

## The Role of Co-Infections in Lyme Disease

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There are several other organisms found in ticks which when transmitted alone, or in combination with Lyme disease, may account for increased severity of symptoms and/or persistence of illness. These organisms cause diseases including not limited to, relapsing fever borrelia (e.g., *B. hermsii*, *B. miyamotoi*), ehrlichiosis, anaplasmosis, babesiosis, (e.g., *B. microti*, *B. duncani*), bartonellosis, Rocky Mountain spotted fever, Q-fever, typhus, tularemia, deer tick virus (i.e., Powassan), tick paralysis and STARI. Mycoplasma's role still needs to be determined.

Ehrlichiosis may cause fevers, headaches, myalgias, arthralgias, malaise, and flu-like symptoms with occasional nausea, vomiting, abdominal pain, diarrhea and cough. Clinical laboratory findings may include positive antibody titers for Human Monocytic Ehrlichiosis (HME) and Human Granulocytic Anaplasmosis (HGA), with morulae in leukocytes (intracytoplasmic colonies), low white cell counts, low platelet counts and elevated liver functions in certain patients.

Babesia is an intracellular parasite found in red blood cells which causes a malarial like illness. Children may complain of intermittent fevers, chills, flushing, day and night sweats, cough and shortness of breath, with an increased severity and duration of Lyme disease symptoms. Diagnosis is made by antibody titers (IFA), blood smear, DNA (PCR) and RNA analysis (FISH assay). Antibiotic treatments include atovaquone and azithromycin, and clindamycin and quinine.

*Bartonella* are intracellular bacteria that can be transmitted by fleas, cat bites or scratches, lice and/or tick bites. When present in combination with Lyme disease, atypical presentations may result including visual problems, headaches, significant lymph node enlargement, resistant neurological deficits, and the new onset of a seizure disorder. Diagnosis is made by acute and convalescent antibody titers (IFA) and by PCR (DNA) analysis.

STARI, Southern-tick associated rash illness, also called Master's Disease, is a Lyme-like illness caused by an unknown organism transmitted by the lone star tick.

Continued severity and/or persistence of illness in a child or adolescent with Lyme disease necessitates searching for these other tick-borne diseases, using the above referenced methodologies. Treatment regimens are evolving, but significant clinical improvement may result once all overlapping co-infections are found and treated.

## Emotional Needs of Children and Their Families: Psychotherapy and Family Therapy Support

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Lyme disease, particularly if it is chronic, affects the lives of children and adolescents in 3 major areas: Family, School, Peers.

The family might find the Lyme patient to be irritable and jumpy, depressed or anxious, and constantly complaining. Disturbances in eating and sleeping patterns are common. In adolescents, the role of hormones further complicates the picture. Mood swings often accompany physical complaints. School issues can be considerable, and vary from day to day. Fatigue, cognitive and mood problems, and symptoms that might be seen as ADD or AD/HD may get in the way of school attendance and academic performance.

Children with Lyme often complain about feeling isolated. Profound fatigue can limit, or prevent, socialization. Peers often fail to understand the variations in the levels of functioning from day to day, resulting in their not believing their friends when they complain of their Lyme symptoms. The Lyme patients' lives are further complicated by trips to the doctor, pills they have to take, blood work and other diagnostics. Their experience of life sets them apart from their peers, and the gap that is created can be very difficult to bridge.

Psychotherapy and family therapy with a Lyme-literate psychotherapist can help in the process of recovery from Lyme disease through developing in patients and parents: understanding of the nature of the illness & strategies to deal with it; ability to cope with the flare of symptoms & side effects of medications, yet function at the highest possible level; ability of parents to advocate on the child's behalf in school; enhanced communications & problem-solving, within & outside of the family.

Lyme disease is a medical illness that calls for non-medical strategies to assure the growth and success of your children.

