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LYME TIMES

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Number 42

CHILDREN'S TREATMENT ISSUE:

Jones on Diagnosis & Treatment
Psychiatric Medications
Pediatric Symptom List
Neurologic Lyme
Donta Treatment Study
Pediatric Nurse Tips
Family Issues
Gestational Lyme

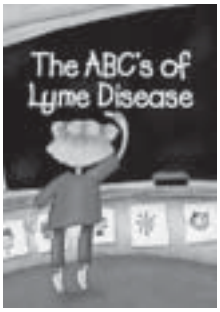
About CALDA

The California Lyme Disease Association (CALDA) is a non-profit corporation that acts as the central voice for all tick-borne disease issues in California and a supporting voice for national issues. Through advocacy and education of the public and healthcare professionals, CALDA seeks to prevent tick-borne diseases, encourage early diagnosis, and improve the quality of healthcare provided to people with tick-borne diseases.

Activities:

- Publishes the Lyme Times, a lay journal, which is distributed nationally and internationally;
- Shares its best practices with other states and national organizations through the CALDA websites (see calda.intranets.com and www.lymedisease.org);
- Acts as a central resource for patients, physicians and support groups providing technical support for their local education and advocacy efforts;
- Instigates and coordinates statewide advocacy efforts;
- Works with statewide governmental and local health agencies, medical associations and tick-borne disease physicians, universities, insurance companies, and diagnostic laboratories;
- Serves on the California Lyme Disease Advisory Committee established by SB1115;
- Maintains a statewide speakers bureau of doctors and patients who can speak with the press or physician groups.

The Lyme Times wishes to thank the LDA for allowing us to use some of the language from their fabulous brochure on children: *The ABCs of Lyme Disease.* This brochure can be obtained in full from the LDA website at www.LymeDiseaseAssociation.org



About the LDA

The national Lyme Disease Association has many accomplishments focusing on children:

- First law in the country to mandate Lyme disease teacher in-services (NJ).
- NJ State-adopted Lyme school curriculum.
- Only fully certified national Lyme disease medical conference focusing on children.
- Brochure devoted to children with Lyme disease (The ABC's of Lyme Disease).
- First book written for children with Lyme (Lyme Disease Is No Fun: Let's Get Well!).
- NJ professional development provider (credits for LD workshop attendance by teachers).
- Article in a school journal from school board perspective **(**NJ School Boards Association "School Leader" The Effects of *Lyme Disease on Students, Schools, School Policy)*.
- Fund, for children without insurance, LymeAid 4 Kids, supported by author Amy Tan.
- Federal News Service Best Practices in School Health Lyme Module, LDA interview & ABCs used.
- In-serviced Rhode Island School Nurses & NJ Div. of Youth & Family Services nurses.
- School advocacy work IEP/504.
- Student & Scout presentations.
- TV and radio interviews, Lyme & schools.
- Appeared in Time for Lyme school video; grant to LAGKC for Kansas school nurse packets.

LDA funded child-oriented research projects:

The Underdiagnosis of Neuropsychiatric Lyme Disease in Children and Adults" Brian Fallon, MD, The Psychiatric Clinics of North America. IQ has been shown to fluctuate and can be restored after treatment for Lyme.

"A Controlled Study of Cognitive Deficits in Children with Chronic Lyme Disease," Felice A. Tager, PhD, Brian A. Fallon, MD, Journal of Neuropsychiatry and Clinical Neurosciences. Lyme disease in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments.

"*Borrelia burgdorferi* Persists in the Gastrointestinal Tract of Children and Adolescents with Lyme Disease," Martin Fried, MD; Dorothy Pietrucha, MD, Journal of Spirochetal and Tick-borne Diseases. *Borrelia burgdorferi* and other tick-borne diseases can survive long-term treatment in the GI tract of children.

LYME TIMES

Journal of the California Lyme Disease Association

Contents

Check out our websites

www.lymedisease.org
CALDA's original website, with information about the organization and about tick-borne diseases. Also links to our allies in the fight against Lyme.

calda.intranets.com
CALDA shares its best practices on this website. Documents you can download, templates you can use, and links to informative websites.

www.lymetimes.org
You can view and download back issues of the Lyme Times as pdf files.

Guest Editorial

Entering the world of professional involvement with Lyme disease in 1991, I was astonished to find some of the most compassionate and intelligent doctors, researchers, advocates, patients, and parents—all passionate about tackling this disabling disease. From the beginning, my particular focus was the children. Many had been infected when they were very young before they were "fully formed" and had a sense of who they were and what was normal for them. Their needs are therefore *far more complex* than the needs of adults with Lyme. So complex, in fact, that we ultimately found it necessary to dedicate two issues to the world of children with Lyme disease—this special children's treatment issue, and a special children's education issue (to be published in the Spring, 2006). We are grateful to Pat Smith, who has been tireless in her efforts on behalf of children, for sponsoring this issue.

The cornerstone in accurate diagnosis and treatment is the pediatrician and no one has more experience than Dr. Charles Ray Jones, who, together with Dr. Steve Harris, has written our anchor article. The treatment of a child is a team effort, however, and we have compiled an incredible team in this issue: Dr. Robert Bransfield on psychiatric medications, Dr. Dorothy Pietrucha on neurological manifestations of Lyme disease in children, Dr. Ann Corson on treating children with Lyme in a more rural environment, nurse practitioner Ginger Savely on the role of pediatric nurses, Dr. Sam Donta's treatment study, and Drs. Martin Fried and Singman on gastrointestinal and opthamalogic manifestations, respectively. This issue also includes the results of the study of 102 children with gestational Lyme disease by Dr. Jones and others as well as extensive bibliographies pulling together for the first time some of the most critical studies on children. And this is just the beginning.

Working with Lorraine and Phyllis to put this issue together has been one of the most gratifying experiences in my years of involvement with Lyme disease. I believe we have met our goal of providing a comprehensive resource that will help combat the ignorance that surrounds Lyme disease in children. While dedicated physicians and researchers seek long-term solutions that will prevent and cure tick-borne diseases, there is room for the rest of us to play our part in curing that *ignorance* that exists in the world of these children and families. Our children need Lyme-literate pediatricians, neurologists, psychiatrists, nurses, psychotherapists, family therapists and parent advocates. We need psychiatric hospitals that will attend to both the psychiatric and medical needs of those children who require hospitalization to be safe. We need Lyme-literate family members, friends, and neighbors.

Can we do less for our kids? They are, after all, our future.

Sandy Berenbaum, LCSW, BCD

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Tick-Borne Diseases in Children and Adolescents:
A Medical Illness with a Multidisciplinary "Cure"

by Sandy Berenbaum, LCSW, BCD

Coming together is a beginning. Keeping together is progress. Working together is success.

~Henry Ford

We in the Lyme world all know that tick-borne diseases are caused by complex organisms that can affect just about any part of the body, and we realize that the key to getting well is finding a Lyme-literate doctor, obtaining an accurate diagnosis, and comprehensive, efficacious treatment. While treating the medical aspect of the disease is paramount, for children and adolescents with chronic Lyme disease, medical treatment alone is *not enough.* Many of these children have Lyme related psychiatric symptoms or educational impairments. Their serious symptoms, combined with the duration of the illness, often leads to gaps in their development. Their isolation can leave them lonely, and inhibit their ability to interact with peers. These issues are best addressed through the coordinated efforts of a team.

Children and adolescents with chronic Lyme, often meet the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria for one or more "mental illnesses"—anxiety disorder, depression, anorexia nervosa, AD/HD, as well as disorders in which behavioral problems manifest—oppositional defiant disorder, conduct disorder, and for some, psychosis. Even though the "mental illness" may be due completely to Lyme, the serious psychiatric symptoms cannot be ignored. For many, psychiatric medications are essential in managing the symptoms during treatment, including the complex issues of managing symptom flares (Jarisch Herxheimer reactions), brought on by the antibiotics. Thus, there is a need for involvement of Lyme-literate psychiatrists who treat children.

These "mental illnesses" carry a constellation of issues. The *anorectic* children, for example, often have an aversion to certain foods, or a rigid pattern of eating, and there is an obsessional quality to their thinking, about food and exercise. Some put a pathological spin on suggestions doctors make for a "yeast free" diet while on antibiotics, some refuse to take any medications by mouth. Weight gain typical of some Lyme patients terrifies the anorectic, and pathological weight loss brings them comfort. These issues need to be dealt with in individual and family therapy to keep the anorectic child safe and healthy during the acute phases of the illness and Lyme treatment.

Anxiety is another symptom common to children with Lyme. The anxiety presents for many in their fears about school failure, even as their cognitively impaired brains struggle to succeed. It takes a Lyme-literate team to deal with the anxious child with Lyme—the medical doctor who treats the illness, the psychiatrist who prescribes the medication for

anxiety, the psychotherapist who teaches the child and family strategies for dealing with the anxiety, helps the child learn to think in a different way (cognitively-based therapy is helpful here), and the Lyme-literate school team who provides support and accommodations for the child who has impairments that affect learning. The school nurse or guidance counselor can provide a brief respite, and support, for the anxious child, in the middle of the chaos of the school day.

Behavioral problems are often due simply to the infection in the brain, and will resolve as the illness is treated comprehensively. However, the treatment could take a long time, and the behaviors need to be addressed and managed during these difficult times. Intervention and support of a Lyme-literate psychiatrist and/or psychotherapist, as well as involvement of a parent advocate who develops a plan for managing behaviors in the school setting can make a significant difference in the life of the child and the family.

Attention needs to be paid to the tasks of the various developmental stages the child with chronic Lyme is going through. The most difficult stage to manage is adolescence, where the Lyme patient may deny the illness and resist treatment to be "normal," in an attempt to individuate. At this stage, some will self-medicate the Lyme symptoms with street drugs. If the child has been ill for a long time, it may be difficult to distinguish between symptoms of the illness and who the child really *is*. It is helpful if these symptoms are addressed in therapy, as well.

Part of the work of childhood is to develop social skills, to learn how to interact with others. Children learn this at home, in their communities, in school, on the ball field. When a child is ill with chronic Lyme, often her exposure to others is very limited. Some children have been on homebound instruction for months and years, not even having the school community to interact with. Socialization needs can be addressed in therapy, and for those who are seriously ill, some social experiences can be built into their week.

While physicians who treat Lyme are focused on diagnosing and treating the *medical illness*, it is also important to recognize that there is more to treating the child with Lyme than ridding the body of infection. We need an integrated approach that includes doctors, nurses, psychiatrists, psychotherapists, neuropsychologists, educators, and advocates. It is important that we are aware of each other's roles, and communicate regularly.

The impact of Lyme disease on children and adolescents is not just a medical issue. By working together to support and treat the *whole child*, we can help our children achieve more than physical health. They can become resilient, life-loving, successful people, and put the nightmare of the Lyme years behind them.

Sandy Berenbaum, LCSW, BCD, may be reached at Family Connections Center for Counseling in Brewster, New York at 203-240-7787.

Congenital Tick-Borne Disease – A Physician's View Point

I feel that congenital tick borne disease is common in my practice and is becoming a serious problem. Some of my sickest patients are children with congenital LD that are bitten again. So many children in my area are being treated for ill defined developmental delays, autistic like syndromes, ADD/ADHD and other psychiatric disorders. Many of my female patients are in their childbearing years. They get pregnant even while still quite ill. I also feel transmission via breast milk is a real possibility and think two of my patients were infected that way. In my area whole families, whole neighborhoods, whole communities are ill. So is the next generation.

~ Ann Corson, M.D.

Pediatric Lyme Disease: Diagnosis and Treatment

by Charles Ray Jones, MD and *Steven J. Harris, MD

Children are one-third of our population and all of our future.

~Select Panel for the Promotion of Child Health

Lyme disease is the most common vector-borne disease in this country and the most common tick-borne disease in the world. The incidence and prevalence of Lyme disease seems to be increasing, with people contracting infection on every continent on earth except perhaps Antarctica. While an understanding about Lyme disease and its manifestations is expanding, a tremendous gap remains as to how to properly diagnose and care for Lyme patients. Children are particularly at risk for an inaccurate diagnosis and inadequate treatment because their symptoms are insidious and subtle. Many doctors and researchers neither understand nor study the unique manifestations of pediatric Lyme disease; moreover, they fail to acknowledge the high incidence of congenital [1, 2] and breast milk [3, 4] transmitted *Borrelia burgdorferi* infection.

Children are more vulnerable than adults to both exposure and infection because they are physically closer to the ground, and play on the ground. They sit on logs [5] and rummage in leaves. They cuddle with pets. Their jungle gyms are near the edge of wooded areas. They go to summer camp and scouting trips. They grow up in the grass and touch everything. One aspect of Lyme in the young children is the emotional component they suffer. They are inexperienced with handling severe difficulties in their lives. Children often get trapped into believing that they will be ill or in pain all of their lives. Many with the onset of Lyme early in their lives have never experienced freedom from pain or disease. One child came into the office after treatment was complete and began saying "I didn't know anybody could feel like this." "I didn't know my body didn't have to hurt." Older children have more reserves and life experiences to draw upon. They often know that this is a temporary setback and that they can get well again. The remarkable aspect of treating Lyme disease in children is that most get better [6-8] and many get well, [7, 9] without carrying the stigma of Lyme disease or its co-infections.

