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In 2008, Massachusetts jumped to number two in national reported case numbers. The situation isn't likely to improve soon. Climate changes are contributing to increased tick populations and expanded tick ranges, increasing disease burden. According to University of Massachusetts researcher Steven Rich who discovered deer ticks halfway up Mount Greylock, one of the coldest areas in state: "Deer ticks used to be limited primarily to a 15-mile zone along the coast of New England....Now they are moving much farther inland as they seemingly adapt to the cold."[i]

In January 2005, my 5 year old granddaughter had a fully engorged deer tick behind her ear. It was 25°. Lyme is hitting our children ages 5-9 the hardest, according to CDC.[ii] A CDC study of 65 children with Lyme showed the median missed school days at 140, with median duration of home instruction, 153 days and 78% of children's grade point average fell. [iii] A Columbia study documented a 22 point drop in IQ, reversed with treatment.[iv]

Two documents greatly influence ability and willingness of doctors to treat Lyme patients, including our children − the first being CDC surveillance criteria. Despite CDC's warning that Lyme surveillance criteria are NOT intended for diagnosis, treatment, or insurance reimbursement but only for disease reporting, most doctors inappropriately use them to diagnose and treat. Patients not fitting the surveillance criteria scramble to find doctors willing to risk making a clinical diagnosis for Lyme disease, one based on symptoms, history, ruling out other diseases, one which does not require a positive test for diagnosis—necessary due to unreliable tests and often no bull's eye rash.

The second document is the Infectious Diseases Society of America (IDSA) guidelines which are meant for diagnosing and treating. They recommend

against any long-term treatment for chronic Lyme; against entire classes of antibiotics; against alternative treatments; against some supplements; and against individual physician discretion in diagnosis and treatment. IDSA says there's NO chronic Lyme disease. Despite a disclaimer that they are only guidelines, experience demonstrates they have become *de facto* law. The misuse by medical boards, health department, hospitals, insurers, schools, pharmacists, IDSA doctors themselves, is so blatant that Connecticut Attorney General Richard Blumenthal felt compelled to legally investigate the IDSA Guidelines' process citing conflicts of interest and exclusionary conduct.

Patients are often delayed in getting or unable to get diagnosed and treated due to these rigid guidelines, leading to increased chronic Lyme and higher costs. An actuarial study showed 37% of cost is incurred before the correct diagnosis is made. [v] A CDC journal cited average early Lyme per patient costs at $161 and neurologic longstanding Lyme $61,243.[vi] Chronic Lyme is more costly to government in terms of disability and education e.g., special services, home instruction[vii] Permitting doctor discretion in this bill can cut costs and most importantly, human suffering.

Other Lyme treatment guidelines allowing doctor discretion, recognizing the need for longer term treatment, addressing early infection and chronic disease, provide the basis for a second standard of care. Published by the International Lyme & Associated Diseases Society (ILADS),[viii] they're ignored by IDSA, not disclosed as a treatment option by most doctors, and used as a basis by medical boards to charge doctors who treat under them. Yet they're published on the Department of Health and Human Services National Guidelines Clearing House website, recognizing them as being evidenced-based.[ix]

One study shows Lyme patients suffer a degree of disability equal to patients with congestive heart failure.[x] These same patients now have to travel many hours outside Massachusetts to find care for Lyme. They don't have the resources nor health to fight the vested interests stacked against them, thus the need for legislation−ensuring that in-state treating doctors cannot be prosecuted for unprofessional conduct solely for providing long-term treatment based on clinical judgment. Rhode Island, Connecticut, and California have passed doctor protection legislation, others are considering it.

Passing a doctor protection bill levels the playing field by providing treating physicians with a measure of protection they are entitled to, since there are two standards of care. Doctors should not be penalized for following the standard that best improves patient health. This bill DOES NOT mandate treatment of any kind but does allow clinical discretion. Massachusetts owes it to physicians and patients. Thank you.

Endnotes

[i] Recorder.com, July 30, 2007.

[ii] Centers for Disease Control & Prevention, *Average Annual Incidence of Reported Cases of Lyme Disease by Age Group & Sex*, http://www.cdc.gov/ncidod/dvbid/lyme/ld_MeanAnnualIncidence.htm.

[iii] Brian Fallon MD *The Underdiagnosis of Neuropsychiatric Lyme Disease in Children & Adult,* The psychiatric Clinics of North America, Vol.21, No.3, Sept.1998.

[iv] Brian Fallon MD *The Underdiagnosis of Neuropsychiatric Lyme Disease in Children & Adult,* The psychiatric Clinics of North America, Vol.21, No.3, Sept.1998.

[v] Irwin Vanderhoof, *Lyme Disease the Cost to Society*, Contingencies January/Februray 1993.

[vi] Martin I. Meltzer *The Cost Effectiveness of Vaccinating against Lyme Disease CDC Emerging Infectious Diseases;* Vol.5, No.3; 1999 May-June;5(3)321-8.

* This is in 1996 costs not adjusted to 2007. The following additional significant costs to society aren't measured by this table: special education needs for children, disability, increased medical and insurance costs, and livestock losses, etc. Also, there are personal loses: friends, employment, self, esteem, domicile, and breakup of families.

[vii] Patricia Smith, Wall Township, NJ, Board of Education member *NJ School District Study on Impact of Lyme Disease on School Districts* presented in Washington DC Congressionally hosted meeting with CDC & NIH, March 12, 1992.

[viii] Daniel Cameron, et al, Expert Review of Anti-infective therapy 2(1) Suppl. 2004

[ix] AHRQ, http://www.guideline.gov/.

[x] Mark S. Klempner, M.D., TWO CONTROLLED TRIALS OF ANTIBIOTIC TREATMENT IN PATIENTS WITH PERSISTENT SYMPTOMS AND A HISTORY OF LYME DISEASE, N Engl J Med, Vol. 345, No. 2 July 12, 2001