

Its Lyme Time!

Protect Yourself Against Lyme Disease-

There are 4 ticks like this • hiding in this picture. Can you find them?

(Hint: Check clothing and tips of blades of grass.)

1 Walk in the middle of trails, away from tall grass and bushes.

2 Wear long sleeved shirt.

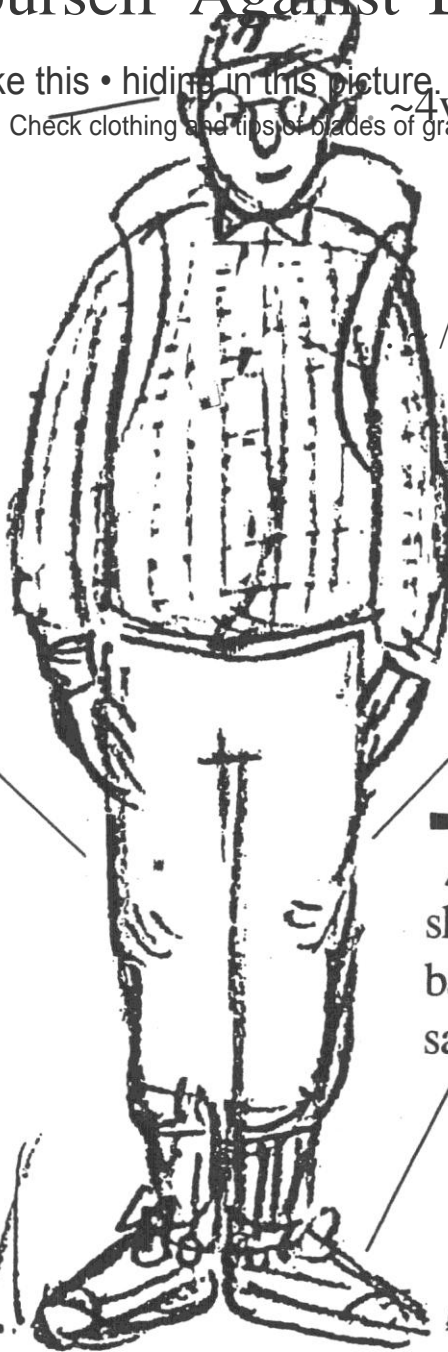
3 Wear white or light-colored clothing to make it easier to see ticks.

4 Wear hat.

5 Spray tick repellent on clothes and shoes before entering woods.

6 Wear long pants tucked into high socks.

7 Wear shoes—no bare feet or sandals.



Lyme disease, the most common tick-borne disorder in the US, can affect the skin, joints, nervous system, heart, and eyes. Lyme disease is transmitted by a tiny tick the size of the period at the end of this sentence.

From the National Institutes of Health Healthline.

1. Lyme disease is transmitted by the bite of a tick, and the disease is prevalent across the United States and throughout the world. Ticks know no borders and respect no boundaries. A patient's county of residence does not accurately reflect his or her Lyme disease risk because people travel, pets travel, and ticks travel. This creates a dynamic situation with many opportunities for exposure to Lyme disease for each individual.

2. Lyme disease is a clinical diagnosis. The disease is caused by a spiral-shaped bacteria (spirochete) called *Borrelia burgdorferi*. The Lyme spirochete can cause infection of multiple organs and produce a wide range of symptoms. Case reports in the medical literature document the protean manifestations of Lyme disease, and familiarity with its varied presentations is key to recognizing disseminated disease.

3. Fewer than 50% of patients with Lyme disease recall a tick bite. In some studies this number is as low as 15% in culture-proven infection with the Lyme spirochete.

4. Fewer than 50% of patients with Lyme disease recall any rash. Although the erythema migrans (EM) or "bull's-eye" rash is considered classic, it is not the most common dermatologic manifestation of early-localized Lyme infection. Atypical forms of this rash are seen far more commonly. It is important to know that the EM rash is pathognomonic of Lyme disease and requires no further verification prior to starting an appropriate course of antibiotic therapy.

5. The Centers for Disease Control and Prevention (eDC) surveillance criteria for Lyme disease were devised to track a narrow band of cases for epidemiologic purposes. As stated on the CDC website, the surveillance criteria were never intended to be used as diagnostic criteria, nor were they meant to define the entire scope of Lyme disease.

