

Perinatal Lyme Disease What We Know & What We Don't Know

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Colorado Breastfeeding Coalition
September 20-21, 2018

Lyme Disease

The Great Imitator

Assembled from Several Lyme Disease Support Organizations
and Online Resources in North America

Thanks to

- Lyme Disease Assn SE Pennsylvania www.lymepa.org
- www.openeypictures.org
- www.ilads.org
- www.lymedoctor.com Kenneth Singleton, MD, MPH
- www.lyme.org
- www.lymefighters.org
- www.lymediseaseassociation.org
- www.lymeiniowa.org
- www.lymeinfo.net
- Don F McNeel M.D., Portsmouth Regional Hospital

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Disclaimer

Anything that seems like medical advice
is really direction to discuss the subject
with your physician.



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My sister Nancy & Lyme



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Lyme Disease

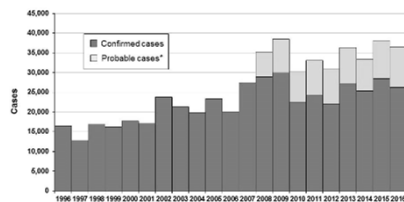
- Most commonly reported vector-borne disease in North America
- Fastest-growing vector-borne disease in North America
- **CDC, 2015** : "≈329,000 LD cases occur annually. LD is a major US public health problem that causes substantial use of health care resources."
 - Nelson CA, Saba S, Kogut RJ, Delaney MJ, Shankar MB, Bruckner RP, et al. Incidence of clinician-diagnosed Lyme disease, United States, 2005–2010. *Emerg Infect Dis.* 2013 Aug;19(8):e1000260. doi:10.1371/journal.pone.0100260.
- **The CDC estimates that 90% of Lyme cases are "underreported"**
 - Unnoticed
 - Undiagnosed
 - Untreated

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Lyme is increasing: CDC

Reported Cases of Lyme Disease by Year, United States, 1996-2016



*National Surveillance case definitions revised in 2008 to include probable cases; details at http://www.cdc.gov/nceid/dzsums/nceid Lyme_disease_2008.htm



"Reported cases of Lyme disease are most common among boys aged 5-9."

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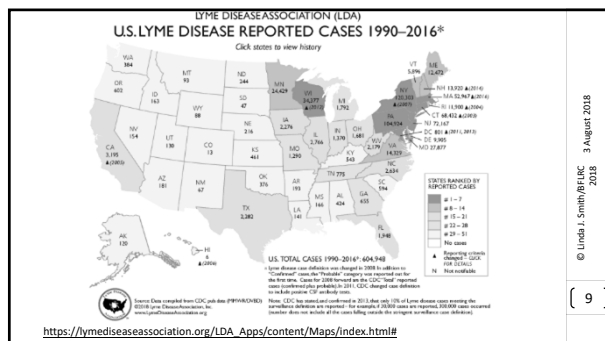


1 dot placed randomly within county of residence for each confirmed case

<https://www.cdc.gov/lyme/stats/maps.html> Reported cases in 2016

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Lyme & Tick-borne Diseases

You get them from a tick bite, but

- Fewer than 50% remember a tick bite
- Not everyone gets a "bull's eye" rash or any noticeable rash
 - The rash is diagnostic, IF it is recognized
 - In some studies, < 9% get a bulls-eye rash
- If you do get a tick bite and a rash, you almost certainly have Lyme and need treatment
- Children can be infected within minutes of a tick bite

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Spirochetes - *Borrelia burgdorferi* the cause of Lyme disease

Spirochete with blebs
(blebs contain proteins which can over-stimulate the immune system)

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Ticks

Deer tick – carries Lyme
Ixodes scapularis
Note: only larvae have 6 legs, all others have 8 legs

