

Lyme Disease: Short Symptom List:

- 1 Headache
 - 2 Burning or stabbing sensations; shooting pains
 - 3 Joint pain, swelling; stiffness of joints or back
 - 4 Muscle pain or cramps
 - 5 Neck stiffness, pain; neck creaks & cracks
 - 6 Chest pain; rib soreness
 - 7 Sore throat; swollen glands
 - 8 Upset stomach or abdominal pain
 - 9 Shortness of breath; cough
 - 10 Change in bowel function
 - 11 Bladder dysfunction; Irritable bladder
 - 12 Testicular pain; pelvic pain
 - 13 Unexplained breast pain/ milk production
 - 14 Numbness; tingling; tremor
 - 15 Facial paralysis (Bell's palsy)
 - 16 Twitching of the face or other muscles
 - 17 Skin hypersensitivity
 - 18 Fatigue, tiredness, poor stamina
 - 19 Unavoidable need to sit or lay down
 - 20 Unexplained fevers, sweats, chills or flushing
 - 21 Unexplained menstrual irregularity
 - 22 Unexplained weight loss or gain
 - 23 Unexplained hair loss
 - 24 & 25 Eyes & Ears: double, blurry vision, vision loss, floaters- hearing loss, buzzing, ringing, pain, light and/or sound sensitivity
 - 26 Heart: pulse skips; Cardiac impairment
 - 27 Heart block; Heart murmur
 - 28 Heart palpitations; Heart valve prolapse
 - 29 Sexual dysfunction or loss of libido
 - 30 Lightheadedness; Poor balance/vertigo/wooziness
 - 31 Increased motion sickness
 - 32 Exaggerated symptoms or worse hangover after alcohol consumption.
- ### Psychiatric symptoms
- 33 Sleep disorders
 - 34 Mood swings; depression; irritability, violent behavior
 - 35 Cognitive loss: forgetfulness/poor short-term memory/memory loss
 - 36 Attention Deficit Hyperactivity Disorder(ADD-ADHD)
 - 37 Autism like syndrome
 - 38 Problem absorbing new information
 - 39 Difficulty with speech, writing/finding words/ name blocking/ dyslexia
 - 40 Difficulty with concentration and reading/difficulty thinking/confusion/poor attention
 - 41 Disorientation: getting lost, going to wrong places
 - 42 Obsessive compulsive behavior (OCD)
 - 43 Rage/panic/anxiety attacks/impaired impulse control
 - 44 Suicidal thoughts or attempt
 - 45 Seizures
 - 46 Psychosis



Some common tick-borne diseases (or coinfections)

Common tick vectors are I.scapularis, I pacifcu, D Andersoni, A americanum, I cookie, D variabilis

Disease (or coinfection)	Pathogen/causal agent
Anaplasmosis, granulocytic	Anaplasma phagocytophilum
Babesiosis	Babesia microti
Ehrlichiosis, monocytic	Ehrlichia chaffeensis
Lyme disease	Borrelia burgdorferi
Powassan encephalitis	Powassan virus
Southern rash illness	Borrelia lonestari
Tick-borne Relapsing Fever	Borrelia species
Tick paralysis	Toxin
Tularemia	Franciscella tularensis

This table is derived from the CDC Website



To Remove a Tick:

- 1 Do not squeeze or twist the body of tick or burn it or use any substance on it.
- 2 Grasp the tick close to the skin with tweezers & pull it straight out.
- 3 Use antiseptic on skin, wash hands; disinfect tweezers.
- 4 Record the date & any symptoms that may follow and see a physician familiar with tick-borne diseases

Save the tick & Keep a record!

DISCLAIMER Empire State Lyme Disease Association is a non-for-profit organization incorporated in NYS dedicated to raising awareness of tick-borne diseases. We support patients and the doctors who help them. We urge the development of accurate testing and cures. This information is for educational purposes only and is not intended to be used as medical advice. Please see a doctor familiar with tick-borne diseases if you suspect you have contracted Lyme or any tick-borne disease. For all medical advice, please see a doctor.



Sizes of tick stages compared to dime

Support Groups - Please see website for complete updated info

Fingerlakes Region Rochester LD Support Group Farmington NY
Adirondack Lyme Disease Fn, 49 Henry St, Saratoga Springs NY
Capital Region Chapter 2228 Western Ave Guilderland NY
Central New York Chapter, Onondaga Free Library Onondaga Hill NY
Ridge Civic Center, Panamoka Trail, Lake Panamoka, Ridge, NY
Manorville Lyme Disease Support Group, Manorville, NY
Courtland County, Marathon, NY ~ Mountaintop Lyme Support,
Hunter, NY ~ Rockland County Lyme Support, Suffern, NY ~ Meetings and events were held in Riverhead, Huntington, Hampton Bays, North Shore, Bayville, Baldwin, if you are still interested, plz contact us!

