Lyme Disease Advisory Committee Meeting
Minutes of the November 14, 2002 Meeting
Department of Health Services Sacramento, CA

The eighth meeting of the Lyme Disease Advisory Committee (LDAC) was held on November 14, 2002, in Sacramento, California.

Committee members in attendance
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Peggy Leonard, Lyme Disease Resource Center
Lee Lull, Lyme Disease Support Network
Susie Merrill, Lyme Disease Support Network
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association
Committee members not in attendance
Victoria Deloney, RN, Public Health Nurse
James Miller, Ph.D., University of California, Los Angeles
Scott Morrow, M.D., California Conference of Local Health Officers
Other attendees
Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services
Peter Mackler, California Department of Health Services
Mark Starr, D.V.M., M.P.V.M., California Department of Health Services
Approximately 35 people representing the interested public and public agencies

I. Review of minutes and opening comments

Dr. Robert Lane, Chair of the LDAC brought the meeting to order at 10:15. Minutes from the July 9, 2002 meeting were approved on September 23, 2002 and are posted on the California Department of Health Services' (DHS) web-site (http://www.dhs.ca.gov/ps/dcdc/disb/disbindex.htm).

Peter Mackler from the Director's office welcomed the Committee and audience. He commented that despite a difficult state fiscal situation, a lot of progress has been made over this past year; he added that the coming year will not see fiscal improvements. DHS will continue to work with resources such as the Committee. Mr. Mackler stated that he will report back to the LDAC concerning Governor Davis' rationale for not signing SB 2097.

II. DHS progress report (Anne Kjemtrup, includes committee discussion)

Dr. Kjemtrup reported on progress in the designated goal areas: 1) education of the medical community and 2) education of the general public. She also gave an update on DHS tick surveillance activities.

Progress in medical community education included work on the physician assessment questionnaire and contacting local public health departments (HD). The Physician Assessment is currently scheduled to appear in the California Medical Board's "Action Report" first edition of 2003.

Nine local HD were contacted and asked what information they would find helpful for physician education on Lyme disease (LD), and if they had any issues of concern with the LD case reporting forms. They were told of the expanded DHS website, and brochures were sent directly to those who requested them. Although none had specific suggestions for physician awareness, most had annual or biannual physician newsletters that may be useful to distribute information on LD. None expressed difficulties with completing the case form. No suggestions for the case reporting form were offered.

General Public Education activities since the last LDAC meeting included brochure distribution, web site postings, presentations, and local agency resource assessment.

Over 6,000 copies of the LD brochure were sent out to the public and public groups, physicians, vector control agencies, and local health departments. Sacramento-Yolo Mosquito and Vector Control District kindly printed more brochures and distributed over 5,000 at the California State Fair in August.

The DHS website was updated with Tick-Borne Disease Question and Answer sheets and the tick testing data are now available (http://www.dhs.ca.gov/ps/dcdc/disb/disbindex.htm). The data on ticks that bite humans is being collected and will be eventually posted on the web. Public Health laboratories do not routinely test for coinfections when testing ticks for *B. burgdorferi*. The tick testing database currently on the web will be updated; attempts will be made to include published data from Mendocino County, likely in the form of a reference citation. The Tick Warning poster has been revised and updated in English and Spanish and is currently being prepared for printing.

Press contacts included an interview given by Dr. Kjemtrup to the Oakland Tribune on the removal of the LD vaccine from the market. The fall/winter press release on tick awareness will go out next month. Presentations on LD and other tick-borne diseases were made by Dr. Kjemtrup to the Santa Cruz Environmental Health Department and to Environmental Health Directors at their annual meeting.

Fourteen local vector control agencies in California were contacted to determine whether they had tick-borne disease educational materials. Agencies were asked to share materials with DHS so that materials could be catalogued and used by DHS or other agencies. Information was acquired regarding the relative effectiveness of different materials in reaching the public and physicians. These agencies were made aware of new DHS educational materials, including the brochure. All agencies distributed material on LD. No district had physician-directed material specifically. Most agencies had a community outreach program that targeted schools, city government, utility companies, health fairs, civic groups, and homeowner associations. Several agencies suggested that a business card sized tick identification card would be helpful to the public and physicians. One agency commented that they are cutting back on educational programs for school children; another indicated that many teachers decline vector outreach programs due to other curriculum demands. Several agencies expressed desire to expand tick-surveillance in their area.