6. The ELISA screening test is unreliable. The test misses 35% of culture proven Lyme disease (only 65% sensitivity) and is unacceptable as the first step of

a two-step screening protocol. By definition, a screening test should have at least 95% sensitivity.

7. Of patients with acute culture-proven Lyme disease, 20-30% remain seronegative on serial Western Blot sampling. Antibody titers also appear to decline over time; thus while the Western Blot may remain positive for months, it may not always be sensitive enough to detect chronic infection with the Lyme spirochete. For "epidemiological purposes" the CDC eliminated from the Western Blot analysis the reading of bands 31 and 34. These bands are so specific to *Borrelia burgdorferi* that they were chosen for vaccine development. Since a vaccine for Lyme disease is currently unavailable, however, a positive 31 or 34 band is highly indicative of *Borrelia burgdorferi* exposure. Yet these bands are not reported in commercial Lyme tests.

8. When used as part of a diagnostic evaluation for Lyme disease, the Western Blot should be performed by a laboratory that reads and reports all of the bands related to *Borrelia burgdorferi*. Laboratories that use FDA approved kits (for instance, the Mardx Marblot~) are restricted from reporting all of the bands, as they must abide by the rules of the manufacturer. These rules are set up in accordance with the CDC's surveillance criteria and increase the risk of false-negative results. The commercial kits may be useful for surveillance purposes, but they offer too little information to be useful in patient management.

9. There are 5 Subspecies of *Borrelia burgdorferi*, over 100 strains in the US, and 300 strains worldwide. This diversity is thought to contribute to the antigenic variability of the spirochete and its ability to evade the immune system and antibiotic therapy, leading to chronic infection.

10. Testing for *Babesia*, *Anaplasma*, *Ehrlichia* and *Bartonella* (other tick -transmitted organisms) should be performed. The presence of co-infection with

these organisms points to probable infection with the Lyme spirochete as well. If these coinfections are left untreated, their continued presence increases morbidity and prevents successful treatment of Lyme disease.

11. A preponderance of evidence indicates that active ongoing spirochetal infection with or without other tick-borne coinfections is the cause of the persistent symptoms in chronic Lyme disease.

12. There has never been a study demonstrating that 30 days of antibiotic treatment cures chronic Lyme disease. However there is a plethora of documentation in the US and European medical literature demonstrating by histology and culture techniques that short courses of antibiotic treatment fail to eradicate the Lyme spirochete. Short treatment courses have resulted in upwards of a 40% relapse rate, especially if treatment is delayed.

13. Most cases of chronic Lyme disease require an extended course of antibiotic therapy to achieve symptomatic relief. The return of symptoms and evidence of the continued presence of *Borrelia burgdorferi* indicates the need for further treatment. The very real consequences of untreated chronic persistent Lyme infection far outweigh the potential consequences of long-term antibiotic therapy.

14. Many patients with chronic Lyme disease require treatment for 1-4 years, or until the patient is symptom-free. Relapses occur and maintenance antibiotics may be required. There are no tests currently available to prove that the organism is eradicated or that the patient with chronic Lyme disease is cured.

15. Like syphilis in the 19th century, Lyme disease has been called the great imitator and should be considered in the differential diagnosis of rheumatologic and neurologic conditions, as well as chronic fatigue syndrome, fibromyalgia, somatization disorder and any difficult-to-diagnose multi-system illness:

BE AWARE OF LYME DISEASE

It's usually caused by a tick bite.

The number of cases has increased tremendously in recent years.

People often have it for years without getting diagnosed correctly.

Prompt diagnosis and treatment gives the best chance for recovery.

It's treated with antibiotics, but the bacteria can be difficult to destroy.

Many people are getting Lyme disease in Kansas

Children play outside and are at special risk

The ticks that commonly bite people in Kansas are deer ticks (black-legged ticks) and lone star ticks (they have red or orange legs). 80% of these ticks cause Lyme disease. Lone star ticks also cause STARI (Master's disease), a Lyme-like illness that usually produces negative Lyme tests but needs to be treated as Lyme disease. Wood ticks also cause a Lyme-like illness. Ticks also cause ehrlichiosis and Rocky Mountain spotted fever in Kansas. These diseases can be fatal if not diagnosed and treated with the right antibiotic. Lyme disease, ehrlichiosis, and Rocky Mountain spotted fever can all cause meningitis, and diagnosing these diseases can be difficult.