The manifestations of pediatric Lyme disease depend on the age of exposure. The age of three has been thought of as a developmental point for particular signs and symptoms to be observed. Those under three years of age, who were congenitally exposed or early tick exposed to Lyme disease often present with severe hypotonia and developmental delay. [1, 9] They elicit an impaired repository of typical childhood skills. Speech and language difficulties are pronounced as well as fine

and gross motor coordination. Many have visual problems, presenting as convergence insufficiency and/or tracking problems. This often manifests as an inability to read. It is not that the child is incapable of understanding the material but rather that their eyes are not able to maintain focus on the lines of a page. The eyes jump from one end of the page to the other, preventing them from following what is in the middle. They have auditory processing difficulties [10], which can be observed when the child is not responding to verbal cues or commands. The child will ask "What?" repeatedly. They question every situation in which they are asked to do a task, often repeating the question. These children have an increased tendency towards demonstrating behavioral problems and mood swings, with excessive irritability [11] and difficulty participating in a large group. They have an increased tendency towards developing sensory integration problems. It may appear to teachers and psychologists to be an attention deficit disorder but in reality, the trouble arises when multiple stimuli are being received all at once. They cannot segregate incoming stimuli making it difficult for them to become focused on an essential point. The child becomes easily confused coupled with erratic behavior. For example a little boy in practice had classic sensory integration problems. While in the office he could not stop running around. In order to properly examine him, it was only possible to auscultate his chest if his forehead was scratched with an index finger at the same time. Many kids maintain constant motion in order to stay focused, some clenching their fists, slapping their legs or stomping their feet on the ground. Those with gestational, breast milk and early exposure to Lyme disease often experience tactile sensitivity, hair sensitivity or light and noise sensitivity. They have trouble handling textures. One boy in our practice could not wear clothes for 5 years, explaining "My skin hurts." "It feels like someone is rubbing a rasp file on my skin until it bleeds; and my hair feels like someone is taking an ice pick and stabbing me on my head." This child also had to wrap himself in a sheet in order to stay warm. He presented with headaches and joint pain. Interestingly otherwise, this little boy would play normally in the office except he wanted to be naked. His mother had had eight miscarriages. Miscarriages are common with mothers with Lyme disease. [1, 12, 13]

> Children are more vulnerable than adults to both exposure and infection because they are physically closer to the ground, and play on the ground. They sit on logs [5] and rummage in leaves. They cuddle with pets. Their jungle gyms are near the edge of wooded areas. They go to summer camp and scouting trips. They grow up in the grass and touch everything.

While eliciting a history on a patient, one should inquire about several dimensions of the child's life. Generally, determine if the child is acting unusually, demonstrating moody, unfocused behavior. Pay particular attention to decreased energy, fatigue and a new onset decline in schoolwork. Additionally, it is important to ask about headaches, [11, 14] sleep disturbance, increased nightmares and upsetting dreams. Many children show a decreased appetite, are reluctant to play, and often experience both cold and heat intolerance. Irritability [11] and weepiness is common in children with Lyme disease. Impaired short-term memory of new onset is also a very important sign to recognize. [15] Another feature is new onset bedwetting and/or encopresis. Joint and general body pains are often seen in children with Lyme disease and co-infections. New onset asthma is also common. In those patients, asthma usually resolves when the Lyme disease resolves. New onset gastroesophageal reflux, nausea with or without vomiting, abdominal pain, diarrhea or occasional constipation of new onset are all important clues to look for when assessing Lyme disease. [16] Frequent urination is common, though pain is rarely seen. A rash compatible with erythema migrans (EM) that

expands over time is another telltale sign of Lyme disease. This is seen in only about 7% of our more than 7000 patients. Multiple secondary rashes may be observed in Lyme disease as well. These appear and disappear rapidly. During a Jarisch-Herxheimer reaction many children develop an erythematous blush, which are discreet and can be warm to the touch or pruritic. The rash persists as long as the Lyme symptoms present. If one already has psoriasis, tick bites causing an EM can result in a flare of psoriatic plaques over the EM, making it difficult to distinguish them. Psoriasis may also progress upon contracting Lyme disease. If a child is expressing discomfort when they are touched, or are favoring one limb for some unknown reason, it is important to consider Lyme disease in the differential diagnosis.

The physician must determine if *Borrelia burgdorferi* or other tick-borne infections are causing disease. For those patients not at gestational or breast milk risk for Lyme disease, one should have a history of exposure to ticks while on vacation, playing with pets, or in their own backyard. Exposure to *Ixodes scapularis* or *Ixodes pacificus* is particularly dangerous. Familiarity with some hallmarks of co-infections can be instructive in obtaining the whole picture of a sick child. Rapid diagnosis of co-infections will alter the course of treatment and recovery. For example, while ascertaining if one has Babesiosis, it is instructive to ask if someone else in family has a *Babesia microti* infection, including any of the pets in the household. Symptoms include increasing night sweats, intractable headaches, muscle pain, burning in the feet and a feeling of warmth in the soles of the feet.

Dr. Jones Mentorship

Dr. Jones is beloved in the community for his treatment of children. He has treated more than 7,000 children with Lyme disease and has an experience level that is unparalleled. Through his mentorship program, Dr. Jones has trained a number of physicians in the treatment of children at no charge. Physicians work with Dr. Jones side-by-side to develop first hand knowledge of the diagnosis and treatment techniques that have made Dr. Jones so successful. Physicians interested in learning from Dr. Jones can contact his office to make arrangements at 203-772-1123.

Ehrlichia (Anaplasma) infections can be of sudden onset, causing abrupt fatigue or collapse, chills and high fever. Ehrlichia patients may have a more indolent presentation with fatigue and headache. *Bartonella henselae* commonly causes headache as well. Often times violacious cordlike stria that can be painful are missed on the history and exam in a patient that has Bartonella. A wide array of new onset gastrointestinal problems is a common and serious manifestation of Bartonellosis. [17] However, perhaps the most noted hallmark of Bartonella infection is new onset psychiatric problems including: rage, anxiety, paranoia, hallucinations and learning disabilities. *Mycoplasma fermentans*, another co-infection, also causes new onset neuropsychiatric problems and cognitive impairment. The severity of these manifestations appear to be even more pronounced than those seen with Bartonella. Gastrointestinal complaints should be considered a hint at the presence of *Bartonella henselae* or *Mycoplasma fermentans* co-infections.

On physical exam the first observation a physician makes is whether the child appears sick. Is there the appearance of dark circles under the eyes? Is the child less animated than one would expect for his age. A lot of children will say they feel fine. But if you re-ask the question: "do you wish you felt better?" they say "yes." Check their balance. Is it impaired when standing on one foot with the eyes closed? Perform tandem gait tests with eyes open and closed, and then have the child walk on their toes and heels. Look for decreased strength in either one limb or the whole body. Evaluate grip strength. How well does the child perform, hopping on one

foot? Observe whether the child has a limp or is favoring a particular limb. Certainly a swollen joint is an important finding, and it's seen in about 5 percent of patients. This is a contradiction to the prevailing belief, but nevertheless it is important to note. Some clinicians have stated that a child cannot have small joint involvement that is associated with Lyme disease. However, almost all of them do, and therefore examine the child for joint sensitivity. This exam is elicited by gently touching every joint in the body, and the examiner does not need to put a lot of pressure on the joints.

One can distinguish joint sensitivity in a child by the subtle movement away from pressure before they even experience actual pain. This is a reflex that is difficult to feign. When testing cranial nerves, look for a difference in sensation on either side of the face. To check blink synkinesis, have the patient close one eye, then the other. In patients with facial neuroinvolvement, it is common to see them use other facial muscles to help them close their eyelid. Look for light sensitivity and noise sensitivity. Assess plantar reflex. Hypo and hyperreflexia are both seen on deep tendon tests. Look for symmetry.

On cardiovascular exam, the blood pressure is usually normal. Listen long enough to heart sounds while the child is sitting, standing and lying down. It is amazing how many arrhythmias are picked up if one listens long enough. On these children perform an EKG and echocardiogram. However, actual heart block in children is relatively rare. Only five children in this practice have had 1st degree heart block (all of them did fine on IV and/or oral antibiotic therapy). On pulmonary exam, listen for wheezes and rhonchi. Many will have respiratory exercise intolerance. They do not necessarily have a cough. No significant findings are usually elicited on gastrointestinal exam.

> The CDC includes 5 cross-reacting antibodies in the Western blot: 28, 41, 45, 58, 66 kda. *These cross-reacting antibodies should have no place in the definition of a positive Lyme Western blot test. One can have these 5 non-specific antibodies in an IgG Western blot and have a CDC positive Western blot. This is absurd! Therefore, the CDC criteria for Western Blot positivity are markedly wrong....It is not the number of bands, but which bands are positive that is relevant.*

On dermatological exam, look carefully for violacious and bluish striae. Hypoplasia of nails is common, and secondary EM rashes are occasionally seen. In very young children, it is not uncommon to see multiple cavernous hemangiomas. Some are quite large and can cause severe bleeding. Surprisingly, lymphadenopathy is not very common in children with Lyme disease. When it is observed, it usually indicates another overriding infection.

Of particular interest is the abnormal presentation of a variety of odd movement disorders with either symmetric or asymmetric presentation. These may also be accompanied by an upper or lower body tremor.

The Centers for Disease Control and Prevention (CDC) recommends the ELISA as a screening test. If the ELISA is positive, the CDC recommends that a more definitive test, the Lyme Western blot be performed. [18] However, the ELISA is not a valid screening test because it lacks specificity and sensitivity. In my practice, 1/3 of the children with a CDC positive Lyme Western blot have a negative ELISA. A valid screening test should have false positives not false negatives. In my practice, I have found that the Lyme C6 Peptide ELISA results in many false negatives as well.

The Lyme Western blot depends on the adequacy of the patient's immune mechanism at the time of exposure to the *Borrelia burgdorferi* spirochete. Immune paralysis can occur if one is inoculated with a large spirochetal load. By the time the immune mechanism recovers, the *Borrelia burgdorferi* spirochetes are intracel-

lular. This is one mechanism underlying seronegative Lyme. The Lyme Western blot has many other potential flaws. If the referent strain(s) of *Borrelia burgdorferi* used in the Western blot are different from the patient's exposure strain of *Borrelia burgdorferi*, the Western blot can be falsely negative. IgeneX Laboratory uses two reference strains of *Borrelia burgdorferi* in performing the Lyme Western blot, thereby increasing the probability of accurate positivity. Another flaw in the Lyme Western blot involves the CDC requirements for positive IgM and IgG Western blots. The CDC includes 5 cross-reacting antibodies in the Western blot: 28, 41, 45, 58, 66 kda. *These cross-reacting antibodies should have no place in the definition of a positive Lyme Western blot test. One can have these 5 non-specific antibodies in an IgG Western blot and have a CDC positive Western blot. This is absurd! Therefore, the CDC criteria for Western Blot positivity are markedly wrong.*

There are 9 *Borrelia burgdorferi* genus specie specific antibodies: 18, 23-25, 30, 31, 34, 37, 39, 83-93 kda. All one needs is one of these *Borrelia burgdorferi* genus specific antibodies to confirm serological evidence of exposure to the *Borrelia burgdorferi* spirochete to support the clinical diagnosis of Lyme disease. The CDC excludes all but two *Borrelia burgdorferi* genus specie specific antibodies in Lyme Western blot IgM and includes only 6 *Borrelia burgdorferi* specific antibodies in Lyme Western blot IgG. This is also wrong because no *Borrelia burgdorferi* genus specie specific bands should be excluded from IgM or IgG because all of the bands in IgG were once IgM. *It is not the number of bands, but which bands are positive that is relevant.* In later stage infection both IgM & IgG may appear indicating late infection and persisting infection.

> Forty-percent of the children in my practice have *Bartonella henselae*, *Babesia microti*, Ehrlichia (Anaplasma), and/or *Mycoplasma fermentans* co-infections.

DNA by PCR (polymerase chain reaction) can be used to determine the presence of *Borrelia burgdorferi* and tick-borne co-infections: PCRs are highly specific but highly insensitive in urine, blood, serum, synovial fluid, and spinal fluid. If the PCRs are positive one can assume that the organism is present, however there are many false negatives. The PCRs are more sensitive in solid tissue obtained from endoscopy, colonoscopy, placenta biopsy, umbilical cord, foreskin remnants, synovial membranes, and other solid tissue biopsies. Thus the diagnosis of Lyme disease remains clinical as the CDC stipulates.[19, 20] *The CDC surveillance criteria are rigid and exclusive and include an EM rash, arthritis involving one knee, facial paralysis, Lyme meningitis, and heart block. Therefore the CDC case definition excludes many of the patients who have Lyme disease.* Neuropsychological testing, spinal taps, MRIs, and brain SPECT scans are useful adjunctive tests.

Specific treatment for Lyme disease varies case by case. Antibiotics in various combinations, depending on whether one has Lyme and co-infections, are the mainstay of treatment. Amoxicillin has been found successful in children by itself or in combination with clarithromycin or azithromycin. Cephalosporins are used either alone (usually cefuroxime, ceftibuten, cefdinir) or in combination with azithromycin or clarithromycin. Tetracycline, doxycycline and minocycline for children over the age of 7, either alone or in combination with a macrolide are also effective. The macrolides and ketolides have been effective as monotherapy in treating pediatric Lyme disease. Metronidazole and tinidazole, usually in combination with macrolides are other choices as well. The children with pervasive developmental delay (PDD) and gestational Lyme disease respond to metronidazole and azithromycin. In combination, these antibiotics have been found to be useful in reversing PDD in children born with Lyme disease and very early onset Lyme disease. Hydroxychloroquine can be used in treatment for one who has a Lyme induced autoimmune reaction. Hydroxychloroquine

can be bactericidal against spirochetes and cell wall deficient forms and suppress the autoimmune reaction triggered by an active Lyme infection. [21]

Children with Lyme disease are more prone to develop autoimmunity if they are HLA DR4 and or HLA DR2 genotype positive as well as having a 31 IgG Western blot. I have observed that children who have an autoimmune reaction respond favorably to antibiotics, indicating that they have a persistent infection driving the autoimmunity. The use of hyperbaric oxygen therapy along with the use of an antibiotic can be a powerful treatment as well. Treatment should extend over 40 dives at 2.4 atmospheres. Intramuscular injections of penicillin can be used for treating neurological Lyme disease, as can intravenous antibiotics: penicillin, ampicillin, ceftriaxone, cefotaxime, imipenem-cilastatin, azithromycin, metronidazole, doxycycline and vancomycin. Ciprofloxacin, levofloxacin, and moxifloxacin are also effective in the treatment of Lyme disease and co-infections, but are generally contraindicated in children under the age of eighteen (age twelve for ciprofloxacin). Sometimes one can use lower doses using two antibiotics and achieve favorable results if the child cannot tolerate necessary dosages with simply a single antibiotic.

