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For Immediate Release

THE TRUTH ABOUT LYME DISEASE: UNDERCOUNTED AND UNDERFUNDED
Dr. Harriet Kotsoris explains the obstacles for Lyme patients and researchers

Greenwich, CT, December 2010 - Lyme disease is on the rise, yet public funding for this epidemic lags behind funding for other illnesses, many of which impact a much smaller proportion of the population. "Lyme disease cases increased 77% over a recent two-year span," says Dr. Harriet Kotsoris, neurologist and medical advisor for Time for Lyme, a research, education, and advocacy group based in Greenwich, CT. "It is the most commonly reported vector-borne illness in the United States and has been documented in 49 states."

Despite being the fastest-growing tick-borne illness in the States, Lyme disease receives less than 10% of government funding for vector-borne diseases. According to research compiled by the California Lyme Disease Association, federal funding for West Nile virus has been 18 times greater than the funding for Lyme disease.

"This inequality in funding is disheartening," says Dr. Kotsoris. "Morbidity associated with chronic Lyme disease is significant. Patients suffer a degree of physical deterioration equal to that of patients with congestive heart failure."

The number of cases of Lyme disease is undercounted. From 1992 to 2006, the number of reported cases more than doubled. Cases spiked 77% from 2006 to 2008; in 2009, the Centers for Disease Control and Prevention confirmed 38,468 probable cases of Lyme disease, an increase of approximately 12% from the prior year.

The CDC admits to the possibility of underreporting by a factor of 10. Thus, there could be more than 200,000 new Lyme cases a year in the United States. Many physicians believe that the real numbers may be even higher. A study published in *Journal of Community Health* reported on a Georgia Southern University study which showed that for every symptomatic patient, one asymptomatic patient exists, and other research illustrated that the rate of clinical diagnosis was 40 times the surveillance rate.

Those numbers are likely to continue to climb, according to research that correlates the malady with environmental changes. According to the National Science Foundation, areas of patchy woods, common in cities, suburban and rural areas, may have higher populations of Lyme-disease carrying ticks than forest fragments because some species thrive in smaller places. Global warming may also be an influence, according to Dr. Durland Fish, professor of epidemiology at Yale School of Public Health, whose findings on this subject appeared in the April issue of *Applied and Environmental Microbiology*. His research showed that as climate change lengthens the span between tick feeding cycles, the most virulent strains – which cause more severe disease in humans – survive.

Dr. Kotsoris outlines several key reasons why Lyme disease is undercounted and underfunded:

- **CDC endorsed tests are unreliable** Very few with proven Lyme disease, perhaps on the order of 10%, can meet the criteria used to issue statistics on "reported" cases. The CDC uses a two-tier system that relies on two widely accepted tests, the Western Blot and the ELISA. These indirect detection tests look for antibodies, not the actual disease-causing bacteria. "There is a 40-60% false negative rate if one takes a test too soon after a tick bite because the immune system has not had time to produce the antibodies the test is looking for," says Dr. Kotsoris. Recent research has shown that these CDC-endorsed blood tests, which are based on a single Lyme strain from Shelter Island, NY, may not be detecting all the bacterial strains of the disease (there are at least 100 different strains in the United States). According to a Johns Hopkins study, the tests miss 75% of infected patients.
- **Symptomatic Confusion** "Because the disease presents in myriad ways, Lyme may be undiagnosed or be misdiagnosed as psychiatric disorders, fibromyalgia, MS, Parkinson's, Lou Gehrig's, chronic fatigue

syndrome, or arthritis, among other illnesses,” Dr. Kotsoris says. “Yet some medical experts dispute the existence of chronic Lyme disease.”

- **The rash myth** The belief that a Lyme disease rash has a distinctive “bull’s-eye” shape and occurs in a high percentage of those infected leads to misdiagnosis. “A Lyme rash can look like almost anything and may occur in fewer than 50% of those infected,” says Dr. Kotsoris.
- **Strict guidelines** for what constitutes Lyme disease have made it more challenging for researchers to gain government funding, as well as find patients who fulfill the criteria and definition of a patient. In a recent interview, Willy Burgdorfer, the discoverer of the bacterial pathogen that causes Lyme disease stated, “[Research] money goes to people who have, for the past 30 years, produced the same thing – nothing.”

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*

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.*