Tick-Borne Diseases Handbook

A Resource for Physicians, Nurses, and Patients

By

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Journal abstracts can be found at www.pubmed.gov or by doing an Internet search of the topic.
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DISEASES Ticks Can Cause

**Lyme Disease:** Causes a multitude of symptoms.

**STARI (Masters’ Disease):** Transmitted by lone star ticks. Identical to Lyme in rash, symptoms, and treatment. Often produces negative Lyme tests. There's no commercial test for STARI.

**Rocky Mountain Spotted Fever:** Can cause high fever and meningitis; sometimes fatal.

**Ehrlichiosis:** Can cause high fever and meningitis; sometimes fatal.

**Anaplasmosis:** Similar to ehrlichiosis; can be fatal.

**Babesia:** Related to malaria. Can cause severe fatigue, sweats, chills, fever, breathing problems, other symptoms. Can be chronic.

**Bartonella:** Related to cat scratch disease. Can cause large, painful lymph nodes; parallel lines resembling stretch marks; headaches; seizures; vision problems; and other symptoms.

**Tularemia:** Rabbit fever. Causes a sore, flu symptoms, swollen glands.

**Mycoplasma fermentans:** Can cause fatigue, joint & muscle pain, cognitive problems.

**Other diseases:** Powassan encephalitis, Q fever, etc.

**Tick Paralysis:** A rare reaction to saliva of female ticks. Paralysis starts in lower legs and moves up the body. Can be fatal unless the tick is found (usually on the head or neck) and removed in time.

> People can get several diseases from a single tick bite.  
> A tick bite doesn't always result in a disease. Some ticks are not infected.
LYME DISEASE CAN CAUSE

- Fibromyalgia
- Chronic Fatigue Syndrome
- MS (multiple sclerosis)
- ALS (Lou Gehrig’s disease)
- Parkinson’s
- Lupus
- Scleroderma
- Rheumatoid Arthritis
- Bell’s palsy
- Learning disabilities
- ADD (attention deficit disorder)
- Autism, Asperger's, autistic-like syndromes
- Alzheimer’s
- Tourette's syndrome
- Guillain-Barre Syndrome
- Obsessive-compulsive disorder
- Bi-polar disorder, other psychiatric illnesses
- Other diseases

When these diseases and conditions are caused by Lyme disease a lengthy course of antibiotics is often helpful. However, people typically feel worse for a while when antibiotics are started, because the dying bacteria cause a Jarisch-Herxheimer (“die-off”) reaction.
LYME SYMPTOMS

➢ **Skin**

EARLY STAGE:
- Red spot or rash at site of bite (in only about 50% of cases)
  - can appear in other sites
  - can be pink, red, or purple
  - may resemble a bruise on dark skin
  - may be oval or circular
  - may develop central clearing
  - may or may not look like a bull’s eye
  - may or may not itch or be hot
  - there may be multiple rashes
  - other rashes may occur

LATE STAGE:
- Severe acne, rosacea, other skin problems
- Rashes and spots resembling bruises may come and go for years

➢ **Musculoskeletal**

- Migrating asymmetrical joint pain, with or without swelling
- Muscle weakness, may be progressive; chronic sore muscles
- Migrating muscle pains, cramps
- Stiffness in neck, back, joints

➢ **Constitutional Symptoms** (general well-being)

- Early on, a flu-like illness
- Swollen glands
- Fatigue, unusual or extreme
- Malaise
- Symptoms that seem to change or come and go
- Pains that migrate to different parts of the body
- Unexplained weight loss or gain
- New onset sensitivities or allergies
- Fevers, unexplained, high or low grade
- Continual or frequent infections (sinus, eye, kidney, bladder)

➢ **Head, Face, Neck**

- Frequent headache, mild or severe
- Stiff or painful neck
- Unexplained hair loss
- Jaw pain or stiffness
- Facial pain; numbness in face
- Sore throat
- Facial paralysis (Bell’s palsy)
- Swallowing problems
- Twitching of face & other muscles
- Tingling of nose, cheek, or face
- Trigeminal neuralgia (TMJ)
- Painful gums, teeth
- Double or blurry vision; fluctuations in visual acuity

➢ **Eyes/Vision**

- Floaters in eyes
- Swelling around eyes

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LYME SYMPTOMS

☐ Sensitivity to light: sunglasses may be needed indoors & at recess
☐ Redness in eyes; Chronic conjunctivitis; keratitis
☐ Flashing lights

➤ Ears/Hearing
☐ Decreased hearing in one or both ears
☐ Noise sensitivity; increased hearing in one or both ears
☐ Buzzing or ringing in ears
☐ Pain in ears

➤ Digestive & Excretory
☐ Frequent or chronic diarrhea &/or constipation
☐ Frequent urination, trouble starting/stopping, urgency
☐ Chronic nausea, vomiting

➤ Central Nervous System (CNS) (neurological, mental, & psychological functions)
☐ Tremors or unexplained shaking; jerking; Tourette’s
☐ Numbness, tingling, pinprick sensations
☐ Clumsiness, balance problems
☐ Burning, stabbing, or shooting pains
☐ Restlessness, restless legs syndrome, a need to move
☐ Gait disturbance, difficulty walking, inability to walk
☐ Seizures
☐ Weakness, partial paralysis
☐ Lightheadedness, dizziness, increased motion sickness
☐ Temporary paralysis during sleep—especially arms
☐ Short or long-term memory loss

☐ Pain in or around eyes
☐ Other eye problems
☐ Dry eyes
☐ Vision loss, blindness

☐ Red, hot ear lobes
☐ Ears popping
☐ Fluid in ears
☐ Frequent ear infections

☐ Stomach pain; maybe ulcer
☐ Loss of bowel or bladder control
☐ Bladder/kidney pain or infections

☐ Word, letter, number reversals
☐ Difficulty concentrating or reading
☐ Difficulty thinking, slowed thinking processes
☐ Mental confusion
☐ Brain “fog”
☐ Slowed, slurred, or jumbled speech
☐ Forgetting how to perform routine tasks
☐ Stammering speech
☐ Disorientation, getting lost
☐ Word retrieval problems
☐ Difficulty writing
☐ Mood swings, irritability
☐ Manic depression
☐ Sudden personality change
☐ PDD/Autism
☐ Unusual depression
Lyme Symptoms

- Hyperactivity (new onset)
- Insomnia, difficulty falling or staying asleep
- Attention Deficit Disorder (new onset)
- Sleeping excessively
- Vivid dreams
- Feeling as if losing your mind
- Oppositional defiant behavior
- Overemotional reactions, crying easily; panic attacks
- Obsessive-compulsive, other psychiatric disorders

» Respiratory & Circulatory System

- Irregular heartbeat: missed beats, galloping, extra beats
- Heart palpitations, racing heartbeat
- Chest pain; rib soreness
- Heart block
- Night sweats, chills
- Shortness of breath, cough

» Reproduction & Sexuality

- Loss of sex drive; sexual dysfunction; pelvic pain; testicular pain; breast pain; endometriosis
- Unexplained menstrual pain or irregularity; joint pains and other symptoms worse during menstruation

Children who have Lyme disease may miss years of school or be absent sporadically. Lyme disease mimics a multitude of other illnesses, and it is often years before a correct diagnosis is made. Lyme disease is one of the causes of learning disabilities, ADD, ADHD, ALS (Lou Gehrig’s disease), multiple sclerosis, lupus, chronic fatigue syndrome, fibromyalgia, arthritis, meningitis, Parkinson’s, autism, psychiatric illnesses, and other diseases. Some children are born with Lyme disease. Antibiotics often help them, sometimes dramatically.
LYME DISEASE RASHES

- The Lyme disease EM (erythema migrans) rash is usually just a red or pink spot. It may be another color like a bruise.
- It can range in size from a dime to 12 inches or larger. The CDC doesn't count it as reportable unless the diameter is at least 5 centimeters, about 2" (larger than a half dollar).
- It may be round or oval.
- It may last a few days, weeks, or months.
- It may or may not develop central clearing before going away.
- It may develop rings, but this classic EM rash is less common.
- It may itch or feel hot, but it may not be felt at all.
- It can be mistaken for ringworm or a spider bite.
- It usually takes at least 24 hours after the bite to appear. It typically appears within 2 to 32 days.
- The spot is usually at the bite site, but not always.
- There may be multiple EM spots from a single tick bite.
- Other rashes can occur.
- Many infected people don't get a red spot or rash.
- Some people continue to get new spots of the EM rash for years, if the disease becomes chronic. The spots may resemble bruises but may develop central clearing before going away. When people with chronic infection get a bruise from an injury, it may develop central clearing. Chickenpox spots may get rings around them if a child who has chronic Lyme gets chickenpox.
**Tick-borne Diseases Pose a Blood Transfusion Risk**

Lyme disease bacteria can survive in stored blood. Blood banks don’t test for Lyme.

There are strains of borrelia, babesia, bartonella, and other tickborne diseases for which we have no tests. People can carry a disease without getting sick. People who have a history of tick bites may unknowingly pass tickborne diseases to people through blood transfusions.

Babesia is a tickborne disease caused by a protozoan. Babesia is similar to malaria. Babesia has been transmitted through blood transfusions and has resulted in the death of at least 9 blood transfusion recipients.

**Babesia Testing:** Although there are no direct tests for most strains of babesia, there is an indirect test that can indicate active babesia infection. It is the eosinophil cationic protein test (ECP) by Quest Diagnostics lab in San Juan Capistrano, CA ([www.questdiagnostics.com](http://www.questdiagnostics.com)). Focus Diagnostics ([www.focusdiagnostics.com](http://www.focusdiagnostics.com)) in Cypress, CA and IGeneX in Palo Alto, CA ([www.igenex.com](http://www.igenex.com)) each have tests for both Babesia microti and Babesia duncani (WA-1).
WHERE IS LYME DISEASE?

- In all 50 states (CDC statistics)
- On every continent except Antarctica.
- At parks, lakes, golf courses (mostly in the bushes), camps, farms, and suburban yards
- In tall grass, piles of leaves, and bushes. (Ticks need to stay cool and moist.)
- In trees, sometimes. (Sometimes ticks drop from trees.)
- Most ticks are in woody areas where there are deer, foxes, or coyotes. Adult ticks prefer to feed and mate on these animals. Then the female tick drops off and lays several thousand eggs.

WHO IS AT HIGH RISK FOR LYME DISEASE?

- Children who play outside; People who work in their yards or gardens
- People whose jobs are outside or who engage in outdoor activities
- Scouts and scout leaders who go to camp
- People living on farms or in suburbs near woods

WHAT HAPPENS WHEN DOCTORS GET LYME DISEASE?

If they recognize it right away and treat it for at least 4 weeks after all signs and symptoms are gone, they may be fine. Otherwise, it can become chronic, and they may have to quit work or work part-time.

Doctors who have chronic Lyme disease become aware of the great need for more doctors to treat it. They often become Lyme disease specialists themselves, sometimes by choice, sometimes because people refer Lyme patients to them.
**Doctors are needed**

- **Who will remove ticks safely**, with fine-pointed tweezers or forceps, a scalpel, or a tick remover that slides under the tick, to keep germs from being injected into the bite.

- **Who will prescribe antibiotics for a tick bite** to prevent Lyme and other diseases.

- **Who will recognize early signs and symptoms** of Lyme disease; treat with at least 4-6 weeks of antibiotics; and continue treatment until 4 weeks after the rash and symptoms are gone, to prevent the disease from relapsing and becoming chronic.

- **Who will treat chronic Lyme** with an extended course of antibiotics, for at least one month after all signs and symptoms are gone.

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**How Long is Too Long to Adequately Treat a Disease?**

- Acne is treated with several years of antibiotics.
- People exposed to anthrax get 2 months of treatment.
- People with tuberculosis often get 2 years of treatment.
- People with HIV/AIDS get many years of treatment.
- **People with Lyme disease deserve adequate treatment.**
People are getting Lyme disease and other tick-borne diseases in Kansas. Lyme disease is disabling many Kansans, causing adults to become too ill to work, and children to miss years of school. Lyme disease has been reported in all 50 states and on every continent except Antarctica. Infected ticks have been found on birds on sub-Antarctic islands. There was an article about Lyme disease in Kansas in the September 1992 issue of *Kansas Medicine*, published by the Kansas Medical Society. The author was the late Glenn Bair, MD, who was treating Lyme disease patients in Kansas.

