

On the subject of Bill C-442 in Ottawa, this was recently published by the Canadian Medical Association Journal, written by president of the [Canadian Lyme Disease Foundation](#) -- good read.

Lyme law not based upon "junk science"

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The article titled, 'Lyme law uses "junk science" says expert' written by Carolyn Brown, published online November 11th, 2014 in the CMAJ is a clear example of exactly why Canadians need specific laws to deal with serious diseases such as Lyme disease that can have such a broad impact on our lifelong health, health care budgets, and workforce.

Every aspect of Lyme disease in Canada from testing, clinical diagnosis, to treatment is currently dictated to medical professionals and the unsuspecting public by a small group of self-appointed experts who simply insist we accept their perspective and opinion while ignoring reams of evidence-based peer reviewed science.

David Patrick is very new to the Lyme disease scene in Canada. By his own admission at a recent meeting he is not an expert on Lyme disease. His opinion always follows that of the Infectious Disease Society of America (IDSA), and at no point has Bill C-442 suggested following the International Lyme and Associated Diseases Society (ILADS) guidelines so for Dr. Patrick to bring this up is curious and misleading.

The Canadian Lyme Disease Foundation, in our support of Bill C-442, has always maintained we want a combined global scientific perspective, from Europeans, South Americans, Central Americans, Asians, Africans, Australians, Russians, Middle Easterners, and North Americans. Borreliosis is a global problem.

Here is a recently published quote by State University of New York associate professor of microbiology, Holly Ahern , "The IDSA insists their guidelines are evidence-based, yet reviews of the guidelines by outside groups, including the Institute of Medicine (the health arm of the National Academy of Sciences), reveals the evidence is primarily medical opinion based on a limited number of studies authored by members of the group impaneled to write the guidelines. The ethics of this approach have been criticized in multiple forums, including a report from the Institute of Medicine in 2011 titled "Clinical Practice Guidelines We Can Trust."<http://canlyme.com/?p=6462>

Junk science, anti-science is not promoted by those who support this Canadian legislation, Bill C-442, and in fact it is quite the opposite. The 'my way or the highway' position of Dr. Patrick and the IDSA is anti-science, anti-open discussion. These quotes, "Patrick says he is concerned that politicized Lyme disease advocacy in the United States has led to incorrect diagnoses." and "The problem is not an intellectual joust. We're seeing the fall-out of false-positive diagnoses." is more of

an example of the IDSA misinforming while ignoring the patient. For every one account they allege are false-positive diagnoses, patients and their experts can report thousands of false-negative diagnostic processes resulting in disability and death.

Canadian Lyme Disease Foundation board members, past and present, as well as our long list of global science and medical advisers are published experts. The founder of the Lyme Disease Association of Ontario, John Scott, is a frequently published scientist. There is no pseudoscience on our end as implied by Dr. Patrick. Our board member Dr. Redwan Moqbel, Head of Immunology, Faculty of Medicine, University of Manitoba, prior to his death in 2013 orchestrated one of the most balanced symposiums on Lyme disease ever held in Canada. Infectious disease doctors from the IDSA presented as did scientists who countered their position. Having a balanced slate of presenters was not easily achieved in that Dr. Moqbel encountered pressure to present only the IDSA perspective. He refused.

According to the United States Center for Disease Control, Lyme disease is occurring at a rate several fold that of A.I.D.S.. According to Health Canada in published papers, current testing in Canada is incapable of detecting the genetic diversity of Lyme bacteria known to infect humans and we have been missing many cases, for decades. According to Health Canada in testimony we will have in excess of 10,000 cases of Lyme disease per year in just five short years. According to the highest level of medicine in North America, the United States Institute of Medicine, the IDSA guidelines are largely medical opinion, not science based. Thanks in large part to the tunnel vision of IDSA dogma, so staunchly adhered to Canada-wide, we in Canada have no infrastructure to deal with the numbers of cases now and in the future.

Canada is not the first to seek legislation to remove some of the power of medical bureaucrats who have determined only they should be heard. Several US states have now enacted legislation giving protection to doctors and patients specific to Lyme disease, protecting them from the bullying of agenda driven bureaucrats who are also abusing the right to self-police, a right granted by legislation enacted by we, the electorate.

Timothy Caulfield indicated that he wants the "processes surrounding biomedical inquiry to drive research priorities" and he further states "I believe the allocation of public health resources should be informed by evidence.". So, he wants the status quo of a small group of self-appointed experts deciding what evidence is to be considered, and this is reflected in the two references he cited. He provided links to papers of very authors of the hotly contested IDSA guidelines written in their own defence. That is not evidence of anything but circular logic. There are hundreds upon hundreds of evidence-based peer-reviewed published research studies that are simply ignored by the IDSA because they draw into question their dogma.

It is time that patients, the ultimate stakeholder, and their experts be brought into every aspect of policy making, research funding, and guideline writing in Canada for any diagnosis that affects them directly. This must include sitting on all national and provincial working groups where evidence is graded and methodologies are discussed that result in any guidelines. Being consulted after that process has been completed is not acceptable. True patient representation is long overdue.

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