

LYME DISEASE IN THE SCHOOLS

Presented in Kansas – May 14, 2003 By Pat Smith President, Lyme Disease Association Former President, Wall Township Board of Education

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. I call them the lepers of the 21st century—our children with Lyme disease. The schools today must play a much larger role in the life of students with Lyme because these students often miss months and years of school. They are not only academically, but also socially and emotionally, isolated from their peers. The emotional damage these children suffer is tremendous and it follows them throughout the most impressionable stages of their lives. For them, 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. In NJ, through the work of the LDA (then LDANJ) we have a law on the books that requires teachers who have children with Lyme disease to be inserviced annually on the disease. A statewide Lyme disease curriculum is available for districts in endemic areas, although its use is not mandated. Unfortunately, many districts are not aware of the law and few comply unless pressed by parents to do so. A large part of the problem with Lyme disease is that the medically community is not doing a good job disseminating information about students with Lyme. Part of the problem relates to the politics surrounding the disease. Those politics are dictating who has the disease and how it can be treated. Antibody testing is unreliable, about 40% accurate. Antibiotics appear to control, but do not necessarily eradicate, infection. Psychiatric symptoms and behavior problems are often overlooked as Lyme manifestations,

although current literature is replete with examples of psychiatric illnesses whose origins are probably bacteriological. When treated early and appropriately, Lyme can often be eradicated and maybe even cured. Unfortunately, within days of a tick bite, the disease can be disseminated and enter the central nervous system and the brain. Once there, antibiotics have a difficult time penetrating to kill the organism. Estimates range from 10-15% of individuals who develop Lyme disease go on to develop chronic disease. Symptoms can range from arthritic to neurologic to psychiatric to ophthalmologic to cardiac. Patients can go blind, deaf, develop heart block, memory loss, mental confusion, seizures, a dyslexic type of condition, and ADD type symptoms. 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. Studies at Columbia University have demonstrated that individuals with LD can have a drop in IQ of 22 points, which can be restored after appropriate treatment. In 1992, I prepared and presented in Washington, DC, to Congressman Smith, the Centers for Disease Control & Prevention, CDC, and the National Institutes of Health, NIH, a 9-district school study showing the impact of Lyme disease on children. As a result of my study, the CDC came to NJ and studied Lyme in 5 of those 9 Monmouth and Ocean districts. This Oct. 1992 CDC study of 64 students showed that the median duration of illness at the time of interview was 363 days, and the mean number of school days missed because the child was too ill to attend was 103 days (with a range of 2 to 548 days). The median duration of home instruction was 98 days, with a range of 5 to 792 days. Another study by NJ family therapist Maggie Smith showed an 11.2 months average school absence due to Lyme disease. The cost estimate available for medical treatment for 54 of the CDC study children was \$5.2 million, and more than one-third of families of the affected children had 3 or more members who had at some time been diagnosed with Lyme, and 40% of the mothers were LD diagnosed. 78% of the parents stated that their children

experienced a fall in grade point average during the time of illness, 79% experienced a decrease in the number of friends. A quote from the CDC study sums up the magnitude of the problem: "Perhaps the greatest costs incurred by the study children were the social costs of the illness and its treatment. Schooling and extra-curricular learning activities were seriously interrupted for most children; often, children spent large blocks of time as semi-invalids, isolated from social groups and missing out on cultural, sports, and social activities. School performance of nearly all children fell, sometimes drastically, and in several instances was said to interfere with selection by colleges and universities." Problems in the schools develop because these patients don't look sick, and sometimes, they don't act sick. Or they may be sick one day and fine the next. Or their symptomatology may vary from day to day, week to week, month to month. Now we have children who are fine one minute, sick the next, not performing in the classroom. They are late for school because they cannot get out of bed in the morning. Maybe they are acting out. They are labeled lazy, uncooperative, faking. Johnny cannot focus on his work no matter how hard he tries. The district says Johnny has ADD, Attention deficit disorder. Jane cannot think. She walks around in a fog, barely getting through the day. She is labeled neurologically impaired. 15 year-old Ben reverses his letters and cannot spell. Officials are puzzled. He won the state spelling bee 3 years ago. Fred tries to do a shop project. He does a fine job of cutting and putting the project together but he refuses to put his plans on paper. The teacher says he's defiant and thinks he knows everything. What do these children all have in common? Each has Lyme disease that has manifested in a different way. Each has gone unrecognized as such by the school. There are thousands of stories out there, and I present five here. A. was an eighth grade student on home instruction. The district was refusing to give her a diploma and refusing to allow her to walk in the 8th grade graduation