Forty-percent of the children in my practice have *Bartonella henselae*, *Babesia microti*, Ehrlichia (Anaplasma), and/or *Mycoplasma fermentans* co-infections. As is seen in adults, the presence of a co-infection requires treatment regimen modification. If one has a Babesia infection, the use of atovaquone or atovaquone with proguanil (Malarone), and azithromycin or clarithromycin is currently the treatment of choice. Hydroxychloroquine or artimesinin may also be used. For Ehrlichia infections, doxycycline or minocycline should be used regardless of the age of the child. The duration of treatment is usually shorter, such as 5-7 days in a child under seven as opposed to a longer term treatment (one month or longer in older children). Bartonella infections are best treated with trimethoprim-sulfamethoxazole, ciprofloxacin with or without azithromycin or rifampin. *Mycoplasma fermentans* is difficult to eradicate. The most effective medications include rifampin with azithromycin, tetracycline analogues with azithromycin, or trimethoprim-sulfamethoxazole with rifampin.

For these children as well as with children who have Lyme disease alone, duration of treatment is measured by clinical response. The criteria used for the cessation of antibiotic therapy is if a child can: 1) be Lyme symptom-free for two months; 2) not have a Lyme induced flare-up as a result of another infection, fatigue, emotional trauma or injury; 3) can show a Western blot that does not reflect active infection and 4) is PCR negative. Many children have been treated very well without the need for metronidazole or tinidazole. If a particular medicine is working and is well tolerated, continue it until the above criteria are met. [22]

Conclusion:

1. It does not take long, certainly less than 24-48 hours, for a small *Ixodes scapularis* tick or nymph to attach, feed and disseminate organisms in a young child with soft, thin, very vascular skin.

2. Children with *Ixodes scapularis* tick attachments in the head/neck area, under the arms or under the collar bones and in the belly button seem to result in *Borrelia burgdorferi* spirochetes disseminating rapidly to the brain causing early central nervous system (CNS) symptoms. This may occur because spirochetes are carried by arteries going to the brain via the circle of Willis.

3. In order to eradicate all *Borrelia burgdorferi* spirochetes, antibiotics should be continued for 2 months after all symptoms of Lyme disease resolve, for 2 months after they no longer have a Jarisch-Herxheimer reaction, for 2 months after they no longer have a Lyme flare-up induced by a non-Lyme infection such as common cold, chicken pox, influenza, tonsillitis or menstruation. If these criteria are met then the child's Lyme disease appears cured and all *Borrelia burgdorferi* spirochetes can be considered eradicated. If antibiotic therapy is stopped prematurely, before all Lyme symptoms have resolved, then these children

will have a Lyme relapse and have more brain and body injury by a more resilient, more difficult to treat Lyme organism. There is no evidence that 3-6 weeks of antibiotic therapy can eradicate all *Borrelia burgdorferi* spirochetes and cure Lyme disease. There has never been a study in the history of Lyme disease that determines the duration of antibiotic therapy needed to eradicate all *Borrelia burgdorferi* spirochetes. There is, however, ample evidence in the peer-reviewed medical literature that the *Borrelia burgdorferi* spirochete can persist after prolonged IV antibiotic therapy of 1month to 1 year or longer.

4. Persisting Lyme symptoms indicate a persisting *Borrelia burgdorferi* infection in need of continuous antibiotic therapy until all symptoms have resolved.

5. In children, persisting Lyme symptoms indicate a persisting *Borrelia burgdorferi* infection and not "Post-Lyme-syndrome", not fibromyalgia, not MS, not CFS (chronic fatigue syndrome), not a psychiatric disorder and not another diagnosis.

6. Withholding necessary antibiotic therapy can result in children with Lyme disease having unnecessary permanently injured lives.

7. I have treated and evaluated over 7000 children with Lyme disease. After receiving 3 months to 7 years of continuous antibiotic therapy, 75% of the children I treat are well and without signs of Lyme disease on follow-up over a period of 1-15 years. One-third of these 7000 children are newly diagnosed or have a persisting deeply entrenched, more difficult to treat *Borrelia burgdorferi* infection, that results from a delay in diagnosing their Lyme disease and/or inadequate initial antibiotic therapy.

**Steven J. Harris is a clinical consultant for IgeneX, Inc.*

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Chronic Lyme Disease in the Pediatric Population

Presented at the 2005 Annual Meeting of the Infectious Disease Society of America in Boston, MA

by Sam T. Donta, MD, Falmouth Hospital, Falmouth, MA

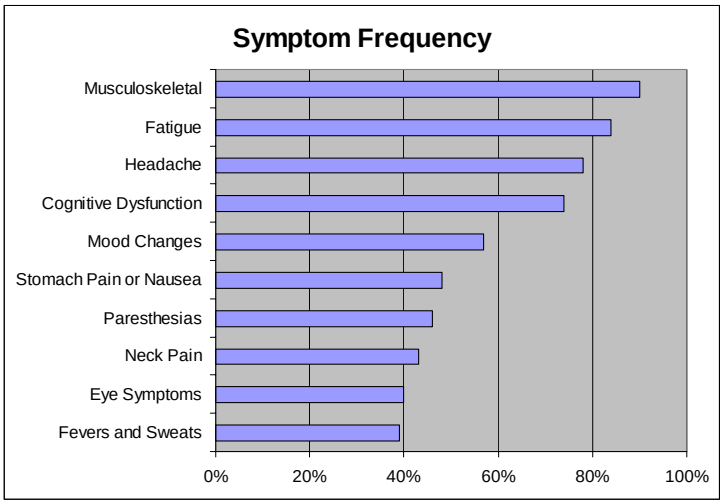
Medicine's ground state is uncertainty and wisdom for both patients and doctors is defined by how one copes with it.

~Atul Gawande
author of "Complications"

Introduction. Lyme disease is an infectious disease caused by *Borrelia burgdorferi* that frequently produces chronic symptoms, often of a vague nature. The basis for these symptoms remains to be defined, but may be the result of a vasculitis involving the nervous system and perhaps other tissues as well. The clinical manifestations of chronic Lyme disease have been detailed in adults with the disease, but have not been done so in pediatric patients. The purpose of this study was to detail the clinical manifestations of chronic Lyme disease in the pediatric population, along with their serologic responses, results of brain SPECT scans, and response to antibiotic treatment.

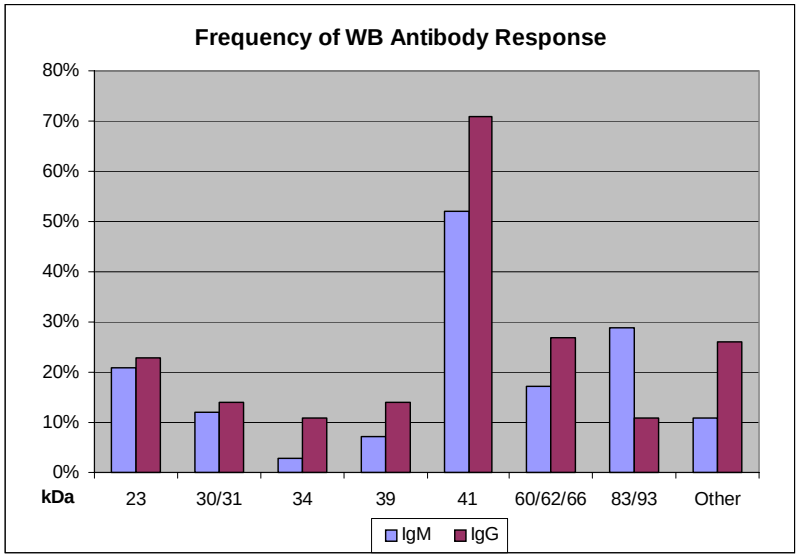
Methods: 101 patients aged 2-19 (median age of 14) with multiple persisting symptoms (88% > 6 months) without any apparent cause were evaluated for possible chronic Lyme disease. The clinical history included the presence or absence of a known tick bite or rash, along with a detailing of the clinical symptoms and signs. The results of Enzyme Immunoassay (EIA) and western blot studies were also detailed. Brain SPECT scans were performed on 29 patients. Finally, the results of antibiotic treatment regimens were evaluated, with outcomes listed as cured, improved, or failed.

Results: The most prevalent symptoms were musculoskeletal (90%), fatigue (84%), headache (78%), and cognitive dysfunction (74%). Other diagnostically helpful symptoms included paresthesias (46%), stomach pains or nausea (48%), eye symptoms (40%), and fevers or sweats (39%). 79% of patients had multiple other symptoms (e.g., dizziness, palpitations, tremors) as well.



Tick bites were known to occur in 24% of patients. Rashes had occurred in 40% of patients (typical rash in 15%, atypical rash in 25%). Bell's palsy had occurred in 5 patients. Brain SPECT scans were abnormal in 18 patients and normal in 11 patients.

Serologic results showed 1 or more reactions by IgM western blotting in 74% of patients and IgG in 82% of patients. EIA were positive in 65% of patients tested.



Treatment with tetracycline or a combination of a macrolide antibiotic with hydroxychloroquine over 4-8 months was associated with cure or sustained clinical improvement in 75% of patients.

Treatment Response and Treatment Duration

Months	Cure	Improved	Failure
<3	2	20	4
4-6	8	20	0
6-8	4	12	0

Summary and conclusions:

1. Chronic Lyme disease in pediatric patients poses diagnostic challenges, but the presence of certain clinical symptoms over a number of weeks or months is typical of the disease.
2. Prior exposure to ticks and typical or atypical rashes occurs in less than half the patients.
3. Typical symptoms are the combination of musculoskeletal pain, fatigue, cognitive dysfunction, and other symptoms that are not otherwise easily explained.
4. Lyme western blots are more helpful than EIA tests in supporting the clinical diagnosis. The specificity of the reactions is more important than are the numbers of bands present in the blots. IgM reactivity is consistent with chronic active disease, and usually becomes negative with successful treatment.
5. Brain SPECT scan abnormalities are often seen in patients and can be helpful in supporting the clinical diagnosis of chronic Lyme disease.
6. Treatment with certain "intracellular-type" antibiotics, i.e., tetracycline or a combination of a macrolide and hydroxychloroquine, is usually effective in curing or resolving most of the symptoms if given over several months.

Bibliography of Studies on Lyme Disease in Children

by Lorraine Johnson, JD, MBA

While we try to teach our children all about life,our children teach us what life is all about.

~anonymous

Children with the most serious neurocognitive and neuropsychiatric symptoms of Lyme disease generally have not received early diagnosis and adequate treatment. Studies indicate that children who are treated timely and appropriately usually do not suffer continued cognitive defects [3,4]. The need for prompt efficacious treatment is critical to avoid significant persistent problems. Space limitations preclude inclusion of complete abstract. Readers are referred to unabridged abstracts at pubmed or to the studies for more comprehensive coverage.

Fallon, B. A., J. M. Kochevar, et al. (1998). "The underdiagnosis of neuropsychiatric Lyme disease in children and adults." Psychiatr Clin North Am **21**(3): 693-703, viii.
Lyme Disease has been called "The New Great Imitator," a replacement for that old "great imitator" neurosyphilis. The article reviews psychiatric and neurologic presentations found in adults and children, and the features, which make it uniquely hard to diagnose, including the complexity and unreliability of serologic tests. Clinical examples illustrate presentations that mimic attention deficit hyperactivity disorder (ADHD), depression, and multiple sclerosis.
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Tager, F. A., B. A. Fallon, et al. (2001). "A controlled study of cognitive deficits in children with chronic Lyme disease." J Neuropsychiatry Clin Neurosci **13**(4): 500-7.
Although neurologic Lyme disease is known to cause cognitive dysfunction in adults, little is known about its long-term sequelae in children. Twenty children with a history of new-onset cognitive complaints after Lyme disease were compared with 20 matched healthy control subjects. Each child was assessed with measures of cognition and psychopathology. Children with Lyme disease had significantly more cognitive and psychiatric disturbances. Cognitive deficits were still found after controlling for anxiety, depression, and fatigue. Lyme disease in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments. Areas for further study are discussed.
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Pietrucha, D. M. (2000). "Neurologic manifestations of Lyme disease in the pediatric population." 13th International Conference on Lyme Disease and Other Spirochetal and Tick-Borne Disorders, Farmington, CT.
Children with neurologic Lyme disease may present acutely

with headache, blurry vision, double vision, confusion, irritability, fever, and/or stiff neck. Chronically, they may be encephalopathic and have lingering headache, personality change, and depression. The most common lingering problem that patients have as a result of involvement of the CNS in Lyme is encephalopathy, which the children call "brain fog." These children complain of persistent headache and fatigue. There may be personality change, irritability, and frequently depression. The impact academically is most significant. These children have fall-off in academic performance, difficulty learning new material, problems with short-term memory, problems with word finding, and a number of them have lost reading skills. Frequently, these children may present with a picture of ADD or may have an underlying ADD or ADHD that is made worse by the Lyme.

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Fried, M.D., M.E. Adelson, and E. Mordechai, "Simultaneous gastrointestinal infections in children and adolescents." Practical Gastroenterology, Nov. 2004: p. 78.

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Belman, A.L., et al., "MRI findings in children infected by *Borrelia burgdorferi*." Pediatr Neurol, 1992. 8(6): p. 428-31.
Cranial magnetic resonance imaging abnormalities were observed in 8 children (ages 4-14 years) with neurologic problems following infection by *Borrelia burgdorferi*. Neurologic features included headache (6), behavioral changes (5), facial palsy (2), papilledema (2), papilledema with diplopia (1), disturbance of sleep pattern (2), and carpal tunnel syndrome (1). Two MRI studies demonstrated multiple focal areas of increased signal intensity in white matter on long TR (both proton-density and T2-weighted) images.

