By Patricia V. Smith

The Effects of Lyme Disease on Students, Schools and School Policy

While it comes as no surprise that the numbers of classified students are increasing, it may surprise some to know that Lyme disease may be causing many of the learning problems experienced by students in Lyme-endemic areas. New Jersey ranks fourth in the nation in Lyme cases.

Many students with Lyme are classified, receiving accommodations and support in an individualized education program or 504 plan. A 1992 New Jersey law requires school districts to annually educate any teaching staff member who instructs students with Lyme disease.

Lyme is the most prevalent vector-borne disease in the United States, and case numbers have increased by 40 percent in 2002. Only 10 percent of cases are reported, which translates to about 240,000 new cases in 2002. Unfortunately, children are at the greatest risk of acquiring the disease, and 10 to 15 percent of Lyme cases become chronic.

In 1992, while I was a Wall Township Board of Education member, Congressman Christopher H. Smith invited me to Washington, D.C., where I presented a study to the Centers for Disease Control and the National Institutes of Health on the impact of Lyme disease on school children in nine New Jersey districts.

Of the 64 students studied, the CDC found that the median duration of Lyme disease was 363 days; the mean number of school days missed due to illness was 103; the median duration of home instruction was 98 days; more than one-third of families of affected children had three or more members at some time diagnosed with Lyme disease, including 40 percent of the mothers; 78 percent of parents stated their children experienced a fall in grade point average during the time of illness; and 79 percent experienced a decrease in friends.

A CDC study quote 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 extracurricular 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."

Lyme can affect all the systems of the body and its signs and symptoms are varied. Often children exhibit problems associated with Lyme, especially behavioral and mood changes, that go unrecognized by districts. At times, children may be improperly classified, labeled neurologically impaired or emotionally disturbed when perhaps a classification including "other health impaired" might be more appropriate to address the medical problems triggering the neurologic and/or psychiatric problems that stem from Lyme.

Children may be identified with attention deficit disorder, medicated for those symptoms, and no cause is ever sought. According to Dr. Brian Fallon, Columbia University associate professor of psychiatry and director of the Lyme Disease Program of the New York Psychiatric Institute, a child who is inattentive and fatigued often should probably be evaluated for Lyme disease.

Another difficult diagnostic situation arises when a child has attention deficit hyperactivity disorder, and then develops Lyme disease. This patient continues to have symptoms associated with hyperactivity, whether behavioral, fidgeting, or interrupting, and now may additionally be inattentive and fatigued due to Lyme.

Districts need to carefully evaluate any child with a history of Lyme disease who is experiencing neurologic, psychiatric, and attention deficit problems to ensure the problems are not organically produced by Lyme, since the bacteria causing the disease can enter the central nervous system less than a day after a tick bite. Additionally, the role of co-infections, diseases transmitted by the same ticks, needs to be examined.

Recurrent short-term memory, concentration and recall problems, mental confusion, and exhibition of dyslexic type symptoms are not uncommon and interfere with the learning process. One Columbia University study documents IQ improvement of 22 points in a 16-year-old after intravenous treatment for Lyme disease.

Fluctuations in, and the variety of, symptoms present another problem for

continued on page 9

the school and often lead to a misunderstanding about a child's condition. Lyme symptoms can vary from day to day, hour to hour. Serious sleep disturbances may cause a child to oversleep in the morning because of difficulty falling asleep at night. Executive functioning may be impaired and the child may have difficulty organizing his/ her day or life. Couple that with forgetting books and homework assignments, especially in a middle or high school, and questions about the validity of the child's illness surface.

Suicide can occur in children with Lyme. In one New Jersey case, the child felt that no one understood her Lyme disease problems. In another, a young man stopped his medications after a psychiatrist told him he did not have Lyme, it was all in his head. He could not bear the pain from the disease. Lyme disease pain has been described in studies as equivalent to that of congestive heart failure.

A district needs to understand its legal obligations in educating a child with Lyme disease. It also needs to recognize that, with a disease of this complexity, it must work closely with the parents and the student who are sometimes the only

continued on page 52

ones who understand what the student is capable of in a particular situation at a particular period of time. Information from Lyme support groups can be very helpful in this process.

School policies often forbid attendance at activities after or during an absence, but the situation involving a child with a chronic condition like Lyme disease does not fit into any existing paradigm.

Board policies often need to be modified for a student with Lyme disease, since a child may be out of school for extended periods of time, although he or she may be capable of attending a particular event. Absences of months to years often make a student a social outcast and recluse. Allowing this minimal school interaction, and not questioning the child's, parent's or doctor's honest assessment of the illness can go a long way toward preventing the development of school phobia, thus easing a child's transition back to school when he or she is well enough to attend.

Boards also need to examine policies relating to homework and class trips. Policies generally set a length of absence required before homework is sent home. Because of the unpredictability of symptoms, and frequent and sometimes short absences of students with Lyme disease, homework needs to be supplied without any waiting period. Outdoor class trip policies and procedures should also include information about the dangers of Lyme disease, thus protecting the staff and children from unnecessary exposure to the disease and the district from unnecessary expense and/or litigation if these elements are not in place.

Lyme presents a myriad of problems for both patient and district, not the least of which is the variable teachable moments of a student with Lyme disease. Proactive intervention by a school district and cooperation with a financially, emotionally, and medically burdened family can ensure student success and often lead to solutions, which are far less costly overall for the student and for the school district.

Patricia V. Smith is president of the Lyme Disease Association, Inc. and vice president of political affairs for the International Lyme & Associated Diseases Society. She is a former president of the Wall Township Board of Education and a former officer for the Monmouth County School Boards Association. Ms. Smith can be reached at Lymeliter@aol.com.