Dr. Kjemtrup presented results of the 2001 California Behavioral Risk Factor Study (BRFS) pertaining to tick-borne diseases. The BRFS is a surveillance effort conducted by DHS and the Public Health Institute in cooperation with the Centers for Disease Control and Prevention.

The BRFS assesses health –related behaviors in 4,000 California adults through telephone survey. In response to the question, “Have you found a tick on your body or clothing in the past 12 months”, 185 (4.4%) said yes, 3,980 (95%) said no, and 23 (0.5%) were not sure. In response to the question, “Have you ever heard that Lyme disease can affect people in California?” 2,835 (67.7%) responded yes, 1,071 (25.6%) responded no, 254 (6.1%) did not know what Lyme disease was, and 28 (0.7%) were not sure.

Dr. Kjemtrup summarized VBDS tick surveillance activities, which were initiated in November with the appearance of adult ticks. Tick surveillance began in Shasta, Sonoma, Santa Cruz, Riverside and Los Angeles Counties. In Mendocino County, VBDS personnel followed-up on a case of human tularemia by searching for the agent in small mammals and ticks in the area where the patient lived.

Dr. Lane reported that he is continuing surveillance in his study areas and will focus on mixed hardwood forests. He mentioned that he has a graduate student who is developing a project concerning *Bartonella* in ticks, small mammals, and will be attempting tick transmission studies with various *Bartonella* species. He also wanted to bring attention to the publication of a new book, Lyme Borreliosis, Biology, Epidemiology and Ecology, published earlier this month.

Dr. Stricker reported that he submitted an abstract to the American Federation for Medical Research meeting, scheduled for February. The abstract presents results of testing Lyme patients for the WA1 type *Babesia*. Dr. Stricker reported that 23% of these patients were seropositive for WA1.

In response to a question on the reporting of babesiosis, Dr. Kjemtrup noted that it is a reportable disease. WA-1 babesiosis can be difficult to diagnose. There are three principle methods to diagnose WA-1 infections: blood smear evaluation, immunofluorescent antibody test (IFAT), or in a research setting, hamster inoculation. PCR occasionally can be helpful. IFAT titers are interpreted in conjunction with compatible clinical signs: no parasites have been identified from people with titers less than 10,000. Currently, a titer of 640 is considered possible evidence of exposure since this is the lowest titer documented from infected, recovered individuals. There is no official surveillance case definition for babesiosis.

III. Overview of reportable disease surveillance and reporting (Mark Starr, DVM, MPVM, Chief, Surveillance & Statistics Section)

Overview of Disease Reporting

Dr. Starr defined surveillance as “information for action”. The purpose of surveillance is to gather and evaluate health information to better control and prevent disease. Disease reporting is only one component of surveillance and public health surveillance focuses on the whole population, not individuals.

Dr. Starr listed several uses for public health surveillance:

- Estimate magnitude of the problem
- Determine geographic distribution of illness

- Portray the natural history of a disease
- Detect epidemics/define a problem
- Generate hypotheses, stimulate research
- Evaluate control measures
- Monitor changes in infectious agents
- Detect changes in health practices
- Facilitate planning

Data sources for surveillance include notifiable diseases, laboratory specimens, vital records, sentinel surveillance, registries, surveys, administrative data systems, and other sources. Dr. Starr focused primarily on notifiable disease reporting.

Notifiable disease reporting is mandated by state law or regulation. Health care providers and laboratories report to local health departments (HD). The local HD submits the report to the state and the reports are transmitted to the Centers for Disease Control and Prevention (CDC) primarily through the National Electronic Telecommunications System for Surveillance (NETSS). Dr. Starr pointed out that the CDC began surveillance for LD in 1982 and the Council of State and Territorial Epidemiologists designated LD nationally notifiable in January 1991.

