

What Everyone Needs To Know About

Pediatric Lyme Disease

What Do We Need To Do?

- **Learn about tick borne illnesses**
- **Recognize the scope of the epidemic**
- **Identify children with Lyme disease**
- **Educate our families, friends, school officials, teachers, nurses and doctors**
- **Understand the needs of sick children**
- **Practice and teach prevention of tick borne disease**

Why Should We Learn About Tick Borne Diseases?

- **Lyme disease and associated co-infections are the fastest growing vector borne diseases in the US**
- **We live in a highly endemic area**
- **Many infected children are going unrecognized, untreated and/or misdiagnosed**
- **Most children who are treated are generally under treated**

Who Should Learn About Tick Borne Diseases?

- **Everyone, especially parents, teachers, school administrators, school health professionals, pediatricians, and family practitioners need to understand and appreciate the protean manifestations as well as the growing prevalence of tick borne diseases**
- **Mental health professionals and educators in Lyme endemic areas need to recognize the possible infectious etiology of neuropsychiatric illness in children**

Who Should Learn About Tick Borne Diseases?

- **Health professionals need to recognize that children previously diagnosed with neuropsychiatric, learning or attention disorders may indeed have infectious diseases that are treatable**
- **It is imperative to identify children with both acute and persistent or chronic tick borne diseases so they may seek appropriate medical, psychological and educational assistance**

Risk Factors

- **Age 10-19**
- **Rural (*suburban*) vs. urban, 3x risk**
- **Single family homes**
- **Homes with yards +/- woods or attached land**
- **Homes within 100 feet of woodland**
- **Tick hosts being seen on land: deer, mice**

Public Health Reports 2001, Volume 116, 146-156. Risk Factors for Lyme Disease in Chester County, Pennsylvania

- **CDC: Any child under 9 yrs at risk with many new cases LD in children under 14 yrs**

MMWR 1991. 42; 557-558

Risk Factors

- Having pets that come in and out, dogs or cats
- Outdoor activities:
 - Horseback riding
 - Hunting, fishing
 - Any activity in the woods or open land or abutting high grasses including field sports, golf
 - Activities in any outdoor area frequented by deer

Anyone can be infected on any warm day of any month of the year!

What Causes Tick Borne Diseases?

- Borrelia burgdoferi, the spirochete that causes Lyme disease
- Babesia microti, an intra-erythrocytic piroplasm akin to the parasite malaria
- Bartonella henselae, a bacterium
- Anaplasma phagocytophilia (Human Granulocytic Ehrlichiosis) and Ehrlichia chaffeensis (Human Monocytic Ehrlichia), both intracellular rickettsial-like bacteria
- Mycoplasma fermentans, an ancient, tiny, intracellular bacterium

What Is The Scope Of The Problem?

- **Explosion of the tick population due to alteration of habitat allowing explosion of rodent and deer populations?**
- **Increasing percentage of ticks carrying infectious organisms?**
- **Increasing virulence of organisms?**
- **Result: massive increase in number of people infected**

Identifying Children With Lyme Disease

- **Lyme is truly the “Great Imitator” of our times just as syphilis was for prior generations**
- **Onset of the illness can be abrupt or indolent**
- **All organ systems of the body can be affected**
- **Symptoms are often vague and shifting from day to day therefore many children are thought to be malingerers or emotionally disturbed**
- **Children often don’t understand what is happening to their bodies and have a hard time explaining often unusual or bizarre symptoms**

Signs And Symptoms

- **Commonly taught beliefs about the presentation of Lyme Disease**
 - Bull's eye rash
 - Bell's palsy
 - Monoarticular joint effusion, esp. knee
 - Third degree heart block
- **Statistics from my practice**
 - 12% remember EM rash
 - 4% Bell's palsy
 - 2.6% monoarticular joint effusion (both elbows)
 - 0% third degree heart block

Signs And Symptoms

- **What are the most common presentations of Lyme Disease?**
 - **Flu-like illness at any time of the year**
 - **Fatigue, often unrelieved by rest**
 - **Neurological and psychiatric symptoms**
 - **Headaches**
 - **Unexplained fevers, often cyclical**
 - **Remember:**
 - **Less than 50% of children remember a tick bite.**
 - **Even less remember an EM rash.**