Shown approximately relative in size

Sesame seed

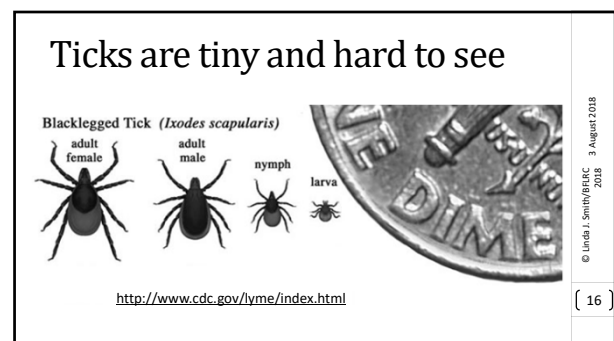
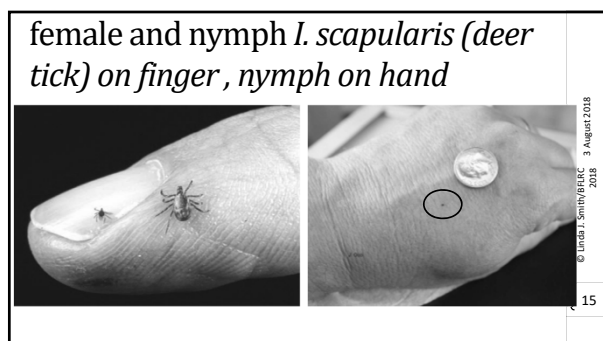
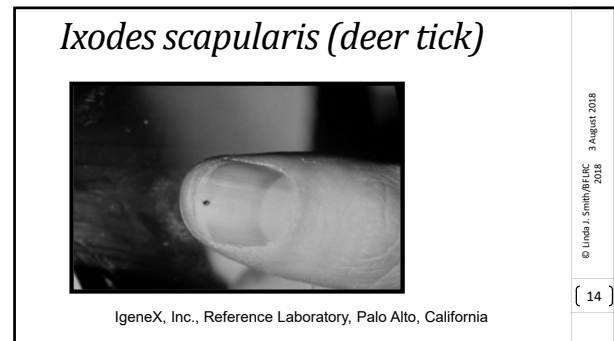
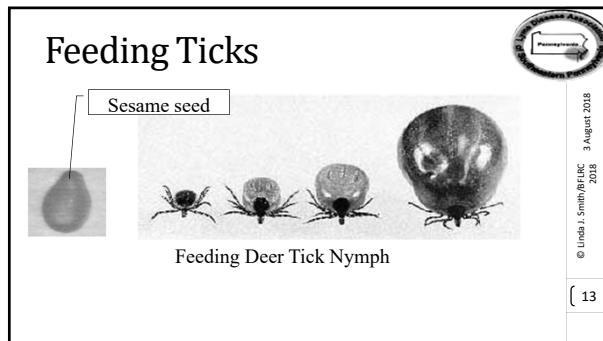
Poppy seed

American dog tick - RMSF
Dermacentor variabilis

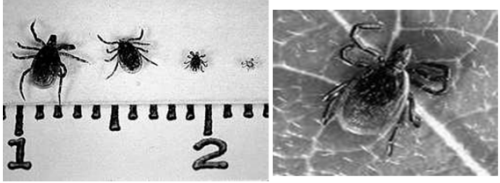
Lone star tick – carries STARI
Amblyomma americanum

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Black Legged Tick



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Proper Tick Removal




- Always use clean tweezers or tick removal tool.
- Grasp the tick as close to the skin as possible.
- While holding the area steady, pull the tick upward away from the skin with one slow steady motion.
- Never use anything to upset the tick so it regurgitates (alcohol, Vaseline, hot match etc.) this can force spirochetes into the bite!

It is difficult if not impossible to determine a point in time at which there is zero risk of transmission in a tick attachment

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Tick Removal Tools



In all cases, after the tick is secured, lift slowly away from the skin until the tick comes free. | Some require twisting slowly to remove the tick.

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YOU REALLY ARE SICK

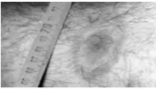
- **Lyme disease is a bacterial infection**
 - Can be transmitted during pregnancy and sexually
- Co-infections are common
- **Lyme disease is treatable**
 - Antibiotics – the right ones and long enough
 - Oral AND intravenous may be necessary
- Untreated Lyme = serious, even lethal consequences

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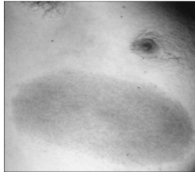
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Rashes – You may not get one

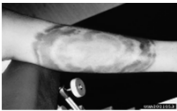
Classic Bull's Eye



Large rash on Chest



Large rash on Arm



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You Might Not See It




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Erythema Migrans could be big

Patina

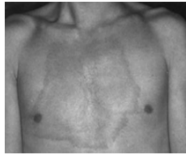
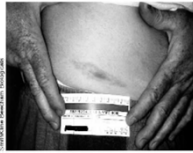


Large rash with gradual change of color intensity

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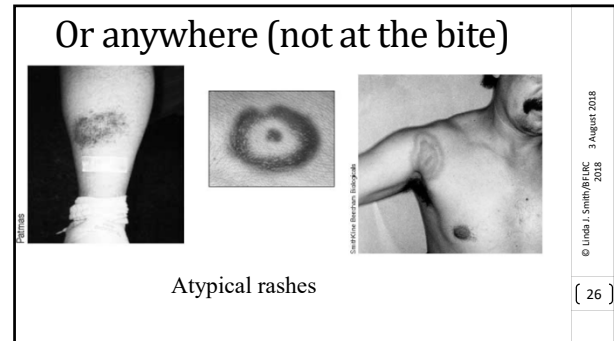
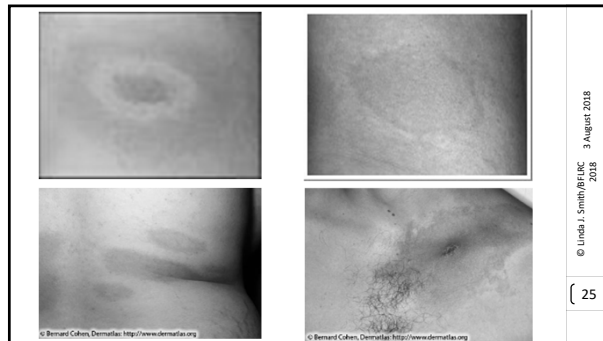
Or irregular



Not always circular!