LYME DISEASE SYMPTOMS

Early Stage

(Begins 2 to 32 days after the tick bite; may last 1- 2 weeks and may then go away)

(People may not get all these symptoms; some don't get this stage but get other symptoms later) An expanding red spot, which may clear in the center; other rashes; or no rash

Chills, with or without fever; stiff neck; headache; muscle pain; joint pains

Digestive problems, runny nose, sore throat, other flu-like symptoms

Late Stage

(If the early stage is untreated or inadequately treated, late stage symptoms may develop days, weeks, or years later)

Sudden onset of trouble learning, remembering, thinking, and concentrating

Personality change, depression, mood swings, psychiatric symptoms Chronic fatigue, sore muscles, chronic headache, chronic joint pain Pains that move from

joint to joint; Sudden, sharp, nerve pains

Heart problems; Ringing in ears, hearing loss

Vision problems, eye inflammation, floaters

Numbness, tingling, other neurological problems

Lyme disease can be mistaken for ADD, ADHD, autism, depression, psychiatric illnesses, drug abuse (in teen-agers), arthritis, Parkinson's, MS, ALS, fibromyalgia, chronic fatigue syndrome, Lupus, Alzheimer's, and Guillain-Barre syndrome.

*The Lyme Association of Greater Kansas City, Inc. provides information and services to people throughout Kansas, Missouri, and other states. For more information, contact LymeFight @aol.com or call (913) 438-5963 (GET-L YME).
www.LymeFight.info*

LYME DISEASE TESTS

The COC 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 both antibody tests. Many Lyme patients have poorly functioning immune systems and 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 often 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. A study found that about 36% of culture-proven cases remain negative on the Western Blot throughout the illness.

Medical Diagnostic Labs (MOL) at 2439 Kuser Rd., Hamilton, New Jersey 08690, phone 877269-0090, www.mdlab.com, has a Western blot test that can sometimes detect Lyme when other labs fail. MDL works with insurance companies.

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. They report that it detects 95% to 97% of cases, with fewer than 4% false positives. IGeneX doesn't work with insurance companies, but many people get out-of-network coverage. Their WB costs \$190 for both IgM and IgG, or \$95 for either one.

Interpreting the Western Blot

The COC 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.

Culture

The Lyme disease bacterium, *Borrelia burgdorferi*, is extremely difficult to grow in culture, so culture tests fail to detect many cases of Lyme disease.

Flow Cytometry Test

Central Florida Research Lab, 245 N. Seminole Ave., P.O. Box 559, Lake Alfred, FL 33850, 1863-956-3538, <http://centralfloridaresearch.com>, has a Flow Cytometry test that detects and measures the amount of antigen or spirochetes in the blood. As a direct detection test, it does not depend on the immune system to develop antibodies. It has found Lyme disease in patients that the Western blot has missed. However, if a person has only a few Lyme spirochetes in the blood and none in the small amount of blood sampled, the test can have a false negative. Central Florida Research lab takes Medicare and Medicaid and works with insurance companies, but it may be out-of-network. Their Flow Cytometry test costs \$300, or \$200 for people without insurance coverage.

CD-57 Test

Lyme patients typically have a very low CD-57 lymphocyte count. Quest Diagnostics has a CD-57 Flow Cytometry lymphocyte test at their lab in San Juan Capistrano, CA, phone 1-800-642-4657. It can be used to diagnose Lyme and to monitor treatment progress. Many insurance policies cover it.

LUAT Test

IGeneX has a Lyme Urine Antigen test (LUA T) that measures dead Lyme bacteria in the urine. It is most likely to be positive a few days after a person starts treatment, after the bacteria start dying.

PROPER TICK REMOVAL

The recommended way to remove an attached tick has changed in recent years. Now that many ticks carry Lyme disease bacteria in their guts, the old methods are no longer safe. Old methods inject germs into the bite site from the tick's gut and make disease more likely.

After a tick has been feeding for a few hours, it vomits germs from its gut into the bite site. It does this every few hours during several days of feeding. If the Lyme bacteria are in the gut, it can thus take several hours for a tick to transmit Lyme disease. Some ticks have germs in their saliva and can transmit Lyme and other diseases as soon as they bite. Remove ticks promptly, before they inject too many germs.

It is more important to remove a tick promptly than to get all the mouthparts out.

The safest way to remove a tick is to slide something under it.