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Belman, A.L., et al., "Cerebrospinal fluid findings in children with Lyme disease-associated facial nerve palsy." Arch Pediatr Adolesc Med, 1997. 151(12): p. 1224-8.
Between 1988 and 1996, a prospective evaluation at a single medical center in a Lyme disease endemic area was undertaken of forty children (aged 3-19 years) with new onset facial nerve palsy who met the CDC case definition of Lyme disease. Cerebrospinal fluid white blood cell count, protein level, or both were abnormal in 27 (68%) of the children. Thirty-six (90%) of the 40 children had a CSF abnormality consistent with central nervous system infection or immune involvement by B burgdorferi. Of the 22 children with CSF pleocytosis, only 7 (32%) had headache and none had meningeal signs.

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Belman, A.L., et al., "Neurologic manifestations in children with North American Lyme disease." Neurology, 1993. 43(12): p. 2609-14.
We describe 96 children referred for neurologic problems in the setting of *Borrelia burgdorferi* infection in North America. The most frequent neurologic symptom was headache, and the most common sign was facial palsy. Less common manifestations were sleep disturbance, and papilledema associated with increased intracranial pressure. Signs and symptoms of peripheral nervous system involvement were infrequent. The most common clinical syndromes were mild encephalopathy, lymphocytic meningitis, and cranial neuropathy (facial nerve palsy). Meningoradiculitis (Bannwarth's syndrome) and peripheral neuropathy syndromes were rare. However, a "pseudotumor cerebri-like" syndrome seems to be unique to North American pediatric Lyme disease.

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Gerber, M.A., L.S. Zemel, and E.D. Shapiro, "Lyme arthritis in children: clinical epidemiology and long-term outcomes." Pediatrics, 1998. 102(4 Pt 1): p. 905-8.
All children seen between 1982 and 1991 at the Pediatric Rheumatology Clinic at Newington Children's Hospital (Newington, CT) with an initial diagnosis of Lyme disease were identified. Medical records were reviewed and structured telephone interviews were conducted to obtain demographic, clinical, and follow-up data. RESULTS: A total of 90 children (aged 1.8-16 years) at the time of diagnosis of Lyme arthritis were evaluated. Lyme arthritis was preceded by early Lyme disease in 23 (26%) of the children; however, only 8 (35%) of these children had been treated with appropriate antimicrobial therapy at that early stage. Ninety percent of the children had arthritis of at least one knee, while small joints were rarely involved. For the 31 children who underwent arthrocentesis, the mean white blood cell count in the synovial fluid was 38 000 cells/mm3 (range, 7000-99 000 cells/mm3) with predominantly neutrophils. For the 79 children for whom an erythrocyte sedimentation rate was determined, the highest level for 61 (77%) was >20 mm/h and for 36 (46%) was >50 mm/h. Antimicrobial therapy was initiated 2 days to 5.5 years (median, 2 months) after the onset of symptoms. Five of the children were never treated with antimicrobials.

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Wilke, M., et al., "Primarily chronic and cerebrovascular course of Lyme neuroborreliosis: case reports and literature review." Arch Dis Child, 2000. 83(1): p. 67-71.
Case study of four children with unusual clinical manifestations. Two patients suffered from a primarily chronic form of neuroborreliosis and displayed only non-specific symptoms. An 11 year old boy presented with long standing symptoms of

severe weight loss and chronic headache,
while another patient had pre-existing mental and motor retardation and developed seizures and failure to thrive. Two children (a 15 year old girl; the other, a 5 year old boy) who presented with acute hemiparesis as a result of cerebral ischaemic infarction had a cerebrovascular course of neuroborreliosis. Following adequate antibiotic treatment, all patients showed substantial improvement of their respective symptoms.

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Bloom, B. J., P. M. Wyckoff, et al. (1998). "Neurocognitive abnormalities in children after classic manifestations of Lyme disease." Pediatr Infect Dis J **17**(3): 189-96.
Case series of five children seen in a Lyme disease clinic in a university referral center for evaluation of neurocognitive symptoms that developed near the onset of infection or months after classic manifestations of Lyme disease. The diagnosis was based on clinical symptoms, serologic reactivity to *Borrelia burgdorferi* and intrathecal antibody production to the spirochete. Evaluation included detailed neuropsychologic testing. After evaluation the children were treated with intravenous ceftriaxone for 2 or 4 weeks. Follow-up was done in the clinic and a final assessment was made by telephone 2 to 7 years after treatment. RESULTS: Along with or months after erythema migrans, cranial neuropathy or Lyme arthritis, the five children developed behavioral changes, forgetfulness, declining school performance, headache or fatigue and in two cases a partial complex seizure disorder. All five patients had IgG antibody responses to B. burgdorferi in serum as well as intrathecal IgG antibody production to the spirochete. Two patients had CSF pleocytoses and three did not. Despite normal intellectual functioning the five children had mild to moderate deficits in auditory or visual sequential processing. After ceftriaxone therapy, the four children in whom follow-up information was available experienced gradual improvement in symptoms.

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Healy, T. L. (2000). "The impact of Lyme disease on school children." J Sch Nurs **16**(2): 12-8.
School nurses are faced with caring for children with Lyme disease in the school setting. To provide that care, school nurses should know the pathophysiology of the disease and understand the body's immune response to the infection. They need to be cognizant of the environments known to have a high geographic distribution of Lyme disease to determine exposure risk. Opportunities await school nursing expertise in community education, medical treatment regimens, health insurance coverage, implementation of the Americans with Disabilities Act (504), and political action to bring public awareness to this potentially debilitating disease.

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Bingham, P.M., et al., "Neurologic manifestations in children with Lyme disease." Pediatrics, 1995. **96**(6): p. 1053-6.
We reviewed clinical manifestations in 97 seropositive children with particular attention to neurologic manifestations. Diagnostic criteria used in other case surveys were applied to determine how often a definitive diagnosis of neuroborreliosis could be made in children. RESULTS: Of 69 children who met criteria for LD, 32% (22) had new neurologic signs, 73% (16) of which were accounted for by facial palsy and aseptic meningitis. Five of those with neurologic findings also had erythema migrans (EM), and one had both EM and arthritis. Neurologic abnormalities resolved spontaneously in five children before their serologic results were known. CONCLUSION Only 27% of children with neurologic abnormalities due to LD had a history of EM or arthritis. Seropositivity commonly constituted the primary basis for diagnosis. Seropositivity for LD in children with neurologic symptoms usually signifies active neuroborreliosis.

HIPAA Releases: Who Needs What Information?

It is not necessary that all information be available to all people, regarding a child's illness, in this "information age." To protect the records of children, and to protect physicians from disclosing that which is not relevant or necessary, parents can consider restricting, in writing, the information they allow their child's physician to disclose. For example, schools need to know the child's diagnosis, functional limitations and restrictions, symptoms to be aware of, medications the child is on, and the supports the child needs in school, nothing more.

Restricting the release of unnecessary information protects a child's and a family's privacy, and keeps everyone aware of their particular role in helping a child live with Lyme.
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When to Suspect Lyme Disease in Children

Pediatric Nurses are in a Unique Position to See the "Red Flags"

by Ginger Savely, FNP-C

In a pediatric setting, the nurse often spends as much or more time with the child than does the physician. Time is invaluable for a correct diagnosis – particularly for children who are not apt historians and frequently omit important information. Children who have been sick a long time may not recognize pain and other symptoms as abnormal. With more time, a provider can pick up on subtle cues that could be crucial for the correct diagnosis.

While taking vital signs and gathering preliminary information from the parent, the nurse is in a unique position to pick up on "red flags" for tick-borne diseases. Many doctors fail to include these diseases in their differential assessment, and the vigilant nurse can be the critical link to a correct diagnosis.

> *Kindness is the language which the deaf can hear and the blind can see.*
>
> ~Mark Twain

The nurse should put up her Lyme radar when a child is a frequent visitor to the office, has many and varied complaints, or has symptoms that have eluded diagnosis by other health care providers. A child that "comes down with everything that goes around" may have immune suppression suggesting chronic infection. Children with tick-borne diseases also have a history of symptoms that do not neatly fit into any diagnostic category. A few of these are: low energy in the absence of anemia; frequent urination in the absence of a urinary infection; visual problems with a normal ophthalmologic exam; clumsiness; frequent "growing pains" and insomnia unresponsive to the usual treatments.

The symptoms of Lyme disease in children are subtle and can be easily missed or confused with other illnesses. These children often present with a history of such diagnoses as juvenile rheumatoid arthritis (JRA), hypercholesterolemia, migraines, Crohn's disease, gastritis, maturation delay, attention deficit/hyperactivity disorder (ADHD) and learning disabilities. The nurse should always be suspect of a previous diagnosis of JRA, especially if the child has also been diagnosed with ADHD or migraines.

The parent may report that the child is moody and unpredictable and that he has frequent headaches and stomach aches. Sudden change of behavior should be noted—the quiet child has become loud and aggressive, the active child has become passive, the happy child has

become weepy and sad, the calm child has started throwing fits and tantrums. In school, the child may be frequently absent, report sick to the school nurse, or bring home notes for poor behavior.

The parent should be asked if the child has ever had a tick attachment, even if the popular belief is that the area does not have ticks that carry disease! Lyme and tick-borne co-infections are found in almost every state. Because ticks may be as small as the period at the end of this sentence and their bite is painless, most people are unaware of the tick bite so it is important to ask about exposure potential. Are there wooded areas near the home? Are there deer around? Does the child play out in the grass? Does the family go camping? Do they have pets? Are tick checks routinely done? Has the family traveled to highly tick-endemic areas? If the child has ever had rashes of any kind, the parent should be asked to describe these in detail.

If environmental factors don't sound suspect for tick exposure, inquiries should be made regarding the mother's health status. If the mother says that she has been diagnosed with fibromyalgia or chronic fatigue syndrome, or that she's had vague complaints of joint pain and fatigue since before the child was born, a congenital Lyme case may be a possibility.

In the assessment of the child the nurse may notice a tendency towards distractibility and hyperactivity. It is often difficult to get the child to stop talking or sit still long enough for vital signs to be taken. The child may be hyper-sensitive to touch and may wince when the blood pressure is taken. He may avert his eyes to the light of an opthalmoscope or complain that the lights in the room are too bright. Reflexes may be so hyper that even brushing against the leg will cause the child's lower leg to kick forward.

Nurses are the parent's and child's first contact in the doctor's office. They can form a strong relationship with the parent and bond with the child. They are the child's advocate. Since most nurses have acute observation skills, they would do well to become vigilant to the "red flags" of Lyme disease. They can then encourage the physician to take note of relevant history and symptoms and to pursue the possibility of tick-borne disease.

Kids and Ticks

In a study to determine the duration of tick attachment on people bitten by ticks in Westchester County, New York from 1985 to 1989, it was found that children 9 years of age and under had the highest proportion (37%) of female ticks attached for more than 48 hours, although nymphs remained attached to adult bite victims longer.

However, children have a high risk of acquiring Lyme disease because they receive more nymphal bites and also because they are less likely to have female ticks removed in time to prevent transmission.

Falco, R. C., D. Fish, et al. (1996). "Duration of tick bites in a Lyme disease-endemic area." Am J Epidemiol 143(2): 187-92.

Lyme Disease in the Eye: A Pediatric and Adolescent Perspective

By Eric L. Singman, MD, PhD, Neuro-Ophthalmologist *Director of Low Vision and Vision Rehabilitation, Family Eye Group, Lancaster, PA*

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.

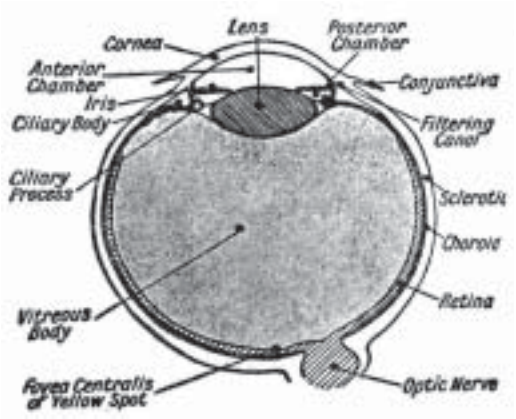
Common Ocular Manifestations of Lyme Disease

Stage 1 Lyme disease:

- Conjunctivitis
- Photophobia

Stage 2 Lyme disease:

- Cranial nerve VII palsy (Bell's palsy)
- Blurred vision secondary to papilledema
- Optic atrophy
- Optic or retrobulbar neuritis
- Pseudotumor cerebri



Late Stage 2 or Stage 3 Lyme disease:

- Episcleritis
- Symblepharon
- Keratitis
- Iritis
- Pars planitis
- Vitreitis
- Chorioretinitis
- Exudative retinal detachment
- Retinal pigment epithelial detachment
- Cystoid macular edema
- Branch artery occlusion

Optic nerve disease can be either bilateral or unilateral and may be associated with other symptoms.
See Zaidman, G., Lyme disease (updated 2004) http://www.emedicine.com/oph/topic262.htm

Gastrointestinal Lyme

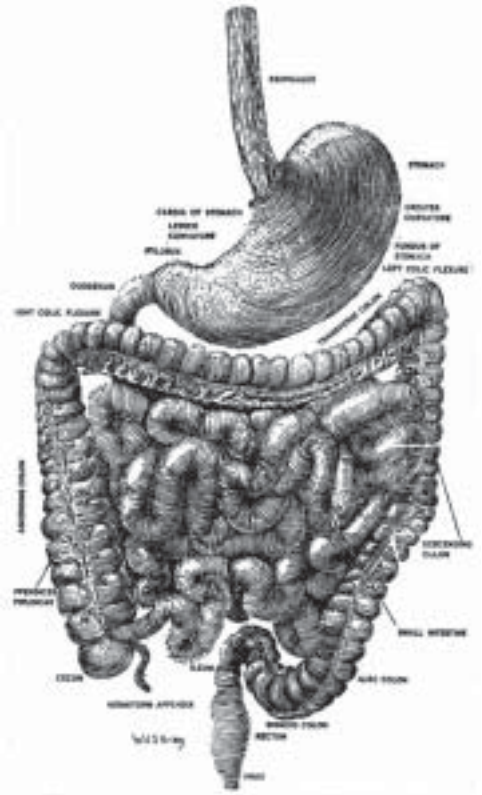
by Martin D. Fried, MD*

Lyme disease has been reported in the gastrointestinal (GI) 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 is 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.

