. CanLyme is a Canada-wide research foundation dedicated to fostering better diagnostic tools and higher treatment standards for patients. What is to be offered at the Clinic is exercise pacing, mindful meditation, and cognitive behavioral therapy, none of which has been shown to be effective in treating chronic Lyme Disease. Patients have been waiting for over 20 years for science that never seems to come and they are now being told to wait for the science again even though animal model research supports treating with antibiotics now, not at some distant point in the future.'

"If we'd been informed at the outset that the Clinic was limited to the wholly inadequate status quo on treatment, we'd never have gone near it, let alone endorsed it," he said. "The purpose of the Clinic as outlined by the BC government was to provide improved treatment for Lyme Disease patients, which is why CanLyme endorsed and participated in the establishment of the Clinic."

"Regretfully, I now have to warn chronic Lyme patients not to expect treatment that addresses established infection at the Clinic and that they may be put in harm's way by further delaying appropriate treatment," said Wilson.

The BC government framed the clinic as a vehicle for gaining made-in-BC experience with better diagnostic and treatment protocols. Then-health minister M. de Jong acknowledged that "Lyme disease is a debilitating chronic ailment" and that "a differing set of best practices" would only occur by means of "studies like the one that is taking place in B.C." There are no such studies underway that will result in proper treatment and funding for proper research is not available.

The Clinic was intended to “provide a model of assessment and high standard of care” to chronic Lyme sufferers who are typically left to suffer in silence. Decisions to keep the straitjacket on treatment at the Clinic were made behind the scenes by the clinic’s organizing committee and were not disclosed to groups serving on the patient advisory committee.

Backgrounder

Lyme Borreliosis is an infection caused by bacteria (*Borrelia*) acquired from the bite (attachment) of various species of ticks. The infection causes many symptoms crossing over many systems of the body including the brain, heart and other organs, the muscle and skeletal structure including connective tissue, the central nervous system, gastro-intestinal system, respiratory system, eyesight and hearing.

In British Columbia there are several strains and species of the genus *Borrelia* however, only *Borrelia burgdorferi*, strain B31, is used as the foundation of the current government Lyme disease test for humans. Health Canada published a warning in the fall of 2012 that these tests are incapable of detecting the diversity of the Lyme bacteria known to occur in Canada and elsewhere (http://www.hc-sc.gc.ca/dhp-mps/medeff/bulletin/carn-bcei_v22n4-eng.php). As a result, the many thousands of Lyme tests run over the years on people experiencing symptoms of Lyme disease have left an unknown number with a false negative test result. A false negative result is the most harmful for the patient. The Canadian Lyme Disease Foundation deals daily with the fallout of these poor tests and inadequate early treatment protocols.

Lyme Borreliosis can result in a chronic active infection if left untreated, or if inadequately treated as occurs frequently in Canada. Lyme Borreliosis can cause total disability and death. Migratory birds are responsible for transporting and depositing infected ticks randomly throughout Canada so there is no place in the country with zero risk of contracting Lyme disease. Only a small subset of the *Borrelia* bacteria will cause the over-stated EM rash that too many doctors require to diagnose Lyme Disease (<http://canlyme.com/2013/01/29/ability-to-cause-erythema-migrans-differs-between-borrelia/>).

The United States Center for Disease Control reported last week that they have been drastically under-reporting Lyme Disease cases. Instead of 30,000 cases per year it should be 300,000 cases per year. (<http://canlyme.com/2013/08/23/lyme-disease-more-common-than-previously-thought-10-times-more-cases-says-us-cdc-putting-number-at-300000-cases-per-year/>)

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