

This restricted meeting in May 2005 was the genesis of the corrupted Lyme disease guidelines issued by the Infectious Diseases Society of America (IDSA) in 2006 and investigated by the Connecticut Attorney General for antitrust violations. Attendees included the NCID, CDC, and Dr. Walter Stamm of the University of Washington and a past president of IDSA. The subject of eliminating “rogue guidelines” advocating long-term treatment for Lyme disease (International Lyme and Associated Diseases Society) was discussed. Disparaging comments were made about Lyme disease patients, their doctors, and the laboratories that serve these patients. Excerpts of the minutes are below.

National Center for Infectious Diseases

<http://www.cdc.gov/maso/FACM/pdfs/BSCNCID/20050512%20BSCNCID%20Minutes.pdf>

The second topic of discussion among members of the breakout group is Lyme disease --- particularly the challenges presented by this disease that extend beyond science. Recently, highly organized groups of people have been expressing concern for CDC’s current case definition and laboratory criteria. Much of this effort has been triggered by unpaid insurance claims from patients with symptoms that are not included in CDC’s case definition for Lyme disease. In addition to these vocal organized groups, laboratories across the country are conducting inappropriate, or questionable, testing for Lyme. The tests are being sent to physicians who have not been appropriately trained to interpret them.

The breakout group issued the following recommendations for DVBID regarding these Lyme-disease-associated issues.

- The IDSA guidelines should be updated; a consensus document should be made available to physicians who need guidance.
 - The CDC guidelines for interpreting laboratory tests should be updated in collaboration with industry and government experts.
 - As updated guidance becomes available, an effort should be made to notify physicians and other practitioners regarding availability of clinical and laboratory documents.
 - CDC researchers should focus on science and not on the concerns of patient groups; other groups may need to step in and assist DVBID with public interface.
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- Dr. Eberhart (CDC) stated that inappropriate laboratory testing and treatment are occurring in many states. Commonalities throughout the states should be identified. Dr. Quinlisk concurred; she receives e-mails from constituents asking why the state health department does not agree with their private doctors. Many of these constituents can not be convinced by science; therefore, accurate information should be distributed to clinicians.
- Dr. Stamm (IDSA) commented that rogue guidelines are legitimizing long-term treatment for chronic Lyme disease; as long as these guidelines can be accessed, this type of treatment can be legitimized.