DON'T USE: A hot match; Liquid soap; Nail polish; Alcohol; Other chemicals *These make the tick contract its body and vomit germs into the bite site.*

DON'T USE: Petroleum jelly or other products to try to smother the tick *Ticks don't need much air. These methods cause the tick to vomit germs.*

DON'T USE: Your fingers; Blunt tweezers

These can squeeze the tick's gut and squirt germs into the bite site.

DO USE: A tick remover that slides under the tick; A V-shaped slit cut into

a plastic card; Fine-pointed tweezers (for large ticks only)

How to use tweezers: Some drug stores sell fine-pointed tweezers. Grasp the tick as close to the mouth (the point of attachment) as possible. Pull the tick straight out, slowly. Don't squeeze the tick's gut (main body). It's hard to remove tiny ticks with tweezers without squeezing the gut. Researchers at Ohio State U. found that the Pro-Tick remover works better than tweezers for tiny nymphs and is more likely to remove all the mouthparts and cement. (When a tick bites, it injects "cement" to hold it in place for a few days. This cement can contain germs.)

How to use the Pro-Tick remover tool sold by the Lyme Assoc. of Greater Kansas City: Slide the V-shaped slit under the tick. Then tilt the tool upward so that the tips point up, at an angle, and lift the tool until the person's skin is lifted slightly. Wait a minute or 2 for the tick to release itself. If the tick does not pull itself out, you can lift it out, slowly. Don't push too hard against the tick with the V-shaped slot, or it could cut the tick's head off and leave mouthparts in the skin. Instead, lift the tick.

How to use a plastic card: Cut a V-shaped slit in the edge of an old credit card or library card. The slit should be short, about ~ inches, and narrow. Follow instructions in the paragraph above.

Pull the tick straight out. Don't twist it out. Twisting can cause mouthparts to break off and stay in the skin. A tick's mouth is shaped much like a pinecone, with barbs like a fishhook that hold its mouth in place. These barbs can break off. They are less likely to break if the tick removes itself.

What happens if mouthparts remain in the skin?

They may cause irritation. You can remove them with a sterile needle or have a doctor remove them. If they stay in the skin, they will work their way out in a few days, as the body continues to make new skin cells and shed old ones.

After removing a tick, disinfect the bite site and tool, and wash your hands with antibacterial soap.

After removing a tick, call your doctor. Some physicians prescribe antibiotics for tick bites; others wait to see if disease symptoms develop. ILADS (International Lyme and Associated Diseases Society) doctors recommend a minimum of 4-6 weeks of antibiotic treatment for an EM rash or other early symptoms of Lyme disease, because the disease can become chronic and disabling with shorter treatment courses. (See [www. ILADS.org](http://www.ILADS.org).) Lyme blood tests within a few days of a tick bite are usually negative, because it can take 4 to 6 weeks to develop antibodies. Many Lyme victims never test positive. Diagnosis is based on symptoms and exposure to ticks.

A camping first aid kit should include a tick removal tool, a needle, rubbing alcohol, cotton balls, antibacterial soap, and a small zipper bag or other container to save a tick for testing. You may want tape to seal the container securely. If you get covered with lots of crawling ticks, you can use alcohol, duct tape or other tape to remove the ticks before they attach themselves to your skin.

To buy a tick removal kit: Send a check for \$4 payable to "Lyme Association" to: Lyme Association of Kansas City, P.O. Box 25853, Overland Park, KS 66225. This tick removal kit contains a tick remover tool, instructions, 2 alcohol wipes, a tick identification card, and a tiny zipper bag to save the tick for testing.

You may want to save the tick for identification and testing. Tick tests for diseases, although not 100% reliable, are more accurate than human tests, which are not very reliable for tick-borne diseases. However, a tick can sometimes have a negative Lyme test and still be carrying Lyme disease. A positive test probably means the tick carries the disease, but it may not have transmitted it. If a tick is removed promptly and properly, it may not transmit a disease.

When you remove a tick, use a magnifying glass to look at the color of the legs. If the legs are black, it is a black-legged tick, also known as an Ixodes or deer tick. If the legs are red or orange, it is a lone star tick. Both can transmit Lyme disease, but lone star ticks often carry a strain that is more likely to produce negative antibody tests.

