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For Immediate Release

## **NEWLY DIAGNOSED WITH LYME DISEASE**

### ***Time for Lyme Medical Director, Dr. Harriet Kotsoris on Five Important Questions to Ask Right Away***

**Greenwich, CT, October 2010** – “My doctor just told me I have Lyme disease. What do I do now?” As the number of confirmed cases of Lyme disease continues to rise—and to show up in places all around the country as well as around the world—this question is becoming more and more common, says Harriet Kotsoris, M.D., and medical advisor to Time for Lyme, Inc., a research, education and advocacy group. “Here in the U.S., Lyme disease is rampant in the Northeast and the north-central states, but it’s no longer unheard-of in states like Montana and North Dakota and Georgia, where it was virtually nonexistent a decade ago.”

According to the latest government figures, there are close to 30,000 Lyme disease diagnoses each year. Lyme disease has been documented in 49 states and is the most common tick-borne disease in the United States. But despite these stats, many people don’t expect to encounter Lyme disease outside of New England. For example, Dr. Kotsoris says, most people know that the Ixodes ticks that carry Lyme disease are often stowaways on white-tailed deer, but probably don’t realize that these ticks are also frequent fliers on field mice, raccoons, opossums, skunks, chipmunks, squirrels, and horses, as well as more than 50 species of migratory birds. This means you can get Lyme almost anywhere there are animals. What’s more, scientists have identified more than 100 strains of the Lyme disease bacteria, *Borrelia burgdorferi*, in the United States—and more than 300 strains worldwide. No wonder Lyme disease is so common.

But what should you do if you or someone in your family gets a Lyme diagnosis? Here are five questions to ask your doctor as soon as possible:

1. **How did I get Lyme disease? I never even saw a tick!** *Ixodes* ticks, otherwise known as deer ticks, are tiny: The biggest adults are less than 1/10 inch long, and the nymphs, which are in the stage of life when they’re most likely to pass along a Lyme infection, are about the size of a poppy seed. As many as half of the people infected with Lyme disease have no recollection of being bitten by a tick, and many never develop the telltale “bulls-eye” rash (*erythema migrans*, or EM). In patients who do develop EM, the rash might not show up for a month after the tick exposure, and when it does, it’s often mistaken for a spider bite or a sting from another type of insect. Ticks are actively questing a host for feeding year round as long as the ground temperature is above freezing
2. **How reliable are the tests for Lyme?** Unfortunately, the blood tests that are widely used today, the enzyme-linked immunosorbent assay (ELISA) and Western Blot, aren’t completely reliable, Dr. Kotsoris says. That’s because they’re what doctors call “indirect detection tests,” which look for antibodies, not the actual disease-causing bacteria. What’s more, she says, taking a test too soon after a tick bite can produce a false-negative result, because the immune system hasn’t had time to produce the antibodies the test is looking for. In addition, none of today’s tests can rule out Lyme disease. This means that you can test negative and still be infected. For that reason, most experts believe that a Lyme disease diagnosis must be a clinical one, based upon your symptoms and recent exposure to ticks, with the lab test thrown in to give a little more certainty. And for the best chance of getting an accurate result, ask your doctor to perform both the ELISA and Western Blot tests, she says.
3. **I feel better than I did a few days ago. Could that mean I don’t really have Lyme?** Lyme disease is one of the trickiest infections to diagnose, in part because its symptoms often come and go. “In many cases, someone with an active Lyme infection will have fluctuating symptoms—fatigue, headaches, body aches and other flu-like symptoms—which might make them believe that they’re not really infected,” says Dr. Kotsoris. And almost 20 percent of Lyme patients never develop the “classic” Lyme symptoms at all. So unfortunately, she says, feeling better isn’t necessarily a sign of good health.

4. **What's the best drug to take?** In most cases, if you've got an early Lyme infection, you'll be given a short course (14 to 21 days) of oral antibiotics such as doxycycline or amoxicillin. If your infection is caught early and is not complicated by co-infections and/or a virulent strain of the Lyme bacteria, this might be sufficient treatment. If your case is more complicated, you might require a longer treatment period. Most important is to seek treatment as soon as possible to attempt to catch the bacteria before they disseminate. It is important to note that even though you may be treated for Lyme, there is still no test to take at the end of that treatment to be sure the infection is gone.
  
5. **I still feel lousy. Could I have another infection, too?** Ixodes ticks can be infected with several types of bacteria at once—and can pass those bugs onto you in a single bite. That means that a Lyme-infected tick can give you Ehrlichiosis, Babesiosis, and other infections. If you had severe initial Lyme disease symptoms, including a high-grade fever that lasted more than 48 hours, or if your rash cleared up but your other Lyme symptoms persisted or got worse after taking antibiotics, you should ask your doctor to test you for a co-infection. “Unfortunately,” says Dr. Kotsoris, “we’re finding that many ticks are carrying and transmitting several infectious agents at once.”

**About Time for Lyme:** *Time for Lyme's mission is to fund innovative Lyme and tick-borne disease research, and to combat and prevent those diseases through education, outreach, public policy initiatives, information sharing and support. (203) 969-1333. [www.timeforlyme.org](http://www.timeforlyme.org)*

**Save the Date:** *Time for Lyme Gala Fundraiser, April 2, 2011: Illusions of Lyme, at the Hilton Hotel in Stamford, CT, from 7:00 pm to 11:30 pm. Call 203-969-1333 for more information and to get involved.*