

Mr. Lyddy and Elected Officials:

PUBLIC HEALTH COMMITTEE: HB 6200

Thanks for your efforts in helping the Lyme victims get the help they medical attention we need. Please encourage and share this letter with anyone who may be instrumental in passing HB 6200. Frankly, I'm sick of fighting the fight, and stopped in order to focus on making my kid well. And it's worked, with the diligent help of Dr. Jones.

My kid was sick. Really sick. After multiple tick bites and my (then) Newtown pediatrician who in 2001 told me Lyme disease doesn't exist on this side of the Connecticut River; perhaps she's schizophrenic; how much one-on-one time do I actually spend with her, say reading; and to request a PPT at the schools for help. After demanding blood work and receiving an off the chart result, she referred me to Yale, where the infectious disease expert that told me, if I stopped treating my kid as if she were sick she'd stop acting sick. This was a phone consult, no examination, despite multiple tick bites, the bulls eye rash (several), and an Elisa and Western Blot test off the charts. The pediatrician then called to say, "I concur."

We finally received appropriate, necessary treatment of IV antibiotics from a rheumatologist at Children's. He took my then 7 year old psychotic, lethargic, debilitating knife-like headaches, violent outbursts, no short-term memory, lack of muscle control on one side of her body and successfully treated her with IV antibiotics and then oral. On medication, my kid was symptom free. After 9 months of treatment (thereabouts, guessing, it's all in our files), he deemed her cured and sent her on her way.

But she wasn't. Symptoms came back tenfold. We saw psychiatrists, rheumatologists, allergists, ENTs, neurologists, OB/GYNs. Her headaches and nightmares landed us repeatedly in the ER.

But our current Lyme doctor (Dr. Charles Ray Jones) saved her life. The good news was, that with oral antibiotics, she was symptom free. Not just symptom free, but improving academically and socially as well. It's simple. On meds, she's a normal, growing, athletic, learning kid. Off, and we're in the ER weekly, suffering from pain that leaves her cowering in a corner, unable to retain the simplest directions, unable to read, succeed in the classroom, or on any team or individual sport. Over the years, we have taken her off meds after months of being symptom free only to land back in the ER, sicker than ever. Her last time off was 3+ years ago, and after 3 months, symptoms were rampant only to be eliminated with antibiotic treatment. We have tried, yet again, this past December to remove the

meds after 2 symptom-free years, and one month into it.... well, so far, so good.
But we're watching her like a hawk.

On antibiotics, she's a champion swimmer, travel soccer player, honor roll student
and confident, thriving teenager.

I honestly can't believe this fight is still going on. Treat these Lyme victims early
and aggressively and they won't become my kid. Continuous treatment has saved
her childhood, and while I'm not convinced this is curable, it certainly is as
treatable as any chronic condition. It won't be until the docs and lawyers and
insurance agencies — and politicians — are directly and personally affected by
this nightmare will the tide begin to turn.

Thanks for your efforts.

Kathryn Mayer
5 Hyvue Drive
Newtown, CT 06470
kathrynmayer@charter.net
203-364-1861
203-240-0785 (cell)