Cases of Lyme disease have been reported in Kansas every year since 1989. The vast majority of Kansas cases don't get reported, which makes many doctors think that Lyme disease is not a problem in the state. This causes them to fail to diagnose it, so they don't treat it or report it, creating a vicious circle. Many patients have been ill for over 10 years and have seen 10 to 40 doctors before they learn they have Lyme disease. Many Kansans with Lyme disease travel to other states for treatment. Their out-of-state doctors are not reporting it to the Kansas Department of Health & Environment. The disease is most likely to be cured if treated early. Even at the late stage, many patients benefit from antibiotics. It may take several years of treatment to get significantly better and resume former activities, and many may never be totally well. After lengthy antibiotic treatment, many children get well enough to get out of their wheelchairs, go back to school, and even play sports.

Support groups have helped over a thousand Kansans with Lyme disease. Almost none of these cases got reported. Many patients don't contact support groups. They may not know they have Lyme disease, and they may not know there are support groups for Lyme disease in Kansas. There have been 8 support groups in Kansas helping Lyme disease patients: 4 active groups in Kansas City, Wichita, Lawrence, and Kansas Tick-Borne Disease Advocates, which helps people in many communities. Four groups no longer hold meetings: in Manhattan, Ottawa, Parsons, and Pittsburg. We meet people everywhere we go who have this disease: at work, church, social gatherings, schools, health fairs, community festivals, and county fairs. If the disease were rare here, this would not be happening. Some Kansans have died as a result of this disease, including a teenage girl.

Most reported cases of Lyme disease in Kansas are in the eastern half of the state, but some cases have been reported in western Kansas. Dogs are also contracting Lyme disease in Kansas. Since 2007, 164 cases in Kansas dogs were reported to IDEXX Reference Laboratories (see [www.dogsandticks.com](http://www.dogsandticks.com) for the counties). As in people, it is estimated that only a minority of cases of Lyme in dogs gets reported. Ehrlichiosis & anaplasmosis are also being reported in dogs in Kansas.
LYME DISEASE IN KANSAS

Treating a tick bite right away usually prevents Lyme disease. Treating early Lyme disease adequately can cure most cases. Chronic Lyme responds to longer treatment. After several months or several years of antibiotic treatment, many people with chronic Lyme can get out of bed and out of their wheelchairs, stop their pain medications, and return to school or work. If antibiotics are stopped too soon, there is often a relapse. The CD-57 test can indicate when the disease is in remission and treatment can stop. Antibody tests are usually negative in the early weeks and also miss many cases later.
LYME DISEASE IN MISSOURI

Lyme disease is a problem in Missouri, although many doctors don't know it. Patients often have difficulty getting diagnosed and treated, which causes symptoms to progress and become difficult to cure. Lyme disease has been reported in all 50 states and on 6 continents. Infected ticks on migrating birds continue to take the disease to new areas. The St. Louis area is at special risk, because it is on two major bird flyways.

In 1990, Missouri ranked 8th highest in the nation in reported cases of Lyme disease. Cases of Lyme disease have been reported in Missouri every year since 1984. Missouri has reported over 1,000 cases of Lyme disease to the CDC. Most Missouri cases aren't reported. The CDC says Lyme disease is vastly under-reported.

A survey by IDEXX Reference Laboratories from 2001 to 2009 found 198 cases of Lyme disease in dogs in 19 counties in Missouri, of which 29 cases were in St. Louis County (www.dogsandticks.com). IDEXX says the actual number of cases is probably much higher.

Ticks in Missouri have been found to carry Borrelia burgdorferi (Bb) bacteria, the cause of Lyme disease. (Edwin Masters, M.D., et al, Archives of Dermatology, Aug. 1998, vol. 134). Another study, by the U.S. Army in 1992 at Fort Leonard Wood in Missouri, found that 40 of 112 Ixodes scapularis (“deer”) ticks taken from deer at the fort were positive for Bb bacteria.

Bb bacteria were found in lone star ticks (Amblyomma americanum) and American dog ticks (Dermacentor variabilis) in southeastern Missouri and around St. Louis in a 1994 study by the Department of Biology at St. Louis University. (Dorothy Feir, C. Reppell, C.R. Santanello, B.W. Li, C.S. Xie, Edwin Masters, R. Marconi, G. Weil, “Evidence supporting the presence of Borrelia burgdorferi in Missouri,” Am J Trop Med Hyg. 1994 Oct;51(4);475-82).

Lone star ticks in Missouri also carry a strain of borrelia bacteria that is slightly different from Borrelia burgdorferi. Dr. Masters found that the rash, signs, and symptoms of the disease are the same as Lyme disease. This strain is called Masters' disease. The CDC calls the disease STARI when transmitted by lone star ticks, although it is identical to Lyme and needs to be treated as Lyme.

In a study of 672 patients in Missouri that met the CDC case definition of Lyme disease, Missouri patients had a slightly higher incidence of the Lyme disease signs of encephalitis or meningitis, second or third degree heart block, and Bell's palsy than Lyme patients nationally, and were more than twice as likely to have arthritis (64.7% versus 30.5%). Only 50.9% of the Missouri Lyme patients had the erythema migrans (EM) rash. (Edwin Masters, MD; H. Denny Donnell, MD, MPH; Michael Fobbs, B.A., “Missouri Lyme Disease: 1989 through 1992,” Journal of Spirochetal and Tick-Borne Diseases, Vol.1, No. 1, 1994.)
LYME DISEASE IN MISSOURI

There have been 10 support groups for patients with Lyme disease and/or Masters' disease in Missouri: in Kansas City, Joplin, Butler, Columbia, St. Louis, Independence, Cape Girardeau, Chillicothe, Jefferson City, and Springfield. The latter six have stopped having meetings, primarily because the leaders and members are too ill to meet. The leader of one group died at the age of 51. The Lyme Association of Greater Kansas City has been active since 1993 and provides information to patients, schools, the general public, and medical professionals throughout Missouri and Kansas.

Study Found Lyme Disease More Severe in Missouri

In 1994 Dr. Edwin Masters of Cape Girardeau, MO reported a study of 672 Missouri cases that met the CDC surveillance definition for Lyme disease. The Missouri patients had a significantly higher incidence of arthritis than patients nationally. The study, “Missouri Lyme Disease: 1989 through 1992,” by Edwin J. Masters, M.D.; H. Denny Donnell, M.D., MPH; and Michael Fobbs, B.A., was reported in the *Journal of Spirochetal and Tick-Borne Diseases*, Vol.1, No.1, 1994. This study found that Lyme disease patients in Missouri were more than twice as likely to develop arthritis than patients nationally, and Missouri patients had a slightly higher incidence of Bell's palsy, encephalitis, meningitis, and 2nd or 3rd degree heart block:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Missouri</th>
<th>Nationally (excluding Missouri)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erythema Migrants Rash</td>
<td>50.9%</td>
<td>73.1%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>64.7%</td>
<td>30.5%</td>
</tr>
<tr>
<td>Bell's Palsy</td>
<td>4.91%</td>
<td>3.9%</td>
</tr>
<tr>
<td>Encephalitis or Menigitis</td>
<td>1.49%</td>
<td>0.95%</td>
</tr>
<tr>
<td>2nd or 3rd Degree Heart Block</td>
<td>1.33%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Radiculoneuropathy</td>
<td>4.46%</td>
<td>No Data</td>
</tr>
</tbody>
</table>

Only 50.9% of Missouri patients had the Lyme disease erythema migrans (EM) rash. This rash is an expanding red spot. Most EM rashes do not develop the characteristic rings. Therefore, only about half of diagnosed patients in Missouri get a large red spot, and even fewer get a bull’s-eye rash. Since cases are often diagnosed based on the rash, the people that don’t get the rash are less likely to get diagnosed. Therefore, the actual number of infected people who get the classic rash is likely to be much fewer than 50% of patients. Dr. Charles Ray Jones of New Haven, CT said that fewer than 10% of his patients had a bull’s-eye rash. (Dr. Jones is a pediatrician who has treated over 11,000 children for Lyme disease. He has cured 75% of them by continuing treatment for at least 2 months after all signs and symptoms are gone. Shorter treatment courses often cause a relapse.)
LYME DISEASE IN MISSOURI

It is unknown whether the higher incidence of arthritis in Missouri is because the disease is more severe in the state, or because the patients in Missouri may have been ill for a longer period of time than the national sample, allowing the disease to progress and develop arthritis. Many doctors are still unaware that Lyme disease is in Missouri and still fail to diagnose it, which often causes symptoms to progress and become chronic. It's possible that arthritis is more common in Lyme patients nationally than this study revealed, if many of the patients in the study had been ill only a short time at the time they were studied.

Lyme-like illnesses in Missouri produce the exact same symptoms and require the same treatment as Lyme, but they are largely being ignored. Patients in Missouri are continuing to suffer for years from Lyme and Lyme-like diseases before getting diagnosed. Some have died too young.
WHY ISN’T A 3-WEEK COURSE OF ANTIBIOTICS ENOUGH FOR LYME DISEASE?

The Borrelia burgdorferi (Bb) bacteria have a 4-week growth cycle and are most vulnerable to being killed during the week that they are reproducing. Treatment of less than 4-6 weeks often fails to kill all the Bb bacteria.

Some people who get treated early seem fine after 3 or 4 weeks of treatment. However, many of them will relapse months or years later, when diagnosis is more difficult. It can take months or years of antibiotics to treat chronic Lyme, and IV treatment may be needed. It is much more efficient to risk over-treating it at the early stage than to have to treat it more extensively later, with the patient enduring years of chronic symptoms. Even at the late stage, many people are helped considerably by long-term antibiotics, although they may never be totally cured.

**Bb bacteria have several tricks to avoid being killed:**

1. **When antibiotics are in the bloodstream, the spirochetes can** leave the bloodstream through the blood vessel wall and **hide in the tissues.**

2. **The Bb spirochetes can avoid detection by the immune system.** A spirochete can enter a white blood cell without being killed, roll around inside it and coat itself with white blood cell matter, and then leave the cell and float around in the bloodstream disguised as another white blood cell. Then the other white blood cells don't even try to attack it.

3. **Bb bacteria can hide in the brain,** where many antibiotics can't reach them.

4. **Bb spirochetes can cluster together and create a biofilm** that protects them from antibiotics and the immune system's white blood cells.

5. **Bb spirochetes can convert into a cell wall-deficient form,** so antibiotics that work by attacking the cell wall can't destroy them.

6. **Bb bacteria can change into a cystic form,** which most antibiotics can't destroy. Some Lyme disease doctors prescribe Flagyl to kill the cysts.

7. **Bb spirochetes can change their outer surface protein,** making it difficult for the body to recognize it and create an appropriate immune response.

*Dr. Charles Ray Jones, who has treated over 16,000 children for Lyme disease, has cured about 75% of them by using these guidelines:*

> Continue treatment for at least 2 months after all signs & symptoms are gone.
**IDSA Lyme Disease Guidelines and Objections**

The Infectious Diseases Society of America (IDSA) Lyme disease guidelines severely restrict diagnosis and treatment. On May 1, 2008, Connecticut Attorney General Richard Blumenthal announced, after an investigation, that the IDSA panel that developed the guidelines violated antitrust laws. He found that leading members of the panel had significant financial conflicts of interest, that they ignored opposing points of view regarding chronic Lyme disease, and that they ignored scientific evidence. He ordered them to convene a new panel, free of conflicts of interest, to review and perhaps develop new guidelines, taking into account all relevant scientific evidence. This panel was ordered to hear testimony in a public hearing, which was held on July 30, 2009. Two patient advocates and 16 doctors and scientists testified. Their testimonies can still be heard at [www. ilads.org](http://www. ilads.org). Click on "About Lyme" and then on "IDSA Hearing Videos."

Information for the following articles is from the California Lyme Disease Association website, at [www.lymedisease.org/news/lymepolicywonk/](http://www.lymedisease.org/news/lymepolicywonk/).