Signs And Symptoms

- **Abdominal pain**
- **Joint pains, migratory and intermittent**
- **Myalgias or muscle aches and pains**
- **Sleep disturbance**
- **Aerobic exercise intolerance**
- **Frequent infections, viral, bacterial and fungal**
- **Recurrent swollen lymph nodes anywhere (neck, armpits, groin)**

Signs And Symptoms

- **Chest pains, shortness of breath, dry cough**
- **Urinary urgency and frequency, dysuria or painful urination**
- **Rashes of all kinds that come and go**
- **Dark circles under the eyes**
- **Intermittent red, hot pinnae or external ears**

In Depth Signs And Symptoms

- **Neurological and Psychiatric Symptoms**
 - **Uncharacteristic behavior outbursts, mood disturbances, irritability, emotional lability**
 - **Social withdrawal, decreased participation in activities**
 - **depression**
 - **suicidal thoughts in over 40%**
 - **Rage and anger management disorders**
 - **New onset anxiety disorders, phobias**

In Depth Signs And Symptoms

- **Oppositional behaviors**
- **Obsessive compulsive disorders**
- **Hallucinations of all kinds**
- **Psychosis**
- **Personality changes**
- **Self-mutilating behaviors**

In Depth Signs And Symptoms

- **90% of children have a deterioration in school performance**
 - **Difficulty with concentration and attention in school with easy distractibility, get labeled as learning disability or ADD or ADHD**
 - **Word finding problems**
 - **Short term memory difficulties**
 - **When measured with formal neuropsychiatric testing, children with neurological Lyme disease demonstrate defects in auditory and visual sequential processing**

In Depth Signs And Symptoms

- **Headaches of all kinds**
- **Aberrations (mostly hypersensitivity) of sensory stimuli of noise, light, sound, touch, taste**
- **Poor balance and coordination**
- **Peripheral neuropathies – numbness and tingling, distal parasthesias, subtle weakness, severely painful neuralgias**
- **Loss of previously acquired motor skills**
- **Movement disorders – spasticity, ataxia, motor or vocal tics**

In Depth Signs And Symptoms

- **Cranial neuropathies, e.g. Bell's Palsy or optic nerve neuritis (can result in visual loss)**
- **Partial complex seizures**
- **Peripheral motor weakness**
- **Apparent demyelinating disease (multiple sclerosis)**
- **Spinal cord involvement (myelopathies)**
- **Pseudo tumor cerebri or increased intracranial pressure, papilledema**

In Depth Signs And Symptoms

- **Sleep disturbances**
 - **Trouble falling asleep**
 - **Frequent awakenings**
 - **Night terrors**
 - **Sleep walking**
- **Constitutional Symptoms**
 - **Fatigue**
 - **Fevers**
 - **Night sweats**

In Depth Signs And Symptoms

- **Gastrointestinal Symptoms**
 - Abdominal pains of all kinds
 - Changes in appetite
 - Mouth sores, sore throats
 - Changes in stooling patterns (unexplained diarrhea or constipation)
- **Musculoskeletal symptoms**
 - Migratory, intermittent joint pains, esp. of extremities, neck and spine and chest wall
 - Deep bone pains
 - Muscle pains, spasms, twitches

In Depth Signs And Symptoms

- **Urological Symptoms**
 - **Loss of bladder control with return to wetting during day or at night**
 - **Urgency and frequency, hesitancy**
- **Cardiac Symptoms**
 - **Chest pains**
 - **Palpitations**
- **Immune System**
 - **Frequent infections, esp. viral**
 - **Increased allergies and chemical sensitivities**

Special Age Groups

Signs And Symptoms

■ Adolescents

- Parents and teachers may think any unusual behaviors are just “normal” adolescence or problems such as illicit drug use or new onset psychiatric disorder
- Mood swings, oppositional behaviors, anxiety, depression
- Self mutilating behaviors
- Teenagers often do not report to or show parents problems with their bodies

Special Age Groups

Signs And Symptoms

- **Adolescents, cont.**
 - **Teens can also turn to alcohol and illicit drugs as self medication**
 - **Teenage girls may have pelvic pain or menstrual problems, ovarian cysts, boys may have testicular pain**
 - **Teens need to be aware that Borrelia may be sexually transmitted and that a fetus can acquire the infection from the mother during pregnancy**

Special Age Groups

Signs And Symptoms

- **Pre-schoolers and toddlers**
 - **Mood swings, sudden emotional outbursts**
 - **Irritability**
 - **Personality changes**
 - **Regression of motor and social skills (developmental milestones)**
 - **Changes in play behavior, tire easily, less active**