Ticks may be sent to be tested for diseases to: IGeneX Labs, Palo Alto, CA (800) 832-3200, www.igenex.com; MOL, Mt. Laurel, N.J. (877) 269-0090, www.mdllab.com; or NJ Labs, New Brunswick, NJ (732) 249-0148. Call for mailing instructions. They prefer live ticks but will test dead ticks. Don't kill it with alcohol, smash it, or bum it if you want it tested. Keep the tick moist in the container with a few blades of grass or a cotton ball dampened with water. (Doctors can send people's blood samples to IGeneX or MOL to test humans for these diseases.)

The cost of tick testing is:

IGeneX \$55 for Lyme, ehrlichia, babesia, or bartonella (4 X \$55 = \$220 if you want all 4).

If you are bitten by several ticks, they test up to 20 ticks for the price of one.

MOL \$155 for Lyme or ehrlichia, \$127 for babesia; bartonella testing is also available.

NJ Labs \$60 for Lyme, or \$175 if the tick has been dead over 2 weeks or killed with alcohol.

They don't test for co-infections, just Lyme.

If you prefer to dispose of the tick, you can kill it by putting it in a container and then adding rubbing alcohol, ammonia, or Windex. Flush it down the toilet, or put the dead tick in the trash.

Make Your Property Safe from Ticks

Ticks need to keep cool and moist. They like tall grass, damp piles of leaves, dense brush, and thick flower gardens. Wild animals can carry ticks into your yard. One tick can drop off a deer and lay thousands of eggs. If a female tick carries Lyme disease, some of the larvae may be born infected. Other larvae become infected by biting an infected rabbit, mouse, chipmunk, bird, or other small animal. The larva then molts into a nymph and gives the disease to the next animal or person it bites. Then it molts into an adult. Adult deer ticks and lone star ticks prefer to feed on deer, but they will bite another large animal or a human. Ticks remain attached and feed for several days. They don't jump or fly. They wait on plants or the tips of grass for a person or animal to brush past and then grab onto the host. Lone star ticks will crawl toward a host and sometimes drop from trees.

- Keep the lawn mowed, and allow it to dry between waterings.
- Put playground equipment in a sunny area away from trees and bushes.
- Keep clotheslines away from brush and shrubs.
- Clear away brush and leaf litter. Widen paths, so people won't brush against plants.
- Prune trees and bushes along walkways so people won't brush against them.
- Prune or remove trees to allow more sunlight into the yard.
- Feed birds only in winter, when they carry fewer ticks. They find seeds and insects in summer.
- Put wood chips or gravel around the perimeter of the yard, to make a barrier between the yard and the woods, so you won't brush against plants when mowing. Teach children (and pets, if possible) not to cross the barrier.
- Sprays containing permethrin are effective but toxic. Bayer Lawn and Garden Multi-Insect Killer, at 1-866- YARD IAC or www.yardiac.com, claims to kill ticks and to be safe, even on vegetables. Liquid garlic is another spray. Spray where ticks are, under bushes and the perimeter of the yard. Spraying the mowed part of the lawn may not be necessary.
- Buy Damminix Tubes at 1-617-742-2400 or www.Damminix.com, or put cotton balls soaked in permethrin and then dried, into toilet paper tubes or short pieces of plastic pipe, and lay them in gardens and brushy areas. Mice or chipmunks crawl into the tubes and take the cotton balls to their nests, where the permethrin kills ticks on the animals without harming them. This method may reduce the number of ticks by more than 90%.
- Some people buy Guinea hens to eat ticks. Some report great success, but others say they don't eat enough ticks. They are noisy; don't buy them if you have close neighbors.
 - Maxforce Bait Boxes can be installed by pest control companies in some parts of the U.S. They contain pesticide applicators that kill ticks on mice and chipmunks that rub against them.
- Buy a Biter Fighter tick and mosquito trap at www.amazon.com for \$67.47 or at Sam's Club.

Keep Wild Animals Out of the Yard

- Plant marigolds or other flowers and shrubs that animals don't like to eat.
- Rub Irish Spring soap on plants deer like to eat.
- Use animal repellents, such as deer and geese repellents sold by Yardiac, 1-866-YARDIAC.
- Don't have dense plants that small animals hide in, such as ivy, near the house.
- Eliminate bird feeders and birdbaths. Spilled birdseed attracts mice.
- Don't leave pet food outside overnight.
- Eliminate stone walls, or fill in spaces between stones, to keep small animals out.
- Keep wood piles away from the house. They attract small animals.
- Build a fence, 10 feet high if you are trying to keep out deer.
- Put garbage in plastic bags in a covered trash can, away from the house.
- Buy a 4-poster deer feeding station to kill ticks on deer on your property, if feeding deer is legal in your area. They are sold by the ALDF. See www.ALDF.com, email DavidLWeld@aldf.com, or write to: David L.Weld, ALDF, Mill Pond Offices, 293 Route 100, Somers, NY 10589.

