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# Pediatric Lyme Disease— A School Issue

## Tips for School Nurses

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Lyme disease is the fastest growing vector-transmitted disease in the United States and school-age children are at high risk of infection. If these children are to receive appropriate and prompt medical intervention, school nurses must have a basic understanding of Lyme disease symptoms and diagnosis and be able to recognize and articulate the impaired behavior and school performance frequently caused by this illness.

### Disease Overview

Lyme disease is a multisystem infection caused by a spirochete (bacterium) generally transmitted to humans from small mammals through the bite and attachment of a deer tick. The bite is often unnoticed due to the small, poppy seed-sized tick. Initial indications of infection *can include* a reddish rash, flulike symptoms (fever, chills), fatigue, joint pain, headache, stiff neck, mental confusion, and sleep disturbance. Symptoms are multivariate and often have puzzling presentation in children. A person can get Lyme disease repeatedly. Several tick-borne co-infections can occur with Lyme disease, adding to the

complexity and seriousness of symptom expression and diagnosis (Krause et al., 2002).

### Infection Incidence and Risk

Lyme disease has been reported in every state in the United States; however, according to the Centers for Disease Control and Prevention (CDC), 12 states—Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Wisconsin—account for 95% of cases reported nationally (CDC, 2008c; Hanincova, Kutenbach, Diuk-Wasser, Brei, & Fish, 2006). The number of U.S. cases of Lyme disease reported for 2007 was 27,444 (latest available CDC data) and represented a 38% increase compared to 2006 (CDC, 2008a, 2008b). Under-reporting is common due to asymptomatic infection, failure of physician reporting, and restrictive CDC surveillance criteria (CDC, 2000, 2008c). People of all ages are vulnerable to Lyme disease and significant infection rates occur in children five- to 14-years-old (CDC, 2008c). Children in endemic suburban residential areas surrounded by deer tick-infested woods and those who participate in outdoor recreational activities are at risk of getting Lyme disease. Each spring, the risk of infection

increases when deer ticks become active and personal outdoor activities increase.

### Physical and Neuropsychological Sequelae in Children

While children with Lyme disease can experience a plethora of symptoms, it is generally the *subtle* neurologic and cognitive deficits that elude detection. These deficits have the most profound negative impact on a child's school performance and social life (Sherr, 2002). Symptom categories include the following: **neurologic**—headaches; neck stiffness; nerve pain in back, legs, or hands; tingling sensation, often in legs and hands; facial paralysis (Bell's palsy); tinnitus; unusual sensitivity to sound or light; **memory deficits**—short-term, slowness of word and name retrieval; **reading comprehension and handwriting skill**—slow or poor presentation; **impaired speech fluency**—stuttering and slurring; **inability to accurately perform previously mastered mathematical calculations; vision problems**—difficulty in the classroom in seeing and following visually presented material, frequent blinking or tics, inability to coordinate eye movement, eye infections or pain, decreased vision or loss; **rheumatologic symptoms**—arthritis, musculoskeletal pain often

attributed to mythical “growing pains”; **coordination impairment**—balance problems and clumsiness or vertigo; **self-regulation impairment**—inability to activate or sustain effort and attention or to manage frustration or confusion, sluggish thinking in expressing thoughts; **dyslexic-like behaviors**—frequent errors in speaking, writing, or spelling; letter and number reversals; **severe and chronic fatigue unrelieved by rest**—falling asleep in class, missing class due to tiredness, sleep disturbance; **emotional and uncharacteristic behavior**—withdrawal from peers, cessation of involvement in sports or other extracurricular activities, inattentiveness, depression, anxiety, panic, aggression, explosive outbursts, mood swings, irritability, hyperactivity, nightmares; **inability to perform at grade level**—inconsistent or sloppy school work, late assignments, decline in grades, overwhelmed by schoolwork, missed school days, and school phobia (Berenbaum, 2002/2003; Fallon, Kochevar, Gaito, & Niels, 1998; Hamlen and Kliman, 2007; McAuliffe, Brassard, & Fallon, 2008; Sherr, 2002).