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Coinfections
You can also get these from a Tick Bite

- **Babesiosis**
 - A protozoan infection much like Malaria
 - Requires special anti-malarial drugs
- **Bartonella**
 - requires different antibiotics than those commonly used for Lyme
 - Also called "cat scratch disease," but seems to be much worse from a tick bite
 - Has become common in our area
 - Rashes may look like stretch marks
- **Anaplasma & Rocky Mountain Spotted Fever**
 - Both respond well to doxycycline, but can be difficult to control if you also have Lyme

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Acorns, mice and Lyme disease

- "Acorns are a key food for white-footed mice. The mice are key predators on Gypsy Moth pupae. When there are many acorns the mouse population increases, which keeps the moth population low. However if there are no acorns, the mouse population collapses allowing the moth population to increase.
- Acorns also attract white-tailed deer into oak forests to feed on acorns. The deer carry adult ticks that drop off and spend the winter in the oak forests.
- The next year the female ticks lay eggs that hatch into larval ticks. The larval ticks are not infected with the bacteria that cause Lyme disease, but become infected when they feed on the mice that have increased because of acorns.
- This means that the risk of Lyme disease can be higher in oak forests two years after a large acorn crop.
 - <http://www.caryinstitute.org/science-program/research-projects/acorn-connections>

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Tests for Lyme Disease

Tests only serve to support a clinical diagnosis

- ELISA (Lyme titer)
 - overall measure of **antibody** level - neither sensitive nor selective (30-60% accurate at best)
- Western blot
 - very specific and reasonably sensitive - best **antibody** test (can be 85% accurate if rational criteria used, not CDC reporting criteria)
- PCR (DNA test) [Polymerase Chain Reaction]
 - **Direct detection** test (not antibodies)
 - **Absolute when positive**, negative means none detected in the sample, repeat testing sometimes used

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Clinical Diagnosis – Not Easy

- Similar symptoms can arise from different conditions
 - Many tick-borne diseases
 - Multiple sclerosis
 - ALS
 - Fibromyalgia
 - Chronic Fatigue Syndrome

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LABS: Can't always Believe a Negative

Two-tier

- fails to detect up to 44% of cases
- does not distinguish between acute, chronic, or resolved infection.¹⁵

56 published articles documenting seronegative Lyme disease¹⁶

<https://www.igenex.com/> - ACCURATE TESTING

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Acute Lyme is usually Recognized

- The well documented clinical picture, of embedded tick bite is generally recognized by most alert physicians in Lyme-endemic areas:
 - “bulls-eye” rash *erythema migrans*
 - flu
 - fever
 - Fatigue
 - mild arthritis
 - transient neurological symptoms

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Chronic Lyme Disease (Lyme Borreliosis Complex (LBC)) IS NOT RECOGNIZED

- Both the diagnosis and the treatment of what has been designated as “chronic” or “persistent” Lyme Disease (with/without co-infection), needs to be recognized.
- This possible multi-organism condition, often from an unsuspected tick-bite, is a complex and potentially serious illness.

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Medical Merry-Go-Round!!

The mystified patient may have visited a merry-go-round, of no less than half a dozen or more unsuspecting physicians and specialists.

This can go on for YEARS before the person is accurately diagnosed.

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Frustration!

- Often in frustration, the concerned physician wishing to put diagnostic closure, on those diverse symptoms ,will attach various descriptive labels to fit the un-well patient.
- Fibromyalgia, chronic fatigue syndrome, chronic viral syndrome, depression, stress or seasonal disorder with migraine headaches.

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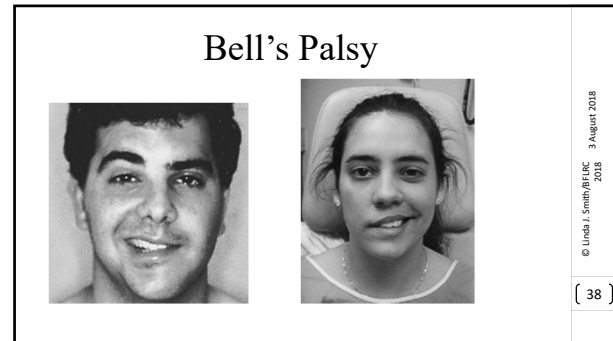
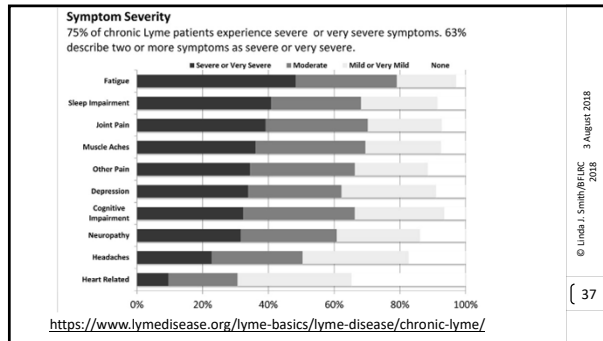
Clinical Overview of Persistent Lyme

