

June 23, 2016

James S. Gessner, President  
Massachusetts Medical Society  
860 Winter Street  
Waltham Woods Corporate Center  
Waltham, MA 02451-1411

Dear President Gessner and members of the Executive Committee:

We are dismayed to learn that the Massachusetts Medical Society has chosen to oppose legislative efforts to provide insurance coverage for the treatment of Lyme disease, when ordered by a licensed physician. We are aware that this is a departure from your previous stance of neutrality. We deeply regret that you did not reach out to its supporters, in order to obtain a more balanced understanding of its nature and goals, prior to your decision.

Indeed, the intent of the legislation is being distorted by special interest groups and their lobbyists: legislators are not seeking to practice medicine, but rather to restore control over treatment decisions to qualified, licensed physicians. The proposed measure does not mandate treatment, and does not even mention the term "chronic Lyme."

It simply would require insurance companies to pay for treatment that licensed physicians deem necessary and appropriate, based on sound clinical judgement. This amounts to individualized patient care, replacing the rigid, one-size-fits-all guidelines currently imposed by insurance companies. We believe that this approach supports the mission statement posted on your website:

**"Our goals are to enhance and protect the physician-patient relationship and to preserve the physician's ability to make clinical decisions for the benefit of patients."**

Mr. Linzer, spokesperson for the Massachusetts Association of Health Plans, is promoting information which is incorrect and outdated. Evidence does exist both for the benefits of extended treatment (i.e., longer than the 28 days currently allowed by most health insurers), and for the persistence of viable bacteria after antibiotic treatment.

In her testimony at the recent hearing in Bolton, MA, for example, Dr. Nevena Zebcevek, Co-Director of the Dean Center for Tick Borne Illness, Spaulding Rehabilitation Hospital, cited three antibiotic retreatment studies in which patients demonstrated improved cognition and fatigue. In his recent presentation at the 2016 Lyme conference at Massachusetts General

Hospital, Dr. Brian Fallon of Columbia University also cited retreatment studies in which patients showed improvement.

Several studies have demonstrated persistence of infection. Researcher Kim Lewis of Northeastern University, for example, has reported on viable Lyme persister cells which survive and thrive in the laboratory after antibiotic treatment. Zhang and his colleagues at Johns Hopkins University, in their recent xenodiagnosis study, found evidence of infection in humans previously treated with antibiotics. Several published clinical case reports further attest to persistence in patients after antibiotic treatment.

Clearly, this is a field in flux, and patients' needs are being submerged by unnecessary and bitter controversy. Many are desperately ill, with children among the hardest hit by this disease. Patients simply cannot wait for care while the "experts" hash out their differences and lobbyists promote their special interests. In the face of scientific uncertainty or controversy, evidence-based medicine upholds the importance of the clinical judgement of the treating physician, and respects the role of patient values. The proposed Lyme legislation is consistent with an evidence-based approach.

Please know too that advocates support only the language in House FY'17 Amendment #729, H.4198 and S.2231, each of which contain identical wording; we do not support Senate FY'17 Amendment #427. The former three measures pertain solely to coverage for antibiotic treatment. Antibiotics have a long track record in the treatment of bacterial infections like Lyme disease, and should not be characterized as experimental. Although antibiotic resistance is a real concern, treatment should never be withheld for patients in need of medical attention.

We are confident that small businesses stand to gain more than they will lose by supporting this legislation. Absenteeism and employee turnover due to illness are very costly. Revenues also decline when people struggling with Lyme disease lose purchasing power due to illness - or when parents must cut back on their work hours in order to care for very sick children.

Lyme disease has reached epidemic proportions in Massachusetts, and statistics from the CDC support this. We need strong leadership to replace the failed "business as usual" approach. We pray that you will reconsider your opposition to this legislation. Take the time to learn more about the emerging, compelling science. Support your courageous colleagues who are hard at work on the front lines of this epidemic, only to have their carefully considered treatment recommendations thwarted by outdated and overly rigid insurance guidelines. Thousands of Massachusetts residents are depending on you.

Sincerely,

The Massachusetts Lyme Legislative Task Force:

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Donna Castle – Ayer  
Janice Dey – Westport  
Susan Fairbank-Pitzer – Danvers  
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