

Please help us by filling out this National Survey and mailing the completed form to the address on the back. *Help us help you! Thank you!*



California Lyme Disease Association SURVEY

Impact of CDC Surveillance Definition of Lyme disease

Date: _____ Patient Identifier ____/____/____ ZIP _____
(initials of your name plus 6-digit birthdate in format 00/00/00 plus ZIP code))

1. ELISA:

- a. Have you ever been told that you did not have Lyme disease because of a negative ELISA test result? Yes _____ No _____
- b. If so, in what year did this occur? _____
- c. Have you ever been denied medical reimbursement by an insurance company because of a negative ELISA test result? Yes _____ No _____
- d. Have you ever been denied disability coverage by the state or an insurance company because of a negative ELISA test result? Yes _____ No _____
- e. Have you ever had a physician refuse to perform a Western Blot test for Lyme disease because you tested negative for Lyme disease with an ELISA test? Yes _____ No _____

2. Western Blot:

- a. Have you ever been told that you did not have Lyme disease because a Western Blot did not have at least 5 of the 10 CDC approved IgG bands or 2 of the 5 CDC approved IgM bands? Yes _____ No _____
- b. If so, in what year did this occur? _____
- c. Have you ever been denied medical reimbursement by an insurance company because a Western Blot did not evidence at least 5 of the 10 CDC approved IgG bands or 2 of the 5 CDC approved IgM bands? Yes _____ No _____
- d. Have you ever been denied disability coverage by the state or an insurance company because a Western Blot did not evidence at 5 of the 10 CDC approved IgG bands or 2 of the 5 CDC approved IgM bands? Yes _____ No _____

3. Diagnosis.

- a. In what year were you first diagnosed with Lyme disease? _____
- b. On what basis were you diagnosed with Lyme disease? (Check below)

ELISA _____ Western Blot _____ PCR _____

Clinical Symptoms _____ Spinal tap _____ Other _____

**CDC considers an immunoblot positive for IgM if 2 of 3 bands are present: 24 kDa, 39 kDa, & 41 kDa...and for IgG if 5 of 10 bands are present: 18 kDa, 21 kDa, 28 kDa, 30 kDa, 39 kDa, 41 kDa, 45 kDa, 58 kDa, 66 kDa, & 93 kDa.*

Tell me about the National Survey Program.

The California Lyme Disease Association (CALDA), an affiliate of the national Lyme Disease Association, has launched a National Survey Program to compile the data necessary to support our healthcare advocacy issues. Survey data is much more useful than anecdotal evidence because it tells the extent of the problem on a broader basis. Many legislators and other public policy officials prefer survey data to illustrate a point.

Do I have to identify myself?

While it is not absolutely required, we strongly recommend that you do so to lend strength to the validity of the study. In order for surveys to be deemed valid for scientific and advocacy use we have to ensure that there are no duplicates. We request your initials plus your 6-digit birthdate (00/00/00) because it is an anonymous but unique identifier. When we compile the data, we will use this number to insure that there are no duplicates. We also request your ZIP code so we can customize reports by state. However, we will not disclose this information to anyone else. Nor will your identity be included in any reports compiled from the data.

What will CALDA do with the information?

CALDA will publish the results in **the Lyme Times** as soon as the survey is completed. People may then use the information in discussions with legislators, public health officials, etc.

*Fold over in thirds so address is on the outside,
seal with tape, stamp and mail.*

Visit the CALDA website at www.lymedisease.org

Please feel free to copy and distribute this questionnaire.

From _____

*Stick
stamp
here*

**CALDA Administrative Office
PO Box 707
Weaverville CA 96093**

ATTN: Surveys