ceremony. Why, Because she had been seen one day at the mall and one day riding her bike. The last few weeks of senior year, M., in the top 1% of her class, was told they would not let her walk in the graduation ceremony because she had a small amount of work left that she could not finish due to her illness. Most of it was repetitious and not necessary to meet the curriculum goals and objectives. E. had been on home instruction all during high school. The district forced him to take Spanish I three times. He completed the course the first two times but was too sick to take the final exam each time. He balked at retaking the course the third time. He was never able to fully complete the remainder of his courses for the same reason. At the end of senior year, he had only 11 credits. His IEP was never fully implemented. He had however, passed a state mandated graduation test. The district was refusing to allow him to graduate. K. scored almost perfect on his SAT's. His IQ exceeded 160. The district refused to allow him to take Advanced Placement courses. The department heads argued that students on home instruction did not have a right to take these courses, the content would somehow be diluted. They felt the student was getting a break being on home instruction. Once, when K. was bedridden, the district requested that he report to school each day that he felt sick so that the school nurse could determine if he were capable of coming to school that day. C. was an honor student out of school four years—three of them spent in intense seizure activity. The district refused to allow her to take honors courses because she was on home instruction and refused AP courses, because they could not fathom why a sick person would want to take them. A teacher once called her at home and insinuated she might be cheating because her grades were so good on home instruction. The math chairman initially refused to allow her to take two math classes in one year to try and makeup a missed course, an option available to all in-school students. She was able to go back to school for a week. This was very important for her to socialize with her peers. She went back, and one teacher sent her to the library for the

period because she couldn't possibly know what the class was doing. Many times her mom cancelled home instruction with the teacher at the door, because she was in a seizure. She could not read for 3 years. At a meeting, her mom explained her myriad of problems to the honors English teacher and asked for the necessary time extensions and a reduction of workload with demonstrated mastery of the subject. The teacher got up, said no one got special privileges in her class, and C. still has to do the same work at the same time as everyone else, and she stormed out of the meeting. The honor society refused her admittance even though she ranked in the top 5 of her class, because she had no after school activities! She had no contact with peers for 4 years. The district called me in in A.'s case and I proceeded to explain that students with Lyme on long-term home instruction are isolated and although very sick, sometimes, they feel OK for a short period of time. During that time, they need to be able to have a life, perhaps go to the mall, ride a bike, even come to school for lunch. The district relented and allowed her to walk in the ceremony and receive her diploma. In the case of M.'s walking in the HS graduation ceremony, due to my intervention, the district extended time to the day before graduation for M. to turn in her missing work. This was still not enough time. M.'s mom took the district to court. The ALJ hearing was scheduled 3 days before graduation. Due to the refusal of the judge to allow me to present evidence about the district's unfair denial, the ALJ ruled to uphold the district's decision. There was no time for a legal appeal. M. is one tough lady. Sick but motivated by anger, M. stayed up for 48 hours and finished the work the day of graduation and not only walked in the ceremony but graduated. She went on to college. E. was able to graduate after my intervention, because I pointed out to the district its improper handling of his educational program. Additionally, I was able to get the district to pay for 2 years at a community college in lieu of the parents taking costly legal action against the district, a case which undoubtedly would have been lost by the district because of

their improper handling of his education. E. graduated from community college and recently got married. I told K.'s district it was unthinkable that an individual with K.'s intellectual ability would not be permitted to take AP courses. Besides the fact the denial was not legal, it would be an extreme embarrassment to the district since K. was now a National Merit Scholar! K. not only took his AP courses at home, but when I stopped by one day, I found him teaching one of his teachers. He graduated Phi Beta Kappa from Drew and heading for Dartmouth where he is almost finished his masters. C. took honors courses at home, including honors biology on a picnic table in her back yard and also took three AP courses. She doubled her math courses senior year. She not only graduated with an A average in the top few % of her class but was accepted to Johns Hopkins University where she finished her junior year, with an IV in her arm. She graduated from Hopkins Phi Beta Kappa and is now a layout editor for a major peer-reviewed journal in Manhattan, NY. After she graduated high school, her mom was able to get the district to review and change the honor society regulations to permit a classified student to be inducted into the honor society with a waiver of that one provision about school activities. The mom, then a board of education member there, was informed that just because the regulation was changed, she shouldn't think the committee of teachers who vote admission will ever let anyone like that in. These students are Lyme success stories. Sadly, for each one of them, there are dozens more who continue to struggle for their very lives. Students with Lyme can be covered under an IEP or 504 plan. All districts that receive federal monies must comply with the provisions of 504, civil rights legislation. Disability under 504 covers any student who has a physical or mental impairment, or who has a record of having a substantial impairment or is regarded as having a substantial impairment, including students with Lyme disease. It also covers all classified students. Students basically have the same rights whether classified with an IEP or under 504. Districts are required to have 504

coordinators, and complaints of non-compliance must be filed in the civil rights office of each state. Districts must make the proper accommodations for learning which may include shortened days, untimed tests, dropping unnecessary requirements, alternate testing methods, a modified home instruction program, and tailoring assignments. Our children are sick. They can't get diagnosed. They can't get treated. They can't get treatment paid for. They have asked for little and society has given them nothing in return. We may not be able to save their bodies but with your help, maybe we can save their minds. Thank you.