### For Further Reading on School Issues

Smith, P. The Effects of Lyme Disease on Students, Schools and School Policy. School Leader, New Jersey School Boards Association, Sept/Oct 2004. see <https://lymediseaseassociation.org/category/about-lyme/lyme-kids-a-schools/>

Lyme Disease: Etiology, Neuropsychological Sequelae, and Educational Impact R. A. Hamlen and D. S. Kliman Pediatric School Psychology [http://www.lymepa.org/Hamlen-Kliman\\_School\\_Psychology\\_-\\_Lyme.pdf](http://www.lymepa.org/Hamlen-Kliman_School_Psychology_-_Lyme.pdf)

May 2010 | NASN School Nurse, DOI: 10.1177/1942602X10364664 You Can Make A Difference to a Child by Reducing Risk of Lyme Disease <https://lymediseaseassociation.org/about-lyme/lyme-kids-a-schools/you-can-make-a-difference-to-a-child-by-reducing-risk-of-lyme-disease/>

When Your Child Has Lyme Disease – A Parent's Survival Guide by Sandra K. Berenbaum, LCSW, BCD, and Dorothy Kupcha Leland <https://lymediseaseassociation.org/book-list/when-your-child-has-lyme-disease-a-parent-s-survival-guide-by-sandra-k-berenbaum-lcsw-bcd-and-dorothy-kupcha-leland/>

## Educating Children with Lyme Disease

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Children may display a multitude of medical symptoms that can make it impossible to keep up in class. Common educational problems for these students include memory loss, fatigue, depression, and the inability to organize, focus and sustain attention. All of these factors have a negative impact on their ability to perform academically. Children whose illness affects school performance may qualify for special education accommodations or services.

Students with disabilities may receive services under either the Individuals with Disabilities Education Act, IDEA, where classification type depends on how severely the illness impacts learning ability or Section 504 of 1973 Rehabilitation Act, civil rights legislation that prevents discrimination. Students qualify for 504 services if their medical condition "substantially limits" their ability to learn. Students with Lyme disease often fit into 504, due to their ever-shifting medical and educational condition. Schools preschool through college that receive federal funding must meet 504 requirements.\*

School district special education policies adopted by the board of education should be examined. Policies that mandate a waiting period for home instruction do not apply to long term home instruction under an Individualized Education Program, IEP. IEP's should be written so that students with Lyme can attend school when medically able and be concurrently eligible for supplemental home tutors, or they can receive home instruction without a waiting period. An extended school year can be written into an IEP, and all subjects and subject levels that are offered in a school setting must be offered, with modifications as necessary, to a student on home instruction. The parent is an integral part of the child study team, and as such, must be informed and be an active participant in the process of making educational decisions for the student. If a conflict exists between parents and school district, a parent can appeal decisions made. If the issue involves 504, appeals can be made to regional Office of Civil Rights. If an IDEA issue, appeals can be made to the US Dept. of Education through the Education Department of that state. A Lyme literate advocate can help at early stages but the appeals process is often more successful when an education attorney is involved. \* 504 requirements - [www.nclld.org](http://www.nclld.org) <http://idea.ed.gov/explore/home>

## Involvement of the Nervous System in Lyme Disease

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The nervous system is frequently affected by Lyme disease. Both the central and peripheral nervous systems are at risk. Frequently, patients with Lyme disease develop an encephalopathy resulting in learning disabilities, difficulties with attention span, memory and word finding, and the patients complain of headache. Acutely, a person may also have a Lyme meningitis with inflammation of the covering over the brain and spinal cord. They may have an inflammation of the brain itself called encephalitis. Nerves can be involved, such as the 7th nerve causing a facial palsy, or peripheral nerves causing neuropathy with sensory changes and weakness. There have been rare cases of stroke, and patients may have seizures with Lyme disease. In children, we can also see increased pressure in the nervous system called pseudo tumor. This also results in headaches and may also affect vision. The muscles may be involved and this can cause weakness and pain.