Also: A Hope 4 Lyme, Big Flats, NY ahope4lyme@yahoo.com

Faith based CNYLS Chittenango Lyme, Sullivan Free Lib, Chittenango NY
Oneonta Lyme Support FoxCare Ctr 1 Foxcare Rd-Ste Rt 7 Oneonta NY

Information compiled from CDC, ILADS, other. Look for books on Lyme & Tick-Borne diseases: Amazon.com, Lymebook.com & www.EmpireStateLymeDiseaseAssociation.org



EMPIRE STATE LYME DISEASE ASSOCIATION, INC

EmpireStateLyme@aol.com

URL: www.EmpireStateLymeDiseaseAssociation.org

Lyme Disease Borrelia, Neuroborreliosis, Borreliosis

Spreads though bite of infected ticks and possibly via semen, breast milk, or in utero

Common coinfections

Babesia (Babesiosis) is a protozoan spread by ticks, blood transfusion and in utero. There are 13 known forms to date; current tests only look for two of the 13. Symptoms include air hunger; cough; fatigue; fevers; headache; sweats; hemolysis; imbalance without true vertigo; shaking chills; mild encephalopathy.

Bartonella, Bartonellosis, cat scratch fever, although common, is among those not on CDC list, spread by bite from infected tick & in utero; Sx incl. headache; sore throat; high fever; encephalopathy; flulike malaise; somnolence; myocarditis; endocarditis; myalgias; jaundice; enlarged lymph nodes-lymphadenopathy; abnormal liver enzymes; hemolysis with anemia; hepatomegaly; splenomegaly; immune deficiency; weakened immune response; papular or angiomatous rash.
Ehrlichia (Ehrlichiosis) by bite from infected tick; Sx incl. high spiking fever, headaches; myalgias; elevated liver enzymes; ongoing fatigue; persistent leukopenia; thrombocytopenia.

TEN QUICK TIPS:

- 1 Lyme disease is worldwide & rampant in NYS.
- 2 A tick bite can transmit tick-borne diseases so record dates, any symptoms, save the tick, photograph any rash; i.e. Keep a record!
- 3 Symptoms may occur soon or months after bite.
- 4 Rashes may be seen soon, months later or may not be seen at all.
- 5 Early diagnosis is better than later diagnosis.
- 6 Tick-borne diseases can be very complicated.
- 7 Coinfection can complicate diagnosis & treatment
- 8 Misdiagnosis with an autoimmune disease or being told you are fine results in late diagnosis.
- 9 Due to inaccurate blood testing, diagnosis cannot solely depend on test results. Symptoms, risk factors, etc, help determine a "clinical" diagnosis.
- 10 Prevention – DEET, Permethrin See website



EMPIRE STATE LYME DISEASE ASSOCIATION, INC

www.EmpireStateLymeDiseaseAssociation.org

EmpireStateLyme@aol.com

RASHES:



LYME IN 15 POINTS

1. Lyme is the most widespread vector-borne disease in the USA. It is a problem worldwide possibly made worse due to the raging controversy over diagnosis and treatment guidelines.

2. *Borrelia burgdorferi* Bb, the bacteria that causes Lyme disease is the most complex bacterium known to science. It follows that Lyme disease is a very complex illness, not always easy to diagnose or treat. (Ref: Clinical Inf. Dis. 2007:45 (15 July))

3. Each year, Lyme disease is under-reported. Of the reported cases, 24,000 meet CDC strict criteria. CDC estimates the 24,000 official cases may be 10 % of the total # of cases that would be accepted if all cases were reported, so 240,000 new cases annually might be the reality. Additionally, since cases must meet strict CDC criteria, 240,000 cases per year may be a low estimate.

4. New York has one of the highest rates, with 75,233 cases reported to CDC from 1990 to 2006. This means the actual # of cases in NY may be 10X as many (amounting to over 750,000 cases-1990-2006)

5. Diagnosis and treatment can be difficult for patients with coinfections. (e.g. Anaplasma, Q fever, Babesia, Bartonella, Ehrlichia, Powassan Encephalitis, West Nile Virus (CT Dept of Agric.), Rocky Mountain spotted fever, fungi, Stari, Master's disease, Tick paralysis, Colorado Tick Fever, Tick-Borne Relapsing Fever)

6. Lyme disease is "The Second Great Imitator" and Lyme & tick-borne diseases can be MISDIAGNOSED as ALS (Amyotrophic Lateral Sclerosis), Parkinson's, Type 2 Diabetes, MS (Multiple Sclerosis), Influenza, Autism, Lupus, Fibromyalgia, Chronic Fatigue, ADHD, Alzheimer's, Arthritis, Depression, Mental Illness, Mononucleosis & more. Misdiagnosis leads to steroids being prescribed and may help an infection thrive. Patients can recover with correct diagnosis & treatment.