**Director, Pediatric Gastroenterology and Nutrition, Assistant Program Director, Department of Pediatrics, Jersey Shore Medical Center, Neptune, NJ*

Common GI Symptoms Due to Lyme Disease

- Gastroparesis
- Small intestinal bacteria overgrowth (SIBO)
- May mimic Crohn's disease or colitis



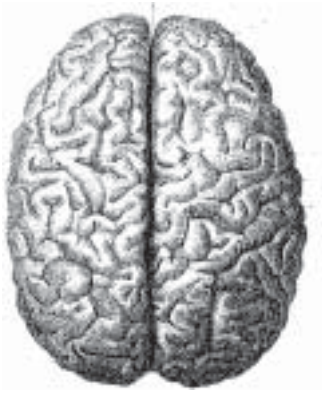
- Abdominal pain
- Vomiting
- Diarrhea
- Heartburn
- Blood in the stool

For further information, see Fried, M.D., M.E. Adelson, and E. Mordechai, *Simultaneous gastrointestinal infections in children and adolescents.* Practical Gastroenterology, Nov. 2004: p. 78.

Fried, M.D., M.P. Abel, D., and A. Bal, *The spectrum of gastrointestinal manifestations in Lyme disease.* J Pediatr Gastroenterology & Nutrition, 1999. **29**(4): p. 495.

Neurologic Manifestations of Lyme Disease in Children

by Dorothy Pietrucha, MD, FAAP



To see things in the seed, that is genius.

~Lao-tzu

Infection with *Borrelia burgdorferi*, which causes Lyme disease, will frequently involve the central or peripheral nervous system or both. Presentation can be acute, subacute, or chronic and can affect children at any age. The onset of neurologic symptoms and signs may be early on or be seen even years after the initial infection.

The acute presenting picture is usually one of a meningitis or meningoencephalitis. Patients may present with no fever, a very low grade fever or headache. They may have flu-like symptoms, photophobia, or pain on flexion of the neck, but not actually have a stiff neck. If a spinal tap is done at that time the opening pressure may be elevated or normal. The white cell count will be elevated, modestly 15 to 20, or can be significantly elevated, 7 to 800 or greater. The protein may be normal or elevated. The glucose will usually be normal and a culture will be negative. They may or may not have positive cerebrospinal fluid (CSF) antibody titer for Lyme and polymerase chain reaction (PCR) may or may not be positive. Usually if the patient is treated in this acute phase, these initial symptoms will clear and frequently these symptoms may clear even without treatment.

This meningitic picture is considered to be aseptic because there is no positive culture for bacteria even though the cause of this is infectious, so the term aseptic meningitis may be used. At the same time that this patient has this aseptic meningitis they may also have involvement of a cranial nerve, the most common being the seventh nerve, the facial nerve. This results in palsy on one side and sometimes both sides of the face, at times call Bell's palsy. This too in children usually spontaneously resolves, although some children may require some physical therapy. Rarely, children may present with a radiculitis, that is inflammation of a nerve root or multiple nerve roots resulting in pain, dysesthesias, numbness, tingling, etc., on the trunk or on the limbs. Frequently, people call the meningitis involvement of the cranial nerves and radiculitis a triad of neurologic Lyme.

Other cranial nerves besides the seventh nerve can be involved in Lyme and theoretically any of these nerves can be involved. The sixth cranial nerve can result in double vision. The fifth cranial nerve can result in significant facial pain and discomfort and other peripheral nerves can also be involved. I have seen two patients with foot drop from Lyme and I have seen at least two or three patients with brachial neuritis, resulting in weakness and pain in the upper extremity.

The involvement of the cranial nerves and the radiculitis represents involvement of the peripheral nervous system from Lyme disease. Usually this is clinically quite obvious because the patient presents with weakness or such severe pain in the distribution of a nerve root or nerve that the diagnosis is rather straightforward. A sensory neuropathy, that is involvement of the sensory portion of the nervous system, more so than the motor, also occurs sometimes resulting in a lot of pain and discomfort, especially distally, that is at the end of the extremities.

I have seen a number of children with severe dysesthesias and discomfort on the soles of their feet without any other significant finding involving the peripheral nervous system. The sensory involvement has been described far more frequently in the adult population than the pediatric population.

The onset of the peripheral neuropathy may be close to the time of the actual infection, the tick bite, or may occur at a later date when the association with the tick bite is not that easily appreciated. Certainly when children present with symptomatology referable to the cranial nerves or other peripheral nerves, Lyme should be in the differential. Involvement with the central nervous system, brain and spinal cord is far more complex and puzzling. The presentation can be, again, acute, subacute or chronic.

Lyme may present with an acute stroke-like picture, an acute hemiparesis which would involve large vessel occlusive disease but this occurs rarely. Patients may present with a more diffuse vasculitis or perivascular inflammatory changes.

> The most common neurologic manifestation of Lyme in children is what we call or have coined Lyme encephalopathy. This is characterized by headache, photophobia, frequently phonophobia and sometimes malaise, fatigue, irritability, difficulty concentrating, problems with memory, difficulty learning new material in school, and what many of the children with Lyme call their “Lyme fog.”

Some children present with a Guillian Barre-like clinical picture, that is ascending weakness with a pleocytosis in the spinal fluid. Patients may present with white matter lesions seen on the MRI, which may be accompanied by signs of upper motor neuron involvement as well as a diffuse encephalopathy. These lesions are similar to the ones seen in patients with MS and that has created some confusion regarding the relationship between Lyme and MS, which I will not discuss at this time.

There have been rare case reports of patients with Lyme presenting with movement disorder, myoclonus and can present with seizures.

I now want to focus on two important neurologic complications from Lyme disease that we see far more frequently in children than adults. One is headaches accompanied by increased intracranial pressure, but not necessarily with papilledema.

Pseudotumor is a term used to describe increased intracranial pressure that has always been thought to be accompanied by papilledema, but this is not the case. More and more clinicians are seeing and reporting patients with increased intracranial pressure without the papilledema.

A number of children with Lyme present with this increased intracranial pressure, which is either the sole cause of or a contributing cause of their headache. Ordinarily the opening spinal fluid pressure is less than 180 mm of water. In these children the pressure is elevated usually significantly over 200 and in my experience when it has been closer to 350 to 400 or higher it is usually accompanied by papilledema. Frequently, the fluid will otherwise be unremarkable, although sometimes there may be an elevated protein.

When there is papilledema there is a potential for vision loss. This has to be treated promptly and aggressively to bring the pressure down so as to prevent any vision loss. If the pressure is elevated, but there is no pressure on the optic nerve, it still should be treated.

The most common neurologic manifestation of Lyme in children is what we call or have coined Lyme encephalopathy. This is characterized by headache, photophobia, frequently phonophobia and sometimes malaise, fatigue, irritability, difficulty concentrating, problems with memory, difficulty learning new material in school, and what many of the children with Lyme call their "Lyme fog."

I have seen this encephalopathy frequently in patients with Lyme and the younger the patient, the greater the chance of irritability, personality change, and a preschooler becoming extremely difficult to manage and the parents becoming quite concerned about this total change in the child's affect. In the older child, there is a more depressive fatigue-like picture and their school performance suffers because of the difficulties they have in remembering what they have learned and in learning new material.

Many of these children, because of this difficulty, are unable to attend school and require home tutoring on a limited basis. They may have some nonspecific findings on the MRI, such as white matter lesions. Their EEGs may show some cerebral dysfunction and as noted above, if a spinal tap is done, the pressure may or may not be elevated.

Because Lyme is a clinical diagnosis, these patients warrant appropriate diagnostic evaluation and then if it is clinically determined that Lyme is the cause for their symptoms and signs, an appropriate therapeutic plan should be put in place utilizing either intravenous or oral antibiotics depending on the patient's clinical presentation, clinical picture and course.

Other medications that may be needed are anti-convulsants, if the patient has seizures, diuretics if there is increased intracranial pressure, anti-inflammatory medications, pain medications, etc. Physical therapy may be needed if there is weakness and certainly and most importantly if the child is of school age, an individual educational plan has to be put in place if the child is unable to continue in a regular school program.

The clinical course for Lyme patients is extremely varied. Some recover within a matter of weeks. Others may take months or even years. The reason for this is poorly understood. Are these patients chronically infected? Are they suffering from some immunopathologic process? Do they have infection? Until we have a definitive answer to this very complex question, we ask the patients to be patient, and we as physicians will continue to use our best clinical judgment in evaluating, diagnosing and treating this disease.

Dorothy Pietrucha, MD, FAAP, is the medical director of the Division of Pediatric Neurology, Child Evaluation Center, Jersey Shore Medical Center, Neptune, NJ. Dr. Pietrucha is on the Scientific & Professional Advisory Board, Lyme Disease Association, Inc.

LYME T-SHIRTS ARE NOW HERE!

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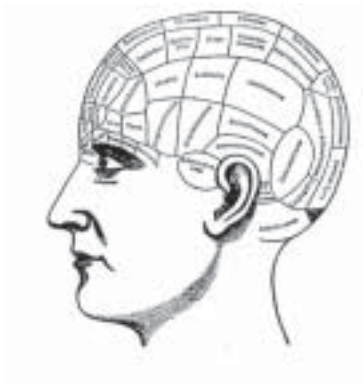
T-shirts are available in sizes small through extra-large. They are $15 each. Place an order at our website www.LymeDisease.org, or send a check with your order to: CALDA Administrative Office, P. O. Box 707, Weaverville, CA 96093-0707. For more information, contact Marisa at mbattilana@hotmail.com

GET YOUR LYME WRISTBANDS!

Do you have yours yet? Get a set and distribute them to your support group, your friends and family, the people you work with! They are lime-green, the color of hope, and say, "Lyme Disease—A Hidden Epidemic" www.LymeDisease.org. Tiny ticks are imprinted in the band.Wristbands are $2 each. Minimum order is 10 bands. Place an order at our website www.LymeDisease.org, or send a check with your order to: CALDA, Administrative Office, P. O. Box 707, Weaverville, CA 96093-0707. For more information, contact Marisa at mbattilana@hotmail.com.

The Pharmacological Treatment of Children and Adolescents with Tick-Borne Diseases

by Robert C. Bransfield, MD, FAPA, DABPN-P, C-ASCP



"My own brain is to me the most unaccountable of machinery - always buzzing, humming, soaring, roaring, diving, and then buried in mud. And why? What's this passion for?"

~ Virginia Wolf

The treatment of tick-borne diseases (TBDs) that have chronic symptoms in children and adolescents requires a comprehensive approach that includes attention to daily routines, school, family dynamics, peer relationships, exercise, psychotherapy, psychotropics and other medical treatments. While recognizing the importance of these other treatment modalities, this paper shall only focus upon pharmacological treatments (the use of psychiatric medications) to treat a variety of psychiatric symptoms of TBDs, including some that are extremely serious. Many of these symptoms may improve and some may fully resolve with comprehensive and adequate TBD treatment.

It is also important to note there are some issues in the treatment of children and adolescents that are different from the treatment of adults:

- Children and adolescents generally have less insight than adults, and children with chronic TBDs may not have a clear reference point for a state of health.
- Illness often results in developmental delays.
- There are even fewer physicians who treat TBDs in children and adolescents than there are who treat adults.
- Very few psychotropics are actually approved for the treatment of children and adolescents.
- Children generally metabolize drugs more rapidly and need higher doses for the same weight compared to adults.

After performing an assessment, I begin treatment planning by asking the patient and his/her family to prioritize in order of significance the key symptoms that are most problematic and appear to contribute most to perpetuating the illness. The symptoms at the top of the list commonly include fatigue, cognitive impairments, sleep disorders, apathy, pain (including headache), depression, anxiety disorders, irritability and anger. Other issues that may call for psychopharmacological intervention include suicide risk, self-destructive behavior, eating disorders, substance abuse, seizures and risks that Jarisch-Herxheimer reactions may cause an abrupt exacerbation of symptoms, including suicidal and aggressive behavior.

It is my basic assumption that impairments caused by chronic disease result in a vicious cycle of chronic stress resulting in compromised

immune functioning, thereby contributing to a perpetuation of chronic infectious disease and chronic symptoms. When this vicious cycle of chronic disease is broken, the body's normal capacity to maintain a state of health becomes stronger and at this point less psychotropics and antibiotics are needed to maintain health. Therefore, many of the treatments described in this article may be temporary when treating TBDs.

Controversies exist surrounding the use of both psychotropics and antibiotics and patient and parents need to carefully consider the risks of the disease vs. the risks of different treatment options. The goal in using psychotropics in children is to achieve a state in which mental functioning is appropriate for the current life situation and results in the capacity to experience well-being, pleasure, fulfilling relationships, productive activities, the mental flexibility to adapt to change, the ability to recognize and deal with adversity and the expression of innate personality. Contrary to inaccurate information disseminated by different special interest groups, the goal in using psychotropics in children and adolescents is not to sedate or blunt personality.

It is then important to create an individualized treatment plan based upon the findings of the assessment, clinical judgment, the best evidence available and patient and parent preferences.

I have generally found treatment of the symptoms that cause the greatest amount of impairment and chronic stress result in the greatest therapeutic benefit. After reviewing the priorities of the patient's symptoms with them and their parents, a sequential treatment plan is developed, which is always subject to revision. Normalizing circadian rhythm (the sleep wakefulness cycle) and treatment of depression and anxiety are the most common treatments. Whenever possible, I attempt to use treatments with multiple benefits. Below is an outline of symptoms and psychopharmacological approaches that address these symptoms. This list is constantly being revised as new information becomes available.