Lyme Disease Prevention

- Wear light colored clothes to see ticks better.
- Wear shoes that cover the feet (no sandals), and socks.
- Wear long pants, tucked into your socks, and a long-sleeved shirt, tucked in.
- Wear a hat or scarf if you will pass under trees.
- Spray shoes, clothing and/or skin with repellent. (See Repellents below.)
- Spray clothing (but never skin) with permethrin (permanone), an insecticide. (See below.)
- Wear repellent when gardening or doing yard work.
- Buy Rynoskin long underwear, socks, and hoods at 1-866-934-7546 or www.rynoskin.com .
- Hike in the center of trails, so you won't brush against plants. Avoid tall grass.
- Check yourself frequently for ticks. Use a mirror, and also feel for ticks. Check underarms, groin, belly button, neck, behind knees, in and behind ears, under hair, and where clothes fit tightly.
- Check pets for ticks before they enter the house. For pets, use Frontline or a flea and tick collar.
- Remove ticks promptly to lessen the chances of getting Lyme disease.
- Undress in a shower stall or dry bathtub, so you can see ticks that drop off.
- To remove unattached, crawling ticks, use sticky tape, liquid soap, or a soapy washcloth.
- Put clothes in the dryer on high heat for an hour to kill ticks on them. If clothes are washed first, dry them on high heat for an extra hour after the clothes have dried. (Ticks can survive the washing machine and dryer, unless dried an extra hour. They can also survive a bath.)
- Put clothes in a trash bag and spray permethrin into the bag, to kill ticks before laundering. (Do the spraying outdoors.) Seal the bag tightly and keep sealed until laundering.

Permethrin (an insecticide) kills ticks on contact. The CDC recommends spraying it on clothes (but never on skin). Spray outdoors, the day before an outing, and allow clothes to dry before wearing. Read and follow the instructions on the can. Spray the outside of shoes and cuffs of socks, but not the bottoms of socks or any clothing that would stick to skin when wet with perspiration, or permethrin could be absorbed through the skin. Don't spray permethrin on the clothing or shoes of young children who put things in their mouths. Permethrin remains effective on clothes for about 2 weeks, even after several launderings. It is in Repel Permanone and other products containing permethrin, sold in the camping department at Walmart, at some other stores, or at www.scs-mall.com .

Repellents containing DEET (N,N-Diethyl-meta-toluamide) are recommended by the CDC. DEET doesn't actually repel ticks. It makes the tick unable to detect carbon dioxide, so that it won't be attracted to people. Excessive and prolonged use of DEET on skin can occasionally cause seizures, especially in children. DEET should be washed off skin when coming indoors. Don't spray DEET on clothing that has permethrin on it, as there may be a chemical reaction. Picaridin, which is in Cutter Advanced, and oil of lemon eucalyptus repel mosquitoes and may possibly repel ticks. Research is needed. Picaridin is not as toxic as DEET and doesn't have to be washed off promptly. Oil of lemon eucalyptus is not recommended for children. Don't apply repellents to the face or hands. Other ideas to repel ticks: cactus juice repellent, Avon Skin-So-Soft, Bounce fabric softener sheets placed in socks, citronella ankle bracelets, bathing with Irish Spring soap, or rubbing a dry bar of Irish Spring soap on the cuffs of socks and long pants. Repellents may need to be re-applied every few hours. Read label directions. No repellent is 100% effective. You still need to check for ticks.

Remove ticks properly. Don't use alcohol, other chemicals, or a hot match, or the tick may vomit germs into you. Don't squeeze the tick's gut (body), or germs may squirt into you. The safest way to remove a tick is to slide something under it, such as a tick remover tool, and lift up. Then wait for a minute or 2 until the tick releases itself. Fine-pointed tweezers may be used for the larger ticks, grasping the tick at the mouth and pulling it straight out, allowing the tick time to release itself. Be careful not to squeeze the tick's body, just the head. The Lyme Association sells a tick remover tool that slides under the tick and removes ticks safely. To buy a tick removal kit, send a check for \$4 to: