Rebuttal to Boston Globe’s problematic Lyme article

From the Massachusetts Lyme Legislative Task Force:


House bill H.4491 builds on the Massachusetts Physician Protection Act, Chapter 112, Section 12DD of the Massachusetts General Laws. It also fulfills the Massachusetts Special Commission to Conduct an Investigation and Study of the Incidence and Impact of Lyme Disease recommendation for “mandatory Lyme disease insurance coverage to be enacted in Massachusetts.” Currently, some insurance providers are denying coverage for Lyme disease treatment to Massachusetts residents, citing restrictive and expired insurance guidelines from 2006. As a result, many Commonwealth residents are unable to afford necessary treatment. If passed, this legislation will help thousands of residents in the Commonwealth suffering from Lyme disease by increasing their access to treatment recommended to them by their treating physicians.

A recent article in the Boston Globe took aim at this legislation. Responses to several of the statements made are listed below (italics are ours).

“Health insurers would have to cover long-term antibiotic treatment for Lyme disease under a measure approved by the Massachusetts Legislature – a vote that places Governor Charlie Baker in the crossfire between mainstream medicine and patient activists.”

Rather, this is the juncture between old-guard medicine and current research. It is not unusual that some are slow to change under the weight of new science. Germ theory
necessitating hand washing before touching patients, H. pylori sparking stomach ulcers, cancer not being one disease but many – all were slow to be adopted by the mainstream but resulted in great gain for patients. Noted Duke University oncologist Dr. Neil Specter, himself a recipient of a heart transplant due to Lyme disease, has called Lyme “the infectious disease equivalent of cancer,” and has called for better science and a personalize approach to care, as in cancer[1].

“Baker has until midnight Thursday to sign or veto the legislation or to let it become law without his signature. The governor, a former health insurance executive, has reservations about the bill. In a letter to lawmakers, he wrote that ‘long-term antibiotic therapy is not clinically recognized as an appropriate form of treatment.’”

Governor Baker is ill-informed on this issue. Long-term antibiotic therapy is clinically recognized as an effective form of treatment by the International Lyme and Associated Diseases Society (ILADS), which wrote guidelines to that effect in 2004 and 2014[2]. The current guidelines are the only Lyme guidelines currently meeting federal standards and housed in the National Guideline Clearinghouse[3].

“Massachusetts had the nation’s third highest incidence of Lyme disease in 2014, with 5,600 confirmed and suspected cases.”

Perhaps more importantly, the US Center for Disease Control and Prevention (CDC) and the Massachusetts Department of Public Health (DPH) have noted that the actual number of cases exceeds the number of reported cases by a factor of ten, meaning that actual new cases of Lyme in Massachusetts exceed fifty thousand, every year [4,5]. In a 2011 report issued by the House Committee on Post Audit and Oversight, Lyme disease was called “a public health crisis” and an epidemic[5]. Of those infected, conservative estimates report that 10-20% will go on to suffer long-term effects that interfere with work,
school, and daily life [6]. Clearly, new thinking is needed to alleviate the consequences of being infected with this disease.

“Dozens of infectious-disease specialists are urging a veto, saying extended antibiotic treatment is ineffective and can be harmful.”

Long-term antibiotic treatment should be taken seriously, and the patient should be closely monitored, but current scientific evidence notes that it can be effective, returning health back to desperately ill patients.

“But patients, often with stories of sickness and recovery, are entreating Baker to sign it, saying weeks-long infusions of antibiotics can relieve lingering symptoms from the tick-borne disease.”

It is important to note that this legislation (H.4491) does not mandate the dispensing of antibiotics nor does it address any one mode of antibiotic delivery (oral, intramuscular, or intravenous). Many patients have been helped with additional oral antibiotics alone. Even the expired Infectious Disease Society of America’s (IDSA) 2006 Lyme treatment guidelines recommended an additional month’s worth of antibiotics under certain circumstances [7].

“Similar mandates have passed in Connecticut and Rhode Island, as advocacy groups push for treatment that runs counter to standard medical advice but that some doctors are willing to provide.”

In a robust survey of 12,281 respondents with Lyme disease, the CDC noted that 56% of patients being treated for Lyme disease were treated for more than one month, 20% of the time for five to eight weeks [8]. Clearly, standard medical advice is different than what this reporter describes, as the majority of patients are receiving such care. Yet there are insurance companies in Massachusetts today that will refuse to
cover even an additional month’s worth of oral antibiotics.