Fatigue may consist of physical and/or mental fatigue. It is often associated with excessive daytime sleepiness, cognitive impairments and apathy. Normalizing circadian rhythm and restoring delta (stage 4 deep sleep) is the primary treatment for fatigue. Therefore, any cortical activating agent in the morning and/or any deep sleep promoting agent at night helps achieve this. The primary cortical activating agent is modafinil (Provigil) and second line agents include psychostimulants, bupropion (Wellbutrin XL, SR or IR) and other activating antidepressants. Deep sleep promoting agents at night include trazodone (Desyrel) and tigabine (Gabitril). Eszopiclone (Lunesta) was recently introduced. It increases all stages of sleep, including deep sleep, and has been demonstrated not to cause tolerance, dependence or rebound in 6 and 12 month studies. Although it may have significant potential, experience with adolescents at this time is very limited.

Insomnia treatments, in addition to those mentioned above, include other sedating antidepressants, antihistamines and melatonin. Other sedating antidepressants include mirtazapine (Remeron), doxepin (Sinequan), amitriptyline (Elavil), trimipramine (Surmontil) and paroxetine (Paxil & Pexiva). The most commonly used antihistamine for sleep is diphenhydramine (Benadryl, Unisom & other over the counter sleep aids). Other options include hydroxyzine (Vistaril & Atarax) and ciproheptadine (Periactin). If more than 3 mg of melatonin is used, it may disrupt the circadian rhythm and cause insomnia the following night. There are many new treatments for insomnia under development by the pharmaceutical industry.

Apathy may respond to treatment with modafinil, which may promote initiative or bupropion that may reduce anhedonia (an inability to relate to the pleasure of life).

Cognitive impairments are treated with a number of strategies. Modafinil may be effective for brain fog, concentration impairments and executive dysfunction. A new and less expensive formulation of modafinil (Attenace) will be available soon to treat ADHD in children. Stimulants (meth-

ylphenidate and amphetamines) have been used for over fifty years and are often effective for the treatment of attention deficits. The long acting forms of methylphenidate (Ritalin LA, Medadate CD & Concerta) and amphetamines (Adderall XR) are used most commonly. A new long acting form of the active isomer of methylphenidate (Focalin LA) shall be released soon and a skin patch form of methylphenidate shall be available at a later date. Memantine (Namenda) helps verbal processing in adults with TBDs and may eventually be useful to some children and adolescents with these symptoms.

Depression treatments include all of the antidepressants and mood stabilizers used in adults. Depression with predominance of apathy is best treated with bupropion, while depression with predominance of anxiety is best treated with paroxetine. The serotonin re-uptake inhibitors (SSRIs) are useful in treating premenstrual dysphoria associated with menarche.Lamotrigine (Lamictal) is particulary effective for treatment resistance depression.

Anxiety disorders include generalized anxiety disorder (GAD), obsessive compulsive disorder (OCD), panic disorder, social anxiety disorder and post-traumatic stress disorder (PTSD). Commonly mixed anxiety disorders are seen with symptoms of more than one type of anxiety. Most of the SSRIs are useful for treating GAD and OCD. Fluvoxamine (Luvox) and clomipramine (Anafranil) are particularly effective for treating OCD. Paroxetine (Paxil) and sertraline (Zoloft) are particularly effective for treating panic disorder, social anxiety disorder and PTSD. Topiramate (Topamax) is also quite useful for treating intrusive symptoms associated with PTSD. Other anticonvulsants and benzodiazepines are also used at times to treat anxiety.

Anger that is brief and episodic, particularly when accompanied by obsessiveness, is best treated with SSRIs, while persistent anger and rage, especially when mood intensity is present, is best treated with valproate (Depakote ER, Depakote), other anticonvulsants and other mood stabilizers. Carbamazepine (Tegretol) has also been used a long time for anger and rage control. More recently, a second generation of carbamazepine and oxcarbazepine (Trileptal) has had increasing use for anger and bipolar illness in children. Unlike carbamazapine, blood monitoring is not needed for oxcarbazepine. A third generation of carbamazapine may be released in about one year.

Psychosis in children and adolescents is most commonly treated with risperidone (Risperdal). However, aripiperazole (Abilify) is being used with increasing frequency with autistic and developmentally disabled children.

Depersonalization sometimes improves when there is improvement of anxiety disorders (especially PTSD and panic disorder), depression, seizures and cognitive impairments. Lamotrigine (Lamictal) can be effective when other treatments fail.

Pain and neuropathy are commonly treated with a combination of a dual-acting antidepressant and an anticonvulsant. The dual-acting antidepressants block the re-uptake of both serotonin and norepinephrine and include duloxetine (Cymbalta), venlafaxine (Effexor XR), Amitriptyline (Elavil) and nortriptyline (Pamelor). Duloxetine, although new, has been proven to be particularly effective in treating chronic pain.

Headaches are treated with the same approach as pain, but muscle relaxants and migraine medications may also be needed.

Seizures may be treated with the commonly prescribed anticonvulsants. These include valproate (Depakote), oxcarbazepine (Trileptal), carbamazepine (Tegretol), topiramate (Topamax), tigabine (Gabitril), and zonisamide (Zonegran).

There are a number of FDA safety warnings associated with the treatments discussed in this paper. Most notably, there is debate surrounding increased risk of suicidal behavior in early treatment of children and adolescents with antidepressants, risk of Stevens Johnson Syndrome with lamotrigine (Lamictal) and oxcarbazepine (Trileptal) and risk of the emergence of seizures with tigabine (Gabitril). All treatment decisions require a clear and complete discussion with the child and parents and a risk vs. benefit assessment.

In summary, children and adolescents with TBDs may have very severe psychiatric symptoms and can respond to a well planned psychopharmacological treatment approach. Although more research is needed in this area, the patients in our office today need to be provided with an individualized treatment plan based upon the findings of their assessment, clinical judgment, and the best evidence available as well as patient and parent preferences.

The form used to perform the clinical assessment is available at: www.mentalhealthandillness.com/lymeframes.html. Additional Internet links and references are available at: www.lymeinfo.net/neuropsych.html.

What's in a name?

Brand and generic names of commonly used psychiatric medications

Generic Name	Brand Name	Generic Name	Brand Name
Amitriptyline	Elavil	Methylphenidate	Ritalin, Medadate, Concerta, or Focalin (enantomer)
Amphetamines	Adderall XR & others	Mirtazapine	Remeron
Aripiprazole	Abilify	Modafinil	Provigil
Bupropion	Wellbutrin XL	Nortriptyline	Pamelor
Carbamazepine	Tegretol	Oxcarbazepine	Trileptal
Ciproheptadine	Periactin	Paroxitine	Paxil
Clomipramine	Anafranil	Risperidone	Risperdal
Diphenhydramine	Benedryl	Sertraline	Zoloft
Doxepin	Sinequan	Tigabine	Gabitril
Duloxetine	Cymbalta	Trimipramine	Surmontil
Eszopiclone	Lunesta	Topiramate	Topamax
Fluvoxamine	Luvox	Trazodone	Desyrel
Hydorxyzine	Vistaril or Atarax	Valproate	Depakote
Lamotrigine	Lamictal	Venlafaxine	Effexor XR
Memantine	Namenda	Zonisamide	Zonegran

Reflections on Lyme Disease in the Family

by Sandy Berenbaum, LCSW, BCD

It is not flesh and blood, but the heart which makes us fathers and sons.

~ Johann Schiller

Ideally, the family is a safe, protective, nurturing unit in which a child develops and grows. The early years are demanding for parents, who, in addition to bonding with their child, must make daily decisions that are vital to their child's life and growth. In contrast, the adolescent years are emotionally challenging, as parents struggle to remain connected, supporting their children's bid for independence, while protecting them from making sometimes disastrous choices, as the child struggles to develop her own ideas and direction.

Let's add Lyme disease to this picture. Parents of children with Lyme disease carry an enormous burden, far greater than those outside the Lyme community are likely to understand. They worry about accuracy of diagnosis, selecting the right doctor and treatment approach, paying for treatment that is very costly, and the complexities of identifying and advocating for educational supports that may be necessary for a child to make it through school.

Other members of the family may be ill as well, often the case with Lyme disease. Aside from the increased financial burden, there is the stress of trying to meet the needs of *several* Lyme disease patients in one family. It is particularly difficult when one of those Lyme patients is a parent, and when the ill parent suffers from neuropsychiatric problems!

Given the complexity and unpredictability of symptoms, and the inadequate understanding of this illness in the greater community, parents often find that they do not have the support of family and friends, as they struggle to cope. Unwittingly, some well-meaning family members may make comments that undermine parents, even challenging the medical decisions that they make. At times, family members mistakenly attribute the child's symptoms and behaviors to willfulness on the part of the child, or inadequate structure and limits on the part of the parents. Failing to appreciate the complex, debilitating nature of this illness, they do not acknowledge the struggle the family is going through, and are therefore not a reliable source of support. This reality in the life of the family of a child with Lyme can be particularly disappointing and painful!

Behavioral problems are not uncommon in children with chronic Lyme. If the child is subject to rages or other severe psychiatric symptoms, this increases the stress level in the family, and makes the

family's day to day life far more complex. Lacking the support and help they would have hoped to get from their family and friends, parents truly feel isolated. They are often out on a limb with their child, but they are also out there *alone.*

Where a young child is concerned, although his parents do their best to help him feel safe and protected, hiding their worries and fears, the child surely senses that something is very wrong. Parents can't help but worry about whether their child will ever fully recover. What might the residual damage be…to his body, to his brain, to his experience of life? On some level, the young child is keenly aware that he is *not* growing up in the carefree environment that peers may be experiencing. Worries certainly permeate the household. Even deciding whether to allow a child to go on a school field trip, or give permission for a teenager to go hiking with friends, may be a struggle for parents, who worry that their child, already very ill, might be reinfected. A sense of normalcy is lost.

Where the adolescent is concerned, a primary issue is how to support the teenager in her efforts to individuate and move toward independence, while taking appropriate precautions for treating the illness. The physical and emotional dependency of a sick teenager may delay or interfere with the task of individuating. Or, the teenager, supported by inaccurate information that is all around them, may separate by challenging the Lyme diagnosis or treatment, and refusing to go to the doctors or take prescribed medications. In denying their illness, teenagers may even come to believe that their symptoms represent *who they are*, as they lose touch with the fact that these symptoms are caused by a *treatable medical illness*. They may therefore see themselves as lazy, not very bright, quick to anger, moody. And, in the process of individuating, they might not believe the evidence their parents and doctors present that these are merely symptoms of the illness, and *not* a manifestation of who they *really* are. How terrifying this is can be for parents!

A child's illness may call on parents to grow in unaccustomed ways. Parents may find themselves thrust into situations beyond their own comfort level, needing to be more assertive with previously trusted school and medical authority figures or more conciliatory with insurers and others, in order to achieve important goals. The needs of their children often push parents far beyond their comfort zone in these areas. It is important that parents recognize where that comfort zone is, and work to move beyond it, for the sake of their child, and his recovery.

In this complex, demanding world, we need to have compassion, empathy, and understanding for those who are struggling to raise children who have chronic Lyme disease. If we can appreciate the challenges that face them, and respect their decisions, perhaps we can make their world a little bit brighter.

Parenting Strategies from the Trenches

After years of helping parents, children, adolescents and families deal with some of these issues, I have developed the following strategies to help parents ease their journey:

- Maintain a problem-focused approach as you make decisions about diagnosis, doctors, and treatment.
- Work at developing a consensus between you and your child's other parent, whether or not you are still together!
- Stay focused on current problems to be solved, and keep worries on the back burner.
- Explain what's going on to your child in concrete, age-appropriate terms.
- Maintain your credibility with your child by being truthful.
- Be careful with the words you use. Avoid words like "psychotic episode", "manic", or "incurable". Lyme disease is a scary illness. Keep your words from making it scarier.
- Be firm when you need to be, but give choices when you can, lots of choices.
- Establish and maintain protective boundaries, protecting yourself and your child from family members and friends who doubt your judgment and parenting

decisions. Let others know what they can and cannot say.
- Build a supportive network - educate your family and friends about Lyme, but don't overload them. Remember, this is *your* issue, not *theirs.*
- Be open to support, but make it clear that you're not open to being second-guessed. Allow people to help in concrete ways when you're overwhelmed. Let them make meals, pick up the kids, or shop for groceries.
- Psychotherapy or family therapy, with a Lyme-knowledgeable therapist, can be an important adjunctive treatment to help you and your children get through the hard times without residual damage. The model I use is helping Lyme patients and their families go from being victims, to survivors, to thrivers. There's nowhere that this model is needed more than with families coping with Lyme disease.

Sandy Berenbaum, LCSW, BCD, may be reached at Family Connections Center for Counseling in Brewster, New York.

Lyme is More Than a Medical Problem

Ann Corson, MD, points out Lyme disease can have a far reaching social impact on children, who may suffer from:

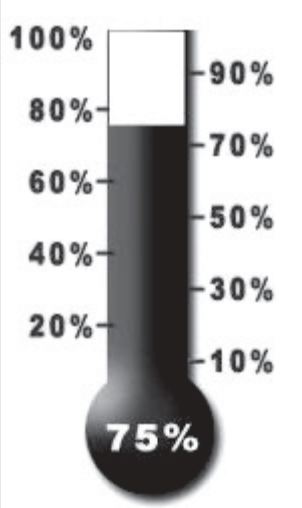
- Isolation
- Loss of peers and normal socialization
- Loss of self-esteem
- Inability to participate in sports or extracurricular activities
- Loss of academic work
- Interruption of normal family life

She calls for those involved with children to be alert to their other needs as well as the medical issues:

- Teachers, school administrators, school health professionals, pediatricians, family practitioners and parents all need to be aware of the varied manifestations of tick-borne diseases.

- Mental health professionals and educators in Lyme endemic areas need to recognize the possible infectious basis of neuropsychiatric disease in children.

Help the national Lyme Disease Association and Time for Lyme reach their goal! $3 million is needed to open the Center. We're 75% there. Care enough to make the difference.



Percent of Money Raised Toward Opening of Columbia Lyme Research Center.

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Jackson, NJ 08527

www.lymediseaseassociation.org/donations.html

A Parent's Journey Toward the Light

If our American way of life fails the child, it fails us all.

~ Pearl S. Buck

My son has neuroborelliosis, *Bartonella henselae* and *Mycoplasma fermentans*. I write with hope that parents, advocates, and medical professionals alike will gain insight into what it's like for a family to cope with severe psychological manifestations of tick-borne diseases.