Any of these symptoms can indicate undiagnosed Lyme disease and should be considered when unusual changes in behavior or academic performance are noted. Frequently, symptoms develop in a child who previously performed well in the school environment. A most challenging manifestation of Lyme disease is that symptoms may persist or they may be episodic and *fluctuating* in type and severity, further confusing diagnosis, as the child may not appear sick in the traditional sense. Disease onset may be gradual, with increasing fatigue, social disinterest, or deteriorating school performance. An important finding is that cognitive and behavioral difficulties are similar to those observed with affective, oppositional defiant, attention deficit, and possibly autism spectrum disorders (Bransfield, Wulfman, Harvey, & Ysman, 2008; Pietrucha, 2001; Ramirez, 2003).

Children generally are not diagnosed initially with psychiatric manifestations of Lyme disease, but if the undiagnosed disease has psychiatric manifestations, a

referral from the school or treating physician to a psychiatrist to address an assumed psychological disorder is likely (Fallon, 2007; Fallon et al., 1998; International Lyme and Associated Diseases Society, 2008; Sherr, 2002).

In cases where facial palsy or skin or neurologic symptoms were the initial indications of infection, when diagnosed and appropriately treated with antibiotics, neuropsychologic, cognitive functioning, and general health outcomes were comparable to those who did not have Lyme disease (Fallon et al., 1998). However, in patients with *late* neurologic manifestations of Lyme disease, improvement was often gradual or patients presented with continuing cognitive symptoms that required IV antibiotic therapy (Tager et al., 2001). Adolescents with a history of treated Lyme disease can be at risk for long-term problems in cognition and school functioning (McAuliffe et al., 2008). Unfortunately, there are children who remain ill for months or years and who have been seen by several physicians who have erroneously labeled the child as hypochondriacal, psychosomatic, depressed, or malingering (Berenbaum, 2002/2003, 2004; Lang, 1997; Smith, 2004; Weintraub, 2008).

### What Can School Nurses Do?

The school nurse may encounter initially a student with an attached deer tick (or ticks), necessitating prompt tick removal (CDC, 2009) and parental notification. A child with Lyme disease also may present to the school nurse with a rash, but more often with fatigue, headache, and/or the neurologic and physical symptoms previously discussed. These latter symptoms are all too frequently overlooked, and thus, school nurse awareness is imperative. At whatever stage of illness a student interacts with the school nurse, it is imperative that the school nurse develop a partnership with the child's parents and teachers, often in consultation with a school psychologist. Effective school nurse, parent, and educator communication is crucial and all should make themselves accessible for discussions about the events in the

child's home and school life, the problems the child encounters, and feelings he or she has as a result. It is vital for school nurses, with parents and educators, to monitor the ill child's behavior, assessing positive and negative changes, and communicating these observations to each other as well as to the child. School nurses, with parents and educators, can be effective postdiagnosis student advocates and active participants in the school accommodations and community medical management of the student's illness.

### Federal Law and Education of Children With Disability

Federal law, that is, Section 504 of the Federal Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990, and the 1993, 1997, and 2004 Individuals with Disabilities Education Acts (IDEA), mandates that students with disabilities in elementary, secondary, and postsecondary schools receiving federal financial assistance not be discriminated against because of disabilities (ADA, 2000; Federal Rehabilitation Act, 1973; IDEA, 2004). Lyme disease is recognized as a covered disability. In many cases, schools are required to provide needed accommodations and/or supportive Individualized Educational Programs (IEPs). As schools are often financially stressed in accommodating the special needs of ill children, it is important that the school nurse, with allied school professionals, play a role in ensuring that the ill child is not left behind, but instead able to function in the school environment to the best of her or his ability.

### Conclusion

Whenever a change in a child's behavior, mood, health, or overall functioning occurs, including suspected affective, oppositional defiant, attention deficit, and possibly autism spectrum disorders, the school nurse should promptly consider Lyme disease, as delays in diagnosis are associated with chronic impairment. Lyme disease has become a permanent part of America's public health and school

landscape, impacting most perilously its young patients, as well as their families and the school community. ■

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