

**Lyme Disease Advisory Committee Meeting
March 10, 2011
Sacramento, California**

Committee members in attendance

Barbara Barsocchini, California LD Association (CALDA)
Karen Chew, LD Support Network
Vicki Kramer, Ph.D., California Department of Public Health (CDPH)
Robert Lane, Ph.D., University of California, Berkeley
Lisa Messner, C.Ph.T. LD Support Network
James Miller, Ph.D., University of California, Los Angeles
Scott Morrow, M.D., M.P.H., California Conference of Local Health Officers (via phone)
Christian Parlier, LD Support Network
Chindi Peavey, Ph.D., Mosquito and Vector Control Association of California (MVCAC)
Raphael Stricker, M.D., California Medical Association (CMA)

Other attendees

Anne Kjemtrup, D.V.M., M.P.V.M., Ph.D., CDPH, Committee Coordinator
Claudia Erickson, M.S., C.H.E.S., CDPH, Health Educator
C. Ben Beard, Ph.D. Chief of the Bacterial Diseases Branch, Division of Vector-Borne Diseases, Centers for Disease Control and Prevention (CDC)

Approximately 20 individuals representing the interested public and public health agencies.

I. Roll Call and Opening Comments

The meeting was brought to order by Mr. Parlier at 9:42 a.m.

II. Review and approval of minutes of 1/20/2011 teleconference

The motion was made and seconded to approve the minutes as written. There was no discussion. The minutes were unanimously approved.

III. CDPH Progress Report

Dr. Kjemtrup reviewed the activities of the California Department of Health (CDPH) with regard to the tick-borne disease prevention. For the general public, tweets and Facebook postings resulted in messages being spread through other health agencies' social media efforts. Embedded bit.ly links enabled some monitoring of the use of the websites: there were over 50 hits to the tick bite prevention webpage. Ms. Claudia Erickson, health educator with the department, highlighted the outreach efforts to a wide audience to announce the public service announcement (PSA) You-tube contest. Many partners have picked up the contest announcement. Ms. Erickson also noted that the "Timothy Tickfinder and his dog Bullseye" tick-bite prevention information for children now has national attention and distribution on the CDC website. Dr. Kjemtrup reviewed

the Vector-Borne Disease Section's (VBDS) efforts in outreaching to the medical community which included lectures to medical and veterinary students and supplying of materials per requests. Local vector control agencies and other partners continue to be an educational focus through presentations given by all VBDS staff and reminders sent of the material available at VBDS.

Discussion, responses and suggestions by the committee included:

- Change "TB" to "tick-bite" in PSA announcement because it might be mistaken for tuberculosis.
- Probable and confirmed cases of Lyme disease (LD) are not distinguishable when reported to CDC but they will be separated out in reporting by CDPH. Tick testing at VBDS uses direct fluorescent antibody test followed by specific PCR test for *B. burgdorferi*
- CDPH is moving more towards using social media for outreach. The smart phone bar code on the bit ly site can access the information.
- The committee discussed reporting issues and Dr. Kjemtrup reviewed some of the methodologies used by other states with high incidence of LD. Though every case is not captured, the endemic level of about 100 reported cases per year provides information to tell public health how to respond (where, when, and how cases occur). It was suggested that a footnote be added in the VBDS annual report indicating that not all cases are acquired in county of residence.

IV. Committee member updates

Ms. Barsocchini provided a CALDA update. CALDA is hosting a booth at the Nurse Practitioner state conference. The conference will have a physician-provided talk on LD. They continue to collaborate with Santa Rosa Medical Group and organize state LD awareness walks. CALDA is awarding physicians' grants to attend the International Lyme and Associated Diseases conference in Toronto, Canada in October 2011.

Dr. Peavey stated that the mosquito/vector control districts have been very busy responding to environmental permitting issues related to mosquito control, but are now doing more tick-borne disease public outreach.

Ms. Chew remarked that there are usually 3-5 new faces each month at the support meeting she moderates. She was struck by the increasing number of children (represented by their parents) attending Lyme support groups.

Dr. Kramer noted that the grim condition of the state budget has impacted VBDS-such that we have lost an epidemiologist to the veterinary public health section as their new chief. The resultant vacant position cannot be filled now and may be lost. Many staff are being reassigned duties to make up for this loss, including Dr. Kjemtrup's assignment as LDAC coordinator. Ms. Denise Bonilla, a biologist with extensive tick-borne disease research experience, will be taking on this duty.