Some diagnostic tests that may be helpful in evaluating the nervous system include an MRI of the brain, EEG, spinal tap, EMG's and nerve conduction studies.

In addition to treating the Lyme disease with appropriate antibiotic therapy, medications may have to be given to help relieve some of the symptoms and the discomfort that patients have as a result of involvement of the nervous system. They may require anti-convulsants for seizures, diuretics to decrease the intracranial pressure, analgesics for pain, appropriate education intervention if there are learning problems, and physical therapy for weakness.

It is important for physicians and patients to recognize how frequently the central and peripheral nervous systems may be involved in Lyme disease.

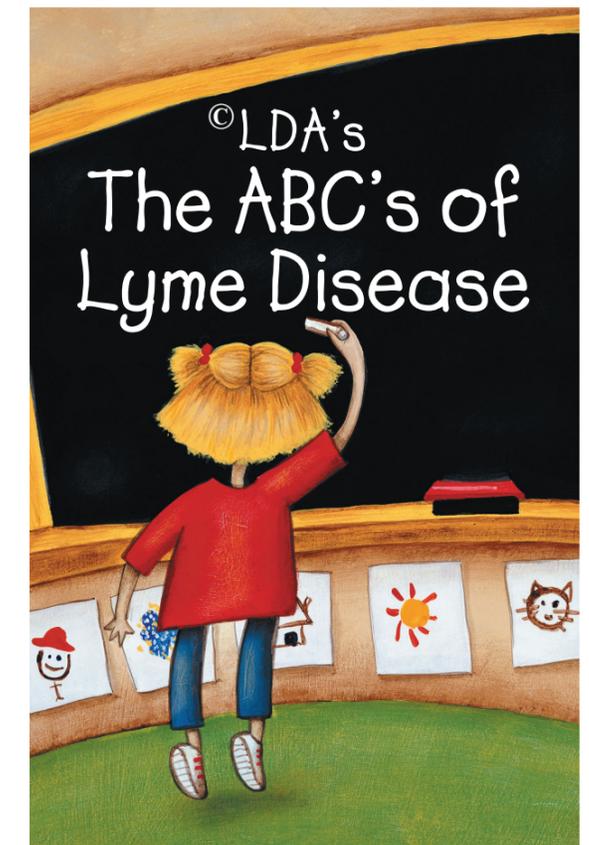
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## Pediatric Overview: The Children of Lyme Disease

**Charles Ray Jones, MD**

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Current research indicates that the Lyme disease bacteria, *Borrelia burgdorferi*, can be transmitted within hours after an infected tick attachment. Failure of parents and teachers to recognize Lyme disease early can result in a child developing a chronic difficult to treat infection in the brain, eyes, joints, heart and elsewhere in the body. In my experience treating over 30,000 children from birth to 18 with Lyme disease, 50%, have no history of tick attachment, 7% or less have an erythema migrans bull's eye rash, but all 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. They tire easily and have dark circles under their eyes and are sick.

Lyme disease has a profound negative impact on a child's life, cognitive function and ability to perform maximally in school. Severe fatigue unrelieved by rest results in decreased stamina and a decreased ability to play and to do school work. Insomnia, headaches, nausea, abdominal pain, impaired concentration, poor short-term memory, an inability to sustain attention, confusion, uncharacteristic behavioral outbursts and mood swings, fevers/chills, joint pain, dizziness, noise and light sensitivity, and difficulty thinking, expressing thoughts, reading, writing, and making decisions as well as being overwhelmed by schoolwork and by life. Pain and impaired cognitive function make it difficult to sustain attention and learn and recall new material.

Although Lyme is usually transmitted by an *Ixodes scapularis* tick (a.k.a., deer tick), it can also be transmitted in utero. The DNA of the Lyme bacteria has been detected in breast milk; however no transmission through human breast milk has been proven to date. The children born with Lyme disease are frequently floppy due to poor muscle tone, irritable and ill early in their lives with frequent fevers, increased ear and throat infections, pneumonia, as well as joint and body pain. They also have gastroesophageal reflux, small windpipes (tracheomalacia), cataracts and other eye problems, developmental delay, learning disabilities, and behavior and psychiatric problems. All respond to months or years of continuous antibiotic therapy.