Special Age Groups Signs And Symptoms

- **Pre-schoolers and toddlers, cont.**
 - **Trouble falling asleep, frequent awakenings**
 - **Nightmares, new phobias, recurrence of separation anxiety**
 - **Diaper rash unresponsive to normal treatment**
 - **Frequent URIs, ear and throat infections, bronchitis, pneumonia**

Congenital Lyme disease

- **Infants can be infected with *Borrelia* transplacentally in any stage of pregnancy and/or via mother's breast milk.**
- **The co-infections: *Babesia*, *Bartonella*, *Mycoplasma* and perhaps even the *Ehrlichias* may be transmitted transplacentally to the developing fetus.**

Congenital Lyme disease

- **Gestational Borreliosis can be associated with repeated miscarriages, fetal death in utero, fetal death at term (stillbirths), hydrocephalus, cardiovascular anomalies, intrauterine growth retardation, neonatal respiratory distress, “sepsis” and death, neonatal hyperbilirubinemia, cortical blindness, sudden infant death syndrome and maternal toxemia of pregnancy.**

Congenital Lyme disease

- **Borrelia spirochetes have been found at autopsy in fetal brain, liver, adrenal glands, spleen, bone marrow, heart and placenta**
 - **None of the infected tissues showed any sign of inflammation**
- **Maternal antibiotic treatment during pregnancy does not guarantee that the fetus will be free of infection**
- **Mothers with Lyme disease should be treated throughout pregnancy**

Congenital Lyme disease

- **Infants either infected congenitally or from breast milk can have**
 - **Floppiness with poor muscle tone**
 - **Irritability**
 - **Frequent fevers and illness early in life**
 - **Joint sensitivities and body pain**
 - **Skin sensitivity**
 - **Gastro esophageal reflux**
 - **Developmental delays**
 - **Learning disabilities and psychiatric problems**

Congenital Lyme disease

- **Infants infected congenitally can have**
 - **Small windpipes (tracheomalacia)**
 - **Eye problems (cataracts)**
 - **Heart defects**
- **Infants infected with breast milk as well as infants bitten very early in life will have many of the same symptoms as congenitally infected babies**
- **Infected infants often show a loss or decline in previously acquired developmental milestones and become slower at learning new skills**

Co-Infections

Co-infections are the rule, not the exception

- 80% of my pediatric patients co-infected
- Co-infections are often best diagnosed clinically
- Co-infected patients are:
 - Sicker
 - More likely to have failed prior treatment
 - Require longer treatment with multiple agents
- Co-infections must be eradicated or Borrelia infection will persist

Signs And Symptoms Of Co-Infections

- **Ehrlichiosis(HME, HGE):** high fevers, headaches, muscle pains, flu-like symptoms. Labs can show low WBC and platelets, increased liver enzymes
- **Babesia microti:** (malarial like parasite that lives inside red blood cells) cyclical fevers and sweats, chills, profound fatigue, headache, muscle pains, deep bone pains, especially of the extremities, SOB, dry cough, poor balance, painful feet

Signs And Symptoms Of Co-Infections

- **Bartonella henselae**: abdominal pain, headache, visual problems, significant lymph node enlargement (e.g. mesenteric adenitis), rashes, unusual “stretch marks”, resistant neurological deficits, radiculopathies, cranial neuralgias, new onset seizure disorders, acute encephalitis, sole of foot pain or burning in am, psychiatric disorders of all kinds
- **Mycoplasma fermentans**: fatigue, abdominal pain, psychiatric symptoms

Evaluation

- **Tick borne disease is a clinical diagnosis**
- **Laboratory testing can be very difficult as many patients are serologically negative for antibodies to *Borrelia* despite active infection**
- **Routine labs are usually unremarkable**
- **Even the majority of spinal taps reveal normal spinal fluid**
- **Full evaluation at labs that specialize in TBD can be very helpful although negative results do not mean absence of disease**

Evaluation

- **“If false results are to be feared, it is the false negative result which holds the greatest peril for the patient.”**

Gestational Lyme Borreliosis. Implications for the fetus. MacDonald, AB, *Rheum Dis Clin North Am*,15(4):657-77.1989.