Dr. Lane reported that his lab has begun a tick study in Malibu, assessing *I. pacificus* nymphal tick and *Borrelia* spp. ecology. He reported the results of recent publications

from his lab including the findings that removal of lizards did not decrease nymphal tick density or risk of LD to people; and in another investigation of human sera collected from a LD-endemic area in N. California, his laboratory detected 11% (3/27) of *Borrelia* positive samples were infected with *B. bissettii*. In response to questions posed by the committee and audience Dr. Lane noted:

- *Borrelia bissettii* grows in BSK medium; it is successfully treated in Europe like a LD infection, and it can be detected by PCR. Though no commercial tests are specifically available, Dr. Ben Beard from the CDC remarked that *B. bissettii* patients should be reactive in Lyme EIA and Western blots that are based on whole-cell antigen.
- Nymphal ticks are difficult to collect in southern California.
- The role of dogs as a tool for human LD has not been studied in California. Dr. Kjemtrup added that the testing for dogs is an in-house ELISA-based test that cannot be reliably used to evaluate risk of LD to people.

Ms. Messner reported that although her position was eliminated at Los Robles Hospital, she was asked to continue her work within the Lyme support community at the hospital.

V. National Trends in Lyme Disease: Challenges, Centers for Disease Control and Prevention (CDC) Strategic Plan (Ben Beard, Ph.D., CDC)

Dr. Beard presented an overview of the National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), under which the Division of Vector-Borne Diseases is housed, and reviewed the CDC's current LD prevention program. He emphasized that LD is of high concern because it is among the top 10 notifiable diseases in the US (#7 with nearly 30,000 reported cases in 2009), and its continued emergence is reflective of the changing ecology in the northeast and expansion of the tick vector elsewhere. Certain features of LD have remained constant since it was first reportable (e.g. percentage of reported patients presenting with erythema migrans, arthritis, neurologic and cardiac abnormalities), and the key challenges include polarization, mistrust, differing views on how to manage LD clinically, ecological variability, and differing societal values. He emphasized that CDC's chief role is prevention and reviewed CDC's long term goals including reducing disease incidence and severity through short-term measurable outcomes by using validated prevention methods and collaboration with key stakeholders. Dr. Beard reviewed CDC's 4- part strategy to strengthen and refine national surveillance, identify and validate effective prevention methods and approaches, improve early and accurate diagnosis and treatment, and leverage collaborative potential for program implementation. He presented the CDC's newly developed LD educational toolkit. He concluded by briefly reviewing CDC's currently funded prevention programs.

Committee member comments included the following.

- On vaccine issues:

- Dr. Miller noted that a vaccine to prevent the disease would be the most efficacious approach; limited funding for such a venture has slowed progress in this area. Dr. Beard noted that Baxter has come out with a 2nd generation LD vaccine that has updated the previously available one with a more broadly protective one (covering more species of *Borrelia*). Trials are being considered in Europe.
 - A comment was made that Lymerix was withdrawn before all testing phases were completed and the data were never released.
 - Dr. Beard added that if a vaccine is produced, it is important to include control and prevention along with vaccine outreach.
 - A recent study poised for publication from the CDC found that doxycycline protects mice against the tick-borne disease and also clears the ticks feeding on them of pathogens.
- Regarding other vector pathogens:
 - *Bartonella* species infect people and animals but tick transmission has not been shown.
 - In response to a question from Ms. Messner about the role of dust mites, Dr. Lane replied that they can cause allergic reactions but do not suck blood and are not vectors of pathogens.
 - In response to a committee question, Dr. Beard noted that the implementation of universal healthcare really should not change the landscape of work at the CDC which is focused on making the best decisions based on available evidence.

VI. Public Comment:

- In response to a question about testing ticks for novel pathogens, Dr. Beard stated that the CDC relies a great deal on university colleagues to do these studies with the exception of Southern Tick Associated Rash Illness (STARI.) where there is a collaborative program in the southeast that involves PCR of human skin EM biopsies and of ticks. No remarkable findings reported to date.
- A member of the public remarked that it would be helpful to record meetings and post .mp3 online for people who cannot attend, as well as post presentations on the website. She also stated that she has had difficulty getting outreach resources (brochures, etc). Dr. Kjemtrup noted audio-visual webinar technology is recently available at CDPH and that this approach may be evaluated for future meetings. Talks presented at the LDAC meeting are available on the website prior to and for a few days after the meeting and she encouraged the speaker to return to the CDPH website to look for the contact information to get material; material is distributed as available.
- In response to a question on the possibility of current LD tests being biased against samples from women, Dr. Beard answered that he was not aware of scientific evidence supporting a difference in testing results between males and females. Dr. Stricker stated that he is aware of evidence that shows that men have an average of 6 bands on the western blot while women have an average of 4

bands, and added that five bands are needed for a positive test. Dr. Miller added that studies in rabbits suggest females were more resistant to certain diseases than males.

