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Public Health Committee
Proposed H.B. No. 6200
An Act Concerning the Use of Long-term
Antibiotic Treatment for Lyme Disease

Thank you for the opportunity to provide testimony in support of H.B. # 6200. I am a doctoral level clinical psychologist in practice in Massachusetts, married to an orthopedic surgeon who is a graduate of Johns Hopkins Medical School. Although I am currently a resident of Massachusetts, I was born and raised in Connecticut, and still have strong family ties to this state.

As professionals working in the healthcare field, my husband and I receive a large number of inquiries on a weekly basis from people concerned about tick-borne disease. My husband has had many patients show up at his office not for an evaluation of degenerative joints, his area of subspecialty, but rather seeking an appropriate diagnosis and treatment for Lyme disease. Often, he is hard-pressed to find appropriate referrals for them. As a practicing psychotherapist, it is not unusual for patients travel from many miles away to see me, from states which have included New Hampshire, Rhode Island and Connecticut, as well as Massachusetts. They seek supportive counseling to deal with the stress of their tickborne disease, as well as help with healthcare advocacy. Many of these patients must travel out of state to obtain medical treatment. We also receive many calls at home, from friends, neighbors, members of our place of worship and more.

We got to this place the hard way. In 1996, when our oldest son was only 11 years old, he returned from sleep away camp with a fever, swollen glands, headaches and fatigue. Little did we know that it would take years for him to get well. Our daughter, in the 4th grade, developed a chronic, croup-like cough and severe gastrointestinal symptoms, followed by balance and gait problems, severe headaches, a tremor and more. She too remained very ill for several years. When our third and youngest child began to show signs of illness, we were dumbstruck. What could explain the onset of such dramatic, debilitating symptoms in three previously healthy, active and happy children?

We consulted with specialists from every academic medical center in Boston and Worcester, but no one could tell us what was wrong with our children. With each and every consultation, blood tests were used to rule out the diagnosis of Lyme disease. Far too late, we began to read the medical literature for ourselves, including published reports which document the extensive problems with diagnostic testing, as well as the difficulty of eradicating the Lyme bacteria. Many patients with undisputed cases of Lyme disease

never recall having had a tick-bite, and many never develop the "classic" bull's-eye rash. It took us about three months to review enough of this material to conclude that none of our children had ever been adequately evaluated for Lyme disease, despite years of illness and numerous visits to prestigious medical centers. We then traveled out of state, like so many of our fellow residents, to find responsible treatment with physicians in Connecticut and New York. I am happy to report that all of our children, if not in perfect health, are now able to lead productive and happy lives.

Our story is far from unique. It troubles us deeply that two published standards of care exist, one of them recommending a more comprehensive diagnostic and treatment protocol, yet most physicians, and most health insurers, subscribe to the short term, more restrictive model of care. We think it should be incumbent upon physicians to provide informed consent regarding the two approaches, explaining not only the potential side effects of medication, but also the very real consequences of untreated Lyme disease.

In our experience, it was those physicians who were wise and courageous enough to challenge the prevailing dogma regarding Lyme disease who saved our children. We applaud you, the members of this health committee, for your willingness to listen to your constituents who are suffering unnecessarily with tickborne disease. We urge you to pass HB #6200, which would allow physicians to prescribe longer-term antibiotics without fear of reprisal, in order to appropriately treat their patients.

Thank you.

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