**AAPS Doctors Object to IDSA Guidelines**

The Association of American Physicians and Surgeons (AAPS) represents thousands of physicians in all specialties, primarily in small and independent practices. Andrew Schlafly, General Counsel for the organization, sent a letter on behalf of the AAPS to the IDSA, objecting to the IDSA Lyme disease guidelines. The letter said that the Guidelines (pages 1089-90) forbid a diagnosis based on clinical findings alone and require that a patient not be diagnosed or treated for Lyme disease unless they have an EM rash or positive test. The letter said:

“These Guidelines should be revised to recognize that the physician must retain full flexibility in the diagnosis and treatment of Lyme disease. Medical Societies do not practice medicine; physicians do. The mandate for specific laboratory confirmation is particularly objectionable, as testing for Lyme disease is notoriously insensitive and unreliable. Patients who do not meet this criterion would often be denied treatment that could mitigate severe chronic disability. In some cases, long-term treatment is required. Physicians must be able to exercise their professional judgment concerning the best treatment for each individual patient, without restraint by one-size-fits-all Guidelines.”

**German Society Objects to IDSA Guidelines**

The German Society of Lyme Borreliosis (Deutsche Borreliose-Gesellschaft) sent a letter to the new IDSA Lyme disease committee objecting to the use of the Guidelines in Germany. The letter said, “The fundamental basis of our objections is that the implementation of the IDSA guidelines
extends beyond the United States and into Europe. Accordingly, our ability to diagnose and treat patients with Lyme disease is being severely restricted by these guidelines, and we believe that the guidelines must be revised to provide greater flexibility in the diagnosis and treatment of Lyme disease, given the poor laboratory test sensitivity, the persistence of the organism despite adherence to IDSA protocols, and the seriousness of this illness.”

GROUP IN BRITAIN OBJECTS TO IDSA GUIDELINES

Lyame Disease Action, an organization in the United Kingdom, sent a letter to the IDSA guidelines committee outlining their objections. The letter stated that the guidelines lead to under-diagnosis and under-treatment. They said a European study found that 100 mg. doxycycline twice a day is inadequate and that 200 mg. doxycycline twice a day is more effective. “Since the risk of irreversible neurological symptoms is increased with duration of infection, it is desirable to reach a therapeutic level in CFS [cerebrospinal fluid] as rapidly as possible. ... Those that are treated with 100 mg. doxycycline twice per day may well not forestall disease progression.” The letter said, “Inflammatary back pain, even without radiculitis, may be related to Lyme disease in endemic areas.” The letter also said that a Health Protection Agency report on laboratory confirmed cases in 1997 noted that only one-third had the erythema migrans rash.
**WHAT IS A HERX?**

A Herx is a Jarisch-Herxheimer reaction. It is a worsening of Lyme disease symptoms after beginning antibiotic therapy or another effective treatment. It was named for Dr. Adolph Jarisch in Austria and Dr. Karl Herxheimer in Germany, both dermatologists who first noticed the reaction in syphilis patients. Syphilis, like Lyme disease, is caused by a spiral-shaped bacterium called a “spirochete.” Both diseases can cause a Herxheimer reaction after beginning antibiotics.

There is no research to prove what causes a Herx. Theories are that it could be caused by toxins released by the dying Lyme bacteria, or it could be an inflammatory response to the dying bacteria. A Herx is an indication that the treatment is working. With Lyme disease, a person gets worse before getting better, because of the Herxheimer reaction.

A Herx can begin a few hours after treatment is started, but it usually doesn’t begin until after one or more days. It can last for a few days or a few weeks. It is usually a worsening of whatever symptoms you already have, but new symptoms can develop. Symptoms often include a bad headache, insomnia, fatigue, depression, cognitive problems, increased pain, and other flu-like symptoms. Heart, vision, and neurological problems can also occur. A Herx can sometimes be life-threatening and may require a trip to the hospital. Call your doctor if symptoms are severe or if depression is severe. Your doctor may want you to stop or cut back on your medication temporarily and/or may prescribe new medicines for the symptoms.

It is often difficult to determine whether you are experiencing a Herx, drug side effects, an allergy to the medication, or a case of the flu. Call your doctor if you have questions.

Many Lyme disease patients get Herxheimer reactions at regular intervals, typically monthly, which is believed to correspond to the Lyme bacteria’s growth (reproductive) cycle. When you first start antibiotics or another treatment, mark it on your calendar, and mark 4 and 8 weeks later. Then, if you feel much worse about 4 and 8 weeks later and get depressed, you will realize that this is expected and that you are actually on the road to recovery.

Dr. Joseph Burrascano, who has treated many Lyme disease patients in New York, said in his September, 2005 “Diagnostic Hints and Treatment Guidelines,” (p. 16, in the section “Course During Therapy”), that treatment for Lyme disease should last at least 4 weeks, to be sure to cover the bacteria’s growth cycle, since that is when the bacteria are most vulnerable to being killed by antibiotics. (See www.ILADS.org.) Relapses can occur and the disease can become chronic with shorter treatment courses. Dr. Burrascano said that, as long as monthly cycles continue, treatment should continue, because that indicates that there are still living bacteria. He also said that, if the treatment is working, these flares should gradually decrease in severity and duration, as the quantity of bacteria affects the severity of the Herx.

People also often get a Herx with alternative treatments, such as nutritional supplements, heat therapy, a Rife machine, and other types of treatment.

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Section Updated 3-29-2013  
Section Authored by Kathy White, MSW, Corresponding Secretary LAoGKC
WHY DON’T MOST CASES OF LYME DISEASE GET REPORTED?

Support groups have helped thousands of people with Lyme and Lyme-like illnesses in central, southern, and western states. Only a very few of these cases were reported.

**CDC reporting criteria is designed to track only a small minority of cases** that meet stringent criteria designed to track the geographic spread and percent of change in the number of cases, not the actual number of cases. The CDC says on their website that reporting criteria is not to be used for diagnosis. Many doctors don’t know this and fail to diagnose Lyme disease.

**The CDC changed their Lyme disease reporting criteria effective in 2008 so that fewer cases could be considered confirmed.** Now, an EM (erythema migrans) rash doesn’t count as “confirmed” unless the tick bite was in a county that is known to be endemic. It doesn’t even count as “probable” but is instead considered “suspect”. “Suspect” cases don’t count in the totals. Counties that have had many cases of Lyme disease, but none reported, don’t count as endemic unless ticks have been tested and at least two stages of ticks have tested positive.

**Many doctors don’t report cases if testing wasn’t done.** Many patients go to the doctor with a Lyme rash or early illness, get treated, and don’t return for follow-up testing.

**The CDC estimates that most cases that meet reporting criteria are not getting reported.**

**Most diagnosed cases don’t meet reporting criteria.** The ELISA and IFA tests can miss up to 45% of cases, and about 36% of culture-confirmed cases remain Western blot negative throughout the illness. A survey of doctors found that most diagnosed cases didn’t get reported.

**Culture tests fail to detect most cases of Lyme.** Culture tests “are rarely positive once the infection has disseminated beyond the stage of erythema migrans,” according to the Lyme and Tick-Borne Diseases Research Center at Columbia University in New York. The Borrelia burgdorferi (Bb) bacteria don’t grow well in the culture medium and have a very slow growth rate. Dr. Edwin Masters of Cape Girardeau, MO cultured spirochetes from the EM rashes of 3 patients. The fastest culture took 5 weeks; the others took longer. The CDC only keeps a culture for 4 weeks, so the CDC has not been able to culture spirochetes from EM rashes in Missouri.
WHY DON’T MOST CASES OF LYME DISEASE GET REPORTED?

The CDC requires 5 positive bands on the IgG Western blot test, or a positive IgM Western blot plus a positive ELISA or IFA plus a visible sign of the disease. Most patients have symptoms (pain, fatigue, numbness, weakness, memory problems) that aren’t visible to the doctor and thus don’t count as signs. Most patients never get 5 positive bands on the IgG Western blot. The CDC doesn’t even count bands 31 and 34, which are so specific to Lyme disease that the vaccine was based on those bands. Those and certain other bands are only caused by Lyme disease, and only one of them needs to be positive to diagnose Lyme disease.

The CDC recommended two-tier testing misses 54% of cases, according to an analysis of 8 research studies. This was reported by Dr. Raphael Stricker, MD, in a presentation to the IDSA Lyme disease guidelines review panel on July 30, 2009.

Doctors think Lyme disease is rare and thus don’t diagnose it. Undiagnosed cases don’t get reported. A low number of reports makes doctors continue to think it’s rare, so they don’t diagnose or report it. This results in a vicious circle. Many patients have been told by doctors, “That looks like a Lyme disease rash, but it can’t be, because we don’t have it here.” “That’s an infected tick bite.” “That’s a spider bite.” “I’m not going to test you for Lyme disease, because we don’t have it here.” “Your Lyme test was positive, even by CDC reporting criteria, but it was a false positive, because we don’t have Lyme here.” These cases don’t get reported.
REASONS FOR FALSE NEGATIVE LYME ANTIBODY TESTS

The ELISA and Western blot are antibody tests that are often negative in Lyme disease patients. This can occur because:

1. The testing is done too soon after the tick bite. It often takes 4-6 weeks for a detectable level of antibodies to develop. (Treatment should begin as soon as Lyme disease is suspected, because a delay in treatment can cause the disease to become chronic.)

2. The patient has a poorly functioning immune system that isn't producing a detectable level of antibodies.

3. The patient is or has recently been on steroids or certain anti-cancer drugs, which suppress the immune system.

4. The patient is or has recently been on antibiotics, which can reduce the production of antibodies.

5. The antibodies may be bound to the bacteria, with not enough free-floating to be detected. (For this reason, some of the patients most ill with Lyme disease test negative, because their antibodies are busy fighting numerous bacteria.)

6. The bacteria have changed their antigenic make-up, evading recognition by the immune system.

7. The patient has a variant strain of the disease that the test fails to detect.

8. The lab has such a high cut-off point that a positive test is determined to be equivocal or negative.

9. The patient has positive bands, but the test is interpreted based on strict reporting criteria and not on criteria for diagnosis.

A study found that about 36% of culture-confirmed Lyme disease cases remain Western blot negative throughout the illness. The ELISA has been used as a screening test before the Western blot. The ELISA misses at least 35% of cases and thus is not an appropriate screening test. A screening test should be able to detect at least 95% of cases.

**No test can prove that a person doesn’t have Lyme.**
LYME DISEASE TESTS

The CDC says Lyme disease is a clinical diagnosis, but testing can be used to confirm a diagnosis. The CDC does not recommend testing in the early stage of the illness, because treatment should begin immediately, and it can take 4-6 weeks for antibodies to develop.

Antibody Tests

The ELISA and Western blot are antibody tests. Many Lyme patients never develop a detectable level of antibodies. The ELISA is a titer test that measures the amount of Lyme antibodies in the blood. It is used as a screening test. It misses at least 35% of culture proven cases. A screening test should be able to detect at least 95% of cases. The Western blot also misses many cases. About 36% of culture-proven cases remain negative on the Western Blot throughout the illness.

IGeneX Labs at 795 San Antonio Rd., Palo Alto, California 94303, 1-800-832-3200, www.igenex.com has the best Western blot (WB) test for Lyme. It detects 95% to 97% of cases, with fewer than 4% false positives. Their WB costs $200 for both IgM and IgG, or $100 for either one. IGeneX bills Medicare directly but doesn’t work directly with insurance companies, although many people who have out-of-network coverage get some reimbursement. Blood should be drawn Mon., Tues., or by noon Wed. and sent overnight by Federal Express for accurate results.

Interpreting the Western Blot

The CDC has very strict reporting criteria for the Lyme disease Western blot. Many patients don’t get enough positive bands to meet the criteria. The following bands are specific for Lyme disease and indicate Lyme even if only one band is positive. Dr. Joseph Burrascano says the bands specific for Lyme are: bands 18, 23-25, 31, 34, 37, 39, 83, and 93. No other disease is known to cause these bands to be positive. Many Lyme patients only get band 41 to be positive. Band 41 may indicate Lyme but doesn’t prove it, because gum disease and syphilis can also cause band 41 to be positive.

CD-57 Test

The CD-57 NK test can diagnose Lyme and monitor treatment progress. Many insurance policies cover it. Lyme patients typically have an absolute CD-57 NK count below 60. Normal is over 200. To determine the absolute count, multiply the percent of CD-57 NK lymphocytes by the absolute total lymphocyte count. LabCorp's CD-57 test is called the HNK1 (CD-57) Panel, code # 505026. It's done at their lab in Burlington, NC. Their significant score is Absolute CD8/CD57. Quest Diagnostics has a CD-57 test in San Juan Capistrano, CA. Their significant score is CD57+/8-ABSOLUTE lymphocytes, at the bottom of the list of scores. IGeneX also has a CD-57 test. Blood for the CD-57 test should be drawn Monday, Tuesday, or by noon Wed. and sent overnight by Federal Express.
LYME DISEASE TESTS

Culture
The Lyme disease bacterium, Borrelia burgdorferi, has a very slow growth rate, making it extremely difficult to grow in culture, so culture tests fail to detect many cases of Lyme disease.

