

# Make Time to Look at Lyme

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An interview with Pat Smith, BA, President, Lyme Disease Association, Inc; Member, Board of Directors, International Lyme & Associated Diseases Society (ILADS); Former President, Wall Township Board of Education, NJ; Former Chair, Governor's Lyme Disease Advisory Council, NJ

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" Sadly, sometimes the nurse is the only support the (Lyme-infected) child has in school," Pat Smith, President, Lyme Disease Association, Inc.

One bite from an almost microscopic tick diseased with Lyme can cause a lifetime of chronic, difficult-to-treat physical and emotional pain. Unlike what many may believe, detection isn't as simple as finding a tell-tale bullseye rash on one's skin. Charles Ray Jones, MD, Pediatrician, Private Practice, New Haven, CT noted in his 2000 report, Pediatric Overview: The Children of Lyme Disease, that, "In my experience treating 5,000+ children birth to 18 with Lyme disease, 50% have no tick attachment history, 10% or less have an erythema migrans (bullseye rash) history." However, he adds that all of these children, "Have a history of living in or having visited a Lyme endemic area and have a decline in the way they play and perform in school."

Further clouding the Lyme picture is the fact that children may or may not experience Lyme-associated problems in a patterned or predictable way: some days are good, some are bad, and others are really bad. Additionally, with so many possible consequences, Lyme can easily be misdiagnosed as something entirely different. The "unpredictability of Lyme," if you will, can also make it difficult to accommodate a student with the disease.

To sort through this minefield of issues, we spoke to Pat Smith, President, Lyme Disease Association, Inc to give us the

latest on Lyme's diagnosis, treatment, and potential preventions as well as best practice ideas for accommodations at school.

BPISH: When it comes to being exposed to ticks, is it known where these exposures are happening most often?

PS: In general, the tick populations do not like well maintained lawns or play areas (short grass, raked leaves) but prefer areas with ground cover and which border woods or fields where the ticks can climb onto high vegetation and wait for a passing animal to brush against them. Pets can also bring ticks into closer contact with humans. Remember however, that ticks can be almost anywhere, since birds as well as small animals such as the white-footed mouse carry them.

BPISH: Are there actions schools can take to minimize potential exposures for students and staff while at school?

PS: Schools can keep play areas and even walking areas well manicured (ornamental shrubs such as pachysandra can harbor ticks), keep children/staff and play apparatus away from edges of woods or fields and preferably place them in dry, sunny areas. Schools can distribute educational material on Lyme including what ticks look like, how to do tick checks, how to properly remove ticks (improper removal greatly increases the risks of disease transmission). Signs in the play yard warning of ticks might be useful reminders of their presence. Light colored clothing and tucking pants into socks is recommended when going into tick infested areas.

BPISH: What about on field trips?

PS: District permission slips can be developed for school trips which may be into heavily forested or field areas, increasing the risk of tick bites. They could incorporate warning information, informing parents of any potential risks, giving them the option of the child not attending, the parent using a repellent on child/clothes, dressing the child more

appropriately or even just reminding parents to perform tick checks at home. These actions protect children from disease and the district and its staff from legal actions (at least one legal action has occurred where a child was alleged to have acquired Lyme on a school trip & the parent was supposedly unaware of the dangers).

BPISH: Do you feel that schools are more reactionary or proactive in dealing with Lyme?

PS: In my 17+ years of Lyme work, I have seen schools slow to react to the impact of the disease, and I use my 12 years past experience on a board of education as an indicator. Individuals within schools now tend to be more concerned about the disease, and often, a knowledgeable advocate in the district will keep the district up to speed on Lyme. Districts that have seen legal or other actions from IEP/504 issues, tend to be more proactive. Unfortunately, lack of knowledge of the impact of Lyme on children often causes a cavalier attitude by the district: Lyme is not serious, cannot produce behavior problems, cannot interfere with learning, kids look fine, they are faking it.

New Jersey has a law which we were successful in having passed 12 years ago requiring mandatory teacher in-service annually for any teachers who have students with Lyme disease. How many districts are in compliance? Perhaps a handful, and mostly those where a parent or school nurse has pursued the issue. NJ also has a state-adopted Lyme curriculum recommended for districts in Lyme endemic areas. I know of few if any schools that use it, and NJ ranks third nationally in reported case numbers. Several districts in Connecticut are working on implementing a Lyme curriculum, again due to parental pressure. So the answer is, parents are proactive and schools generally are reactive to parental pressure.

BPISH: What do you recommend as the effective components to an IEP for a child impacted by Lyme?

PS: Although children with Lyme may be classified with an IEP or 504 plan, sometimes sufficient accommodations can be made without them if the district is cooperative. A lot depends upon the severity/nature of the child's symptoms as to what accommodations are necessary. Children with Lyme experience something I describe as "transitory learning disabilities" since they may vary year to year, month to month, even day to day. Possibilities must be built into an IEP, since conditions change so frequently. A child may require home instruction, special instruction, be in a regular classroom, or may be on home instruction and in school part time at the same time. IEPs often need to contain provisions for instruction over holidays, weekends and the summer, since teachable moments are unpredictable. Also, provisos need to be made for students on long-term home instruction to attend school for special events, lunch, or even for a class visit just to break up the isolation from his/her peers.

Often students can only take core course subjects because they need to conserve all their strength just to get out of bed and complete those subjects. Quality vs. quantity is an issue I have often dealt with in the schools. Students who have the ability to take honors or advanced placement courses are often discouraged from doing so. They need to be supported in that choice and permitted to demonstrate a mastery of the curriculum without having to have the extras normally piled on those students. Many honors students with Lyme have gone on to higher education and distinguished themselves at prestigious colleges, no thanks to districts usually.

BPISH: What are the best role(s) a school nurse can play in helping an infected child?

PS: If the child already has the disease, the nurse can ensure that the child is permitted to come to the nurse's office whenever necessary and lie down when needed. His/her problems must never be taken lightly. Changes in behavior of the student should be immediately reported to parents since that

may signal CNS involvement or that a change in medication is required. New symptoms the nurse may see should also be reported to parents. The nurse should also try to become well-informed about the disease and encourage district officials to provide in-services for staff and help for the student. Sadly, sometimes the nurse is the only support the child has in school.

BPISH: Are you aware of any federal or state pending legislative action that readers could write to their representatives in support of?

PS: Currently Maryland has introduced two bills, one in the senate on doctor protection, another in the House on a Lyme task force formation. New Jersey has identical bills in the Assembly & Senate pertaining to mandatory insurance coverage for LD. New Hampshire has a resolution seeking support for federal research for LD.

[In-service Ideas for Lyme Disease](#)