- In response to questions as to whether the CDC's overall data distorts the local conditions of LD (the speaker noted that only 20% of the LD patients in her area had an EM rash as opposed to the CDC statement that 80% present with a rash), and if revisions to the surveillance case definition are being considered, Dr. Beard stated that the EM data indeed reflects the national situation as reported to the CDC and added that the EM is just part of the clinical picture of LD; laboratory tests are still done and the definition for LD remains constant. Dr. Stricker added that a problem with using the EM rash in the diagnostic criteria is that studies of LD tend to focus too much on the EM rash.
- A member of the public commented that she was concerned about the possibility of getting LD from blood transfusions. She mentioned a laboratory in Texas that does a PCR test for LD that she stated had FDA approval and that she tested positive at this laboratory when her physician refused to treat her because she had fewer than 5 positive bands on her western blot test. Dr. Beard noted that physician education is a huge priority for CDC. He added that the blood supply is not currently screened for *Borrelia* because there is no evidence that LD can be transmitted via blood transfusion; there is currently no FDA approved PCR test for LD. Dr. Stricker asked if the CDC planned on using the movie "Under Our Skin" to heighten awareness about LD. Dr. Beard said they would not be using the movie.
- The speaker relayed her experience of being treated for LD in the northeast when she was young and later in life developing multiple sclerosis type symptoms that she wondered if were related to her previous LD; her doctor told her they were not. She expressed her wish that more effort could be made to educate physicians.
- A representative from the Humboldt Lyme Awareness Group reported that over the last few months residents with diagnosed LD relayed that in follow up by the Humboldt Health Department they were told that they do not have LD. Dr. Kjemtrup replied that health departments do not diagnosis Lyme disease and that she will check in with Humboldt County.
- In response to a question as to what evidence would be required to show that *B. burgdorferi* could persist after antibiotic treatment in some patients, Dr. Beard replied that though some studies suggested evidence of *B. burgdorferi* presence after treatment, there is not good evidence that these are live, persisting organisms involved in a pathological process relating to clinical symptoms. He added that the definition of persistence should be refined as well- DNA could be persistent for weeks or months after treatment but eventually goes away. Treatment guidelines focus on persistence of disease: if symptoms persist after a month of treatment, then another month of treatment may be given. Wrong antibiotic choice could certainly lead to persistence. The committee discussed persistence with Dr. Miller noting that *B. burgdorferi* does not behave like syphilis in reactivation studies and Dr. Stricker mentioning an article that reported 27 cases of persistent *Borrelia* infection, some documented by culture, after what is considered adequate treatment. It was stated that better culture methods are needed.

- The speaker noted that endemic habitat can be everywhere including in urban San Francisco where raccoons run through backyards. She felt there should be LD informational door hangers. She also inquired on the status of research on other repellents such as Nootkatone and orange oil. Dr. Kjemtrup replied that VBDS biologists have looked for ticks on numerous occasions in San Francisco and did not find any. Dr. Beard spoke about collaborative studies with the CDC and Oregon State University using Nootkatone. The speaker emphasized that more work needs to be done with local, state, and national park employees to evaluate occupational health risk. She inquired if the results from the CDPH survey of national park employees documented cases and treatment. Dr. Kjemtrup replied that the National Park Service study was on exposure to ticks and tick-bites, not on acquiring disease. One of the LDAC goals for 2011 includes the development of resources for occupational health.
- In response to a statement urging CDC to focus more on physician outreach, including reminding them about the top ten reportable diseases, Dr. Beard answered that physician education is very important including the need to assess physician perceptions about Lyme. Tick-borne diseases are on the rise and physician education has not kept up.
- In response to a question as to what agency focuses time and resources on diagnosis and treatment improvements, Dr. Beard responded that the budget is a huge issue and that the CDC works with the NIH and other organizations to coordinate efforts including working with the EPA on LD integrated pest management. The CDC is sponsoring a clinical trial right now focusing on chronic symptoms in Lyme disease patients. Dr. Peavey encouraged people to contact their local congressmen about the importance of LD and vector-borne disease funding in general.
- The speaker stated that many of the points in Dr. Beard's talk did not apply to California (e.g. Re-forestation patterns and deer population increases). She added that the surveillance definition for LD was too restrictive.

VII. Meeting adjourned 3:30 by Mr. Parlier