

Pediatric Overview The Children of Lyme Disease

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Lyme disease is a tick-borne infection caused by the bacteria *Borrelia burgdorferi* and is increasingly detected in children. Parents and teachers should recognize that pediatric presentations are often subtle, atypical, and easily missed. Failure to do so may lead to a difficult to treat infection that can affect the child in numerous ways. The classic erythema migrans (EM) “bull’s-eye” rash may be absent in more than half of cases. Infection can be transmitted within hours, shorter if the tick is agitated during removal. Many families never see a tick, so absence of a clear bite does not exclude disease. In-utero transmission also happens, so a tick bite is not always necessary.

Symptom awareness is crucial. Beyond fever and fatigue, children may present with migratory joint or limb pain; intermittent swelling of knees or other joints; headaches (often pressure-type), neck pain, light or sound sensitivity, light-headedness, or vertigo. Neurologic and neuropsychiatric features can include facial palsy, tingling, numbness, burning or stabbing pains, allodynia, clumsiness, gait changes, motor tics which can lead to school bullying and regression in gross and fine motor skills. Cognitive and behavioral changes are common: “brain fog,” memory or word-finding problems, school decline, slowed processing, anxiety, depression, oppositional behavior, or new ADHD-like symptoms. PANS (Pediatric Acute-onset Neuropsychiatric Syndrome) and PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections) have been linked to Lyme and Bartonella in some cases.

Sleep disturbance, frequent abdominal pain, nausea, vomiting, diarrhea or constipation, poor appetite, and weight changes are often seen. Palpitations, chest pain, shortness of breath, new exercise intolerance, or fainting can suggest cardiac involvement. Recurrent sore throats, swollen glands, temperature dysregulation and dysautonomia may occur. Ticks frequently carry co-infections (e.g., Babesia, Bartonella, Anaplasma, Ehrlichia), which can intensify symptoms. Babesia may cause high fevers, drenching sweats, air hunger, and more marked fatigue. Bartonella is associated with neuropathic pain, striae-like skin lesions, swollen tender nodes, and prominent neuropsychiatric or behavioral changes. Anaplasma/Ehrlichia can cause higher fevers, muscle pain and liver enzyme elevation.

Standard two-tier serology (ELISA followed by Western blot) has limited sensitivity, especially in later or persistent cases. A negative test does not exclude Lyme in a compatible

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clinical picture. Diagnosis is primarily clinical, supported—but not ruled out—by laboratory findings. For typical EM, antibiotics should be started promptly without waiting for tests.

Treatment is individualized, with amoxicillin, cefuroxime, azithromycin or doxycycline (age-appropriate) commonly used. Duration is guided by clinical response rather than strict short courses, particularly in disseminated or neurologic disease. Ongoing care includes monitoring for Jarisch–Herxheimer reactions, managing pain, sleep, mood, and school issues, and considering co-infections and other contributors in persistent pediatric illness.

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.

Emotional Needs of Children and Their Families: The Role of Psychotherapy & Family Therapy

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Lyme disease can drastically affect children and adolescents in three major areas: family life, school, and peer relationships. Household routines may get upended, as parents rearrange work schedules and family activities to accommodate the child’s needs. The young patient may be irritable and jumpy, depressed or anxious, and constantly complaining. Patterns of sleeping and eating may be disrupted. In adolescents, the role of hormones further complicates the picture. Mood swings often accompany physical complaints. Furthermore, other siblings in the family may feel their own needs are being ignored.

Fatigue, pain, sensitivity to light and sound, as well as cognitive impairment can make things difficult in the classroom. Some students can stay in school if given necessary accommodations. Others may need alternative educational approaches, such as online classes or other versions of homeschooling. Some young people with Lyme are simply too ill for any school at all.

Too sick to participate in activities with friends, children with Lyme often feel isolated. Their experience of life sets them apart from their peers, with a gap that can be difficult to bridge.

A Lyme-literate psychotherapist can help the family navigate the process of recovery 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
- The ability of parents to advocate on the child’s behalf in school. The student with chronic Lyme disease often needs a 504 plan or an IEP, with modifications, accommodations and in many cases, special services, to succeed 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 Resource: www.lymefamilies.com – www.lymeliteratepress.com, *When Your Child Has Lyme Disease – A Parent’s Survival Guide*
Sandra K. Berenbaum, LCSW, BCD and Dorothy Kupcha Leland

The ABCs & 123s of Lyme Disease provide practical and helpful details about Lyme disease & other tick-borne illnesses. These materials are available to the public with the understanding that COTBDAA and the LA4K Program do not offer medical or professional services. ©2000-2026 Colorado Tick-Borne Disease Awareness Association. All rights reserved.

Laboratory Testing for the Major Tick-Borne Diseases

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While the diagnosis of the major tick-borne diseases is a clinical one, it is helpful to have laboratory confirmation. This is especially true because many Lyme patients are concurrently infected with multiple tick-borne pathogens, and testing is the best way to sort this out.