In most circumstances, an *Ixodes scapularis* tick attachment should be treated with one month of antibiotic therapy. Lyme disease can also result in an autoimmune disorder caused by antibodies targeting the brain and peripheral nervous system. This infection induced autoimmune encephalopathy and polyneuropathy can be treated with continued antibiotics, IVIG, as well as plasma exchange.

## A Parent's Guide to Understanding the Visual Consequences of Lyme Disease

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Lyme disease affects visual processing in the brain yet symptoms are often mistaken for other problems associated with functional ocular disorders, balance and movement disorders and cognitive dysfunction. When a child is infected, often they experience symptoms including blurring, double vision (diplopia), photophobia, distortion of space, visual strain and headaches when performing near vision activities, difficulty with balance, dizziness, convergence and focusing difficulty.

Standard eye exams may show difficulties with convergence and accommodation (focus of the eyes), which can occur without Lyme disease. This often causes doctors to try and treat the convergence and/or focusing problems with vision therapy rather than understand that these are characteristics of a visual processing dysfunction in the brain caused by Lyme related disease.

Recent research has found a biomarker using visual evoked potentials (VEP), demonstrating that Lyme-related disease causes dysfunction with spatial visual process in the brain, which causes a balance interference between two visual processes in the brain, causing the functional vision difficulties. A compromise to the spatial visual process causes the child's vision to isolate on detail. Reading is no longer fluent. Instead of the spatial visual process seeing the shape of several words before the higher process sees the letters, the child begins to see the words as isolated details of letters—'focal binding'—producing intensity within the visual process that interferes with comprehension, memory and produces fatigue, headaches and visual fatigue. This condition also affects the children when in busy moving environments. The world becomes over-whelming, producing anxiety and even panic attacks at times.

Treatment requires an inter-professional team, including the treating physician, a vision specialist such as an optometrist or ophthalmologist practicing Neuro-Visual Processing Rehabilitation (NVPR), a neuro-psychologist specializing in Lyme disease and a social worker. The vision exam may include a sensorimotor evaluation, comprehensive refraction, and dynamic testing of accommodation and convergence, a VEP and a vision-balance gait analysis. Special prescriptive glasses for distance and near vision with prisms that rebalance the spatial visual process may be recommended.

### Suggested Resources:

<https://www.LymeDiseaseAssociation.org>

<https://Columbia-Lyme.org>

<https://www.ILADS.org> 🦋 <https://www.IGeneX.com>

## The Rheumatic Manifestations of Lyme Disease in Children

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Lyme disease can cause a variety of arthritic manifestations in children that can mimic many other rheumatological disorders. It can present with monoarticular arthritis, but more commonly will develop into a migratory polyarthritis. Joint swelling frequently does not occur, but may occasionally be seen in late stages of the infection. Patients often complain of "traveling" arthritis. The most commonly involved joints are the knees, hips, neck, wrists, hands and temporomandibular joints.

It is not uncommon for a patient to have concomitant muscular pain. The muscle pain is most often found to be in a diffuse pattern, and not localized to the classic "trigger point" locations seen in fibromyalgia. Children with Lyme disease may also experience morning stiffness, rest pain and muscle weakness. Difficulties in the child's ability to participate in sports activities will be noticed. Inflammatory myopathies, such as dermatomyositis and polymyositis have also been documented in chronic Lyme disease.

The proper evaluation of these patients should include the appropriate serology for tick-borne disorders, accompanied by levels for antinuclear antibodies, rheumatoid factor, and creatinine kinase and sedimentation rate. Cross-reactive antibodies against the Lyme bacteria may yield low levels of false positive autoantibodies. Appropriate antibiotic treatment should be given until the joint and muscle symptoms dissipate. Partial treatment may result in the development of chronic arthritis.