Passive surveillance is initiated by the health care provider who reports a case or suspected case to the local HD. **Active surveillance** refers to health departments initiating data reporting on specific diseases. With **laboratory surveillance**, laboratories report positive results to the local HD, who then follows-up with the health provider who ordered the test. **Sentinel surveillance** refers to looking at other information (e.g. ticks, reservoirs) that translate to risk for humans, or collecting disease information from sentinel sites for specific diseases (e.g., influenza). **Surveys** (e.g. BRFS survey) identify risks of disease, not the disease itself. Other data sources for surveillance include pharmaceutical sales and syndrome surveillance.

How Disease Reporting Works

Title 17 in the California Code of regulations, section 2500-2638 specifies the requirements for both provider-based (80+ diseases) and laboratory-based (25+ diseases) reporting. Underreporting of all diseases is estimated at 20-50%, but this varies by disease. Underreporting is due to reasons such as the disease not being severe enough for the patient to seek out physician care, or physicians not reporting cases to the local HD. Changes must be made to the regulations in order to make changes to the reportable diseases list.

Physicians and laboratories report diseases or suspected diseases (physicians do not have to wait for lab results to report) to the local HD by use of a Confidential Morbidity Report (CMR). For laboratory reportable diseases, the local HD should theoretically receive a report from both the physician and the laboratory. Benefits of laboratory reporting include readily available data (diagnostic test results) easily transmitted by already existing reporting systems, relatively few laboratories to communicate with (compared to the number of physicians), and a strong history of compliance by

laboratories. Disadvantages of laboratory reporting include the submission of data with limited information (e.g. name of patient and test results only), a lack of accurate tests for some diseases, and an increased workload for health departments.

The responsibilities of the California Department of Health Services (DHS) after receiving surveillance data and reports from the local HD are to process and review the case reports, analyze the data for trends, outbreaks, and unusual diseases, produce summaries and recommendations, and report results to the CDC. DHS also supports and assists local HDs with case investigations, control, prevention, etc. Summary reports are available online: (http://www.dhs.ca.gov/ps/dcdc/html/publicat.htm).

All reporting is based on National Surveillance Case Definitions (as established by the Council of State and Territorial Epidemiologists and CDC). Case definitions are used to establish standard criteria to be able to compare trends state to state and from time to time (comparing "apples to apples"). These are not diagnostic criteria. If a case is "not counted", that does not mean that it is "not a case".

Electronic Reporting

1. The California Electronic Laboratory Disease Alert and Reporting System (CELDAR) is a new pilot program for laboratory reporting. It allows laboratories to report results electronically to a central data repository and local HD can get this information directly from the repository. Laboratories like this system because it simplifies their reporting activities and leverages their existing information systems.

2. The National Electronic Disease Surveillance System (NEDSS) initiative is a CDC initiative to standardize surveillance systems across states. The proposed initiative would support development of interoperable systems that would facilitate communication between city/county HD, state HD, and CDC.

3. Web based reporting by providers has been shown to be feasible. Current efforts however are concentrating on implementing CELDAR.

Discussion

Dr. Starr offered the following responses to questions posed by the Committee.

- An example of a clinically reportable disease that is not laboratory reportable despite the availability of a good test is Hepatitis C. One reason Hepatitis C is not laboratory reportable is because HDs would be overwhelmed by the large number of tests that would be submitted to them. In addition, there would be minimal public health benefit because resources are unavailable to follow up on each case. Periodic evaluation of diseases for lab reporting is done for several reasons, such as changes in diagnostic tests. Changing the regulations generally takes 1.5 to 2 years.

- Specific and accurate tests are needed for accurate reporting. Most lab reportable diseases have a specific and accurate test with good agreement between labs.

- If physicians are following the surveillance case definition as clinical diagnostic criteria, then physician education is needed to ensure that physicians are aware that the surveillance case definition is not what a diagnosis should be based on.

