



P.O. Box 8211 • McLean, VA 22106-8211 • Phone & Fax 703-821-8833 • NatCapLyme@natcaplyme.org

Statement on CDC Guidelines Posting Policy

On behalf of the National Capital Lyme Disease Association this statement is published to express our serious concern over the CDC continued posting and endorsement of the IDSA treatment guidelines and refusal to post the ILADS Guidelines. The ILADS Guidelines are actually written to a higher standard and are newer than the IDSA Guidelines, which are based on outdated and, in some cases, discredited studies. It should be noted that the IDSA Guidelines have been removed from the National Guidelines Clearinghouse, but they remain on the CDC website at: <http://www.cdc.gov/lyme/treatment/>. Given their withdrawal from the NGC, they should be withdrawn from the CDC website.

Should the IDSA resubmit its guidelines to the National Guidelines Clearinghouse, we will be anxious to review the new peer reviewed literature they will cite to support them and how the IDSA has met the standard set forth in the congressionally funded, Institute of Medicine (IOM) report, [Clinical Practice Guidelines We Can Trust](#). At that time, the Lyme patient community will demand an opportunity to review and comment on them.

The current, withdrawn IDSA guidelines are based on several studies that are frequently cited to prove the proposition that long term antibiotic treatment is useless and potentially dangerous. However, a hard look reveals that studies frequently cited to support those assertions have either been criticized for design flaws and premature conclusions or may actually show statistically significant benefits from extended courses of antibiotic therapy. Nevertheless, neither the IDSA nor the CDC has responded to that criticism or provided objective analysis of it.

CDC officials have stated that the CDC “believes” the IDSA’s guidelines are the best evidence-based information for physicians. But “belief” alone is not science and is insufficient when the so-called evidence basis has been rebutted.

To justify the CDC’s failure to seriously address the issue of treatment protocols, its officials have represented many times that the CDC mission is one of prevention, not treatment. Yet, the partisan posting of only the decade old, withdrawn IDSA guidelines while a legitimate controversy over treatment protocols rages on across the USA and a minimum of 329,000 new cases of Lyme are diagnosed every year cannot be seen as anything other than emersion in the controversy over treatment.

Patient groups have clearly demonstrated that thousands of sufferers from Lyme and associated tick-borne diseases are losing their battle for health and the pursuit of happiness due to the failure of our national institutions to address this growing epidemic in any meaningful way. To paraphrase the great physician, philosopher and scientist Moses Maimonides; there is no point to science without progress.

Physicians who do try to treat chronic Lyme patients are investigated and prosecuted by state medical boards and a principal weapon used against them is the CDC's endorsement of the IDSA guidelines. Indeed, they are frequently referred to simply as "the CDC guidelines." The result is that doctors are afraid to report the real incidence of Lyme and patients are left to fend for themselves.

Meanwhile, the CDC and NIH have diverted their focus to the highly dubious goal of creating a vaccine before we even have a valid and reliable test for the disease or have classified all of the strains of the disease, complicating the ability to know whether a vaccine can even be valid. The CDC and Mayo Clinic recent discovery of a new species of Lyme disease bacteria (*Borrelia mayonii*) validate this concern. <http://www.cdc.gov/media/releases/2016/p0208-lyme-disease.html>

We in the Lyme community trenches can only conclude that the CDC's continued endorsement of those supposedly evidence-based studies without objective analysis of the criticism is hypocritical at best. We ask of our government and our expert agencies to come to the aid of those who are sick and for whom a reliable answer has not been found. If they cannot, then leave us to find to answers on our own, but please do not post blockades to our efforts.