Evaluation

- **Two tiered CDC testing ELISA / WB**
 - **Developed for surveillance *not* diagnosis.**
 - **The CDC itself states that it is inappropriate to use surveillance case definitions for establishing clinical diagnoses, determining the standard of care necessary for a particular patient, setting guidelines for quality assurance or for providing standards for reimbursement.**

Evaluation

- **Two tiered CDC testing ELISA / WB**
 - **College of American Pathologists concluded that current ELISA not sensitive enough to use as a screening test**
 - **Half the patients positive on Western Blot have negative ELISA**
 - **ELISA misses half the patients with Lyme disease**
 - **Western Blot most useful test to detect antibodies to Bb, but test varies considerably from lab to lab**

Evaluation

- **Western Blot**
 - **Band numbers required by CDC case definition was developed initially for surveillance, not diagnostic criteria**
 - **Only one species-specific band is necessary to demonstrate exposure to Bb therefore confirming a diagnosis of Lyme disease**
 - **These include bands 18, 23-25, 31, 34, 37, 39, 83, and 93 kDa.**
 - **CDC included non species-specific bands in their criteria. This is not logical.**

Treatment

- **Two Standards of Care**
 - **Parents and their children have the right to know that two standards of care exist for the treatment of Lyme disease**
 - **ILADS guidelines 2004 vs. IDSA guidelines 2000**
 - **www.guidelines.gov National Guideline Clearinghouse web site. Put “lyme” in home page’s search engine or guideline no. 003481**

Treatment

- **Treatment lasts as long as is necessary**
 - **Until children are completely symptom free for several months with no more cyclical Herxheimer reactions**
 - **No recurrence of Lyme symptoms with concomitant illnesses or stresses**
- **Sickest children often need many months of intravenous, intramuscular and oral antibiotic therapy**
- **Children whose diagnosis and treatment are delayed may suffer permanent neurological and physical impairment**

Understanding The Needs Of Sick Children

- **Social impact**
 - **Symptoms fluctuate so friends, family and teachers often don't believe the sick child**
 - **Isolation**
 - **Loss of peer group and normal socialization**
 - **Loss of academic work**
 - **Loss of self-esteem**

Understanding The Needs Of Sick Children

- **Physical impact**
 - **Children feel sick, they hurt, their brains don't work**
 - **Inability to participate in sports or other extracurricular activities**
- **Family impact**
 - **Interruption of normal family life, stress on working parents and siblings**

What Can Schools Do?

- **Identify children with persistent neuroborreliosis so they can receive appropriate medical, psychological and educational assistance**
- **Allow for individual educations plans**
 - **Late arrivals, early dismissals**
 - **Flexibility in assignment due dates**
 - **Removing time limits from test taking**
 - **Allow course auditing or changes**
 - **Tutor support at school or home (on-line)**

What Can Parents Do?

- **Make sure schools are abiding by the two Federal laws that protect students with Lyme disease and supercede state codes and regulations:**
 - **IDEA: Individuals with Disabilities Education Act www.ideapractices.org**
 - **Section 504 of the 1973 Rehabilitation Act www.504idea.org**

Prevention

- **Avoid exposure to ticks**
- **Clear away underbrush, cut back shrubbery**
- **Get the deer out of your yard (fences, melorganite, wirelessdeerfence.com, deerscram.com)**
- **Spray yard with permethrin**
- **Wear protective clothing and use appropriate insecticides while outdoors**
- **Damminix® or Maxforce® for mice**
- **Treat domestic animals with topical insecticides**
- **Lobby local government regarding tick and deer control and elimination**

Caveats

- **Any child who becomes ill after a tick bite needs a full evaluation for the presence of co-infections**
- **Any child who becomes ill after a tick bite who was treated with 3 to 4 weeks of oral antibiotics has most likely been inadequately treated**
- **Initial inadequate treatment makes future treatment more difficult**

Caveats

- **Neurological and/or neuropsychiatric signs and symptoms are often the first and only presenting sign of infection**
- **Neurological and/or neuropsychiatric signs and symptoms are often the most common indication of persistent infection after inadequate treatment**

Caveats

- **In 1989, Dr. Andrew Pachner predicted that “If, as it now seems, the Lyme spirochete is indeed highly neurotrophic and able to remain dormant in the CNS for long periods, we may well see a sizable number of individuals who currently have latent neuroborreliosis presenting in the future with symptomatic infection.”**

Neurological Manifestations of Lyme Disease, the New “Great Imitator” Pachner, A. *Reviews of Infectious Diseases*. Vol II, Supplement 6. September-October 1989.

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