LUAT Test
IgeneX has a Lyme Urine Antigen Test (LUAT) to measure dead Lyme bacteria in the urine. It is most likely to be positive a few days after treatment begins, after the bacteria start to die.

PCR-DNA Test
This test is more sensitive than antibody tests, as it does not depend upon the immune system to create antibodies. It detects the DNA of disease organisms. Spiro Stat Technologies is a lab that does PCR and DNA testing for Lyme and other diseases caused by spirochetes. They also have tests for some other diseases carried by ticks. Tests include: Borrelia burgdorferi, Borrelia lonestari, 5 other species of borrelia, babesia microti, bartonella henselae, ehrlichia, anaplasma, 9 species of Rickettsia, tularemia, and other diseases. Their entire panel of tests costs $500. They do not currently have tests for Babesia duncani (WA-1), Babesia MO-1, or other strains of babesia or bartonella. Lubbock, TX 1-877-767-7476 (toll-free); www.spirostat.com.
INTERPRETING THE CD-57 TEST

Many Lyme disease specialists are now using the CD-57 test to assist in the diagnosis of Lyme disease and to monitor treatment progress. Interpreting the test results can be difficult.

"Advanced Topics in Lyme Disease"
by Joseph Burrascano, M.D. October 2008, page 8

"Our ability to measure CD-57 counts represents a breakthrough in LB [Lyme borreliosis] diagnosis and treatment. Chronic LB infections are known to suppress the immune system and can decrease the quantity of the CD-57 subset of the natural killer cells. As in HIV infection, where abnormally low T-cells counts are routinely used as a marker of how active that infection is, in LB we can use the degree of decrease of the CD-57 count to indicate how active the Lyme infection is and whether, after treatment ends, a relapse is likely to occur. It can even be used as a simple, inexpensive screening test, because at this point we believe that only Borrelia will depress the CD-57. Thus, a sick patient with a high CD-57 is probably ill with something other than Lyme, such as a co-infection. When this test is run by LabCorp, (the currently preferred lab, as published studies were based on their assays), we want our Lyme patients to measure above 60; a normal count is above 200. There generally is some degree of fluctuation of this count over time, and the number does not progressively increase as treatment proceeds. Instead, it remains low until the LB infection is controlled, and then it will jump. If the CD-57 count is not in the normal range when a course of antibiotics is ended, then a relapse will almost certainly occur."

"Understanding the CD57 Test: Everything You Always Wanted to Know About the CD57 Test" by Ginger Savely, RN, FNP-C

Posted January 28, 2009 at: heallyme.wordpress.com/2009/01/08/understanding-the-cd-57-test

"... Many disease states that are often confused with chronic Lyme (MS, systemic lupus, rheumatoid arthritis) are not associated with low CD57+ NK counts. ... It is important to distinguish between CD57+ T-cells and CD57+ NK cells. ... Many ... laboratories claiming to perform the CD57 test are actually looking at CD57+ T-cells rather than CD57+ NK cells. ...To measure the CD57+ NK level, it [the lab] first measures the percentage of lymphocytes that are CD57+ NK cells. Then an absolute count is calculated by multiplying that percentage by the patient’s total lymphocyte count. The standard normal range ... is 60 to 360 ... A test result below 60 ... would be ... associated with chronic Lyme disease. However, a recent study of my Austin patients has led me to believe that 100 ... is a more reliable threshold. ... [The] blood sample needs to be drawn into an EDTA tube (lavender top) on Monday through Thursday and sent immediately to either LabCorp in Burlington, NC, or Clinical Pathology Laboratories (CPL) in Austin, TX. LabCorp and CPL are the only two labs that perform this test properly. Quest does NOT. The LabCorp test code is #505026 and is named HNK1 (CD57) Panel. The CPL test code
INTERPRETING THE CD-57 TEST

is #4886, CD57 for Lyme disease. The test is time-sensitive, so blood should not be drawn on a Friday or results may be inaccurate.

Doctors can contact Ginger Savely through her website, www.gingersavely.com.

A note from Kathy White:

A doctor has found the CD57 results at Quest the same as LabCorp. He sent blood from one patient to both labs on the same day, and the results were identical. He later repeated this with another patient and, again, the results from both labs were identical.

The test results show many numbers. The significant score at Quest is the CD57+/CD8- Absolute lymphocyte score at the very bottom of the list. The significant score at LabCorp is reported as Absolute CD8-/CD57.
DID YOU KNOW?

Ticks can transmit Lyme disease as soon as they bite.

It takes many ticks about 24 hours or more to transmit Lyme disease, if the germs are only in the tick’s gut. However, Dr. Willy Burgdorfer, discoverer of the Borrelia burgdorferi bacterium that causes Lyme disease, said at the Lyme disease conference at Bard College in N.Y. on Nov. 13, 1999 that "There is no such thing as a safety period." He said about 5-10% of [infected] ticks carry Lyme bacteria in their saliva and can transmit the disease as soon as they bite.

An article was published about a patient who developed Lyme disease from a tick that had only been attached for 6 hours. ("Disseminated Lyme disease after short-duration tick bite," by Patmas MA, Remorca C. Journal of Spirochetal and Tickborne Diseases 1994; 1:77-78.) The authors concluded that “the current recommendation against treatment of short-duration tick bites may need reconsideration.”

The Lyme Association of Greater Kansas City has members who contracted Lyme or a Lyme-like disease in less than 4 hours of tick attachment.

Tweezers can squeeze a tick’s gut and inject disease germs.

A tick remover that slides under a tick removes large and small ticks safely. Fine-pointed tweezers may remove large ticks safely, if the points are small enough to grasp the tick’s mouth without squeezing its gut. Using tweezers, fingers, a hot match, liquid soap, nail polish, alcohol, or other chemicals can cause germs to be injected into the bite site. This can cause Lyme disease even if the tick was attached only a short time.

Deer ticks aren’t the only ticks carrying Lyme disease.

Researchers have found Lyme disease Bb bacteria in at least 10 species of ticks. The ticks that are commonly biting people: Ixodes scapularis (“deer”) ticks, western blacklegged ticks, lone star ticks, wood ticks, and American dog ticks, are all transmitting Lyme or Lyme-like illnesses that need to be treated as Lyme. People are developing the Lyme disease rash and symptoms after bites by all these ticks. Many people who have not had prompt and adequate treatment in the early stage have gone on to develop more severe, chronic Lyme disease symptoms after bites by all these ticks. Many of these people have become disabled. People have died from Lyme and Lyme-like diseases in Missouri and Kansas, usually after several years of illness.
DID YOU KNOW?

Lyme disease isn’t always transmitted by a tick.
In 1967 Dr. G. Schaltenbrand reported that about 10% of borreliosis [Lyme disease] patients at his clinic in Germany were getting the EM rash and neurological symptoms from the bites of horseflies, although Ixodes ticks seemed to be the primary vector. His study was published in a German medical journal, Verhandl Dtsch Ges Inn Med, 72:975-1006. This was referenced in a book published in English in 1993, Aspects of Lyme Borreliosis, edited by K. Weber & Willy Burgdorfer (pp. 1-20). However, 46 years after it was published in German and 20 years after it was mentioned in a book in English, most Americans still don’t know this.

People in the U.S. are developing Lyme disease symptoms and EM rashes after bites by horseflies, deerflies, fleas, mosquitoes, and other biting insects. Studies that found Lyme disease Bb bacteria in mites, flies, fleas & mosquitoes are at www. pubmed.gov.
LYME DISEASE TRANSMISSION STUDIES

1. "Isolation of Borrelia burgdorferi from arthropods collected in Texas," by G.J. Teltow, P.V. Fournier, and Julie A. Rawlings; Microbiological Services Division, Bureau of Laboratories, Texas Dept. of Health, Austin. Am. J Trop Med Hyg, May 1991. This study found Lyme disease Bb bacteria in lone star ticks (Amblyomma americanum), Gulf Coast ticks (Amblyomma maculatum), deer ticks (Ixodes scapularis), and cat fleas (Ctenocephalides felis) in Texas.


3. "Incidence of the spirochete Borrelia burgdorferi in arthropods (Arthropoda) and antibodies in vertebrates (Vertebrata)." By P.Pokorny. [Article in Czech.] Cesk Epidemiol Mikrobiol Imunol, Jan. 1989; 38(10:52-60). This study found Bb bacteria in 30 species of arthropods (arachnids and insects), including 13 species of mites, 15 species of flies, and two species of fleas.

4. "Lyme Disease Transmitted by a Biting Fly." N Engl J Med, 1990, June 14; 322 (24): p. 1752. Steven W. Lugar, MD, Old Lyme, CT. "Letter to the Editor." A man from Old Lyme, CT was bitten several times by a large fly he believed was either a horsefly or a deerfly. A large 16 cm by 11 cm erythema migrans rash developed around the bite area. He became ill with Lyme disease symptoms at that time. He tested positive for Lyme disease antibodies on the IgM and IgG Western blots.

5. "Ticks and mosquitoes as vectors of Borrelia burgdorferi s. l. in the forested areas of Szczecin." By Kosik-Bogacka DI, Kuzna-Grygiel W, Jaborowska M. Department of Biology and Medical Parasitology, Pomeranian Medical U., Szczecin, Poland. Folia Biol (Krakow). 2007;55(3-4):143-6. This study found Lyme disease Bb bacteria in mosquitoes in Poland.

6. "Isolation of Borrelia afzelii from overwintering Culex pipiens biotype molestus mosquitoes." Ann Agric Environ Med. 2006;13(2):345-8. Zakovska A, Capkova L, Sery O, Halouzka J, Dendis M.; Dept. of Comparative Animal Physiology and General Zoology, Faculty of Science, Masaryk University, Czech Republic. This study found B. afzelli (a strain of Lyme disease) in mosquitoes in the Czech Republic.


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LYME DISEASE TRANSMISSION STUDIES


This study found Lyme disease bacteria in horse flies, deer flies, and mosquitoes. After infected mosquitoes fed on uninfected hamsters, one hamster developed antibodies to Bb, proving that mosquitoes in the U.S. can transmit Lyme disease.
LYME DISEASE IN CHILDREN

Diagnosing Lyme disease in children can be difficult, because: they may not look sick; children may be unaware that a constant headache, ringing in the ears, and numbness and tingling aren't normal and may not report it; they may be unable to describe their symptoms; and frequent complaining may cause adults to think they are just trying to get attention. Pains can come on suddenly and be very intense, and then suddenly be gone. This may be difficult for adults to understand and believe.

Children with Lyme disease often complain of headaches, stomach pain (sometimes accompanied by an ulcer), chest pain, ear aches, sore throat, and joint and muscle pains. Joint pain may or may not be accompanied by swelling. There can be episodes of stiffness. Headaches can be frequent or constant, lasting months or years. They can be mild, or so severe that medication doesn't totally relieve them. Sunlight can cause eye pain and make headaches worse. Children with Lyme disease may need to wear sunglasses at recess, even on cloudy days, and maybe even indoors. They may need to go to the bathroom frequently and suddenly, and may not be able to wait for the teacher's permission. There may be vision and hearing problems, which may come and go.

Cognitive problems can come and go throughout the day. Concentration and memory problems can make math especially difficult. Slowed thinking can make it difficult to comprehend oral and written language. A child with Lyme can suddenly not recognize familiar places and can get lost in the school. The disease can cause learning disabilities and low IQ scores. Word, number and letter reversals in written and oral speech (dyslexia) are common. Sometimes IQ scores jump after a child begins antibiotic treatment. Children with autistic or psychiatric symptoms may talk and act normal when on antibiotics.