“At issue is a condition that patient activists call ‘chronic Lyme disease’ and that the US Centers for Disease Control and Prevention has labeled ‘post-treatment Lyme disease syndrome.’”

Chronic Lyme disease is not at issue in this legislation. The words “chronic Lyme disease” and “post-treatment Lyme disease syndrome” do not appear anywhere in the bill. This legislation is about insurance coverage for Lyme disease that is diagnosed by a licensed physician in accordance with Massachusetts General Law 112, Section 12DD, which has been on the books since 2010.

“In a small number of patients, symptoms such as fatigue, muscle aches, joint pains, numbness, and impaired thinking persist after the standard two to four weeks of antibiotic treatment.”

This statement could not be more misleading or downright dangerous to patients. In report after report as early as 1990, it has been noted that long-term consequences of untreated or undertreated Lyme disease could include heart block, brain lesions, measurable memory impairment, blindness, hearing loss, and death[9, 10, 11]. And Dr. Mark Klempner of U-Mass, in one of the antibiotic re-treatment trials, described the debility of such patients “were equivalent to those observed in patients with congestive heart failure.” [12]

“The reasons for this reaction are not understood, but most medical specialists blame the symptoms on damage to tissues and the immune system caused by the Lyme bacteria — not on bacteria lingering in the body.”

Current science indicates that persistence of the organism might also be the cause [13, 14].
“Individual anecdotes don’t amount to medical evidence, said Dr. Benjamin Kruskal, chief of infectious disease and travel medicine at Atrius Health, a large group practice.”

Thousands of reports, including those documented in the medical literature, are no longer “anecdotes,” but a cohort of patients that needs to be taken seriously.

“Evidence of what works emerges only from studies that compare people who get the treatment with those who don’t, and such studies have clearly shown no value to long-term antibiotics, Kruskal said.”

On the contrary, such studies have clearly shown value. In two of four short-term retreatment trials, significant and sustained improvement was seen [15]. The author spoke with the author of one of those retreatment trials, Brian Fallon, saying he referred to “two small studies.” But those small studies and one other are the studies, with a total of 212 patients among them, upon which all this theory of the ineffectiveness of antibiotics is based. These are the “numerous well-defined studies” referred to later in the article by Dr. Daniel Kuritzkes. Three studies, 212 patients, with results that one of the studies’ lead authors described as “equivocal” in this article.

“People who recovered after the treatment might have gotten better anyway, or might have benefited from the placebo effect, in which a patient’s belief in getting better will bring about improvements, doctors say.”

The placebo effect would only work for a short period of time at best, but thousands of patients report sustained improvement with longer treatment, and ILADS and the IDSA have both recommended retreatment [2, 7].

“Among those writing in opposition to the legislation were the Massachusetts Infectious Disease Society, representing more than 500 infection specialists, along with physicians from
hospitals as well as Atrius Health. They noted that long-term antibiotic treatments have serious risks, including blood clots, blood infections, and intestinal infections. Additionally, the overuse of antibiotics promotes the growth of drug-resistant bacteria, they said."

Five hundred members do not vote on letters sent by their elected officers. Statewide and nationally, there are infectious disease doctors who are in favor of treating with long-term antibiotics. Long-term treatment does carry some risk, but close monitoring can mitigate such risk, which must be weighed against the risk of permanent debility or death.

It has been shown that long-term antibiotic therapy does not promote drug-resistant Lyme bacteria, though drug resistance in general should always be a concern. If the Massachusetts Infectious Diseases Society is truly concerned about drug-resistant bacteria, perhaps a concerted effort to legislate against the routine administration of antibiotics to meat animals would be in order [16], but let Lyme patients have their life-saving antibiotics.

H.4491 bridges the gap between patients being prescribed treatment for Lyme disease and their ability to pay for it through insurance coverage. Insurers who deny coverage for care are costing Massachusetts families and the Massachusetts economy. Thousands of patients across the Commonwealth are looking for the Governor and the legislature to pass H.4491. The time is now.

REFERENCES:


The online version of the original article, “Bill puts state in center of debate on Lyme care,” can be found at https://www.bostonglobe.com/.../ft15pM7WKG01wcCL3x.../story.html