- The case reporting form is a tool for the local HD, and usually physicians do not fill out the form, rather they fill out a Confidential Morbidity Report (CMR) card. While a case may not be counted, that does not mean it is not a clinical LD case, it simply means that it does not fit the surveillance case definition. About 75-80% of cases submitted to DHS are counted. Those that are not often lack information and are sent back to the local HD county for further information.

- All reports are monitored (both counted and not counted) by looking at provisional data. If suddenly a surge of reports occur, whether they fit the definition or not, the reason behind the surge e.g. existence of a new test, would be investigated. DHS does not have a “two tiered” system (maintaining information on diseases that fit and do not fit the surveillance criteria) for any disease.

Additional comments offered by the committee included:

- Local HD and physicians may find the case form confusing to fill out and may be frustrated when cases are not counted.

- The rate of LD appears low if only the statewide incidence is considered. Locally, risk can be moderate to considerable. The risk at those local levels is the message that needs to get out.

- Population based data can create false risk assumptions. One case in a county with low population could appear as a high risk area, and many cases in a high population county may make it appear as a low risk area.

- Some studies in the eastern United States find a 10-fold underreporting for LD.

- Connecticut State HD uses passive, active and laboratory reporting for LD, resulting in an increase in the number of reported cases. Public health information gained from this increased effort was to document limited spread of the disease. It was anticipated that physician burn-out from active reporting will result in a decrease in the number of reported cases, artificially suggesting that the disease incidence is decreasing.

- The implementation of laboratory reporting in California would stimulate Lyme disease reporting by physicians, likely resulting in more cases reported in the State.

- Interlaboratory disagreement still exists for Lyme disease tests. The currently available CDC-based laboratory criteria are surveillance-based; they are not really based on the number of bands that are on the test. They're based on the number of bands that CDC says should be on the test so you've already got that bias built in. Any physician education should report on the vagaries of current tests.

Subsequent to the discussion, a motion was proposed by Ms. Lee Lull:

1) a) That at least one hour be set aside at the next meeting to discuss surveillance and underreporting problems unique to LD.

b) Establish a subcommittee on LD reporting to report back to the committee at the next meeting or two, as needed, and have a Department consultant, preferably Dr. Mark Starr, available for consultation to the subcommittee if members have questions of the Department.

The motion passed unanimously. Subsequently, Dr. Kramer (after conferring with Dr. Starr) suggested that the subcommittee meet with Dr. Starr in attendance. It was agreed that Committee members who would like to serve on the subcommittee would volunteer via email and would meet as soon as possible. The subcommittee would report back to the LDAC at the next meeting.

IV. Discussion of Goal Matrix

The committee was reminded of the mission of the LDAC:

The mission of the Lyme Disease Advisory Committee is to make recommendations to the California Department of Health Services on strategies to enhance the awareness of the public and the medical community about Lyme disease in California, and thereby reduce exposure to, and suffering from, this and other tick-borne diseases.

The current goal matrix was presented with goals accomplished, in progress, and open for discussion indicated (Appendix 1). New goals should be phrased in a manner consistent with the Committee's mandate to advise on DHS tick-borne disease educational activities.

Educate Medical Community:

Discussion on educating the medical community included the following topics:

- Make information available on the types of laboratory tests for Lyme disease. A person from a public health laboratory could come to the next or subsequent meeting to go over the different diagnostic tests. A document summarizing this information could potentially be prepared and made available on the DHS website.

- A medical society or organization willing to host a tick-borne disease conference has not been identified to date. Trying to address local HD grand rounds on an ongoing basis is not practical. There is a DHS grand round system that reaches public health officials and hospitals around the state. DHS could look into getting a mix of professionals (typically from DHS only; however, getting outside experts will be investigated) for these grand rounds. Usually the format is a conference call with PowerPoint presentations and accompanying handouts.

- The American Association for the Advancement of Science California Conference might be a good venue for a seminar but requires several years advanced planning.

Specific suggestions for educating the medical community are listed in the updated goal matrix (Appendix 2).

Educate General Public:

VBDS produces an annual report, available online, which is a compendium of annual vector-borne disease activity in the state and includes LD.