Traditional “standard” tests, classified as serologies, include the IFA, ELISA, and Western Blot. These are falling out of favor due to limited accuracy. They use crude, single-species antigens that frequently miss other, equally important species and strains, and have poor sensitivity and specificity. Replacing these old-tech tests are new ones that utilize advanced recombinant antigen technology and direct detection methods. While there are many labs that test for Lyme and associated tick-borne diseases, the list below highlights the better-known ones.

- **Recombinant Protein Antigen Assays:** Unlike standard serologies, these use genetically engineered protein antigens to increase accuracy and allow for extended species coverage. These tests are the usual starting point and are available from IGeneX for Lyme *Borrelia* (FDA-cleared), tick-borne relapsing fever (TBRF), *Bartonella*, and *Babesia* species.

- **T-Cell Response Assays:** This method measures the host’s cellular immune response to infections and can be used as a diagnostic test. It is most sensitive very early and very late in an infection and is useful for patients with B-cell immune deficiencies whose lack of antibody production may render standard serologies falsely negative. Available from Armin Labs for the major tick-borne diseases, and from IGeneX for Lyme and *Bartonella*.

- **FISH (Fluorescent in-Situ Hybridization):** This test uses fluorescent probes to “light up” pathogen RNA under a microscope. It is a direct-detection method available through IGeneX for *Babesia* and *Bartonella*, and from T-Labs for *Borrelia*, *Bartonella* and *Babesia*. Notably, it can detect these organisms even if they are embedded within biofilms.

- **Standard Blood PCR,** while highly specific, is insensitive because the number of pathogens in the blood is often too low to be detected by this method. Droplet-digital PCR is a slightly more sensitive PCR process, available at Galaxy Labs.

- **Culture-Enhanced PCR** solves this by growing the bacteria in a specialized medium first, increasing the pathogen’s numbers to detectable levels. From IGeneX for Lyme, TBRF, *Babesia*, *Bartonella*, *Anaplasma*, *Ehrlichia* and *Rickettsias*, and from Galaxy for *Bartonella*.

Knowledgeable clinicians often utilize a multi-test panel that combines several complimentary methods to increase accuracy and to ensure that concurrent infections are not missed.

The Role of Co-Infections in Lyme Disease

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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, but not limited to, relapsing fever *borrelia* (e.g., *B. hermsii*, *B. miyamotoi*), ehrlichiosis, anaplasmosis, babesiosis, (e.g., *B. microti*, *B. duncani*, *B. odocoilei*), bartonellosis, Rocky Mountain spotted fever, Q-fever, typhus, tularemia, deer tick virus (i.e., Powassan), tick paralysis and STARI.

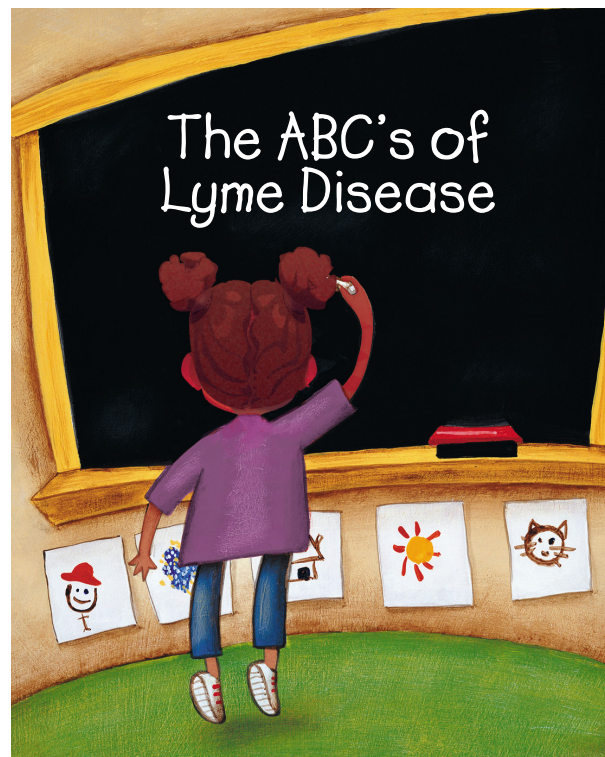
Ehrlichiosis and Anaplasmosis may cause fevers, headaches, myalgias, arthralgias, malaise, and flu-like symptoms, with occasional nausea, vomiting, abdominal pain, diarrhea and cough. Meningoencephalitis is possible. Look for positive antibody titers for Human Monocytic Ehrlichiosis (HME) and Human Granulocytic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

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. Tafenoquine is being evaluated for resistant cases.

Bartonella are intracellular bacteria that can be transmitted by fleas, cat bites or scratches, lice, flies, 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 and psychiatric problems, and the new onset of a seizure disorder. Diagnosis is made by acute and convalescent antibody titers (IFA), Immunoblots, PCR (DNA) analysis and FISH testing.

STARI, Southern-tick associated rash illness, also called Master’s Disease, is a Lyme-like illness, and Alpha-gal syndrome (AGS) with delayed allergic symptoms (including gastrointestinal problems) can result from a lone star tick (*A. americanum*) bite.

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 coinfections are found and treated. With many TBDs early treatment with doxycycline can save lives.



Important Information for Parents, Educators & School Nurses



LymeAid 4 Kids National Program



The ABC’s & 123’s of Lyme Disease are part of the LA4K National Program.

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