My son was previously healthy and high functioning, with a jovial spirit. Three months following a mosquito bite which swelled to the size of a softball, he began exhibiting extreme psychological symptoms including Obsessive Compulsive Disorder (OCD), anorexia, and rages. Serendipity led us to a doctor experienced in treating Lyme disease who diagnosed my son with Lyme through DNA and serological assay testing. His Western blot showed positive for both past and recent infection.

Though my son's symptoms began responding to oral antibiotics, a very traumatic event in his life reversed progress. He was attacked by a peer, and beaten, the victim of a bullying incident. His condition worsened and a brain SPECT scan showed little blood circulating to his brain.

Symptoms spiraled into periods of psychosis, suicide attempts, and uncontrollable raging. Normally an extraordinarily bright, articulate, and compassionate child, he was reduced to a vegetative state in which he could only watch pre-school cartoons. This activity was often broken by rageful psychosis and periods of extremely dangerous behavior.

A few examples of the daily happenings for many months would be: screaming obscenities, stalking family members and throwing objects or swinging sticks, trying to start the car (he was middle school age at the time), climbing onto the roof, attempting to jump out of moving cars, running miles away on foot, and attempting to hang himself with masking tape.

These symptoms were surely life-threatening, yet we had no access to emergency healthcare without the threat of harm to my son. I was educated enough to know what the enemy was. It was an infection which had invaded my son's mind and body. After contacting physicians and mental health professionals and doing my own research, I came to realize there was no inpatient facility that would have been willing, experienced, or knowledgeable enough to keep my son safe while continuing his Lyme treatment. The unbelievable truth of the

matter was that any hospital we would have approached for help would have committed my son to a psych ward and would not have approved, nor overseen the treatment necessary to address his raging infection. Any given institution would likely have withdrawn antibiotics and replaced them with multiple psychotropic agents. I know in my heart that he would have been irreparably damaged had I delivered him to the mental health system for help.

Instead, with the long distance support of our doctors and the necessary antibiotic therapies prescribed, my husband and I provided home care. This was a minute by minute endeavor, the only way it could work. The treatment required consisted of IV and oral antibiotics, which often produced psychiatric Jarish-Herxheimer reactions that were completely refractory to all psych meds tried on my son.

For protection, it was necessary to remove all objects such as medications, car keys, garage door openers and anything imaginable that could be dangerous during psychosis. It was necessary to create a total lock down psych ward at home for these months.

I believe extensive reading of medical documentation put out by specialists enabled me to cope. My husband had not read about or experienced the disease as I had, so his faith required more stretching. We had to know this was not our son. We had to have faith that the unimaginable neuropsychiatric Herxheimer would end. We had to have faith that when he ran away, we could find him. We had to know that physically holding him for two hours while he screamed like Linda Blair in the movie The Exorcist was necessary and would one day stop. We had to know the extremely bizarre OCD behaviors would end. We had to trust that the antibiotics were reaching the cause, and that our bright, gentle, happy son would emerge from this Hell. I often envisioned the boy I knew was there trapped inside. I held that image no matter what he looked like, or what he did.

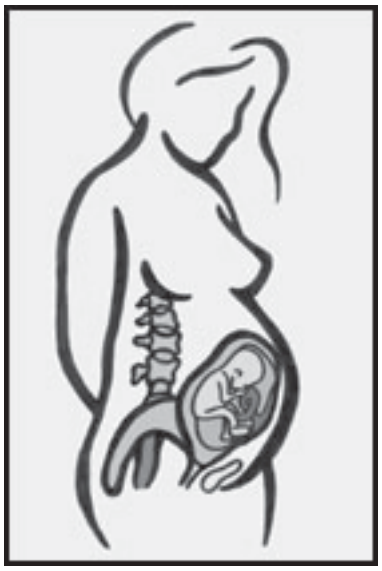
For protection, it was necessary to remove all objects such as medications, car keys, garage door openers and anything imaginable that could be dangerous during psychosis. It was necessary to create a total lock down psych ward at home for these months.

In four months time, on solely an intensive antibiotic regimen, the psychotic rages finally did stop. My son remained detached, and Rifampin was added for Bartonella. He began coming back to life and continued slow but steady improvement thereafter, also improving with treatment for *Mycoplasma fermentans*. He continues treatment and has returned to a part-time schedule at school. There are no rages, no OCD behaviors, no anorectic tendencies, though there are still some remaining cognitive deficits reactive to the infection. My son has returned and is near well. We owe this to the rare doctors willing to treat our son's tick-borne diseases to efficacy.

While our family was able to pull together and weather this storm, we want the Lyme community to be aware of the profound lack of resources for those with psychiatric manifestation requiring hospitalization. It is currently impossible to find a hospital educated in the symptoms of neuroborelliosis and the treatment of Lyme disease that will provide the safe psychiatric environment necessary, while supporting the treatment protocol recommended by the physician treating the Lyme disease. As a community, this is something that we must change. No parent should have to choose between providing adequate treatment for Lyme and a safe psychiatric environment for their child.

Lyme Disease and Pregnancy

by Joseph J. Burrascano Jr., M.D.



Making the decision to have a child - it's momentous. It is to decide forever to have your heart go walking outside your body.

~Elizabeth Stone

It is well known that *B. burgdorferi*, the agent of Lyme, can cross the placenta and infect the fetus. In addition, breast milk from infected mothers has been shown to harbor spirochetes that can be detected by PCR and grown in culture.

The Lyme Disease Foundation in Hartford, CT had kept a pregnancy registry since the late 1980s. It was found that if patients were maintained on adequate doses of antibiotic therapy during gestation, then no babies were born with Lyme. My own experience over the last ten years agrees with this.

Dr. Charles Ray Jones, a pediatrician who practices in Connecticut, has treated and kept records on literally hundreds of babies born with Lyme disease, having contracted it as an intrauterine infection. He treats these children with antibiotics and finds that they generally do well, provided that treatment is aggressive and of adequate duration. Occasionally, he has to retreat these patients as Lyme infections are chronic and can tend to recur.

The options for treating the mother include oral, intramuscular, and intravenous therapy.

Oral regimens include amoxicillin, 1000 mg every 6 hours, and cefuroxime axetil (Ceftin), 1000 mg every 12 hours with food. We always document peak and trough serum levels at the start of gestation and at least once more during treatment. We like to see a peak level above 10, with a trough at least 3. These levels apply for either medication.

For patients who are very ill, or in those who cannot tolerate oral medications or achieve adequate levels, then parenteral therapy is given. Choices include benzathine penicillin (Bicillin LA), 1.2 million units IM three times per week. Intravenous can include ceftriaxone, 2g IV daily, or cefotaxime, 6g daily either as a continuous infusion or as 2g IV q8h.

During pregnancy, symptoms generally are mild as the hormonal changes seem to mask many symptoms. However, post-partum, mothers have a rough time, with a sudden return of all their Lyme symptoms including profound fatigue. We advise against breast feeding for obvious reasons as mentioned above, and we always advise help in the home for at least the first month, so adequate rest and time for needed treatments is assured.

Gestational Lyme Disease Case Studies of 102 Live Births

by Charles Ray Jones, M.D., Harold Smith, M.D., Edina Gibb, and Lorraine Johnson, JD, MBA

Background:

Maternal-fetal transmission of *Borrelia burgdorferi* (Bb), the causative agent of Lyme disease, although found to be associated with adverse outcomes and increased cases of congenital infection, has been met with divergent professional opinions requiring further research to resolve. The exact incidence and capability of transplacental transmission of the spirochete, *Borrelia burgdorferi*, has raised concern as a result of transmission of several other spirochetal agents, including Treponema pallidum. Syphilis and Lyme disease (LD) are both caused by spiral-shaped bacteria, called spirochetes, so the inference may be drawn that the disease processes are likely to be similar. Years of research on congenital syphilis (CS), caused by the spirochete T. pallidum, demonstrated that CS surveillance is complicated by difficulty in establishing the diagnosis, that most infants born with CS have no signs of disease at birth, and that it is almost entirely preventable with early prenatal screening and treatment. (1)

Gestational Lyme disease continues to be an often misunderstood and misdiagnosed condition. A significant number of past studies conducted on LD during pregnancy have repeatedly found pregnancies resulting in adverse fetal outcomes and cases that presented with clinical findings possibly caused by transmission of Lyme disease but the lack of positive diagnostic testing using ELISA, indirect fluorescent antibody (IFA), and Western blot has left researchers still questioning the cause of these findings as being Lyme disease. Therefore, in light of a recent report by Dr. Steven Phillips, et al (2) showing the inadequacies of currently accepted standards for serologic diagnosis using the ELISA and Western blot, dismissal of Bb in maternal-fetal transmission based on this type of testing is not possible. Another reason for concern is that prior clinical studies determined that shorter courses of antibiotic treatment have resulted in 50% of victims suffering from a persistent infection both in early localized Borreliosis and later disseminated intracellular Borreliosis. (3) The insidious nature of gestational LD can present a complicated diagnosis due to the delay of presentation, the multisystemic often transient nature of symptoms that can vary in degree of severity and change with progression of the disease, and finally, the unreliability of standard diagnostic tests.

Gestational Lyme: Frequency, Prevention & Treatment

According to Charles Ray Jones, M.D., out of over 7,000 children seen, 300 (approximately 4%) have gestational Lyme. Data from his practice indicated that of 66 mothers with Lyme disease who were treated with antibiotics prior to conception and during the entire pregnancy, all gave birth to normal healthy infants. However, 8 pregnancies resulted in *Borrelia burgdorferi* and/or *Bartonella henselae* positive placentas, umbilical cords, and/or foreskin remnants. Those with positive PCRs were treated with 6 months of oral antibiotics and are without symptoms 3 months to 4 years later.

Objective:

To better define the diversity in manifestations of gestational Lyme disease and present a more homogenous list of clinical symptoms. Provide more effective treatment protocols that address the three major *Ixodes*

scapularis tick-borne illnesses (Lyme disease, Babesiosis, and Erhlichiosis).

Methodology:

Comprehensive case history studies on one hundred and two pediatric or adolescent patients diagnosed with gestational Lyme disease. The diagnosis of the children was clinical. Although identical testing was not performed for each child, positive diagnostic tests were as follows: ELISA—25%, Western blot—58%, LUAT—25%, Culture—37%, PCR (urine)—4%, PCR (blood)—7%, SPECT scan—11%, MRI—8%. The rate of various co-infections were: strep—7%, leptospirosis—5%, fungal or yeast—4%, ehrlichiosis—6%, babesiosis—14%.

Results:

The mothers of children in this study all had either untreated or partially treated LD, some as a result of *Ixodes scapularis* tick attachments actually during their pregnancy. Most often, the mothers were diagnosed prior to their children when the children were between one and five years of age. A retrospective analysis of the progression of symptoms revealed that oftentimes many initial symptoms were present in the infants, however, were overlooked until they gradually progressed in frequency and severity.

All the mothers had untreated or inadequately treated Lyme prior to or during pregnancy and 16% had received some treatment prior to their pregnancy. Sixty-six percent had a difficult pregnancy, most notable for, but not always inclusive of the following: complications during pregnancy, false labor, history of spontaneous abortions, severe fatigue unresolved by rest, nausea, vomiting, fevers, impaired cognitive function, inability to function during the pregnancy, and illness that continued beyond the delivery. Forty-one percent of the mothers breast fed their children. Although gestational Lyme disease symptoms may present subtly at birth, the implication may be drawn that serious neurological disease will result without prompt diagnosis and treatment. In fact, the children of this study were diagnosed typically between one and five years of age and by this point were completely stricken with a deeply entrenched and chronic Borrelial neurological infection. Several of the cases experienced further deterioration following exposure to Bb through subsequent tick bites and a significant number were also infected with multiple tick-borne pathogens.

Systemic abnormalities were common, with 59% of the children exhibiting low grade fevers, 72% with fatigue and lack of stamina, and 23% with night sweats. Forty-two percent of the children were pale and sickly with dark circles under the eyes. GI symptoms were also common: GERD (27%), abdominal pain (29%), diarrhea or constipation (32%), and nausea (23%). Twenty-three percent of the children had cardiac abnormalities, including palpitations/PVC, heart murmur, and mitral valve prolapse. Orthopedic disorders presented as jointed sensitivity (55%), pain (69%), generalized muscle pain or spasms (23%), and stiffness or retarded motion (23%). Upper respiratory infections were common.

Only 6% of the children presented with a greater degree of arthritic symptoms, while the majority of children presented with extensive neurological symptoms. Neurological presentations most common in this study were headaches (50%), irritability (54%), and poor memory (39%). Developmental delays occurred in 18% of the children, 11% had seizure disorder, 30% had vertigo, 14% had tic disorders, and 9% had involuntary athetoid movements. Many disabling symptoms affecting learning and rendering children unable to perform well in and out of school, including cognitive (27%), speech delay (21%), reading/writing (19%), articulation (17%), auditory/visiual processing problems (13%), word selectivity (12%), and dyslexia (8%). The neuropsychiatric symptoms were widespread (anxiety—21%, anger or rage—23%, aggression or violence—13%, OCD—11%, irritability or mood swings—54%, emotional—13%, depression—13%) and sadly dididid not exclude even suicidal thoughts (7%). Hyperactivity, lack of concentration, and the diagnosis of ADD all together afflicted 56% of the children in the study. Sensory sensitivity manifested as hyperacuity (36%), photophobia (43%), motion sickness (9%), and other (tactile, taste or smell)

(23%). Nine- percent of the children had autism.

Awareness among physicians also must be raised as to the less obvious adverse outcomes of maternal transmission of Lyme disease to the unborn fetus. A common symptom in infants is hypotonia (7%) as a result of neuroborreliosis. One child with symptoms of drooling, poor muscle tone and speech impediment improved with antibiotic treatment such that the child was able to pursue activities of a normal 2-year-old. In another case, the amniotic fluid and cord blood both tested positive for Bb, and the infant was born weighing only 5lbs. Although the child initially did have signs of early Lyme disease her continued treatment has prevented progression of symptoms. She is still undergoing antibiotic therapy but is doing well.

