

## **Resolution 1: Patient First Treatment for Ontarians with Lyme Disease**

Submitted on behalf of Halton Chapter. Resolution carried May 20, 2018.

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Authors declare no conflict of interest.

**WHEREAS** people with Lyme disease and/or co-infections in Ontario are not consistently receiving appropriate diagnosis and treatment of these diseases due to inadequate testing protocols and a lack of up to date education of medical professionals on the clinical diagnosis of these diseases;

**WHEREAS** there is a lack of education and awareness regarding persistence of infection, transplacental transmission, co-infections, other possible modes of transmission (sexual, blood supply, needle sticks, organ donation and other insect vectors), symptoms (acute vs. chronic), surveillance of chronic cases, modes of testing, treatment, and the existence of up to date, evidence-based guidelines published by ILADS;

**WHEREAS** these challenges along with the politicization of this disease has created fear and uncertainty amongst healthcare professionals thereby forcing patients with Lyme disease and/or co-infections to pay for out of Country testing and seek health care outside of Canada at their own expense;

**THEREFORE** be it resolved that the Registered Nurses' Association of Ontario (RNAO) advocate, at all levels of government, for Lyme disease prevention programs and the rights of all patients with symptoms consistent with Lyme and/or co-Infections to receive evidence-based, patient-centred care for both acute and multi-systemic chronic presentations of the disease in Canada; emphasizing healthcare provider education that acknowledges alternate modes of transmission, persistence of infection, and integration of a collaborative clinical model inclusive of ILADS guidelines in the treatment of this illness.

### **BACKGROUND:**

Lyme Disease is a serious and rapidly growing public health crisis in North America, caused by the bacterium *Borrelia burgdorferi*. It is spread by ticks that are carried by migratory birds and animals such as deer and mice. In 2016, there were an estimated 178,000 cases in US States bordering Ontario [4]. Canadian scientists predict that by the year 2020, 80% of the population of Eastern Canada will be living in a tick-populated area [11].

Limitations of current testing [7] and treatment protocols have left thousands of Canadians improperly diagnosed and inadequately treated for the disease. Many have been forced to seek treatment outside of Canada at their own expense resulting in financial hardship, significant stress and strain on families [2]. Bill C442 was passed in 2014 with a mandate of creating a national strategy for Lyme Disease, embracing a collaborative process of all stakeholders including patients [1]. In May 2017, the Federal Framework for Lyme Disease was released [15]. In June 2017, the House of Commons Standing Committee on Health called for a study of the Federal Lyme Framework [8].

Canadian patients, advocates, nurses, treating physicians, scientists, and researchers agree that the Lyme Framework failed its mandate and is insufficient to drive meaningful patient-centered change in Canada [8]. It neglects to acknowledge the vast body of peer reviewed literature which documents persistence of infection resulting in chronic Lyme disease [9] as well as clear evidence of vertical transmission from mother to child in utero [12]. It is silent to voiced concerns over other possible modes of transmission (sexual, blood supply, needle sticks, organ donation and other insect vectors). Alternate testing options are not addressed, it does not adequately address co-infections that may accompany Lyme disease and does not address treatment guidelines for chronic Lyme disease.

In a collective response to the failed framework, in August 2017, a petition with over 52000 names [3], 14000 comments and 2700 personal letters from Lyme patients [13] and their families were handed to the Federal Minister of Health and Chief Public Health Officer of Canada [10]. Patients have an important role to play through personal and public advocacy by presenting their lived experience to health professionals and decision makers including politicians at all levels of government [6].

Patients have the right to timely and appropriate clinical diagnosis and treatment of Lyme disease and all co-infections utilizing evidence-based and up to date guidelines developed by specialist bodies that include ILADS. The ILADS guidelines are currently the only guidelines endorsed and listed on the National Guidelines Clearinghouse that must meet the U.S. Institute of Medicine (IOM) standard for the development of clinical practice guidelines [14].

Evidence based practice obliges practitioners to respect patients' values and preferences alongside clinical judgment and relevant scientific evidence [5]. Nurses have a critical role to play in education, facilitating awareness, early detection and patient advocacy in areas such as Public Health, Emergency Rooms, Physician and Nurse Practitioner offices, summer camps and through policy change. Education has the ability to lift the veil of uncertainty surrounding Lyme disease for both patients and healthcare professionals and to bridge the gaps that currently exist, enabling early diagnosis and appropriate patient-centered treatment.

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