Children with Lyme can be too tired to go to school and may need to go part-time or receive home schooling. The symptoms and severity of symptoms can vary from day to day. A child may feel well enough to go to school one day, but not the next. Absences may be frequent. The children can also have social problems, being too tired to play with friends, and being teased if they have trouble walking, talking, or learning. Other children may avoid them, because of an unfounded fear that the disease is contagious. Lyme disease can cause sudden panic attacks, irritability and mood swings. Children with Lyme may have only mild problems, or the effects can be severe enough to put a child in a wheelchair. Children whose mothers have active Lyme disease during pregnancy can be born with damage to the brain, heart, liver, and other organs. They can have a variety of problems, including frequent illness, speech delays, other development delays, or severe multiple disabilities. Antibiotic treatment throughout pregnancy can prevent congenital Lyme disease.
LYME DISEASE IN TEENAGERS

Teenagers with Lyme disease also have special problems. The disease can cause a sudden drop in grades, mood swings, depression, suicidal thoughts, personality changes, sleep problems, poor concentration, cognitive problems, and a loss of interest in school and school activities. These changes can be mistaken for drug abuse. A drug test is often ordered to rule this out. Hormone changes can also be blamed, or teenagers can be accused of being lazy or rebellious and not trying hard enough in school. All these problems can make it more difficult to get diagnosed.

Teenagers with Lyme may be too tired to attend school or to complete their work. They may need to go to school part-time or not at all. Home teaching may be needed. They may have a drop in grades, especially in subjects that require a person to remember previously learned concepts, such as math, foreign language, and chemistry and other science courses. They may do fine in history and English.

Loneliness can be a problem for teenagers with Lyme. They may be too tired to participate in social activities with friends. It's hard for them to predict how they will feel from day to day, making it difficult to make social plans, which often have to be canceled. (This withdrawal from friends is not typical of drug abusers, who may change friends, but will socialize.)

Students who are ill with Lyme disease in high school are often feeling better and performing better by the time they go to college. They can arrange for an untimed SAT test with a letter from a doctor. They may need this, since Lyme disease slows the thinking. If a Lyme patient has a year or so of poor grades from illness, the doctor can write a letter explaining the health problems and asserting that the patient's health is improving with treatment. This letter can be included with a college application.
LYME DISEASE NEUROLOGICAL SYMPTOMS

Lyme disease can cause physical, emotional, cognitive, and psychiatric symptoms. These symptoms can be constant or may come and go from week to week, day to day, or even during the day. They can vary in intensity from one minute to the next. A person can suddenly get a terrible pain in the knee. It may be fine in a few minutes, and then the elbow may suddenly hurt intensely. A headache may last for years but may vary in intensity throughout the day. The ability to concentrate and to comprehend oral and written speech may vary throughout the day. Blurry vision may come and go from day to day. Lyme can affect the heart, vision, and hearing.

**Thinking Problems**
Lyme disease causes problems with concentration, memory, thinking, and making decisions. People can suddenly not recognize familiar places. Children may get lost walking to school or in the school building and may walk right past the classroom door. People may have new difficulty with spelling, writing, math, and writing checks. Adults may get lost driving familiar roads.

**Conversation Problems**
Thinking problems can change throughout the day. A person may be unable to carry on a conversation or think of words to say in the afternoon, but talk fine in the morning. It can be difficult to think of words to say, put the words in the right order in sentences, put the right sounds on words, and hold the thought long enough to finish a sentence. Episodes of stuttering and jumbled speech can occur.

Listening and comprehending oral and written speech can also be difficult. A person may not be able to concentrate well enough to listen, especially to a long sentence, and may forget what has just been said, making it difficult to respond appropriately. The mental process slows down, so a person may only be able to remember or understand part of a sentence. When several sentences are said in a row, the person with Lyme may still be processing the first sentence and miss the rest of what is being said. Reading can also be difficult. It may be hard to concentrate, and a person may need to read a sentence several times before understanding it.

**Mood and Psychiatric Symptoms**
Personality changes, mood swings, violent outbursts, depression, and panic attacks can occur. There can be sudden suicidal impulses. Some people get visual and/or auditory hallucinations. Insomnia is common. A wide variety of psychiatric illnesses can be caused by Lyme disease, including obsessive-compulsive disorder and bipolar disorder. When these conditions are caused by Lyme disease, antibiotic treatment often helps tremendously.
LYME DISEASE NEUROLOGICAL SYMPTOMS

Neurological Diseases
Lyme disease symptoms vary considerably from person to person. Some people develop neurological diseases. Others may get pain and fatigue. The neurological symptoms often cause a gradually increasing weakness in the legs, arms, and the rest of the body. Lyme disease is often an underlying cause of neurological diseases such as MS, Parkinson’s, Alzheimer’s, ALS, autism, ADHD (attention deficit hyperactivity disorder), Tourette's syndrome, and Guillain Barre syndrome. Lyme disease can cause paralysis. These diseases can be helped by antibiotics when the cause is Lyme disease. When autism is caused by Lyme disease, antibiotics may cause a sudden change in behavior. It may become bizarre at first, as the bacteria die off. A few days later, behavior may be normal, but autistic behavior may return after the antibiotic treatment ends. When there is an unusual response to antibiotics, the possibility of Lyme disease should be considered.
NEUROLOGIC MANIFESTATIONS OF LYME DISEASE IN CHILDREN AND ADOLESCENTS

Reprinted from the Lyme Association of Greater Kansas City's Prime Time Lyme, June 2003 issue

Dorothy Pietrucha, M.D., Pediatric Neurologist

Central Nervous System Symptoms

Central nervous system symptoms of Lyme disease include: meningitis, encephalitis, myelitis (muscle inflammation causing spasticity), leucoencephalopathy, vasculitis, and encephalopathy. Meningitis is an early symptom. Some children get over the meningitis without treatment and get well; others, if untreated, end up chronically ill later. Encephalitis can cause seizures or coma. Dr. Pietrucha knows a pediatric neurologist who was in a coma for 6 weeks because of Lyme disease. With treatment, he seems to have made a full recovery. Leucoencephalopathy causes widespread demyelinating lesions of the brain, brainstem, and cerebellum. It can result in paralysis, blindness, aphasia (impairment of the ability to speak or write), ataxia (poor coordination), dysarthria (impairment of the speech muscles), dementia, confusion, and coma. Vasculitis can cause strokes (even in children), focal ischemia (inadequate blood flow to a certain area), and hemorrhage. Vasculitis can cause a beaded appearance of the blood, and narrowing and irregularity of the blood vessels, but these are not common. Early symptoms of Lyme disease can include flu-like illness, stiff neck, headache, other aches and pains, and photophobia (eyes sensitive to light). These can be signs of meningitis. Later, encephalopathic symptoms can occur and include fatigue, headache, learning disabilities, memory deficits, word finding difficulties, and depression. These are the most common CNS symptoms. They can cause the child to struggle in school and can cause a need for special supportive services.

Tests

Children, more often than adults, get increased intracranial pressure, especially in those with headaches. The opening pressure should be measured during a spinal tap. When testing spinal fluid, cultures are rarely positive. Cultures are negative in late infection. Sometimes the spinal fluid is positive on the ELISA or Western Blot.

CAT scans aren’t very helpful. The MRI and EEG are more useful. At least 30% of patients have an abnormal EEG, even if they don’t have seizures. The EEG may reveal a slowing or asymmetry. Antibiotic treatment helps. A certain percentage of people with Lyme disease will have seizures. This is not epilepsy; it is Lyme with seizure problems. With antibiotic treatment, the seizures will go away or be reduced in frequency.
NEUROLOGIC MANIFESTATIONS OF LYME DISEASE IN CHILDREN AND ADOLESCENTS

Reprinted from the Lyme Association of Greater Kansas City's Prime Time Lyme, June 2003 issue

The MRI may reveal lesions, which can be scattered in a variety of places in the central nervous system. They can be in the medula, basal ganglia, thalamus, upper pons, subcortical frontal lobe, and lower brainstem. She showed slides of an MRI with a brain lesion before and after antibiotic treatment. It was much smaller and barely noticeable after treatment.

Peripheral Nervous System Symptoms

Symptoms of Lyme disease in the peripheral nervous system include cranial neuritis, radiculopathy, and neuropathy. Cranial neuritis is inflammation of a cranial nerve. Any cranial nerve can be involved, but Lyme most often affects the 7th cranial nerve, resulting in Bell’s Palsy. The paralysis can be on one or both sides of the face. When it affects both sides, the child may be unable to talk or to chew food. Dr. Pietrucha has treated about 10-12 patients with Bell’s Palsy. Many of the children with Bell’s Palsy don’t feel ill, but their mothers report that they are irritable, having difficulty in school, or having sleep problems. Other children with Bell’s Palsy have a stiff neck, and their eyes are very sensitive to light. Bell’s Palsy is sometimes treated with steroids. This can make the Lyme disease worse, especially if the child is not also receiving antibiotics. Radiculopathy and neuropathy seem more common in adults than children. Adults are more likely to be bothered by and to report numbness and tingling. Children can get myositis (muscle inflammation) and myalgia (muscle pain). There can be actual changes in the muscles.

Children may have knee pain, back pain, crushing chest pain, heart palpitations, and pain in the gastro-intestinal tract. There may be nothing wrong with the digestive system; stomach pain can be caused by the nerves. Or, Lyme spirochetes can be found in the GI tract and cause pain even with very little inflammation. Children can get aching feet, and sore skin, which can hurt when touched.

Patient Stories

- One boy developed Bell’s Palsy on the right side of his face and had a mild headache. A year before, he had lost the hearing in his right ear, and was given a CAT scan, which didn’t show any problems. Now that he had Bell’s Palsy, he was given an MRI, which revealed a brain tumor. “We can’t assume that every Bell’s is Lyme,” Dr. Pietrucha cautioned.
- Another child got Lyme disease with heart problems, carditis and palpitations. He was cured with antibiotics. However, he still had neurological problems, which were difficult to...
NEUROLOGIC MANIFESTATIONS OF LYME DISEASE IN CHILDREN AND ADOLESCENTS

Reprinted from the Lyme Association of Greater Kansas City's Prime Time Lyme, June 2003 issue

diagnose. It was discovered that, in addition to Lyme, he also had a brain tumor unrelated to the Lyme.

➢ Another boy had a headache, malaise, weight loss, arthralgia (joint pain), and palpitations, and his right shoulder drooped. He went from doctor to doctor and was told that he was fine and just didn’t want to go to school. After 8 months, he woke up with Bell’s Palsy. Then he was diagnosed with Lyme disease, was treated, and has recovered.

➢ Another boy had bilateral Bell’s Palsy. He was unable to talk or chew food. He started antibiotic treatment for Lyme just 2 or 3 weeks after he became ill, and he recovered.

➢ One girl had her right foot drop, and she was dragging her foot. She couldn’t bend her ankle, and she told the doctor she couldn’t see out of her left eye. Her vision was tested. Her sight was almost gone in the left eye from optic neuritis, and she could only see 20/200 in the right eye because of papilledema (swelling of the optic nerve). She was treated for Lyme disease with antibiotics. She was able to bend her ankle just 72 hours after treatment began. Her vision eventually returned to 20/20.

➢ A 13-year-old boy got a tick bite while camping. He became ill with flu-like symptoms and a stiff neck. He went to the doctor with a headache and dizziness. He had 6th cranial nerve palsy (causing the eye to deviate outward and result in double vision), and bilateral papilledema (swelling of the optic nerve in both eyes). He recovered with antibiotic treatment.

➢ A 5-year-old boy had been ill for 2 years, after a tick bite. He had been tired and weak and had fevers, abdominal pain, and joint aches and pains. He was ataxic (had poor coordination) and needed help to walk. He recovered 2 months after beginning antibiotic treatment and was able to walk and climb stairs. Then he started getting worse. An MRI showed many lesions, and he developed seizures, learning disabilities, ataxia, and dysarthria (poor speech because of muscle problems). He is in a wheelchair and is not responding to treatment.

➢ A girl with Lyme disease became progressively weaker with symptoms similar to Guillain-Barre syndrome. She later developed papilledema. She recovered with antibiotic treatment.

➢ A teen-age girl had abdominal pain caused by radiculitis (an inflamed nerve). There was nothing wrong with her stomach. She got better with treatment for Lyme disease. Her sister also had Lyme disease. The sister experienced chilliness and myalgias and didn’t improve with treatment.

➢ A girl had papilledema, and she was seeing double because of 6th cranial nerve palsy. She had no headache or other Lyme symptoms and felt well. An ophthalmologist diagnosed her with Lyme disease. She recovered after antibiotic treatment.