Specific suggestions for educating the general public included are listed on the updated goal matrix (Attachment 2).

Educate School Children:

Specific suggestions in this category are listed in the updated goal matrix. The Goal Matrix will be updated and circulated among the LDAC for feedback.

The next meeting of the LDAC will be Tuesday, March 25, 2003.

V. Public Comments

Meg Hughes: Ms. Hughes, leader of the Grass Valley Lyme Disease Support Group, read a statement expressing her opinion that most doctors do not think that Lyme is a problem in California. She advocated for more physician education. She stated that there are studies showing that *B. burgdorferi* has been cultured post treatment from brain, skin, heart, spleen, lymph nodes, spinal fluid, joints, joint fluid and eyes, even from seronegative patients. She felt that DHS does not listen to Lyme patients and she expressed a desire to have a change in leadership.

Phyllis Mervine: Ms. Mervine had prepared a letter for the Committee. She made two additional comments pertaining to today's meeting before reading a portion of her letter. She noted that at medical symposia that are too full or too expensive to participate, having a table with information is often helpful. She has done this and has resources she is willing to share. She also had put on a medical conference in her area last March with DHS participation. DHS had given CME credit for the conference and she looks forward to putting on a similar conference next March. A summary of her letter follows. Senate Bill 2097, although passed almost unanimously by the legislature, was vetoed by Governor Davis. She felt that the Governor had obviously been misinformed about the fiscal impact of SB 2097 since the bill would have only increased the LDAC by one volunteer, did not give LDAC veto power, and decreased costs to DHS by no longer providing for travel reimbursement. Ms. Mervine felt the reasons for the veto were not adequate. She thought that the LDRC could support DHS's stated mission of reducing occurrence of preventable disease, providing leadership in health care and fostering partnerships with community-based organizations. She commented that recommended preventive measures against tick bites have been shown not to be adequate to prevent LD in Rhode Island and therefore, early diagnosis and treatment of LD is the next line of defense. She stated that in many counties of California physicians do not recognize Lyme disease. She referred to studies in Mendocino County that demonstrated 37% of residents in a community had definite or probably Lyme disease, yet the reported incidence for Lyme disease in Mendocino County is 1.7%. She also referred to Butte County where physicians did not appear to report LD until 1997 and subsequently Butte County was shown to be highly endemic for LD. Similarly in Humboldt County, the yearly incidence jumped from 14.2/100,000

to 65.7/100,000 after a 1994 surveillance study. She cited additional studies supporting that lack of recognition or treatment of LD results in a tremendous cost to the State in terms of health care costs, disability, unemployment and lost tax revenue as well as individual pain and suffering. She stated that the average cost f treatment and loss of income was $67,000.00 and that even with patients who develop an erythema migrans rash, it took 3.4 doctors to diagnose the patient. She suggested that Dr. Stephen Harris of San Diego serve as a volunteer on the LDAC and she supported the creation of a reporting subcommittee of the LDAC to improve the LD reporting system.

Terry Charonet: Ms. Charonet offered several suggestions regarding LD education to the Committee. At the suggestion of the Committee some of these suggestions have been added to the updated goal matrix (Appendix 2). She emphasized that every hospital and school library should have brochures available and that all school nurses and advice lines should also have brochures and other information. She thought that HMOs might be willing to pay for the brochures. She stated that education for nurses is important because information often trickles from nurses to the physician. She commented that often in rural areas, much of medical care is obtained through school nurses.
Myrna Vallejo: Ms. Vallejo stated that she is currently in her 18th year of disability from LD. She noted that many people have had their lives destroyed by this illness and that it is important that awareness be increased so that others are not hurt. She stated that SB 1115 acknowledged that LD is crippling and that blood tests are unreliable. She questioned why DHS “actively” opposed SB2097 and felt that DHS’ agenda was not the same as that of Lyme patients; that current DHS leadership is not doing their job. She wanted it clear that she is grateful to those on the LDAC who want to help Lyme patients.

Meeting adjourned 3:30.