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Title of Resolution: Fair Treatment For Canadians Suffering from Chronic Lyme Disease And Other Tick-borne Diseases

RESOLVED, That the Canadian Federation of University Women (CFUW) strongly urge the federal government and all relevant provincial bodies (governments, public health agencies, medical associations, and colleges of physicians and surgeons) to:

- Recognize all 15 of the 2022 World Health Organization's (WHO) ICD-11, the medical diagnostic codes for chronic Lyme disease, and thus, recognize chronic Lyme as a **treatable** disease in Canada;
- **Provide access to treatment** for chronic Lyme (and other chronic tick-borne diseases) under our publicly-funded health care systems (e.g., OHIP, etc.) so that chronic Lyme disease patients do not have to pay out of pocket for medical care;
- **Employ the International Lyme and Associated Diseases Society (ILADS) *Diagnostic and Treatment Guidelines*** as the primary guidelines in the treatment of acute and chronic Lyme disease and other tick-borne diseases.

RESOLVED, That CFUW urge medical schools across Canada to:

- Include comprehensive, evidence-based learning about Lyme disease and other tick-borne disease in their curriculum;
- Adopt the ILADS diagnostic and treatment guidelines as the primary, evidence-based approach to diagnosis and treatment of Lyme disease and other tick-borne diseases;
- Educate medical doctors and other health practitioners to rely on a **clinical diagnosis** of Lyme disease as recommended by Health Canada.

Background:

"For much of her life, Jane Bailey was in peak physical condition. But that all changed in the summer of 2013, when a tick made a temporary home inside her ear canal. "It was in there for three-and-a-half days," she recalled. By the time she got it removed, "it was the size of a kidney bean." The 48-year-old Nova Scotian biology teacher with a military background is convinced she's been suffering from persistent symptoms of Lyme disease ever since. A month after her vacation, she began to experience fatigue, joint pains and heart palpitations. She couldn't sleep and had trouble remembering names. "I was below 95 pounds. I was skeletal. It was just falling off me, all my muscles were atrophying," she told White Coat, Black Art host Dr. Brian Goldman. "If I did manage to walk, I looked like an 80-, 90-year-old woman stooped over, trying to shuffle along in extreme pain. It was the worst time of my life." By that time, Bailey began to do some research herself. It turns out she's one of a number of patients caught up in a contentious debate in the medical community about how to treat long-term or chronic cases of Lyme disease — or even whether the condition exists at all." (Sept 20, 2019, CBC White Coat, Black Art)

Lyme disease in North America, is an infection caused primarily by the bacterium, *Borrelia burgdorferi*, which is transmitted to humans through the bite of an infected tick. A leisurely hike in the woods or a walk with your dog may be all it takes to receive a tick bite that could turn your life upside down. With larval ticks being the size of a poppyseed, you may not even know you were bitten. As a result of climate change, tick populations have grown and rapidly expanded northward, leaving Lyme disease now the most common vector-borne illness in North America.

The Centre for Disease Control (CDC) estimates there are over a 500,000 new cases of Lyme disease in the U.S. each year; the per capita incidence of Lyme disease in Canada is comparable. Globally, it is estimated that over 14% of the world's population is or has been infected with Lyme disease (Dong et al., 2022).

The Controversy

Getting a Lyme diagnosis is not a given. Doctors in Canada do not receive adequate training to properly diagnose and treat Lyme disease. When a patient comes to their office after a tick bite, doctors look for that 'bullseye rash' — a red ring with a red center — and yet about only 9% of Lyme cases produce a bullseye (Stonehouse et al, 2010). More commonly, a solid red oval appears at the bite site, but in up to 50% of Lyme cases, no rash appears at all (hopkinslyme.org). Moreover, up to 30% of people diagnosed with early (acute) Lyme disease will go on to develop *chronic* Lyme disease (Maloney 2016, Aucott et al. 2013).

Chronic Lyme sufferers experience persistent and often debilitating symptoms of extreme fatigue, joint and body pain, and neurological issues including significant cognitive deficits, neuropathy, anxiety, depression, and other psychiatric effects, all of which can continue for decades. Despite these debilitating, persistent symptoms, **chronic Lyme is not recognized as a treatable disease by the Canadian medical community**. While the World Health Organization (WHO) recognizes the existence of chronic Lyme through their globally endorsed diagnostic codes (Newby 2022, The International Classification of Diseases, 11th edition), the medical profession in Canada follows the Infectious Disease Society of America (IDSA) guidelines for the diagnosis and treatment of Lyme disease, guidelines that do not acknowledge the existence of chronic Lyme. This is despite a large and growing body of published scientific research, including over 700 peer-reviewed scientific articles (<https://www.ilads.org/wp-content/uploads/2018/07/CLDLList-ILADS.pdf>), that show chronic Lyme exists and that it occurs as a result of a *persistent infection* by Lyme bacteria, despite antibiotic treatment (Shor et al. 2019, Cameron et al. 2014, Embers et al. 2012).

While the medical community continues to debate the existence of chronic Lyme, Canadians suffering from the disease are **denied access** to medical treatment from doctors operating under provincial publicly-funded health care systems. The repercussions of having their illness not recognized are profound. Sufferers don't qualify for disability benefits and the treatment options, which must be personally financed, are only available at private clinics in Canada, the U.S. and abroad. Thousands of Canadians desperate to find treatment to alleviate their debilitating symptoms are having to remortgage their home or drain their retirement savings, paying tens of thousands of dollars for treatment.

Adding to the challenges concerning the debate over chronic Lyme is the lack of adequate diagnosis of Lyme disease in its early (acute) stage. This is so important because misdiagnosed and untreated cases of early Lyme disease most often go on to become chronic Lyme. Back in 2012, Health Canada recognized that the blood testing kits (2-tier testing) used by Canadian doctors to diagnose acute Lyme have "limitations" and as such recommended that "...blood test results should be used to support a **clinical diagnosis** of Lyme disease and should not be the primary basis for making diagnostic or treatment decisions." (FilFil 2012). In other words, a diagnosis of Lyme disease should be based on a medical exam, including physical findings and symptoms, history of a tick bite, and prevalence of Lyme disease where the patient lives or has visited. Despite this government recommendation, the vast majority of medical doctors under Canada's publicly-funded health care system continue to rely primarily on this blood test for diagnosis. In a meta-analysis of 18 scientific studies, Cook and Puri (2016) showed that the probability that these 2-tier bloods test would detect a Lyme infection is,

on average, only 54%. Thus, because of improper reliance on blood tests, nearly half of Lyme cases are not properly diagnosed (and treated). Diagnosis is made even more challenging by the rapidly increasing incidence of coinfection by other tick-borne diseases, such as Babesiosis and Anaplasmosis (Scott and Pesapane 2021; Scott et al. 2021), Bartonellosis, and Rocky Mountain Spotted Fever. Most chronic Lyme sufferers are coinfecting with other tick-borne diseases. These coinfections significantly increase the level of illness and render successful treatment even more challenging (Ball 2021). The ILADS guidelines recognize the complicating role of other tick-borne diseases in diagnosis and treatment. Furthermore, Canadian doctors are not trained to diagnose and treat diseases such as Babesiosis, Anaplasmosis, Bartonellosis and Rocky Mountain Spotted Fever, thereby posing significant additional health risks for patients.

Double standards

Chronic Lyme is very similar to long-haul covid-19 — both are chronic, multi-system inflammatory syndromes caused by an infectious agent. The symptoms of chronic Lyme disease and long-haul covid are very similar. Although the cause of long-haul covid is not fully understood, there is evidence of persistent viral infection. Long-haul covid is taken more seriously in Canada, with sufferers generally able to access ongoing medical treatment under publicly-funded health care. In contrast, chronic Lyme is not taken seriously, not recognized as a treatable disease, and chronic Lyme sufferers are denied treatment. When it comes to antibiotics, there are a number of persistent bacterial infections that doctors routinely treat with months or even years of antibiotics (Stricker et al. 2011) and yet Lyme sufferers in Canada are limited to a mere 6 weeks of antibiotics, despite persistent symptoms and improvements while taking the antibiotics (Ball 2021).

High suicide rate

Due to chronic symptoms, lack of access to medical care, extreme financial hardship, and the neurological impacts of persistent infection, the suicide rate of chronic Lyme sufferers is remarkably high. Fallon et al. (2021) examined data from nearly 7 million people and found that the suicide rate of chronic Lyme sufferers was 75% higher than the general population.

This can, and must, change.

Without accurate and appropriate diagnosis and treatment, adequate doctor education on Lyme disease, and because of the strict adherence to the IDSA guidelines, doctors in Canada are impeded in their ability to properly care for their patients, leaving those patients invisible and marginalized within the medical system and to those guiding public policy. **Canada must also adopt the diagnostic and treatment guidelines for Lyme and other tick-borne diseases set forth by ILADS** (an organization created by doctors and health professionals worldwide who accept the large body of published science on Lyme disease), guidelines rooted in credible science that recognize the existence of chronic Lyme, as a result of persistent infection. Adopting the ILADS guidelines in Canada's publicly-funded health care system will allow patients to receive the treatment they desperately need, without suffering extreme financial hardship.

The human, social, and financial costs of chronic Lyme disease

Not only does chronic Lyme disease take a huge toll on individual lives, as the number of Canadians infected with Lyme and other tick-borne infections rises rapidly, so will the social, and financial costs. Any disease, which results in disability, can lead to impacts at the level of society if enough of the population is affected. Given the rapid rate at which acute and chronic Lyme disease are growing in Canada, there is potential to have a large portion of the Canadian population infected with Lyme. The cost to both government and society of this scale of disability could be significant.

Conclusion

The debate over chronic Lyme disease has been described as “one of the biggest controversies that medicine has seen,” as Dr. John Aucott, the director of the Johns Hopkins Lyme Disease Clinical Research Center, described it in an interview with the Atlantic Monthly in 2019. Significant change is needed to give access to the thousands of Canadians already suffering from chronic Lyme, and the thousands more that will no doubt deal with this disease as, due to the impacts of climate change on the prevalence of both ticks and the diseases they carry, the incidence of Lyme and other tick-borne diseases skyrockets in Canada.

Implementation:

CFUW National, clubs, provincial/regional councils can communicate directly with the Canadian federal health minister, provincial ministries of health and other key provincial bodies such as public health offices, medical associations and colleges of physicians and surgeons to urge them to do the following:

- a. Accept chronic Lyme as a **treatable** disease in Canada, providing access to treatment under publicly-funded health care, by recognizing the WHO (World Health Organization) codes for chronic Lyme as well as the large body of peer-reviewed science research;
- b. Adopt the ILADS guidelines as the primary diagnostic and treatment guidelines for all medical practitioners in Canada;
- c. Base treatment and diagnosis of Lyme disease and other tickborne diseases on peer-reviewed science.

CFUW National, clubs, provincial/regional councils can communicate directly with medical schools across Canada and request the following changes:

- b. That medical school curricula include comprehensive, evidence-based learning (based on peer-reviewed science) about Lyme disease and other tick-borne diseases;
- c. That medical school curricula adopt the ILADS guidelines for training in the appropriate and effective diagnosis and treatment of Lyme disease and other tick-borne diseases;
- d. That, in alignment with the ILADS diagnostic and treatment guidelines, medical doctors and other health practitioners be taught to rely on a **clinical diagnosis** of Lyme disease as recommended by Health Canada until new, highly reliable tests are available to support diagnosis.