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Summary of Dr. Dorothy Pietrucha’s presentation at the Nov., 2000, Princeton Lyme Conference prepared by Kathy White, Corresponding Secretary, LAoGKC
NEUROLOGIC MANIFESTATIONS OF LYME DISEASE IN CHILDREN AND ADOLESCENTS

Reprinted from the Lyme Association of Greater Kansas City's Prime Time Lyme, June 2003 issue

- Preschool-aged children with Lyme disease may suddenly develop a personality change and become irritable and depressed, constantly fussy. One very young child was not eating well and had a diaper rash that wouldn’t heal despite all efforts. The child was treated with antibiotics and recovered. The diaper rash went away and never came back. It was really a Lyme rash.
As with all serious and disabling diseases, there are some factors, which come into play other than the disease itself that complicate things for the patient and family. These issues are sometimes more devastating than the disease itself.

One of the biggest problems with Lyme is that it can render the victim completely helpless and unable to work or take care of the family. The disease can mimic other diseases in combination such as Lou Gehrig's disease, rheumatoid arthritis, multiple sclerosis, polymyalgia rheumatica, fibromyalgia syndrome, psoriatic arthritis, Alzheimer's and lupus. It is painful and it causes debilitating fatigue and weakness to the point of paralysis at times. It can cause seizures and Bell's palsy, meningitis and encephalitis. It can cause bone pain, muscle pain & joint pain so severe that it can be frightening.

As with all severe disabling diseases, this one carries with it a whole host of problems other than the disease itself. The following are but a few.

1. **Guilt** – feeling bad about feeling bad, particularly when one is unable to work or keep up their share of the housework and child rearing. This carries over into marital relationships as well because, although the Lyme person looks well on the outside, often they feel as if they are dying on the inside. It is hard when loved ones and friends want to go someplace and have a good time and the Lyme patient wants to stay home due to fatigue or pain. They oftentimes feel guilty for being such a dull partner. The symptoms can also lead to guilt surrounding the lack of sexual interest, because this disease is a neurologic disease and can cause some sexual problems as well.

2. **Isolation/desertion** – Often the Lyme patient has the sympathy of friends, physicians and family at first. But as the months pass and the years pass and the patient continues to complain of varying symptoms, and the blood tests and scans continue to come back negative, friends and family pull away. They begin to doubt the sanity of the person. The physicians begin
Psychological Issues of Lyme Disease


blaming the patient and suggesting emotional overlay, hysteria, depression or psychogenic problems. The family follows suit.

This kind of abandonment only makes things worse for the Lyme person. They not only have to deal with chest pain, numbness, tingling, infections, fevers, dizziness, pain, weakness, fatigue and memory loss, etc., but they have to do it with strange looks, nasty comments and mistrust by the people who at one time were close to them.

3. Validation of the person – It is difficult to feel validated as a person when others are telling you that you are nuts and that your symptoms do not exist or that you are bringing them on yourself. Validation must be done now from within more, and one finds themselves in the dilemma of trying to beef up their own self-esteem with positive affirmations. This is a time when we all need to feel support, and so often we feel just the opposite. Employers accuse patients of faking illness; family accuse them of not wanting to work or carry out daily chores; friends accuse them of being hypochondriacs and no longer being the kind of friend that they were in the past. Children worry if it is their parent, and spouses become concerned as well. Parents begin to doubt the validity of the severity of symptoms, and the Lyme patient sinks into depression, at last fulfilling the prophecy of the doctors who, for so long, had suggested that to be the case in the first place.

Lyme is like having symptoms of all the major diseases compiled into one. It can leave one in quiet desperation. Lyme disease is an infection, and an infection that affects the brain. Adding insult to injury, the brain manifestations such as subtle encephalitis and meningitis can cause patients to be emotionally labile, or perhaps moody.

Most Lyme patients are people whose lives have been filled with activity and outdoor things; and, for the most part, these are people who lived life to its fullest and suddenly were struck down. The adjustment is not easy. There is fear of the future and fear of the present. With concomitant brain inflammations and central nervous system problems, it can cause a variety of emotional problems unlike anything the patient previously knew.

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PSYCHOLOGICAL ISSUES OF LYME DISEASE


We are hoping that the physicians in the Midwest will stop and take a good look at what is really going on here. We do have a problem, and it is a problem that, at some point, must be addressed. Unfortunately, I am finding more and more people who have suffered with Lyme for over 6 years, and it concerns me greatly. It is my sincere hope that soon each and every physician in Kansas City and the surrounding areas will include Lyme in their differential diagnoses, when symptoms are suggestive of a combination of rheumatologic, neurologic or cardiac.

Lyme disease is not a benign disease. It is a very serious spirochetal disease, which must be treated with aggressive antibiotic therapy. – Kathy Cavert

Midwest Lyme Aid was published from 1990-1994 by the Midwest Lyme Disease Support Group. The group was founded by Kathy Cavert in 1990 and met in Independence, MO. It was the first Lyme disease support group in Missouri. Some members of the Midwest Lyme Disease Support Group formed the Lyme Association of Greater Kansas City in January 1993.

Kathy Cavert had degrees in secondary education and criminal justice and also studied psychology. She had worked as a mental health counselor and a high school science teacher. She started a support group shortly after being diagnosed with Lyme disease. She provided help to Lyme disease victims who lived throughout the United States and in some foreign countries. Kathy passed away as a result of Lyme disease in February 2000 at the age of 51.
LYME DISEASE SIMILARITIES TO SYPHILIS

Lyme disease is caused by Borrelia burgdorferi bacteria (Bb). Bb bacteria are spirochetes (spiral shaped), closely related to the spirochetes that cause syphilis.

Lyme and other borrelia bacteria are carried by lone star ticks, wood ticks, American dog ticks, and other ticks. Lyme-like diseases have the same rash, symptoms, and severity as Lyme. They need to be treated as Lyme, even if Lyme test results are negative.

<table>
<thead>
<tr>
<th>Symptom or Issue</th>
<th>Syphilis</th>
<th>Lyme Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infects many bodily systems and organs</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Leads to arthritis, insanity, movement disorders, and blindness</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Called “The Great Imitator” because it mimics many other diseases</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Has an early stage and a late stage. If the early stage is not treated adequately, more severe symptoms may develop weeks, months or years later</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Treatment for the disease can cause a Jarisch-Herxheimer reaction*</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Disease can pass through the placenta to an unborn child**</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Spirochete found in blood, semen, vaginal fluid, sweat, tears, joint fluid, breast milk, and other bodily fluids</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Disease can be spread through sexual contact</td>
<td>Yes</td>
<td>There is evidence that it can. Further research is needed.</td>
</tr>
</tbody>
</table>

*A Jarisch-Herxheimer reaction is a temporary worsening of symptoms as the body reacts to the dying bacteria. Symptoms can include a severe headache, pain, depression, and insomnia.

** Bb bacteria have been cultured from placentas. Some children born to infected mothers have Lyme disease symptoms, test positive for the disease, and improve with antibiotic treatment. Antibiotic treatment throughout pregnancy can prevent a baby from being born infected.
Babesia is a common co-infection with Lyme disease. Many ticks are carrying both diseases. Babesia is similar to malaria. Babesia and malaria are caused by closely related protozoans. Babesia is treated with anti-malarial drugs. Babesia can cause severe fatigue, episodes of excessive sweating, chills, fevers, headaches, nausea, poor balance, and breathing problems such as "air hunger." People may not get all these symptoms.

Babesia is largely undiagnosed, because: most doctors are unaware of it, symptoms resemble other diseases, and there are no tests for most strains of babesia. It became a nationally reportable disease in January 2011, but reports will be low until doctors become aware of the disease and learn how to diagnose it.

Many people with chronic Lyme disease also have chronic babesia, especially those with neurological symptoms. Some people who have both diseases have symptoms similar to MS, Parkinson’s, or ALS. Babesia makes it difficult to recover completely from Lyme disease, and Lyme makes it hard to recover from babesia.

**Babesia Testing**

There are several strains of babesia that are infecting humans. We only have tests for Babesia microti, Babesia duncani (also called WA-1), and Babesia divergens. Babesia duncani is much more common in the central states than babesia microti. Babesia MO-1 was first discovered in Missouri, but there is no commercial test for it. Some people in the central states test positive for Babesia divergens. It could be that they really have MO-1 and that it may be genetically similar to Babesia divergens.

If a person tests negative on babesia tests but babesia is suspected, the eosinophil cationic protein test (ECP) may detect it. It detects protozoan infection without specifying the strain. Babesia would cause a person to have a higher than normal score on this test.

Quest Diagnostics has an ECP test. They can also test for Babesia microti.

Medical Diagnostics Laboratories (MDL) in New Jersey can test for Babesia microti and the WA-1 strain. Phone toll-free 1-877-269-0090, website www.mdlab.com. (They also have Lyme Western blot tests. If the Lyme Western blot is negative at MDL, the Western blot test at IGeneX may detect it.)

IGeneX Laboratories in California can test for B. microti and B. duncani (WA-1). Phone 1-800-832-3200, website www igenex.com. They don’t work with insurance companies, but some people have out-of-network coverage.
Babesiosis Reporting Criteria

The CDC announced in the January 14, 2011 issue of the Morbidity and Mortality Weekly Report that Babesia is now a nationally notifiable disease.

2011 Case Definition  CSTE Position Statement Number: 10-ID-27

Clinical Presentation
Babesiosis is a parasitic disease caused by intraerythrocytic protozoa ... Babesia are transmitted in nature through the bites of infected ticks but can also be acquired through contaminated blood components from asymptomatic parasitemic donors or, more rarely, transplacentally. Babesia infection can range from subclinical to life-threatening. Clinical manifestations, if any, can include hemolytic anemia and nonspecific influenza-like signs and symptoms (e.g., fever, chills, sweats, headache, myalgia, arthralgia, malaise, fatigue, generalized weakness). Splenomegaly, hepatomegaly, or jaundice may be evident. In addition to signs of hemolytic anemia, laboratory findings may include thrombocytopenia, proteinuria, hemoglobinuria, and elevated levels of liver enzymes, blood urea nitrogen, and creatinine. Risk factors for severe babesiosis include asplenia, advanced age, and other causes of impaired immune function (e.g., HIV, malignancy, corticosteroid therapy). Some immunosuppressive therapies or conditions may mask or modulate the clinical manifestations (e.g., the patient may be afebrile). Severe cases can be associated with marked thrombocytopenia, disseminated intravascular coagulation, hemodynamic instability, acute respiratory distress, myocardial infarction, renal failure, hepatic compromise, altered mental status, and death.

Clinical evidence
For the purposes of surveillance:

- Objective: one or more of the following: fever, anemia, or thrombocytopenia.
- Subjective: one or more of the following: chills, sweats, headache, myalgia, or arthralgia.

Epidemiologic evidence for transfusion transmission
For the purposes of surveillance, epidemiologic linkage between a transfusion recipient and a blood donor is demonstrated if all of the following criteria are met:

(a) In the transfusion recipient:

i. Received one or more red blood cell (RBC) or platelet transfusions within one year before the collection date of a specimen with laboratory evidence of Babesia infection; and
BABESIOSIS REPORTING CRITERIA

ii. At least one of these transfused blood components was donated by the donor described below; and

iii. Transfusion-associated infection is considered at least as plausible as tickborne transmission; and

(b) In the blood donor:

i. Donated at least one of the RBC or platelet components that was transfused into the above recipient; and

ii. The plausibility that this blood component was the source of infection in the recipient is considered equal to or greater than that of blood from other involved donors. (More than one plausible donor may be linked to the same recipient.)

Laboratory criteria for diagnosis

For the purposes of surveillance:

Laboratory confirmatory:

- Identification of intraerythrocytic Babesia organisms by light microscopy in a Giemsa, Wright, or Wright-Giemsa–stained blood smear; or

- Detection of Babesia microti DNA in a whole blood specimen by polymerase chain reaction (PCR); or

- Detection of Babesia spp. genomic sequences in a whole blood specimen by nucleic acid amplification; or

- Isolation of Babesia organisms from a whole blood specimen by animal inoculation.

Laboratory supportive:

- Demonstration of a Babesia microti Indirect Fluorescent Antibody (IFA) total immunoglobulin (Ig) or IgG antibody titer of greater than or equal to (≥) 1:256 (or ≥1:64 in epidemiologically linked blood donors or recipients); or

- Demonstration of a Babesia microti Immunoblot IgG positive result; or

- Demonstration of a Babesia divergens IFA total Ig or IgG antibody titer of greater than or equal to (≥) 1:256; or
**Babesiosis Reporting Criteria**

- Demonstration of a *Babesia duncani* IFA total Ig or IgG antibody titer of greater than or equal to (≥) 1:512.