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- 🦋 Published book for 8-12 year olds with Lyme  
*Lyme Disease Is No Fun: Let's Get Well*, Mary Wall, MSED

## Neuropsychiatric Effects of Lyme Disease on Children and Adolescents

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Children with Lyme disease may develop neuropsychiatric symptoms affecting mood, thinking, and behavior. The infection itself may have direct effects on the brain or indirect effects through the activation of the immune system which produces substances which affect the brain. For example, marked fatigue would result in trouble paying attention or staying awake in class as well as struggles with parents about getting to school on time.

Common psychiatric presentations in younger children include irritability and increased separation anxiety or other fears. In older children, mood swings and anxiety attacks are more common. Less frequently, children may develop new onset motor or vocal tics, obsessive compulsive disorder, or rarely an encephalitis with behavioral regression that looks very much like an autistic spectrum disorder.

Common cognitive problems include trouble with visual and auditory attention and slower mental processing speed. Children with unrecognized Lyme disease may be misdiagnosed as having primary attention deficit disorder — a mistake that not only results in unnecessary school problems for the child but also may allow a treatable acute infection to become a more entrenched chronic one. For example, these children may have trouble directing or maintaining focus on what the teacher says in class or storing into memory what he/she reads. The decline in school performance alarms parents and may result in a lowering of the child's self-esteem such that he/she feels stupid - until the cause is identified. Neuropsychological testing may reveal that the child's IQ has declined considerably, with the performance subtests more heavily affected than the verbal subtests. School systems must make special accommodations for these medically-disabled children.

As an adjunct to the medical work-up of these children, brain SPECT scans can be helpful in differentiating primary psychiatric disorders from the secondary neuropsychiatric effects of a diffuse brain illness such as Lyme disease.

### For Further Reading:

Tager FA, Fallon BA, Keilp J, Rissenberg M, Jones CR, Liebowitz MR.

A controlled study of cognitive deficits in children with chronic Lyme disease.

J Neuropsychiatry Clin Neurosci 2001 Fall;13(4):500-507.

Fallon BA, Kochevar JM, Gaito A, Nields J. The Underdiagnosis of

Neuropsychiatric Lyme Disease in Children and Adults. In Diagnostic Dilemmas.

Edited by David Tomb. Psychiatric Clinics of North America, 1998; 21: 693-703.

## Lyme Disease in the Eye: A Pediatric and Adolescent Perspective

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Lyme disease is a significant infectious disease that has become endemic in certain areas of the country with the encroachment of human development on natural areas. Adolescents and children are probably at a higher risk for this illness because they spend more time in areas where they might suffer a bite from a tick carrying the infectious spirochete, *Borrelia burgdorferi*. As a neuro ophthalmologist, I see Lyme disease patients presenting with a number of ocular findings, including optic neuritis, neuroretinitis, anterior uveitis, keratitis, dry eye and episcleritis. Furthermore, these patients can have central nervous defects, including hyperintense white matter lesions of the brain and even an arachnoiditis leading to intracranial hypertension. Because of the neurasthenic effects of this illness, patients often present with reading difficulties such as fatigue, tearing, letters running together, or even frank double vision.

Lyme disease can mimic so many diseases, including multiple sclerosis, chronic fatigue syndrome, myasthenia gravis and fibromyalgia. Therefore, a young patient's health care team must ensure that the patient has been correctly diagnosed. Intracranial hypertension is a difficult diagnosis, particularly when it presents in an uncommon way. In addition, physicians must be cognizant of the fact that Lyme disease may include co-infections.

If Lyme disease attacks the optic nerve, it can lead to blindness. For this reason, a cursory examination might not elucidate the etiology of a child's or adolescent's vision problems. Neuro ophthalmologists are particularly trained in examining the entire visual pathway.

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