

Dear Mr. Lyddy and Members of the Public Health Committee:

Thank you for being an advocate for Lyme patients. I am one of those chronic Lyme patients (16 years) who continues to require long-term antibiotic therapy every one and a half to two years. Sometimes an oral six week dose of antibiotic will be enough to suppress the infection, but I will likely live with this condition for the rest of my life. It's not my condition that drives me to become a Lyme disease advocate and great proponent of the scientific research necessary to unraveling the tick-borne disease puzzle, it is for my children and for all children. Two of my four have had the disease passed on through utero. Gestational Lyme is difficult to treat and often takes years of antibiotic therapy. My daughter had 5 years of antibiotic therapy, was in remission for 3 years and is currently symptomatic once again, testing positive and under oral antibiotic treatment again. I am concerned for both my children who require medical treatment and the pediatric Lyme specialist who handles our children is presently under investigation and may lose his license to treat. The most exasperating aspect of the controversial Lyme issue is the lack of awareness and understanding by the majority of medical doctors nation-wide. My niece at age 9 had a bull's eye rash on her arm several years ago (in Mass.) and her pediatrician told my aunt not to worry because "children can't get Lyme"! It took my niece years to recover, lost school days, lost social life, wasted time and money. Devastating, really. My youngest son was not tested and diagnosed until he was 6. Up to that point, the schools and doctors suspected perhaps a spectrum of autism, learning disabilities, ADHD, ADD...BUT he would not test positively for anything and so he continued getting support in school through his language delay diagnosis. However, once he was tested and treated for Lyme, his world began to turn around- he has improved TREMENDOUSLY! He is almost 2 years into oral antibiotic therapy. What would happen if he could not receive treatment? He'd likely get diagnosed with an attention deficit disorder and be put on drugs to get through the school days, but that is irresponsible because the treatment for ADD only lasts for a few years. It's a big artificial band-aid, the wound does not heal or disappear. It manifests itself as other diseases and disorders. (I know of some pretty awful stories). The real crime here is the misdiagnosis, lack of early and proper treatment and a total lack of awareness from our medical doctors, especially the pediatricians, and the long-term poor quality of lives these patients will be forced to lead.

I'm sorry this was rushed. I have a Board meeting on Friday morning so I can not attend, but I appreciate your taking the time and effort to help both the patients and the doctors trying so diligently to treat their patients properly. The bottom line, of course, is that we need federal funding for the scientific research in Tick-borne diseases!! Please feel free to reach me at cell 203 803-0483.

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