**Case classification**

**Confirmed:** A case that has confirmatory laboratory results and meets at least one of the objective or subjective clinical evidence criteria, regardless of the mode of transmission (can include clinically manifest cases in transfusion recipients or blood donors).

**Probable:**

(a) a case that has supportive laboratory results and meets at least one of the objective clinical evidence criteria (subjective criteria alone are not sufficient); or

(b) a case that is in a blood donor or recipient epidemiologically linked to a confirmed or probable babesiosis case (as defined above) **and:**

   i. has confirmatory laboratory evidence but does not meet any objective or subjective clinical evidence criteria; or

   ii. has supportive laboratory evidence and may or may not meet any subjective clinical evidence criteria but does not meet any objective clinical evidence criteria.

**Suspected:**

A case that has confirmatory or supportive laboratory results, but insufficient clinical or epidemiologic information is available for case classification (e.g., only a laboratory report was provided).

**Comment:**

The validity of the diagnosis ... is highly dependent on the laboratory ... Confirmation of the diagnosis ... by a reference laboratory is strongly encouraged. ... If the IgM result is positive but the IgG result is negative, a follow-up blood specimen drawn at least one week after the first should be tested. ... In persons who are immunosuppressed or who have asymptomatic *Babesia* infections, active infections can be associated with lower titers. ...

*Babesia microti* is the most frequently identified agent of human babesiosis in the United States; most reported tick-borne cases have been acquired in parts of northeastern and north-central regions. Sporadic U.S. cases caused by other *Babesia* agents include *B. duncani* (formerly the WA1 parasite) and related organisms (CA1-type parasites) in several western states as well as parasites...
BABESIOSIS REPORTING CRITERIA

characterized as "B. divergens like" (MO1 and others) in various states. Serologic and molecular tests available for B. microti infection do not typically detect these other Babesia agents.

[A note from Kathy White: There is no test for the MO1 strain, which was first discovered in Missouri and may be a prevalent strain in the central states. Therefore, many cases in this area may not meet reporting criteria, which can lead to the illusion that babesia is not here. Many members of the Lyme Association of Greater Kansas City contracted babesia along with Lyme disease. Many have tested positive for Babesia duncani. Most do not have Babesia microti. Many have MO1 or a different strain and may test positive for a protozoan infection on the Eosinophil Cationic Protein (ECP) test at Quest Diagnostics.]
HEARTLAND VIRUS DISCOVERED IN MISSOURI


A new phlebovirus associated with severe febrile illness in Missouri.


Source: Viral Special Pathogens Branch, Division of High-Consequence Pathogens and Pathology, Centers for Disease Control and Prevention, Atlanta, GA 30333, USA.

Abstract: Two men from northwestern Missouri independently presented to a medical facility with fever, fatigue, diarrhea, thrombocytopenia, and leukopenia, and both had been bitten by ticks 5 to 7 days before the onset of illness. Ehrlichia chaffeensis was suspected as the causal agent but was not found on serologic analysis, polymerase-chain-reaction (PCR) assay, or cell culture. Electron microscopy revealed viruses consistent with members of the Bunyaviridae family. Next-generation sequencing and phylogenetic analysis identified the viruses as novel members of the phlebovirus genus. Although Koch's postulates have not been completely fulfilled, we believe that this phlebovirus, which is novel in the Americas, is the cause of this clinical syndrome.

PubMed ID: 22931317 [Indexed for MEDLINE] (A free, open access article.)

This free article, "A New Phlebovirus Associated with Severe Febrile Illness in Missouri," tells of two farmers in northwest Missouri who came separately to a hospital in St. Joseph, MO in June 2009, and were each admitted. They both experienced fever, fatigue, diarrhea, and loss of appetite. Both presented with a fever of 100 degrees Fahrenheit, and each developed a fever of 102 the day after being admitted. They had low white blood cell counts, low platelet counts, and slightly elevated liver enzymes. These are signs and symptoms of ehrlichiosis. They were treated with doxycycline for suspected ehrlichiosis, without noticeable effect. Eventually test results came back negative for ehrlichiosis. The CDC eventually discovered that they had a new virus. It is suspected of being transmitted by lone star ticks.

The first patient, age 57, had recently been bitten by a tick nymph, which was removed with tweezers. He became ill the following day and went to the hospital on the 5th day of illness. He was treated with IV doxycycline for suspected ehrlichiosis. In addition to the fever, fatigue, diarrhea, and loss of appetite, he also had nausea, a headache, and short-term memory problems. Tests for ehrlichiosis, spotted fever group rickettsias, and influenza were negative. He spent 10 days in the hospital. He continues to have fatigue, headaches, and short-term memory problems, even three years later.

The second patient, age 67, had received many tick bites during the previous two weeks before becoming ill. He had removed the ticks with his fingers and tweezers. He went to the hospital a week after the last tick bite, after about 4 days of being ill. In addition to fever, fatigue, diarrhea,
and loss of appetite, he also had muscle pain, a dry cough, and short-term memory problems. He was treated with 14 days of oral doxycycline for suspected ehrlichiosis. He spent 12 days in the hospital. Test results came back negative for ehrlichia, anaplasma, and borrelia. Upon discharge, he still had fatigue, loss of appetite, and short-term memory difficulty. These symptoms went away after 4-6 weeks.

**Heartland Virus Mentioned on NBC News**

NBC News had a story on August 29, 2012 by JoNel Aleccia, titled "New tick-borne virus puts the bite on Missouri farmers." It gave more details about the two men who were hospitalized with the virus in 2009. Robert's wife had removed his tick with tweezers. The other man estimated that he had had about 20 tick bites per day over the previous two weeks while rebuilding fences on his farm.

Scientists at the CDC did genetic analysis and discovered that the men had a new, previously unknown virus. Both men took a couple of months to recover. Robert is able to work, but he said that now, 3 years later, he still has fatigue, problems with short-term memory, and headaches. The other man, who is now 70, said he feels fine.

So far, the Missouri men are the only known victims of the new disease. It is a phlebovirus, a serious virus in the same family as hantavirus. Health officials have been looking for other signs of the virus in the area but have not found any. It isn’t known whether or how many other people have had this virus without getting diagnosed, and how many may have been infected without becoming ill or only having a mild illness.

The disease is called "the Heartland virus" because both men were treated at Heartland Regional Medical Center in St. Joseph, MO, and because it was discovered in the nation's heartland. Dr. Scott M. Folk, M.D., infectious disease specialist in St. Joseph, MO, was consulted on these cases.


**Heartland Virus Related to SFTSV Virus**

"Heartland Virus: New Phlebovirus Found in Missouri," by Anna Tomasulo, appeared on Sept. 15 in "The Disease Daily," published by HealthMap at Boston Children's Hospital. It said this phlebovirus is closely related to "severe fever with thrombocytopenia syndrome virus" (SFTSV), a phlebovirus discovered recently in China, which causes death in 12% of cases. This article is at: [http://www.healthmap.org/news/heartland-virus-new-phlebovirus-found-missouri-83012](http://www.healthmap.org/news/heartland-virus-new-phlebovirus-found-missouri-83012).
HEARTLAND VIRUS DISCOVERED IN MISSOURI

CDC Seeking Information on Suspected Cases
The Kansas City Star had an article on Sept. 12, 2012 titled "Heartland Virus Puts Missouri – and Ticks – In the Spotlight," by Sangeeta Shastry. It says that two northeast Missouri hospitals are working with the CDC to get patients with similar symptoms to volunteer to be tested for the Heartland virus and other infections. The CDC is also contacting other hospitals in western Missouri to find additional patients. The CDC has had phone calls from people all over the U.S. who suspect this disease. The extent of this disease isn’t yet known.

The CDC is trying to discover which animals and insects might carry this virus. They suspect ticks but are seeking proof. For several months, researchers have been collecting thousands of ticks from the two farms of the men who contracted the virus, and from surrounding conservation areas in northwest Missouri.

The Heartland virus is the first new virus discovered in the U.S. since the discovery of the hantavirus in 1993.

This article is at: http://www.kansascity.com/2012/09/12/3809683/missouri-virus-sparks-research.html
Researchers at the University of Virginia have recently reported that lone star ticks are capable of causing people to suddenly become allergic to meat from all non-primate mammals, including beef, pork, lamb, venison, and buffalo. Allergists Thomas Platt-Mills, MD, PhD and Scott Commins, MD reported their findings in the May 2012 issue of The Journal of Allergy and Clinical Immunology. (2012 May;129(5):1334-1342.e1. “Relationship between red meat allergy and sensitization to gelatin and galactose-α-1,3-galactose.” Mullins RJ, James H, Platts-Mills TA, Commins S.) The two doctors first published their findings about this sugar allergy in meat in 2009.

They suspect that the disease is caused by young lone star tick larvae, and that the more tick bites a person gets, the worse the allergy will be. Unlike most food allergies, the reaction may not develop until 3-6 hours after eating meat. Symptoms may include a rash, hives, swelling of the throat, breathing difficulty, a drop in blood pressure, fainting, and death. People may awaken suddenly in the night with serious symptoms. Over 1,500 cases from eastern states have been reported to researchers at the University of Virginia during the past 10 years, which includes over 1,000 cases in Virginia. New York and North Carolina are also high in reported cases. Lone star ticks are also abundant in central and southern states. Some cases have occurred in Missouri. The researchers suspect that there may be many undiagnosed and unreported cases.

Reporter Kate Morisse said on June 20 on the TV program "Good Morning America" that a tick bite may be spreading meat allergies up the East Coast. "People will eat beef and then anywhere from three to six hours later start having a reaction; anything from hives to full-blown anaphylactic shock," said Dr. Scott Commins, assistant professor of medicine at the University of Virginia in Charlottesville, who was interviewed for the TV program. He said, "We think it's something in the saliva." Commins said blood levels of antibodies for alpha-gal, a sugar found in red meat, rise after a lone star tick bite. He expects that experiments with tick saliva and the antibodies will prove a connection.

Dr. Platts-Mills has had this allergy for a few years. He discovered after getting numerous tick bites from a hike that his IgE level for alpha-gal allergy went way up. He concludes that the number of tick bites may affect the severity of the allergy. A few people, after avoiding tick bites for a long time, have had a drop in their IgE levels. The researchers believe the allergy may eventually go away if the patient can avoid future tick bites. Most people with this allergy have had repeated tick bites, but it can be just one or two a year over a period of years.

Most food allergies cause an immediate reaction, so this delay of 3 to 6 hours is unusual. Also, most meat allergies are a response to a protein antigen. This is different because it is a response to a sugar antigen.
TICKS AND RED MEAT ALLERGY

A story by Kris Van Cleave, a reporter for ABC TV-7 in Washington, D.C, was posted at www.wjla.com. It told of a man who got an extremely itchy tick bite that lasted a long time and created a large red itchy area. A few hours after eating a hamburger, he developed hives all over. Then he passed out and had a seizure. He said he is glad he prefers seafood to beef.

The August 13, 2012 issue of Discover Magazine had an article by Helen Chappell titled "How a Tick Bite Made Me Sick." The article said that it's possible that other kinds of ticks could cause this allergy. People are getting this allergy in a tick-endemic region of Australia, where there are no lone star ticks. People have reported that fat meat causes more severe symptoms than lean meat. Some people with this allergy are able to tolerate lean meat or only get mild hives from it.
**MORGELLONS DISEASE**

Morgellons causes painful open sores that last for months or don’t heal. It causes black granules and white, clear, red, blue, black, and green fibers to emerge from the skin. People can remove the fibers from sores or intact skin with tweezers. The fibers are often difficult to pull out. Many of the fibers are hard and feel like splinters. Morgellons also causes stinging and crawling sensations under the skin and intense itching. These symptoms interfere with sleep.

It has been reported in all 50 states, Canada, Europe, and world-wide. The incidence is increasing. You may see someone with the sores someday. You may refer people to our Lyme Association for Morgellons information.

Almost everyone with Morgellons has Lyme disease or another tick-borne disease. Most people with Lyme disease don’t have Morgellons. Some Lyme specialists are treating Morgellons. Lyme support groups can help people find a Lyme specialist. Antibiotic treatment for Lyme disease helps most Morgellons patients. Doxycycline and IV Rocephin are often used. Many patients also need antiparasitic and/or antifungal drugs. Some have improved by taking NutraSilver colloidal silver internally. (See stories at www.nutrasilver.com.) When starting a treatment, patients typically have a temporary worsening of symptoms (Jarisch-Herxheimer reaction), with a mass exodus of fibers for a few days. Patients who relapse after treatment stops usually benefit from continued treatment.