The most striking aspect of these cases is the multisystemic threat that this illness possesses. There were cases which manifested few symptoms. This does not make their disease innocuous but is more representative of a low infectious load and a healthy immune response. However, this was more the exception than the rule. Some abnormalities alone might appear trivial and even unrelated, however, it is the combination of symptoms and the assault that the Bb bacteria makes on many systems that develops a pattern. As the chart below suggests, most children had more than one body system involved. Instead of seeking numerous causes from separate origins to explain vague, mounting, multisystemic symptoms, it is much more logical to realize one probable cause, which in these cases is Lyme disease. All children in the study improved with prolonged antibiotic therapy.

Frequency of Gestational Lyme Symptoms in Children

According to Charles Ray Jones, M.D., most of the children born with gestational Lyme disease have manifestations of the disease at, or shortly after birth.

%	Symptoms
40	Gastroesophageal reflux with vomiting and coughing
80	Irritability
60	Low grade fevers, pallor, and dark circles under their eyes
72	Fatigue and lack of stamina
23	Secondary rashes
45	Other rashes
30	Eye problems: posterior cataracts, myopia, astigmatism, conjunctival erythema (Lyme eyes), optic nerve atrophy and optic neuritis and/or uveitis
40	Frequent upper respiratory tract infections and otitis
20	Abdominal pain
40	Noise, light and skin sensitivity
50	Arthritis and painful joints
18	Developmental delay, including language, speech problems and hypotonia
80	Cognitive problems, learning disabilities and mood swings
30	Cavernous hemagiomas
	Diagnostic Tests
50	Positive Western blots
20	Positive PCRs
21	Positive LUATS
37	Positive Bb blood cultures
11	Positive Brain SPECT
80	Neuropsychological evaluation confirmed cognitive problems

Gestational Lyme Disease Bibliography

by Lorraine Johnson, JD, MBA

Transmission of Lyme disease by tick is well known. However, some studies have provided evidence of gestational transmission and others have suggested transmission through lactation. In addition, transmission by intimate human contact has been hypothesized. Given the implications, for the fetus and infants, it is essential that more research be done in this area, so that the mother can be treated efficaciously.

Bale, J. F., Jr. and J. R. Murph (1992). "Congenital infections and the nervous system." Pediatr Clin North Am **39**(4): 669-90.
Borrelia burgdorferi can potentially infect the fetus and cause adverse fetal outcomes.
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Gardner, T. (1995). Lyme disease. Infectious diseases of the fetus and newborn infant. J. S. Remington and J. O. Klein. Philadelphia, Saunders. **Chap. 11:** 447-528.
"A total of 46 cases of adverse outcomes of these 161 cases of gestational Lyme borreliosis were found, including miscarriage, stillbirth, perinatal death, congenital anomalies, systemic illness, early-onset fulminant or mild sepsis and later-onset chronic progressive infection....Thirty-seven percent of the total number of adverse outcomes were miscarriages or fetal deaths, 11 percent were neonatal deaths and 48 percent were either fetal or neonatal deaths." The effect of antibiotic therapy was dramatic in these patients: with antibiotics, 85% of neonates were normal, while 15% had an adverse outcome. In striking contrast, without antibiotics, only 33% were normal, while 67% had an adverse outcome.
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MacDonald, A. B. (1986). "Human fetal borreliosis, toxemia of pregnancy, and fetal death." Zentralbl Bakteriol Mikrobiol Hyg [A] **263**(1-2): 189-200.
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MacDonald, A. B. (1989). "Gestational Lyme borreliosis. Implications for the fetus." Rheum Dis Clin North Am **15**(4): 657-77.
Great diversity of clinical expression of signs and symptoms of gestational Lyme borreliosis parallels the diversity of prenatal syphilis. It is documented that transplacental transmission of the spirochete from mother to fetus is possible. Further research is necessary to investigate possible teratogenic effects that might occur if the spirochete reaches the fetus during the period of organogenesis. Autopsy and clinical studies have associated gestational Lyme borreliosis with various medical problems including fetal death, hydrocephalus, cardiovascular anomalies, neonatal respiratory distress, hyperbilirubinemia, intrauterine growth retardation, cortical blindness, sudden infant death syndrome, and maternal toxemia of pregnancy. It is my expectation that the spectrum of gestational Lyme borreliosis will expand into many of the clinical domains of prenatal syphilis.
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MacDonald, A. B., J. L. Benach, et al. (1987). "Stillbirth following maternal Lyme disease." N Y State J Med **87**(11): 615-6.
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Markowitz, L. E., A. C. Steere, et al. (1986). "Lyme disease during pregnancy." Jama **255**(24): 3394-6.
Because the etiologic agent of Lyme disease is a spirochete, there has been concern about the effect of maternal Lyme disease on pregnancy outcome. We reviewed cases of Lyme disease in pregnant women who were identified before knowledge of the pregnancy outcomes. Nineteen cases were identified with onset between 1976 and 1984. Eight of the women were affected during the first trimester, seven during the second trimester, and two during the third trimester; in two, the trimester of onset was unknown. Thirteen received appropriate antibiotic therapy for Lyme disease. Of the 19 pregnancies, five had adverse outcomes, including syndactyly, cortical blindness, intra-uterine fetal death, prematurity, and rash in the newborn. Adverse outcomes occurred in cases with infection during each of the trimesters. Although B burgdorferi could not be implicated directly in any of the adverse outcomes, the frequency of such outcomes warrants further surveillance and studies of pregnant women with Lyme disease.
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Schlesinger, P. A., P. H. Duray, et al. (1985). "Maternal-fetal transmission of the Lyme disease spirochete, *Borrelia burgdorferi*." Ann Intern Med **103**(1): 67-8.
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Weber, K., H. J. Bratzke, et al. (1988). "*Borrelia burgdorferi* in a newborn despite oral penicillin for Lyme borreliosis during pregnancy." Pediatr Infect Dis J **7**(4): 286-9.
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Brzostek, T. (2004). "[Human granulocytic ehrlichiosis coincident with Lyme borreliosis in pregnant woman—a case study]." Przegl Epidemiol **58**(2): 289-94.
Thrombocytopenia, fever and fatigue were observed in a 25 year-old woman in her 29th week of pregnancy in a Lyme endemic area. In the last 7 weeks erythema migrans was present. The woman was not treated by that time. The infant presented thrombocytopenia in the first few weeks of life. 3 months after delivery erythema migrans disseminata was observed, by that time Lyme borreliosis and HGE were serologically confirmed. It was not confirmed that the infection was transferred to the infant, but it is possible that thrombocytopenia was caused by the infection with A. phagocytophila.

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Goldenberg, R. L. and C. Thompson (2003). "The infectious origins of stillbirth." Am J Obstet Gynecol **189**(3): 861-73.
In areas where syphilis is very prevalent, up to half of all stillbirths may be caused by this infection alone. Malaria may be an important cause of stillbirth in women infected for the first time in pregnancy. Toxoplasma gondii, ... and Lyme disease have all been implicated as etiologic for stillbirth.
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Gustafson, J. M., E. C. Burgess, et al. (1993). "Intrauterine transmission of Borrelia burgdorferi in dogs." Am J Vet Res **54**(6): 882-90.
10 female Beagles were inoculated intradermally with …B burgdorferi. Of 10 spirochete-inoculated (SI) females, 8 became infected with B burgdorferi as evidenced by spirochete culture results and/or PCR-detected B burgdorferi DNA in the tissues of females or their pups. Of the 10 SI females, 8 delivered litters (3 to 7 pups) that had at least 1 neonatal or 6-week-old pup with B burgdorferi DNA-positive tissues (by PCR), and spirochetes were cultured from tissues from pups of 2 litters.
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Lactation

Schmidt, B. L., E. Aberer, et al. (1995). "Detection of Borrelia burgdorferi DNA by polymerase chain reaction in the urine and breast milk of patients with Lyme borreliosis." Diagn Microbiol Infect Dis 21(3): 121-8. In addition to urine, breast milk from two lactating women with erythema migrans was tested and also found reactive.

Altaie, S. S., S. Mookherjee, et al. (1996). Abstract # I-17 Transmission of Borrelia burgdorferi from experimentally infected mating pairs to offspring in a murine model. FDA Science Forum. Transmission via breast milk demonstrated in murine model.

Maraspin, V., J. Cimperman, et al. (1999). "Erythema migrans in pregnancy." Wien Klin Wochenschr **111**(22-23): 933-40.
From 1990 through to 1997, 105 pregnant women with typical EM were investigated at the Lyme Borreliosis Outpatients' Clinic of the Department of Infectious Diseases at the University Medical Centre in Ljubljana, Slovenia. All patients were treated for 14 days except three (2.9%) in whom the treatment with ceftriaxone was discontinued because of mild side effects. Ninety-three (88.6%) out of 105 patients had normal pregnancies; the infants were delivered at term, were clinically healthy, and subsequently had a normal psychomotor development. In the remaining 12 (11.4%) patients an adverse outcome was observed. Two (1.9%) pregnancies ended with an abortion (one missed abortion at 9 weeks, one spontaneous abortion at 10 weeks), and six (5.7%) with preterm birth. One of the preterm babies had cardiac abnormalities and two died shortly after birth. Four (3.8%) babies born at term were found to have congenital anomalies; one had syndactyly at birth and three had urologic abnormalities which were registered at the age of 5, 7, and 10 months, respectively. A causal association with borrelial infection was not proven in any infant. For at least some unfavourable outcomes a plausible explanation not associated with Lyme borreliosis was found.
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Harvey, W. T. and P. Salvato (2003), "Lyme disease: ancient engine of an unrecognized borreliosis pandemic?", Medical Hypotheses 60(5), 742–759.
No serious or credible epidemiological studies have attempted to identify the true rate of human congenital [Bb] transfer. The only method we have of estimating congenital human [Bb] transfer is by other intra-human illnesses. Transfer rates of Cytomegalovirus, Toxoplasmosis and Treponema pallidum range from 14% to 68%.

Transplacental Babesia infection in dogs

"This is the first confirmed report of transplacental Babesia infection in any animal species."

A Babesia gibsoni infected bitch was mated with an uninfected dog in order to determine whether this parasite could be vertically transmitted. The bitch delivered a litter of four live and one stillborn pup. The four pups died from congenital babesiosis between 14 and 39 days post-birth. Babesia gibsoni DNA was detected in tissue from all five pups. These results show that vertical transmission occurred by the uterine route and not via the transmammary route. This is the first confirmed report of transplacental Babesia infection in any animal species.

Fukumoto S., Fatal experimental transplacental Babesia gibsoni infections in dogs, Int J Parasitol. 2005 Jun 23
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Do you think you may have Lyme disease?

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LymeAid 4 Kids is a fund created by the national non-profit Lyme Disease Association with the help of internationally acclaimed author Amy Tan who is also supporting the fund. All contributions to LDA are tax deductible to the extent allowed by law.

Join CALDA

CALDA operates on a national basis, cooperating with all LDA affiliates and chapters and supporting patients in all states, by:

- Collecting and disseminating data on behalf of the Lyme community through the LYME TIMES;
- Sharing best practices with other state and national organizations;
- Acting as a central resource for patients, physicians and support groups;
- Providing technical support for local education and advocacy efforts.

Back issues of the Lyme Times may be viewed at www.lymetimes.org

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- ***$50 - Supporting***
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- ***$250 - Patron***
- ***$1000 and up - Gold Circle***
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I enclose an additional $_____ as a tax-deductible contribution to the Ted Hoggard Memorial Fund for education and research.

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I enclose my check or money order for the total amount of $_____.

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Helpful Pediatric Internet Links

California Lyme Disease Association

www.calda.intranets.com

This INTRANET contains advocacy information for patients, children and families. Issues of the special children's treatment issue of the Lyme Times as well as the upcoming children's educational issue are available here. Back issues with articles about children and Lyme are also available.

Lyme Disease Association, Inc.

www.lymediseaseassociation.org

The LDA operates on a national level and provides considerable resources for parents, schools and families. Their book "Lyme is No Fun", the ABC's pamphlet, published articles and video are included as well as information on their fund, Lyme Aid 4 Kids, which assists families without insurance obtain a diagnosis.

Int'l Lyme & Associated Disease Society

www.ilads.org

Position papers and practice guidelines on the latest diagnostic methods and treatments in the management of tick-borne diseases.

Lyme Info

www.lymeinfo.net/directory.html

Links dedicated to children with Lyme, including teachers' resources, scout badges, etc. Scroll down to "Children and Families" under directory.

Columbia University-Lyme Disease Research Studies

www.columbia-lyme.org/index.html

Neuropsychological testing, medical workup, cognitive/neuropsychiatric problems in children with Lyme is covered.

Parents of Children with Lyme

www.poc.org/index.html

Educational links, Lyme links, personal stories, and information on tick-borne diseases.

Time for Lyme

www.timeforlyme.org

The video "The Student, the Educator and Lyme Disease" is in the resource section.

LDA of Southeastern Pennsylvania

www.lympepa.org

Maintains Lymeteens, a private email group for teens with Lyme disease.

Educational Assistance Resources

Pacer Center-Parent Advocacy Coalition for Educational Rights

www.pacer.org

The Families and Advocates Partnership for Education (FAPE)

www.fape.org

Nat'l Assn of Parents with Children in Special Education

www.napcse.org

National Association of State Boards of Education

www.nasbe.org

Nat'l Dissemination Center for Children with Disabilities (NICHCY)

www.nichcy.org

Special Education, Law & Advocacy-Wrightslaw

www.wrightslaw.com

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For more information:
ILADS: visit www.ilads.org or call 1-301-263-1080
LDA: visit www.LymeDiseaseAssociation.org or call 1-888-366-6611

The purpose of this issue is to educate families, healthcare providers, educators, insurers and public healthcare policy makers. Purchase bulk issues at a discounted rate ($3 an issue/10 issue minimum for members) for community outreach efforts. Individual copies are available to non-members for $10 per issue.

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