CFUW National, clubs, provincial/regional councils could publicize the issues around chronic Lyme disease and other tick-borne diseases through social media, to draw public attention to the lack of access to health care for those suffering from chronic Lyme and other tick-borne infections and the challenges around diagnosis and treatment of Lyme and other tick-borne infections.

CFUW members can write to their local MP and MLA/MPP to ask that:

- a. Chronic Lyme disease be accepted as a **treatable disease** by all health care professionals in Canada, and
- b. Those suffering from chronic Lyme disease and all tickborne disease have access to diagnosis and treatment **under publicly funded health care**.

Bibliography:

“Why Patients caught Are Caught in the battle Over Treating Chronic Lyme Disease”, CBC Radio 1, Sep 20, 2019

<https://www.cbc.ca/radio/whitecoat/why-patients-are-caught-in-the-battle-over-treating-chronic-lyme-disease-1.5288979>)

“Lyme Disease is Baffling Even to Experts”, Septemer, 2019

<https://www.theatlantic.com/magazine/archive/2019/09/life-with-lyme/594736/>

Aucott, J.N., Rebman, A.W., Crowder, L.A., Kortte KB. (2013) “Post-treatment Lyme disease syndrome symptomatology and the impact on life functioning: is there something here?” *Qual Life Res* 22:75–84.

Ball, S.L. (2021). *Lyme disease, ticks, and you: a guide to navigating tick bites, Lyme disease, and other tick-borne infections*. Firefly Books, Richmond Hill, Ontario.

Canadian Institute for Health Information.

[ICD-11 \(International Statistical Classification of Diseases and Related Health Problems, 11th Revision\) | CIHI](#)

Cameron, D.J., Johnson, L.B., and Maloney, E.L. (2014). “Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease.” *Expert Review of Anti-infective Therapy*, Volume 12, 2014, *Issue 9*, <https://doi.org/10.1586/14787210.2014.940900>.

Cook. M.J. and Puri , B.K. (2016). “Commercial test kits for detection of Lyme borreliosis: a meta-analysis of test accuracy.” *International Journal of General Medicine*, 18, no. 9, 427-440.

Dong, Y., Guozhong, Z., Wenjing, C., Xin, X., Yu, Z., Zhenhua, J., Jiaru, Y., Jingjing, C., Meixiao, L., Yuxin, F., Jing Kong, S., Bingxue, L., Peng, Y., Aihua, L., and Fukai, B. (2022). “Global seroprevalence and sociodemographic characteristics of *Borrelia burgdorferi* sensu lato in human populations: a systematic review and meta-analysis.” *BMJ Global Health*, 7, e007744, DOI 10.1136/bmjgh-2021-0007744.

Embers ME, Barthold SW, Borda JT, Bowers L, Doyle L, Hodzic E, Jacobs MB, Hasenkampf NR, Martin DS, Narasimhan S, Phillippi-Falkenstein KM, Purcell JE, Ratterree MS, Philipp MT. (2012). “Persistence of *Borrelia burgdorferi* in rhesus macaques following antibiotic treatment of disseminated infection.” *PLoS One*.7(1):e29914. doi: 10.1371/journal.pone.0029914. Epub 2012 Jan 11. Erratum in: *PLoS One*. 2012;7(4):10.1371/annotation/4cafed66-fb84-4589-a001-131d9c50aea6. Erratum in: *PLoS One*. 2013;8(9). doi:10.1371/annotation/f84663e3-0a2c-4243-8f97-3a58133c1b0f. Erratum in: *PLoS One*. 2013 Sep 24;8(9):null. PMID: 22253822; PMCID: PMC3256191.