It is suspected that Morgellons may be transmitted by ticks and/or by contact with soil. Many patients develop the disease after gardening or other contact with soil. It is unknown whether it is contagious. Many patients have family members, close friends, and dogs or cats with the sores and fibers. Perhaps they all had a common exposure. Many families have just one person infected.

**New Research: Morgellons Similar to a Cattle Disease**

Recent studies have shown that Morgellons is similar to bovine digital dermatitis (BDD), known to farmers as "hairy wart disease" (1). BDD causes sores on the feet of cattle and fibers to grow out of the sores, and weight loss, lameness, and reduced milk production. It spreads rapidly among cattle, perhaps by contamination of soil. Spirochetes (spiral shaped bacteria) are associated with BDD and are believed to be the cause. It is treated by walking the cattle through oxytetracycline foot baths.

Spirochetes are also now suspected of being the cause of Morgellons. A recent study of four Morgellons patients found spirochetes in their skin (2). Lyme disease is caused by spirochetes. It is not yet known whether Morgellons is a less common manifestation of Lyme or whether a different spirochete may be involved. In addition to spirochetes, some patients may also have an unknown fungus, nematodes, or other parasites, as anti-fungal and/or antiparasitic drugs help some patients.

Keratin, a protein found in hair, nails, skin, and the hooves and horns of animals, has been found in the fibers of Morgellons and BDD. Collagen was found in some of the Morgellons fibers. (The BDD cattle disease fibers were not tested for collagen) (2). Researchers have found that, unlike hair, the fibers of both of these diseases fluoresce under UV light (3).
MORGELLONS DISEASE


A Morgellons conference is held every April in Austin, TX. The one in 2013 will be April 13 & 14. See www.thecehf.org for conference information, links to the above articles and other recent research, and DVD’s of prior conferences for sale. Also see www.gingersavely.com.
MORE ABOUT MORGELLONS DISEASE

(This page is for medical professionals and Morgellons patients.
It's too unpleasant for most people to read.)

People can have the fibers without the sores. If they have fibers, they have Morgellons, because that is the definition. It's a fiber disease. There are no tests for Morgellons. The disease is diagnosed based on patient history and visible fibers. A doctor who does not see any protruding fibers can look for fibers under the skin with an EyeClops BioniCam microscope. Information about it is in the section below. Some people have the sores without the fibers.

Dr. Ginger Savely, DNP, is a nurse practitioner with a PhD in Nursing Practice (not an MD). She has treated over 500 Morgellons patients, more than anyone else in the U.S.A. She said at the 2011 Morgellons conference that fibers can come out of the skin of patients as a single fiber or in clumps, "fuzzballs." The fibers and fuzzballs often emerge from fingertips or from under the fingernails. Fibers can come out through sores, intact skin, the ears, eyes, nose, and mouth. Fibers coming out through the eyes feel like sand or splinters in the eyes. Fibers in the eyes cause vision problems. Morgellons can be associated with vision problems even without fibers in the eyes.

Many patients also have black specks emerging from their pores that look like blackheads on the skin. Microscopic examination reveals that these black specks are actually balls of tightly clustered tiny fibers. They look like black sand when patients find them on their bedsheets in the morning.

The fibers are not just under the skin. They can grow inside the body. They have been found in urine, feces, the colon, liver, lungs, and the brain. They may also be affecting other organs. A doctor who has Morgellons had surgery to remove a clump of fibers from his liver and one lung.

Randy Wymore, Ph.D., is a researcher who has been analyzing Morgellons fibers in his lab at Oklahoma State University. The fibers can be stiff and hard, especially the longer ones. The fibers are translucent and glow under UV light.

Most people with Morgellons are ill. In addition to fibers and sores, they have insomnia, fatigue, memory problems, mood swings, and depression which leads some to suicide. Some have joint pain, vision problems, muscle weakness, and other symptoms. Most (about 95%, according to Ginger Savely) have Lyme disease in addition to Morgellons. It can be difficult to determine to what extent Lyme is causing or exacerbating some of these symptoms.

Some patients have a thick, black, oily substance that oozes out of their pores. Some people with Morgellons lose their hair in clumps, and their teeth may turn black, starting at the gum line, and then crumble and fall out. Osteoporosis may develop in the bones.

Finding Morgellons Fibers

Ginger Savely advises doctors to buy an EyeClops BioniCam microscope to examine the skin of Morgellons patients. Other microscopes are too powerful. She says magnification of 30 to 100 is
MORE ABOUT MORGELLONS DISEASE

best for viewing Morgellons fibers under the skin, with 60 giving the best view. The BioniCam microscope is sold as a child's toy and is available at Amazon.com and sometimes at Toys R Us. The price is usually slightly over $100. It has a light, and illumination is important for seeing fibers under sores and intact skin. Digital photographs can be taken with this microscope.

To use the microscope, first wipe the skin with an alcohol wipe or dampened non-linty eyeglasses paper, to remove any environmental fibers that may be on the skin. Rubbing intact skin with the paper may bring the fibers closer to the surface for easier viewing. The fibers that show up are usually blue or red but can be other colors. You usually have to place the magnifier on several areas of skin before finding fibers, so this is not a quick examination.

Morgellons is on the increase. If you have never seen a person with it, you may someday. You may notice open sores on the face, neck, and/or hands. Clothes may cover other areas. The Lyme Association of Greater Kansas City provides additional Morgellons information and literature upon request.
Many people with Lyme disease are being helped by taking transfer factor capsules. Transfer factors are tiny molecules that transfer immunity from one entity to another. Transfer factors are in colostrum, the early milk that transfers immunity from a mother to a baby, and in egg yolks. The transfer factors sold in capsules are derived from colostrum and/or eggs. Transfer factor capsules pose no problem for people with allergies to milk, chickens, or eggs, because the tiny transfer factor molecules contain no lactose or milk products, and no chicken or egg products.

Transfer factor capsules have been developed to help people fight chronic Lyme disease, co-infections, herpes viruses, and other illnesses. Lyme disease can lower the immune system and activate dormant herpes viruses.

**Herpes Viruses Include:**

- **Herpes simplex 1,** which causes fever blisters
- **Herpes simplex 2,** which causes genital warts
- **Chickenpox** (HHV-3), which causes shingles when reactivated
- **Epstein Barr virus,** HHV-4 (Human Herpes virus 4), which causes mononucleosis; reactivated mono can cause chronic fatigue
- **Cytomegalovirus,** HHV-5, which can reactivate with mono-like symptoms
- **HHV-6 A & B:** HHV-6B causes roseola in babies
- **Pityriasis rosea,** HHV-7, can cause mono-like illness when reactivated
- **Kaposi's sarcoma,** HHV-8

Chronically active HHV-6 A has been found in many patients who have Lyme disease, MS, fibromyalgia, and CFS (chronic fatigue syndrome). HHV-6 can cause fatigue and other symptoms and can lower the immune system. Many patients with chronic Lyme disease have coinfections from the tick bite as well as chronically active Epstein Barr virus, HHV-6, and/or other active herpes viruses.

A research study conducted by Joseph H. Brewer, MD and Greg B. Wilson, PhD found that CFS patients who took transfer factor with immunity for HHV-6 for 6 months had a significant improvement in their symptoms, and their immune systems improved significantly and went back to the normal range, according to a test of their NK (natural killer) cells. Natural killer cells are white blood cells that fight diseases. A control group of CFS patients took transfer factor that did
transfer factor

not contain specific immunity to HHV-6. After taking it for 6 months, these patients did not have significant improvement in their symptoms or natural killer cell count.

People taking transfer factor often notice a significant improvement in energy after a few months. If the product is stopped, there is usually a relapse. People who benefit from the product may need to stay on it for life. When first starting transfer factor, there are typically flu-like symptoms for a couple of weeks or longer, as the immune system becomes activated and kills diseases. The dying germs may release toxins that cause these symptoms, or it may be an inflammatory response to the dying germs. People can keep these "die-off" symptoms to a minimum by starting gradually, taking one capsule every other day or less often, or a half capsule every day or every other day, eventually working up to the recommended dose.

A doctor can order testing for herpes viruses at ViraCor in Lee's Summit, MO, 1-800-305-5198. There is interesting information about herpes viruses at their website, www.viracor.com. Testing is also available at Immunosciences Lab in Beverly Hills, CA, 1-310-657-1077, www.imunonosci-lab.com. Patients should discuss with their doctor which transfer factor product is appropriate for their needs and the best dosage. These products are available without a prescription, but they should be taken only under the supervision of a physician.

Companies Selling Transfer Factor Products

Specialty Products (formerly called Chisolm Biological Laboratory) in Warrensville, SC sells transfer factor with antibodies for Lyme and other diseases at 1-800-664-1333. Their Immune Factor 2 capsules contain antibodies for Lyme disease (Borrelia burgdorferi), Epstein Barr virus, chlamydia pneumonia, CMV, HHV-6A, HHV-6B, babesia, ehrlichia, and bartonella. They recommend one capsule per day. It costs $140 for a bottle of 30 capsules or $390 for 90 capsules, plus shipping. They also have other transfer factor products.

Researched Nutritional in Los Olivos, CA sells LymPlus, which contains transfer factors for the same diseases as Immune Factor 2, at about the same price. In addition to other transfer factor products, they also sell Multi-Immune, which contains shiitake mushrooms, decaffeinated green tea, vitamin B12, zinc, and other ingredients good for the immune system. Multi-Immune is also available without the mushrooms. Researched Nutritional products are sold through doctors or by calling 1-800-755-3402, but the patient’s doctor must be registered with Researched Nutritional in order for the patient to purchase their products. Their website is www.Researchednutritionals.com. They recommend that a doctor test for these diseases before deciding which product is best for a specific patient.

Some Lyme patients who cannot afford these specific transfer factor products report that they do benefit from taking less expensive regular colostrum from a health food store. 4Life sells transfer
TRANSFER FACTOR

factor products derived from cow colostrum and egg yolks at 1-800-852-7700, or at www.transferfactor-4-Life.com. Their products boost the immune system but are not specifically for Lyme or other diseases.

This paper is provided for information only. The Lyme Association of Greater Kansas City does not recommend any specific products or forms of treatment. Patients should consult their health care provider for appropriate individualized treatment.
LYME DISEASE REFERENCES

**Websites**

International Lyme & Associated Diseases Society  www.ilads.org

(A professional medical society. For Dr. Burrascano’s Treatment Guidelines, click on "About Lyme" at top of home page and then on "Treatment Guidelines.")

Lyme Disease Association  www.lymediseaseassociation.org

National news and resources  www.Lymedisease.org

Good basic information (Canada website)  www.canlyme.com

Medical abstracts  www.pubmed.gov

Medscape medical abstracts  www.medscape.com

LDA of Southeastern PA  www.Lymepa.org

Information for patients  www.Lymenet.org

Free or discount medicine info.  www.needymeds.com  www.pparx.org


Lyme Assoc. of Greater Kansas City  www.lymefight.info

**BOOKS**

Babesia Update 2009: A Cause of Excess Weight, Migraines and Fatigue? A Common


Everything You Need to Know About Lyme Disease, by Karen Vanderhoof-Forschner. Describes symptoms, co-infections, tests, tick life cycle, history, congenital Lyme, antibiotics.

Insights into Lyme Disease Treatment: 13 Lyme-Literate Health Care Practitioners Share their Healing Strategies, by Connie Strasheim and Maureen McShane, M.D.

63 – Tick-Borne Diseases Handbook
LYME DISEASE REFERENCES


Reason for Failed Lyme Disease Treatment, by James Schaller, M.D. (This book is designed to be a supplement to The Diagnosis and Treatment of Babesia and not to replace it.)

The Diagnosis and Treatment of Babesia, by James Schaller, M.D. 2006

The Lyme Disease Solution, by Kenneth B. Singleton, M.D.

The Use of the Herb Artemisinin for Babesia, Malaria and Cancer, by James Schaller, M.D.

The Widening Circle: A Lyme Disease Pioneer Tells Her Story, by Polly Murray, discoverer of the epidemic. Describes symptoms in her family and history of the discovery of the disease.

Treatment of Chronic Lyme Disease: 51 Case Reports and Essays in their Regard, by Burton Waisbren, Sr., MD, FACP, FIDSA

(The Lyme Association of Greater Kansas City does not endorse any specific products or forms of treatment and advises patients to consult a doctor.)