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Province of Legislative Assembly British Columbia

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Dr. A Dodek, President and Members of the Council College of Physicians and Surgeons of British Columbia 400 858 Beatty Street Vancouver, BC V6B 1C1

Dear Dr. Dodek and Council Members:

I write to express my deep concern about the advice on diagnosing Lyme disease in the October 2008 Bulletin, which reinforces the prevailing lack of awareness among B.C. doctors. The approach recommended actually contradicts the policy of the B.C. Ministry of Health and the B.C. Centre for Disease Control, which state that Lyme disease is to be diagnosed from patient symptoms and that diagnosis is not dependent 'in most cases' upon a positive blood test. "Your doctor will probably be able to tell if you have Lyme disease based on your symptoms and whether you may have been exposed to deer ticks. In most cases, blood tests to diagnose Lyme disease are not necessary." B.C. HealthGuide, MoH, p. 110. "Lyme disease should be diagnosed through a clinical evaluation of the patient's symptoms and risk of exposure to infected ticks. A blood test may also be administered.. .but this should not be interpreted in the absence of a clinical diagnosis." BC Centre for Disease Control, February 29, 2008, news release. The Bulletin implies that diagnosis of Lyme disease depends upon a positive blood test, which in B. C. is known to be unreliable due to its high level of false negatives (unreliable serology is presumably why the CDC makes 'symptoms' the basis of diagnosis). This error would be bad enough, but the College Bulletin compounds it by making testing for Lyme depend in turn upon the patient presenting with evidence of a tick bite and a bull's-eye rash. Only some of those bitten by an infected tick ever develop a discernible bull's-eye rash, while many who ultimately test positive for Lyme don't recall a tick bite or a rash. There is robust evidence from long-term patients that B.C. doctors lack the knowledge of symptoms to diagnose Lyme disease clinically, which means most people are not promptly cured and go on to develop debilitating late-stage Lyme disease. There is a pressing need for

all those responsible for medical practice in B.C. to develop a focus on raising doctor awareness of Lyme's symptoms.

The College's advice makes a bad situation worse - it reinforces doctor ignorance of the incidence, symptoms, diagnosis and effective treatment of an infectious disease that is clearly on the rise across North America. It also repeats the claim that Lyme is infrequent in B.C., which further encourages doctors not to learn how to recognize it. Of course we have only a few 'proven' cases a year - most instances of Lyme infection will be missed with an approach that depends on unreliable indicators (i.e. bull's-eye rash, blood test).

What most patients who present with Lyme symptoms hear from their doctors is that 'it's very rare' or that 'we don't have it here'. This attitude is so widespread as to constitute a barrier to

accessing timely medical care - an obligation of our public healthcare system. Until doctors are given the basic tools to recognize the symptoms of Lyme and its multiple coinfections, healthcare resources will be wasted as patients are serially misdiagnosed with diseases they don't have and are condemned to live with the debilitating physiological and neurological effects of chronic Lyme disease.

The College Bulletin doesn't even mention the primary symptoms doctors should be aware of (persistent flu-like symptoms, aches and pains in the joints, disorientation and fatigue). Nor does it mention Lyme's mimicking of other diseases, or the growing likelihood of complex coinfections like Babbesia. All these omissions work to ensure that Lyme continues to be under-diagnosed in a province where its incidence is on the rise.

Finally, the College compounds the harm to Lyme sufferers by perpetuating the claim that chronic Lyme disease "remains controversial", meaning that it may in fact not exist. This equates to a life-sentence for anyone undiagnosed in the early stages (which is virtually everyone contracting Lyme in B.C. today) when a relatively short course of antibiotics may have nipped the infection in the bud.

The only thing missing here is a reiteration of the standing caution that long-term antibiotics are unnecessary and dangerous, which closes the door to the only treatment that has proven effective for those debilitated by chronic Lyme disease. But implying that chronic or late-stage Lyme doesn't exist has pretty much the same effect anyway, doesn't it!

What I see from collecting case histories of people with chronic or late-stage Lyme disease are clear patterns of under-diagnosis, lack of awareness of symptoms, failure to promptly treat, failure to recognize flaws in serological testing, failure to monitor and tailor antibiotic treatment to the severity of the Lyme infection, and refusal to allow long-term or intravenous antibiotic treatments for chronic Lyme sufferers even when there is serological evidence of disease. These patterns in my view add up to a systemic failure to provide timely access to medically necessary care. The net result is untold human suffering coupled with the financial hardship for many of having to seek appropriate care out of country. I would be pleased to have the opportunity to present a number of case histories directly to the College Board, so that it might become more informed about the devastating impacts in human lives. I am sure the College is sincerely committed to 'excellence in medical practice', so I request formally that it correct the impressions left in the October issue, that it acknowledge the deficiencies in current practice as regards Lyme disease, and that it work with all agencies overseeing infectious diseases to equip B.C. doctors with the knowledge required for timely

Sincerely yours,

clinical diagnosis.

David Cubberley, MLA Saanich South