

Congressional Forum – Talk on Lyme in the Schools

The LDA sponsored a congressional forum with Congressman Robert Andrews (NJ) and Pat Smith, President, Lyme Disease Association, Inc. gave this talk to the NJ congressional delegation who attended.

Education is the key to the future. I am sure everyone in this room agrees with that statement. Yet we have in this country today a whole segment of the population who are denied access to that key. They are the lepers of the 20th century—children with Lyme disease. I speak to you now not only as a mother but also as a past 12-year member and past president of a board of education. I travel across this state as an advocate trying to help our children get the education which they deserve and so desperately seek, yet are often denied. I have seen many problems associated with educating classified children, i.e., children with learning disabilities, but rarely have I seen the degree of ignorance, and outright callous indifference I have witnessed toward children with Lyme.

Children with Lyme are behind the eight ball. They have no classic symptoms, the symptoms they do exhibit frequently have physical, psychiatric, and emotional components, and often go unrecognized as Lyme disease symptoms. Districts many times have difficulties fitting these children into the public school mode, first because school officials do not think Lyme is serious, and second, because they do not understand the accommodations necessary to educate these children. They do not know nor do they seem to care about the legal requirements pertaining to this education.

For example, the state of NJ requires under 18A that districts annually in-service teachers who instruct children with Lyme. This is rarely done. You, as federal legislators, have no control over NJ's failure to monitor district compliance with state laws, however, you certainly have jurisdiction in the federal arena. 504 is a federal statute which applies to all

public schools who receive any federal aid. Children can be placed under 504 if they have a physical or mental impairment that substantially limits one or more major life activities (walking, learning, working), or have a record of having a substantial impairment, or are regarded as having an impairment. After listening tonight, there should be no doubt that Lyme students qualify for placement. Yet districts continually fail to place students in this category. Or they place students under 504 but do not make the proper accommodations for learning—shortened days, untimed tests, dropping unnecessary requirements, alternate testing methods, a modified home instruction program, and tailoring assignments.

School physicians who may never have seen the child contradict the child's personal physician and that child is not able to be classified or may not get the proper educational accommodations. Children are often misclassified or labeled as ADD, attention deficit disorder, when what they need is to be treated for the underlying disease causing their symptoms. Their symptoms fluctuate rapidly from month to month, day to day, hour to hour. No one believes they are really sick.

The emotional damage these children suffer is tremendous and it follows them throughout the most impressionable stages of their lives. To get out of bed is an accomplishment, to shower is a miracle. They have few or no friends, no regular school attendance, no sports or activities, and no self-esteem. Some contemplate suicide, unfortunately, some are successful.

Districts are easily able to fool parents into thinking they are doing all they can when in fact, they are doing nothing for the child. I have helped several children who were on the verge of graduation when the districts suddenly realized the children had not been getting the proper requirements. Instead of accepting responsibility for their failure to provide a thorough and efficient education, the districts tried to prevent the children from graduating. Fortunately, they were

unsuccessful.

Children who are exceptionally bright and have Lyme are often penalized and told they may not take honors courses, advanced placement, and other courses designed for gifted students. Why are we being penalized, they wonder, when our only crime seems to be having a disease we have no control over? Even the local chapters of the National Honor Society discriminate against these students, many with A averages and 1300+ SAT scores. In a country which prides itself in being progressive and promoting human rights, we have blatant discrimination going on in our public schools.

I have witnessed outright emotional cruelty in meetings with school personnel when a child's plight is not believed and the parent is brutally questioned in an accusatory fashion. I have seen some of these same personnel look the other direction when an athlete is accused of a substance abuse problem or is failing and could potentially be removed from a school sports team.

What do our children with Lyme have to do to get help? To what depths must parents go to get that unalienable guaranteed right for their children, a public education? Facing loss of home, loss of job, public scorn, and inadequate medical care, these poor parents are unprepared to handle the task of securing an education for their children. They are already struggling to rescue their children from a disease whose tortures never end.

Ladies and gentlemen, I have been there. Like Dante in Dante's Inferno, I have been unwillingly dragged down into the bowels of Hell. There I have seen unspeakable devils, devils which no Spielberg movie can even begin to match, grip my child with an unrelenting hold. I begged and pleaded with a deaf universe to give me answers or at the very least, give me strength to carry on. I sought compassion from friends, from doctors, from educators. Sadly, I got very little, my child, less. When Lyme

comes in the window, humanity goes out the door.

Help the children in this great country of ours. Help them obtain the key to a successful future: education. You have the power. You award school districts nationwide monies to educate children with special needs. It is up to you to ensure those needs are being met. If they are not, you must provide a more readily accessible avenue for parents to follow. You can ensure that doctors are properly educated about Lyme. You can ensure that monies are withheld if districts are discriminating against children with Lyme. You are too far away to do it personally, but you can require the states to enforce the provisions of 504 and other statutes which guarantee that our children should be treated as human beings, sick ones at that, ones who need and deserve an education like their non-sick peers automatically get.

You have all heard the saying about walking a mile in my shoes. Tonight I ask you to take my hand or the hands of those around you and we will take you on a journey that will forever be burned into your soul, like it is burned into ours and our children's. With your help, thousands of sick minds and bodies can become productive again, and new growth will cover the wounds. With your help, the scars will just become a fading symbol of a distant past, a nightmare we will never experience again. You have the power. You can provide the resources, you can provide the direction. You can make Lyme disease a priority, you can make it a memory. You can end the nightmare.