7. Contracting Tick borne disease: Most likely mode of transmission is from the bite of infected ticks. Others may include from infected insect or arachnid bites; across the placenta from an undiagnosed, infected mother to fetus; & possible human sexual transmission from the male only.

8. For diagnosis, a "requirement" that a tick be attached for 24, 48 or 72 hours for transmission of disease can not really be met. People get rid of a tick as soon as they see it, so they can usually tell the time of tick removal but not the time the tick was first attached! Regarding studies: most have not used a baseline of fewer attachment hours than 24 hrs, so there are no results for less than 24 hrs of tick attachment. Note: Mice or lab animals' response to tick-borne disease are different than human responses. While studies are helpful, perhaps they should not be used as rules to determine if a human has contracted a tick borne disease. Additional:
a. If a person is the tick's second host, after it drops off its first host, the bacteria may already be in the tick's mouth from its first feeding and spirochetal transmission could be very rapid;
b. A tick can regurgitate bacteria into the bite site if it is squeezed with removal.
c. Be careful! NYS Health Dept determined that a tick a man found crawling on his arm had been feeding for 48 hours; but it hadn't bitten the man!

9. Rashes & Symptoms: A rash does not always occur with Lyme disease, or it can appear for several hours & then disappear, or appear years later or it can be missed due to the location of the rash on the body. A rash can be a bull's eye or can take on other appearances. Rashes can be more difficult to see on darker skin. Not seeing a rash does not mean absence of tick borne disease. Symptoms are as unpredictable as rashes and can seem like many other ailments & may occur days or even months after a tick bite. (see Lyme Disease: Short Symptom List)

10. Lyme and Tick-Borne Diseases can lead to neurologic, cardiac, psychiatric and arthritic symptoms in humans, can affect any of the body's systems and/or organs and can lead to death. If illnesses are not diagnosed correctly and treated early and adequately, over time immune system breakdown can render patients severely ill and more difficult to cure. Estimates are that from 15%-30% of those infected with Lyme may develop chronic disease.

11. Children are the highest risk group for Lyme. Studies show there is a significant IQ drop in students with Lyme but IQs go up after treatment.

12. Lab tests for Lyme are not reliable: people may test negative and still have the disease. Patients report having problems getting diagnosed & are often late diagnosed. In 1988 the NYSDOH sent a letter to every NYS physician to warn that Lyme blood tests miss 45% of patients & that tertiary Lyme may need prolonged treatment. CDC criteria were developed for surveillance not diagnosis. Theories about false positives, negatives or "over-or-under-diagnosis" don't concern patients who need care.

13. For this care, it is essential that a "clinical" diagnosis be made: meaning that the doctor meets and talks to the individual in person, then carefully evaluates all the symptoms and also evaluates for coinfections

14. Treatment A minimum of 30 days of antibiotics used to be typical. Many experts now suggest a minimum of 90 days and longer treatment may be necessary. There has never been a definitive study proving the theory that 30-days of antibiotics cures Lyme disease. The LYME CONTROVERSY centers on the different opinions on short-term vs. long-term treatment. If symptoms return after short-term treatment, all the bacteria may have not been eliminated and the person could become much sicker & suffer chronically. Doctors see patients recovering on long-term treatment & now believe 1-4 years on antibiotics can help them to become symptom-free.

15. Prevention: Cover your skin when walking in Deer-infested areas, woods, or tall grass. Tuck pants into socks. Use DEET, Permethrin, etc & follow labels; thorough tick checks for you & pets. Extra precautions for hunters: Remove game with a tarp, hang game over bleach solution for ticks to fall into, wear plastic gloves & apron when cleaning.

SUGGESTED RESOURCES:

See www.EmpireStateLymeDiseaseAssociation.org
The Lyme Disease United Coalition, LDUC www.LDUC.org
www.RoadBack.org - The Road Back Foundation
www.LymeInducedAutism.org - Lyme Induced Autism Fn.
www.NatCapLyme.org National Capital Lyme Disease Association
PAL Partners Against Lyme www.paltad.org
Testing: Igenex, Inc, Clongen Labs
Books on Lyme & Tick-Borne disease: Amazon.com, Lymebook.com,
www.EmpireStateLymeDiseaseAssociation.org/Books