Fallon, B.A., Madsen, T., Erlangsen, A., and Benros, M.E. (2021). “Lyme Borreliosis and Associations With Mental Disorders and Suicidal Behavior: A Nationwide Danish Cohort Study.” *The American Journal of Psychiatry*, 178 (10), 921-931, <https://doi.org/10.1176/appi.ajp.2021.20091347>

Filfil , R. (2012). Health Canada, Canadian Adverse Reaction Newsletter. Volume 22, Issue 4, pages 1-2. https://publications.gc.ca/collections/collection_2012/sc-hc/H42-4-1-22-4-eng.pdf

International Lyme and Associated Disease Society

<https://www.ilads.org/wp-content/uploads/2018/07/CLDList-ILADS.pdf>)

Johns Hopkins Lyme Disease Clinical Research Center. <https://www.hopkinslyme.org/lyme-disease/lyme-disease-signs-symptoms>.

Lantos PM, Rumbaugh J, Bockenstedt LK, Falck-Ytter YT, Aguero-Rosenfeld ME, Auwaerter PG, Baldwin K, Bannuru RR, Belani KK, Bowie WR, Branda JA, Clifford DB, DiMario FJ Jr, Halperin JJ, Krause PJ, Lavergne V, Liang MH, Meissner HC, Nigrovic LE, Nocton JJJ, Osani MC, Pruitt AA, Rips J, Rosenfeld LE, Savoy ML, Sood SK, Steere AC, Strle F, Sundel R, Tsao J, Vaysbrot EE, Wormser GP, Zemel LS. (2021). "Clinical Practice Guidelines by the Infectious Diseases Society of America, American Academy of Neurology, and American College of Rheumatology: 2020 Guidelines for the Prevention, Diagnosis, and Treatment of Lyme Disease." *Neurology*. 2021 Feb 9;96(6):262-273. Doi: 10.1212/WNL.0000000000011151. Epub 2020 Nov 30. Erratum in: *Neurology*. Feb 9;96(6):296. PMID: 33257476.

Maloney, E.L. (2016). "Controversies in persistent (chronic) Lyme disease." *J Infus Nurs*. 2016 Nov/Dec, 39(6):369-375. doi: 10.1097/NAN.000000000000195.

Newby, K. 2022. "What you need to know about the new Lyme ICD-11 diagnostic codes" <https://www.lymedisease.org/newby-icd11-diagnostic-codes/>.

Scott, J.D. and R. R. Pesapane. (2021). Detection of *Anaplasma phagocytophilum*, *Babesia odocoilei*, *Babesia* sp., *Borrelia burgdorferi* Senu Lato, and *Hepatozoon canis* in *Ixodes scapularis* Ticks Collected in Eastern Canada. *Pathogens*, volume 10, 1265. <https://doi.org/10.3390/pathogens10101265>.

Scott, J.D, Sajid, M.S., Pascoe, E.L, and Foley, J.E. (2021). Detection of *Babesia odocoilei* in Humans with Babesiosis Symptoms. *Diagnostics*, 11, 947, <https://doi.org/10.3390/diagnostics11060947>

Shor, Samuel, Christine Green, Beatrice Szantyr, Steven Phillips, Kenneth Liegner, Joseph Jr. Burrascano Jr., Robert Bransfield, and Elizabeth L. Maloney. (2019). "Chronic Lyme Disease: An Evidence-Based Definition by the ILADS Working Group" *Antibiotics* 8, no. 4: 269. <https://doi.org/10.3390/antibiotics8040269>

Stonehouse, A., Studdiford, J.S., Henry, C.A. (2010). An update on the diagnosis and treatment of early Lyme disease: focusing on the Bull's Eye, you may miss the mark. *Journal of Emergency Medicine*, 39, no.5: e147-151.

Stricker, R.B., DeLong, A.K., Green, C.L., Savely, V.R., Chamallas, S.N., and Johnson, L. (2011). "Benefit of intravenous antibiotic therapy in patients referred for treatment of neurologic Lyme disease." *International Journal of General Medicine* 2011:4 639–646

World Health Organization (2019). "International Statistical Classification of Diseases and Related Health Problems (11th ed.)." <https://icd.who.int/>