MAJOR Sx CATEGORIES

- CNS – Cognitive, Psychiatric, Sleep Disorders, Cranial Neuropathies, Inflammatory Encephalopathy, Sensory
- Peripheral Nervous System – Mononeuritis multiplex
 - (extremities, thoracoabdominal, pelvic), MS like state, ALS like state
- Musculoskeletal – Migratory arthralgias/arthritis
- Immune Dysfunction Syndrome – Fibromyalgia
- Cardiovascular – Arrhythmias, Myocarditis, Heart Block, Pericarditis
- Dermatologic – Acrodermatitis Chronica Atrophicans (ACA), broad range of EM and non specific rashes on or off antibiotic therapy

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- Musculoskeletal Sx in Persistent Lyme**
- Migratory pattern most common
 - May affect large or small joints
 - May lead to joint replacement – LD seldom suspected – peculiar ropy fibrinous material
 - Pre-tibial tendonitis/bone pain reported
 - Plantar fasciitis syndrome reported
 - Poorly responsive to NSAIDS, DMARDS
 - Limited Bb quantities in tissue – difficult to recover by PCR
 - Occasional coexisting RA syndrome - ? causal effect
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- Cardiovascular Sx in Persistent Lyme**
- Arrhythmias – unexplained tachycardia most common – Hx of thorough W/Us – respond to Rx
 - Myocarditis – probably under reported – rarely serious
 - A-V Conduction Disturbances – classic late complication, occasionally requiring pacemaker
 - Pericarditis – usually mild and often misdiagnosed – can present as frequent effusions
 - Vasodepressor syncope
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Immune Dysfunction Syndrome

- Fatigue Sx universal in Persistent Bb, often debilitating
- Testing of classic IDS patients leads to high yield of laboratory + LD - ? Implications
- Fibromyalgia a common accompaniment, occasionally the major Sx
- IDS associated with LD will respond to Rx, but recovery may take months or years and is usually the last Sx complex to resolve
- Rx of sleep and pain disorders paramount
- Role of endocrinopathies probable but not defined
- Likely cause of IDS in this setting – chronic immune activation due to unresolved Bb infection – abnormal cytokine profile documented in IDS
- **NEVER GIVE STEROIDS IF LYME IS PRESENT or suspected**

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Immune Dysfunction Syndrome in LBC, Cont.

Key distinctions between persistent LBC and classic IDS (CFIDS), even where Bb is a contributing cause for IDS, have to do with the presence or history of clinically significant neurologic Sx and/or joint pain or arthritis in these LBC cases.

Other debilitating Sx such as cognitive dysfunction, CNS irritability, and Fibromyalgia are common to both syndromes, likely due to a similar etiology which is dysregulation of the immune system

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Central Nervous System Excluded As Producing Legitimate Symptoms:

'The neurological, neuroendocrine, neuropsychiatric and neurocognitive sequelae of "chronic, persistent Lyme" are almost always overlooked.'

Bernard Raxlen, MD. Psychiatrist

"You're not crazy – you're SICK."

-physician treating my sister after 4 years of undiagnosed Lyme

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Neuropsychiatric Symptoms

- Panic attack, long lasting
- Mood disorders: irritability, rage response, violence
- Manic or psychotic episodes
- OCD: children and Adults
- Eating Disorders
- Depression
- Self destructive behavior
- ? Autism -Dr Jones

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Neuropsychiatric Symptoms

- Cognitive Overload: short circuiting, confusion, loose focus
- Brain Fog: lack of clarity, depersonalization, derealization, loss of self and place
- Sensory hyper acuity to light and sound (sunglasses, earplugs, indoors)
- Spatial Orientation: lost in a familiar place, bump into objects
- Speech and Fluency: word search, stutter
- Demyelinating like symptoms: MS, ALS

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YOU REALLY ARE SICK

- **Lyme disease is a bacterial infection**
 - Can be transmitted during pregnancy and sexually
 - Co-infections are common
- **Lyme disease is treatable**
 - Antibiotics – the right ones and long enough
 - Oral AND intravenous may be necessary
 - Untreated Lyme =serious, even lethal consequences

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The IDSA disagrees with ILADS

- The Infectious Disease Society of America has issued guidelines for Lyme disease which make it difficult for you to be diagnosed or treated for Lyme disease
- International Lyme And Associated Diseases Society issues evidence-based guidelines for diagnosis and treatment
- <http://www.ilads.org/>

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The IDSA disagrees with ILADS

Health insurance companies and HMOs are denying treatment based on the IDSA guidelines

Doctors who treat Lyme successfully are being taken to court for "over-treatment"

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Lyme Protests - worldwide
<https://www.facebook.com/worldwidelymeprotest>



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Treatment: Early Lyme- ILADS

Optimal dose and duration of therapy
Has not been standardized
Benefit-increased dosages
Benefit- longer treatment, similar to TB and leprosy...similarly slow-growing pathogens.
Some Clinicians recommend ...higher daily doses

Amoxicillin 3,000–6,000 mg
Doxycycline 300–400 mg
Azithromycin 500–600 mg.

