

## **PEDIATRIC LYME DISEASE AND ASSOCIATED TICK-BORNE INFECTIONS: Causes and Physical and Neuropsychological Effects in Children**

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Abstract: Whenever a change in a child's behavior, mood, or overall functioning occurs, including a suspected attention deficit/hyperactivity disorder, Lyme disease (LD) or tick-borne infections (TBIs) should be considered quickly as delays in diagnosis frequently lead to debilitating chronic illness and cognitive impairments. Parents and educators need to be aware of the possibility of LD and TBIs as they may be first to recognize the possible underlying infectious origin of aberrant student behavior. Lyme disease and TBIs have become a permanent part of America's public health landscape, affecting most perilously its young, their families, and school community. Many children seriously affected by these infections have alterations in personality, cognitive functioning, and behavior.

Lyme disease is the fastest growing vector-transmitted disease in the United States with about 20,000 new cases reported each year. Lyme disease occurs nationwide; however, twelve states—Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Wisconsin—account for 95% of cases reported. People of all ages are vulnerable to LD, yet significant infection rates occur in school-aged children. Children in endemic suburban residential areas surrounded by tick-infested woods and those who participate in outdoor recreational activities are at risk of getting LD and associated TBIs. Even the city child on a nature outing is at risk with the greatest potential for infection in the spring.

Lyme disease and TBIs are multi-system bacterial and protozoan diseases. These disease-causing microorganisms are transmitted to humans from small mammals through the attachment and feeding of a deer tick or a lone star tick. A single tick may co-transmit several of these microorganisms in the same attachment, which is often unnoticed due to the small, poppy seed-sized tick. Initial indications of infection can include but are not limited to a reddish rash, flu-like symptoms (fever, chills), fatigue, joint pain, headache, stiff neck, mental confusion, and sleeping disturbance. Symptoms are complex and often have puzzling presentations in children. An individual can have LD and TBIs repeatedly.

Physicians are challenged to diagnose early TBIs based on clinical presentations (patient history, exposure risk, and symptoms). Laboratory test data are of limited reliability, identifying only about 50% of infections. A large body of clinical evidence illustrates that diagnosis of LD is especially difficult when the rash is absent, laboratory tests are negative, uncharacteristic symptoms occur (based on physician experience), and/or atypical psychiatric symptoms are present. The task of separating a primary pediatric psychiatric disorder from psychiatric LD and certain TBIs can be daunting and brain imaging technologies and psychological testing may be required. Every child with LD or TBIs has a unique profile of symptoms, which can vary significantly during the process of infection. Although children with TBIs can experience a plethora of symptoms, it is often the subtle multiple cognitive and neurologic deficits that elude prior detection. These deficits have the most profound negative impact on a child's school performance and social life. Frequently symptoms develop in a child who previously performed well within the school environment. A challenging manifestation of TBIs is that symptoms may persist or they may be episodic and fluctuating in type and severity, further confusing diagnosis. Based on teacher or parental observations, the child may not appear sick in the traditional sense.

Disease onset can be gradual with increasing fatigue, social disinterest, or deteriorating school performance. An important finding is that multiple cognitive and behavioral difficulties are similar to those observed with affective, oppositional defiant, attention deficit, and possible autism spectrum disorders. Further complicating diagnosis is the inability of children and teenagers to express their feelings to parents, teachers or friends. Children are not initially diagnosed with psychiatric manifestations of TBIs because their complaints are seen as vague and inconsequential. If the undiagnosed disease has psychiatric manifestations, then a referral from the school or treating physician to a psychiatrist is likely. Adolescents with a history of treated LD can be at risk for long-term problems in cognition and school functioning.

The most important action for parents is to prevent infection. Many universities and public health departments can provide information on tick repellants, protective clothing, high risk areas and behaviors to avoid, landscape chemical applications, and tick control on pets. However, if symptoms and school problems occur due to LD or other TBIs, it is imperative that parents and teachers collaborate, in consultation with a school psychologist and/or nurse to take appropriate medical intervention. Effective parent/teacher communication is crucial to discuss events in the home and school life, the problems they encounter, and feelings that result. It is vital for the parents and school to monitor the ill child's behavior, assessing positive and negative changes, and communicating these observations. Parents and educators can be post-diagnosis advocates and active participants in seeking necessary school accommodations. Frequently, children with LD or associated TBIs and who struggle to remain in school hear comments from their classmates (often behind their back) about their "drama" and that they are just faking for attention. This experience can be devastating to the child's emotional stability and parents and teachers need to support the child and raise awareness in the school community.

Federal law, that is, Section 504 of the Federal Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 2000, and the 2004 Individuals with Disabilities Education Act (IDEA), mandates that students with disabilities in elementary, secondary, and post-secondary schools receiving federal financial assistance not be discriminated against because of their disabilities. In many cases, schools are required to provide needed accommodations and/or supportive Individualized Educational Programs (IEPs). Accommodations include shortened days, un-timed tests, dropping unnecessary requirements, alternative testing methods, separate/quieter testing locations, and modified home instruction programs. Children with Lyme disease should lead as full and normal a life as they are capable of given the severity of their illness.