

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 which include, but are not limited to, Ehrlichiosis, babesiosis, bartonellosis, Rocky Mountain spotted fever, Powassan encephalitis, Q fever, tick paralysis, anaplasmosis, and STARI.

Ehrlichiosis may cause high fevers, headaches, myalgias, and flu-like symptoms. Clinical laboratory findings may include positive antibody titers for Human Monocytic Ehrlichiosis (HME) and Human Granulocytic Ehrlichiosis (HGE now called anaplasmosis), with morulae in leukocytes (intracytoplasmic colonies), and low white cell counts, low platelet counts with elevated liver functions in certain patients.

Babesia microti is an intracellular parasite found in red blood cells which causes a malarial like illness. Children may complain of intermittent fevers, chills, day and night sweats, as well as having 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 henselae are intracellular bacteria that can be transmitted either by a cat bite or scratch or a tick bite. 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, both by titers and serial PCR's. Treatment regimens are still evolving, but significant clinical improvement may result once all overlapping co-infections are found and treated.

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.

Lyme Disease Association, Inc.

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- Is a national all-volunteer 501(c)(3) corporation.
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- Devotes over 95 cents of every dollar to programs.
- Partnering with Time for Lyme affiliate and Columbia to open endowed Lyme Research Center.
- Helps children with Lyme get a proper education.
- Sponsored first national medical conference focusing on Lyme Disease in Children & Adolescents.
- Has 34 partner organizations nationwide including affiliates, chapters, supporter groups.
- Published book for 8-12 year olds with Lyme
- Established LymeAid 4 Kids fund for kids with no insurance

Educating Children with Lyme Disease

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Former President, Wall Township Board of Education, NJ
Former Chair, Governor's Lyme Disease Advisory Council, NJ

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 the 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.

Resources
<http://www.ideapractices.org>
<http://www.504idea.org>
<http://www.specialeducationadvocacy.com>

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, SPECT scan, 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.

Other recommended resources:

<http://Columbia-Lyme.org>

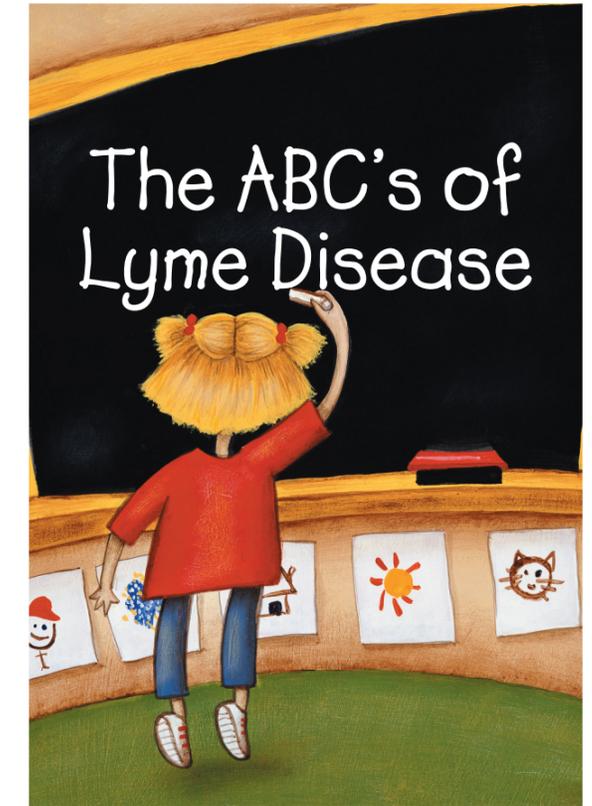
<http://www.LymeNet.org>

<http://www.Lymeinfo.net>

<http://www.ILADS.org>

<http://www.IGeneX.com>

<http://www.LymeDiseaseAssociation.org>



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Pediatric Overview: The Children of Lyme Disease

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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 in its course 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 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, 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 are tired, wilt easily, 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 behavior 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 a feeling of being overwhelmed by schoolwork plague a child with Lyme disease. Pain and impaired cognitive function make it difficult to sustain attention and to learn and recall new material.

Although Lyme is usually transmitted by *Ixodes scapularis* (deer) and Lyme-like STARI (Southern tick-associated rash illness) by *Amblyomma americanum* (lone star) ticks, it can also be transmitted in utero and possibly through breast milk. These children, frequently floppy with poor muscle tone, are irritable and ill early in their lives with frequent fevers, increased incidence of ear and throat infections, pneumonia, joint and body pain. They have gastroesophageal reflux, small windpipes (tracheomalacia), cataracts and other eye problems, developmental delay, learning disabilities, and psychiatric problems. All respond to months or years of continuous antibiotic therapy.

When Lyme disease is a possible diagnosis, the children should be evaluated by a Lyme knowledgeable physician who will continue antibiotic therapy until all Lyme symptoms resolve. In most circumstances, *Ixodes scapularis* tick attachment should be treated with one month of antibiotic therapy.

Lyme Disease in the Eye: A Pediatric and Adolescent Perspective

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Lyme disease is a significant infectious disease that has become much more common lately 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, anterior uveitis, keratitis, dry eye, and episcleritis. Furthermore, these patients seem to 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 double vision.

Lyme disease can mimic so many diseases, including multiple sclerosis, chronic fatigue syndrome 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.

If Lyme disease attacks the optic nerve, it can lead to blindness. For this reason, examining just the eyes 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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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 three 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:

- ☛ An understanding of the nature of the illness, and strategies to deal with it.
- ☛ The ability to cope with the flare of symptoms and side effects of medications, yet function at the highest possible level.
- ☛ The ability of parents to advocate on the child's behalf in school.
- ☛ Enhanced communications and problem-solving, within and 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 <http://lymediseaseassociation.org/Schools.html>

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 a 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.

Gastrointestinal Lyme

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Lyme disease has been reported in the gastrointestinal tract of children and adolescents. Pediatric gastrointestinal Lyme disease may present as abdominal pain, vomiting, diarrhea, heartburn, blood in the stool, and it may mimic Crohn's disease or colitis. Blood tests for diagnosing Lyme disease may be negative while gastrointestinal and other Lyme disease symptoms persist. The diagnosis is made clinically on the basis of symptoms and by excluding other possible etiologies.

Once treatment has begun with antibiotics, most patients reported a decrease in the frequency and severity of their abdominal pain. In addition to antibiotics, a low fat diet further alleviated some of the abdominal symptoms associated with Lyme disease. In patients who reported having a crampy, colicky, below the belly button pain, treatment also included antispasmodic and anticholinergic medications.

After treatment was completed, some residual abdominal pain may persist for a couple of months at a markedly reduced level of severity. This diminished pain usually represents the activation and persistence of the immune system to fighting the infection even long after the infection is gone.

In addition to Lyme disease, other co-infections such as Bartonella, mycoplasma, H. pylori and babesia have been confirmed to occur in the GI tract.



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