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Ukiah, CA - - For the third straight year, California legislators will declare May Lyme Disease Awareness Month, thanks to Senator Jack Scott (D-21st District, Pasadena). Mendocino County Supervisors will vote on a similar resolution at their April 24 meeting. May is the peak of the nymphal tick season. These immature ticks cause most human cases of Lyme disease, since they are the size of poppy-seeds and people don't even realize they have been bitten. An average of 7% of local ticks are infected with the bacteria that cause Lyme.

“Many Mendocino County residents have Lyme disease and don't know it or can't get treated locally for it,” says patient advocate Phyllis Mervine, president of the nonprofit California Lyme Disease Association (CALDA). “Tests are not always definitive and doctors prefer less controversial diseases like MS, fibromyalgia, chronic fatigue, or even psychiatric illness, which can look identical to Lyme, so people never get treated appropriately. The alternative is traveling long distances to see a Lyme specialist.”

If not treated promptly, Lyme disease can lead to a debilitating chronic illness that attacks the brain, heart, joints, and other organs and causes extreme fatigue, headaches, depression, panic attacks, OCD, pain, and other symptoms. Although debate continues over the best treatments for chronic Lyme, studies show it often responds to longer treatments and combinations of drugs.

There are two “practically opposite” standards of care for diagnosing and treating Lyme, which causes confusion, Mervine says. CALDA works closely with the International Lyme and Associated Diseases Society (www.ILADS.org), whose published peer-reviewed guidelines recommend an individualized treatment plan that sometimes includes long-term antibiotic treatment. As part of their educational mission, CALDA offers \$800.00 scholarships to healthcare professionals who attend the ILADS and the national Lyme Disease Association annual scientific conferences for the first time. This year both conferences will be held near Boston on October 26-28.

The other guidelines are published by the Infectious Disease Society of America (IDSA). CALDA is supporting a civil investigation of IDSA by the Connecticut Attorney General for possible antitrust violations in the formulation of their guidelines, which recommend no more than three weeks of treatment and deny the existence of chronic Lyme. After the IDSA guidelines were published in December, 2006, ILADS wrote and requested their immediate retraction, saying that the guidelines committee selected research that agreed with their opinion and ignored opposing views. Of 18,537 articles about tick-borne diseases listed on National Library of Medicine website, the committee looked at only 400, the letter said.

ILADS president Dr. Raphael Stricker, a Bay Area Lyme specialist and CALDA board member, worries that the IDSA guidelines do not offer an answer for the thousands Lyme patients left with a poor quality of life after their three-week treatment.

“Many recommendations in the IDSA guidelines are based on the weakest evidence, namely opinion rather than scientific fact,” said Dr. Stricker. “The guidelines make doctors afraid to diagnose or treat Lyme disease, and this chilling effect harms patients and patient care.”

Mervine adds that insurance companies often use the IDSA guidelines to deny reimbursement of the cost of treatment, and medical boards use them to discipline doctors. Although California is one of the few states with a law protecting doctors who treat people with chronic Lyme, provided certain conditions are met, many shy away from Lyme because of the controversy. The resulting difficulty in finding a doctor and desperation drive many patients to experiment with unproven and sometimes risky alternatives, Mervine says.

CALDA publishes a quarterly lay journal, the Lyme Times, which can be ordered on the CALDA website, www.lymetimes.org. There is an online group “CaliforniaLyme” at Yahoo Groups where almost 500 members share support and information. Any California resident can apply to join. Healthcare professionals interested in the scholarship to attend the ILADS/LDA conferences should call Lee Lull at 415-927-9553 or email CALDAgrants@yahoo.com for an application. CALDA will have a booth at the upcoming Health & Wellness Fair, April 29, Sunday, 10am-4pm in the Fine Arts Building at the Ukiah Fairgrounds.

About California Lyme Disease Association (CALDA)

CALDA, an affiliate of the Lyme Disease Association, is a non-profit corporation that acts as the central voice for all tick-borne disease issues in California and a supporting voice for national issues. Through advocacy, research and education of the public and health care professionals, CALDA seeks to prevent tick-borne diseases, encourage early diagnosis, and improve the quality of healthcare provided to people with tick-borne diseases. CALDA publishes the Lyme Times, a lay journal that is distributed nationally and internationally. For more information, visit www.lymedisease.org

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