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Treatment: Late Lyme-ILADS

The duration of therapy should be guided by clinical response

The practice of stopping antibiotics to allow for delayed recovery is not recommended for persistent Lyme disease. In these cases, it is reasonable to continue treatment for several months after clinical and laboratory abnormalities have begun to resolve and symptoms have disappeared.²⁰

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To Be Safe, Avoid ticks



- Recognize the ticks
 - The deer tick nymph is the most dangerous because it is so small, very active and will bite anything for a blood meal
- Avoid ticks – cut the lawn
 - stay out of edges of woods and shrubbery
 - avoid mulch, especially where mice live
 - wood chips better than shredded bark or roots
- Use repellents before going out
- Check for ticks **during** every outing
 - Use a wash cloth when showering

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Protect Yourself

- Dress for protection
 - physical
 - Light colors - long pants
 - Special socks best - pulled over pants/cuffs
 - chemical
 - DEET (works by vapors) - 25 -35% spray on skin (adults) & **clothing** (10% maximum for children) ["Off, Sawyer's"]
 - Permethrin (works by contact) spray on **clothing** [Permanone] (Get it at sporting goods stores)
 - Never on skin!
 - lasts 2-4 weeks through several washes



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Helpful Tips

- Records of your symptoms are most important
- Get copies of all test results – they are your tests, not the doctor's. Do it every office visit.
- Prepare **carefully** and **thoroughly** for the office visit
 - Bring written notes and calendar record of symptoms (examples on our web site www.Lymepa.org)
 - Bring a list of medications to give to the doctor
 - Bring written questions you want answered
 - Don't leave until all your questions are answered and you have written your notes on the answers
 - If necessary, bring your spouse or a close friend to help with the notes
 - Bring past notes for reference & read them before the visit

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Review of Lyme

- Multisystem disease
- Transmitted by deer ticks
- Caused by a spirochete
- Affects every system especially the neurological, musculoskeletal and cardiac
- Can be seronegative
- Treat with antibiotic and consider co-infections, persistence infections and other diseases if symptoms continue

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Perinatal Lyme Disease What We Know & What We Don't Know

Perinatal issues - overview

- Sexual transmission male ↔ female
- Diagnosis / signs of infection in pregnant women
 - Consequences of undiagnosed / untreated Lyme in pregnancy
- Transmission to fetus/baby during pregnancy
- Congenital Lyme infections in infants
 - Signs/symptoms
 - Treatment
 - Consequences of undiagnosed / untreated Lyme in children

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Lyme Acts Like syphilis

- Almost certainly transmitted sexually
 - Many hard-to-refute case reports
 - Little documentation & research on humans
- Documented transmission via placenta
 - CDC: MMWR 1985
 - "Lyme disease acquired during pregnancy may lead to infection of the placenta and possible stillbirth; however, no negative effects on the fetus have been found when the mother receives appropriate antibiotic treatment."
 - "There are no reports of Lyme disease transmission from breast milk. <http://www.cdc.gov/lyme/Transmission/>"

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During Pregnancy

- Documented transmission via placenta
- CDC: MMWR 1985
- "Lyme disease acquired during pregnancy may lead to infection of the placenta and possible stillbirth;
 - however, no negative effects on the fetus have been found *when the mother receives appropriate antibiotic treatment.*"
 - "There are no reports of Lyme disease transmission from breast milk." <http://www.cdc.gov/lyme/Transmission/>
 - Key point: "mother receives appropriate antibiotic treatment"
- Documented transmission to baby/fetus
 - Congenital Lyme

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Recognize Lyme & Treat Mother

- Take a thorough history
- Investigate suspicious or confusing symptoms
- Find and work with a Lyme-literate physician (LLMD)
 - www.lymediseaseassociation.org
 - <http://www.drjoneskids.com/doctor-referrals/lyme-literate-websites>
 - Consider high likelihood of co-infections
- Treat mom with enough antibiotics and LONG enough!!!
 - Multiple antibiotics often needed
 - Two months after all symptoms are gone
 - AND she believes all infections are gone
- Do NOT stop treatment and "wait & see"

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Retrospective Study:

Gestational Lyme Disease Case Studies of 102 Live Births

by Charles Ray Jones, MD, Harold Smith, MD, Edina Gibb, Lorraine Johnson, JD, MBA

- From the *Lyme Times*- California Lyme Disease Association (CALDA) 2005
- <http://www.lymedisease.org/>

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Methods:

- 102 case studies of children with gestational Lyme
- Diagnosis was clinical: based on history and physical
- Lab results were used only to support clinical diagnosis or to help describe the study population
- Children in the study were typically diagnosed between 1 and 5 years of age.

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Study population:

- All mothers in the study had either untreated or partially treated Lyme
- 16% had been treated prior to pregnancy
- Some bitten by tick during pregnancy, some prior
- Majority of mothers diagnosed prior to the child's diagnosis
- 66% reported a difficult pregnancy
- Many mothers had Lyme symptoms that continued beyond the pregnancy
- 41% breast fed
- A number of the children had subsequent tick bites after diagnosed with congenital Lyme
- A number had tick-borne co-infections
- All children in the study improved with appropriate antibiotics

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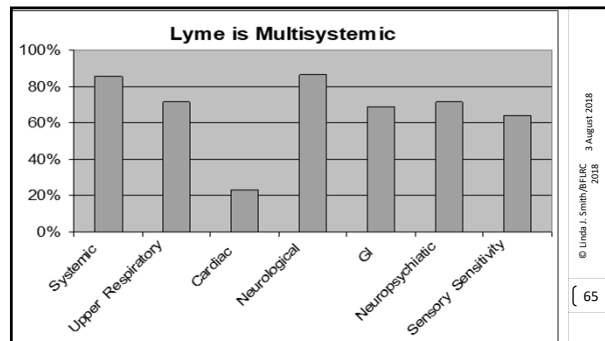
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Most common sx's and sx's of gestational Lyme include:

- 90% Hypotonia**
- 80% Irritability* (The irritability referred to here is a persistent irritability associated with impulsivity)
 - 80% Cognitive problems including learning disabilities and mood swings
 - 72% Fatigue and lack of stamina
 - 69% Pain
 - 60% Low grade fevers, pallor, sickly, and dark circles under eyes
 - 50% Arthritis or painful joints (stiffness or decreased ROM)
 - 45% Unspecified rashes
 - 40% GERD and vomiting with coughing (nausea, diarrhea, constipation, abdominal pain)
 - 40% Frequent URI and otitis
 - 40% Noise, light, and skin sensitivity
 - 30% Eye problems (cataracts, myopia, astigmatism, conjunctival erythema (Lyme eyes), optic nerve atrophy, optic neuritis, uveitis)
 - 30% Developmental delay including language and speech problems
 - 30% Cavernous hemangiomas (dilated bvs especially in brain but can be anywhere, can be asx or sx)
 - 23% Secondary Lyme rashes
 - 23% Night sweats
 - 23% General muscle pain or spasms
 - 23% Cardiac abnormalities (palpitations, PVCs, murmurs, mitral valve prolapse, etc.)

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Hypotonia

Tone: A normal tension or responsiveness. In muscles, normal tone is a constant slight contraction that helps maintain posture and coordination.

Hypotonia:

- Present in over 90% of the cases of gestational Lyme
- Children described as floppy, limp, rag dolls, or pillows full of pudding.
- Variety of possible causes
- In Lyme, Bb is thought to impede sensory input or the activation of muscle or other functions, or directly impact the cerebellum.
- Features of hypotonia:
 - Arms and legs hang by sides
 - Decreased DTRs
 - Little resistance to passive motion
 - Decreased muscle tone
 - Delay in gross and fine motor skills
 - Excess flexibility
 - Drooling
 - Speech difficulties due to decreased muscle strength
 - Rounded shoulders
 - Leaning

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Persistent irritability associated with **impulsivity** is present in @ 80% of cases.

This irritability is not garden-variety crabbiness that may accompany long-term illness. Rather, this is a persistent irritation that often accompanies impulsive acts. While this irritability is improved with appropriate treatment, the impulsivity may never completely resolve. The irritation may result from the frustration associated with the impatience and impulsivity.

Features:

- Acts without thinking
- Does not think things through
- Takes unnecessary risks
- Short fuse
- Can't wait for turn
- Blurts
- Says the wrong thing
- Interrupts
- Intrudes
- Emotional liability

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Additional study results from the retrospective study:

Results of lab tests:

ELISA	25 % positive
Western blot	58 %
Bb culture	37 %
PCR (urine)	4 %
PCR (blood)	7 %

The testing most correlated with a diagnosis of congenital Lyme was neuropsychological evaluations with 80% confirming suspected cognitive problems.

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Additional study results from the retrospective study:

Rate of co-infections:

Strep	7 %
Leptospirosis	5 %
Fungus or yeast	4 %
Ehrlichiosis	6 %
Babesiosis	14 %

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There are two treatment considerations in these cases:

1. If the mother has Lyme disease, she needs to be treated in a way that gives the best chance of protecting the fetus from contracting the infection.
2. If born with congenital Lyme, the neonate must be treated to give the best chance to eliminate the infection and reduce the potential for long-term damage.

In both cases, antibiotics must be selected that will hit both the active and dormant states of the Bb and will not cause damage to the developing fetus or newborn.

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Treatment of the pregnant woman with Lyme:

- A Lyme pregnancy registry was maintained for a number of years
- If the Lyme-infected mother was on adequate doses of antibiotic therapy during gestation then NO babies were born with Lyme
 - mother treated with 2 antibiotics... NO Lyme babies
 - mother treated with 1 antibiotic ... ~25% Lyme babies
 - mother not treated with antibiotics... ~50% Lyme babies
- Unfortunately, many cases are not recognized or are undertreated

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Oral options:

Amoxil (amoxicillin) 1000 mg q 8, OR
Ceftin (cefuroxime) 100 q 12, OR
Omnicef (cefdinir) 300 to 600 mg bid

PLUS

Zithromax (azithromycin) 500 mg bid

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Parenteral options:

In mothers who are very ill or who can't tolerate or achieve adequate levels with oral medications, consider:

- Benzathine PNC (Bicillin): 1.2 million units IM 1 to 3 times a week
- Ceftriaxone (Rocephin): 2 g IV daily
- Cefotaxime (Claforan): 6 g daily either continuous infusions or as 2 g IV q 8

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After birth, the maternal Lyme may no longer be mollified by the pregnancy hormones and symptoms may return in full force. There may be profound fatigue and these women may need additional help post-partum.

Continue to treat the mother's Lyme as appropriate.

Breast feeding can ONLY proceed in actively ill Lyme patients IF the mother is on appropriate antibiotics, since live spirochetes have been isolated from breast milk.*

NOTE: I have found NO documentation of isolation of live spirochetes in breastmilk after nearly 9 years of searching for evidence. LJS, September 2018

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Treatment of the neonate with congenital Lyme:

- Have a high index of suspicion
- Although only subtle symptoms may be present at birth, **SERIOUS NEUROLOGIC SEQUALAE** may result if not promptly diagnosed and treated.
- These problems can be severe and debilitating.
- Patients often have entrenched and chronic Bb neurologic manifestations by the time the diagnosis is made.
- Kids do well if treatment is aggressive and for sufficient duration.
- Some patients respond and have a disease-free period and think the disease is gone, only to recur. Recurrence could be due to a new bite or flare of old disease. Retreat.

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Treatment options for the child with gestational Lyme:

Combination of PCNs, CSs, and macrolides.

TCNs are not usually used in children under 8.

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If you are unsure whether to treat a mother or child:

Gardner: 1995 study of Lyme disease of the fetus and newborn: 161 cases

In mother with active Lyme:

- Treated with antibiotics: 85 % of the neonates were normal (15% abnormal)
- No antibiotics: 33 % of the neonates were normal (67% abnormal)

Many of these untoward events were significant including miscarriage, stillbirth, perinatal death, congenital anomalies, sepsis, or chronic progressive infection.

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In 1989, Alan MacDonald documented the adverse outcomes in cases of Lyme infection during pregnancy. These adverse events were found to occur irrespective of trimester of initial infection and appear to be in excess of adverse outcomes compared to what is observed in matching uninfected populations.

Untoward outcomes documented in Lyme infected mothers:

Prematurity	Hydrocephalus
Blindness	SIDS
Toxemia	Fetal death
CVS anomalies	Growth retardation
Respiratory distress	Hyperbilirubinemia

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Confounders in recognizing congenital Lyme

- May be asymptomatic at birth
- First signs and symptoms may be delayed for varying periods causing the mother's Lyme during pregnancy to be forgotten
- When sxs noted, commonly overlooked or attributed to something else
- Signs and symptoms may mimic other conditions leading to misdiagnosis
- Co-morbidities are common
- Manifestations may affect multiple systems leading to pursuing wrong leads
- Symptoms may wax, wane, and change with varying degrees of severity
- Difficulty in gathering supportive laboratory data (many false negatives)
- Negative lab results do not rule out the disease
- Mother may have Lyme but if not currently active, may not know the child is at risk
- In general, the longer the child goes without appropriate diagnosis, the more severe and complicated the clinical course

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Interesting questions:

1. Does Bb affect the genetic material of the fetus?
2. What happens to the fetus if the spirochete causes teratogenic effects during organogenesis?
3. Does infection in the father matter?

Answers:

We aren't sure.

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Acknowledgements:

Eva Sapi, PhD, University of New Haven, Connecticut
Phyllis Mervine, CALDA, www.lymedisease.org
Lyme Disease Foundation, Hartford, Connecticut
Harold Smith, MD
Edina Gibb
Joseph J. Burrascano Jr., MD
Lorraine Johnson, JD, MBA, Gestational Lyme Bibliography, CALDA,
www.lymedisease.org
Dr. Kathy Spreen, MS, MPH, co-author of *A Thousand Pearls* Charles Ray Jones'
Compendium of Pediatric Tick-Borne Disease

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Unanswered question #1

- Does the Lyme spirochete survive in infectious form in human milk?
- Lawrence & Lawrence:
 - "Little published information exists on whether *B. burgdorferi* can be transmitted via breastmilk. "
 - "The lack of adequate information on transmission of *B. burgdorferi* via breastmilk cannot be taken as proof that it is not occurring. ... discuss with parents or the mother whether to continue or withhold breastfeeding ... "doxycycline should not be administered for >14 days while continuing breastfeeding because of possible dental staining in the neonate." (p. 462, *BF: A Guide for the Medical Profession* 8th edition)

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Unanswered question #2

- Who "isolated live spirochetes from breast milk," when and where?
- Phone Interview with Dr. Jones, March 18, 2012:
 - Anecdotal reports including Dr. Alan MacDonald
 - Lida Mattman: reported to have found cyst and cell-wall-deficient forms of *B. burgdorferi* in breastmilk. ("Cell Wall Deficient Forms," 1974, 2001) - no reference was found in this book
 - Dr. Jones: *B. burgdorferi* has more potential to mutate into other forms (cell-wall deficient L-form or cysts) to avoid immune mechanism
- "Absence of proof does not equal proof of absence"

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More questions...

- HMBANA: Almost certainly NO because the spirochete is not lipophilic
 - Only fat-soluble compounds can move across the lactocyte's phospholipid cell wall and therefore enter the milk
- Hale: even if bacteria (including spirochetes) appear in milk, few (if any) organisms survive in intact (infectious) form
- No conclusive research evidence to date to confirm or refute passage in infectious form into milk

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Dr. Jones' recommendations

- Consider Lyme
- Treat mothers aggressively during pregnancy
 - High rates of prematurity, pre-eclampsia
- 5-7% of congenitally infected have permanent damage
- Hypotonia is #1 symptom – floppy baby
 - Hypersensitive to sound, skin, light, probably has headaches
 - They don't feed well, don't sleep well
 - Unhappy, can't get comfortable – probably in pain
 - "Child from Hell"
- Geographic – live in endemic area
 - History of Lyme or tick bite in ANYONE in family or Pets
 - Call local DVM - # animals with TBD's in the neighborhood

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Dr. Jones, cont:

- Any household with a pet having Lyme probably has 1-2 people with Lyme
- Genetic potential: Some people have pheromones that attract insects including ticks
- Children born with congenital Lyme do better than those bitten in first year, regardless of feeding method
- Children bitten in 1st year get very sick (↓ immune response)
- Children with recurrent Strep – investigate for Lyme
- Ticks carry BB in salivary glands – infect in minutes or even quicker in small children – can attach & fall off quickly
- Treatment may take 3-7 years
- Treat for 2 months after all SX resolve **and** child feels Lyme is gone
- LYME IS TREATABLE!

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Dr. Anne Eglash, Wisconsin

- **"There are no known case reports of infant or child Lyme disease thru breastfeeding.**
- As a family physician I work in a region endemic with tick borne illnesses including Lyme, anaplasma, and babesiosis.
- These occur anytime the ground is not frozen, so spring summer and fall. I also direct the University's lactation clinic in the same region.
- **In 25 years I have not seen a tick borne illness occurring via breastmilk or breastfeeding.**
- Anaplasma/ehrlichiosis is as prevalent as Lyme; also Rocky Mountain Spotted Fever." (personal correspondence, 3/31/2018)

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Dr. Tina Smillie, MD

- "I'm also in an endemic area, near Lyme CT for which it's named.
- No new evidence of any vertical transmission ever. EVER.
- There is a difference between finding DNA by PCR in 2 women's breastmilk 25 years ago and finding a motile spirochete in milk.
- DNA does not equal infectious bacterium, is merely another marker for maternal infection, and says nothing about the infectivity of the milk, and there are zero reports of motile spirochetes in breastmilk."
- (April 1, 2018, personal communication)

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Summary: what we know

- Lyme is probably transmitted sexually male ↔ female
- Getting an accurate diagnosis & adequate treatment can be challenging, frustrating, and expensive
- Lyme can be transmitted to the fetus/baby during pregnancy
 - Stillbirths, congenital malformations, prematurity, preeclampsia
- Congenital Lyme infection in newborns is documented
 - #1 symptom is hypotonia
- Pregnant women can and should be treated thoroughly
- Infants and children can be treated successfully
 - Successful treatment can take 3-7 years
- Untreated children can have severe consequences
- Delays and under-treatment have devastating consequences

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Summary: what we don't know

- Whether *Borrelia burgdorferi* survives in infectious form in breastmilk (CDC says no)
- Whether *B. burgdorferi* is capable of infecting the infant through breastfeeding (probably not)
- Why ISDA guidelines ignore strong evidence of chronic Lyme and recommend inadequate treatment
- Why many Lyme cases are not tracked by the CDC, even though CDC states "Lyme disease is the most commonly reported vectorborne illness in the United States. In 2014, it was the fifth most common Nationally Notifiable disease."

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Recommendations

- Take Lyme seriously!
 - Read Lyme books, join Lyme e-lists and organizations
 - Make Lyme information available to pregnant women & families
- Show the documentary "Under Our Skin" to anyone who will watch it
- Document what you are finding in YOUR practice
 - To the CDC and national health authorities
 - To Local Health Departments
 - In your / your institution's charting /health records
- Talk to infectious disease & public health professionals
- Consider doing your OWN research: even case reports matter
- Stay in touch – I'm still researching this topic!!

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THANK YOU!

- Dr. Kenneth Singleton, MD, MPH and Ursuline Singleton, RD/LD, IBCLC
 - Dr. Charles Ray Jones, MD
 - Open Eye Pictures – “Under Our Skin” (DVD) <http://underourskin.com>
 - Nancy Dahlstrom, MFA
 - www.ilads.org
 - www.lymediseaseassociation.org
 - www.lymeinfo.net
 - www.ilads.org
 - And many others...
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