

## **IDSA Lyme guidelines removed from NGC; ILADS guidelines still there**



The National Guidelines Clearinghouse—a federal database that provides treatment information to health care professionals and insurance companies—has removed the IDSA Lyme disease treatment guidelines from its website recently.

This means that the only Lyme disease guidelines listed on the NGC are those of ILADS, which were posted in 2014. This is quite good for the Lyme community. Here's the backstory.

In 2006, shortly after the IDSA published its most recent guidelines on the treatment of Lyme disease, an antitrust investigation was filed by then-Connecticut Attorney General Richard Blumenthal. (Blumenthal is now a U.S. senator.)

The IDSA settled the antitrust investigation by agreeing to review its guidelines in a public hearing—which provided essentially equal time for the IDSA and patients, clinicians, and scientists who held opposing views.

The hearing panel released its findings in 2010. The panel for the hearing was exclusively IDSA members so it is no surprise that they endorsed their own society's guidelines—although panelists did recommend 25 changes. Nevertheless, the IDSA advised the NGC that the IDSA had reviewed its guidelines and that no change was necessary.

Based on the IDSA's assertion, the NGC allowed the IDSA guidelines to be posted for an additional five years essentially without having to actually review and revise the guidelines. LymeDisease.org [protested this extension with the NGC.](#)

However, in 2014, the NGC [revised its criteria for listing guidelines](#) to conform to some of the [standards adopted by the Institute of Medicine in 2011 for creating trustworthy guidelines.](#) These standards included using a rigorous evidence review system. The ILADS guidelines, which were authored by Lorraine Johnson (LymeDisease.org), Dr. Dan Cameron (ILADS), and Dr. Betty Maloney, conformed to the high evidentiary standards of the IOM. Although the IDSA guidelines did not conform, because they were filed before the NGC adopted the IOM standards, they were given a "free pass" on compliance.

LymeDisease.org thought it was highly likely that the IDSA would file another "no change" extension of its guidelines and that the NGC would continue its "free pass" for non-compliance with the IOM standards. However, the NGC recently delisted the IDSA guidelines. This is

because the guidelines had passed their five-year mark and did not comply with the more stringent requirements.

The IDSA guidelines are currently undergoing revision. The IDSA's guideline revision process was publicly posted for comment in May 2015. LymeDisease.org and the Lyme Disease Association led an effort to gather comments from close to 90 groups protesting the process—which among other things—[did not include a Lyme patient](#) as required by the Institute of Medicine.

LymeDisease.org launched a patient survey called for comments on the IDSA guidelines on March 27 and filed [comments from over 6,100 patients](#) in less than a month. After the protest regarding the failure to include a Lyme patient on the panel, in response to pressure by U.S. congressmen, the IDSA suggested that it might reconsider putting a Lyme patient on the panel. We do not know the revision schedule for the IDSA guidelines.

But for now those guidelines have been removed from the NGC as outdated and not in compliance with current standards. This leaves the ILADS guidelines for the treatment of Lyme disease as the only guidelines currently posted on the NGC.

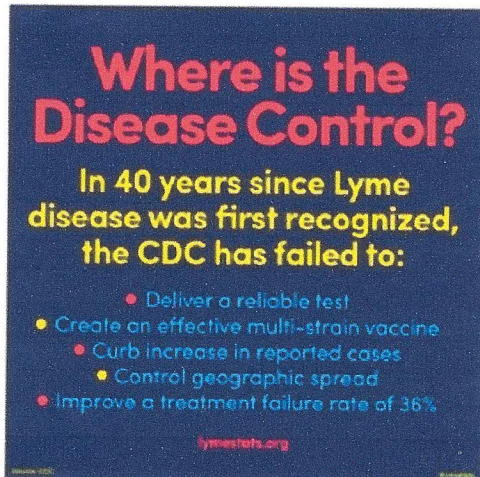
*The LYME POLICY WONK blog is written by Lorraine Johnson, JD, MBA, who is the Chief Executive Officer of LymeDisease.org. You can contact her at [lbjohnson@lymedisease.org](mailto:lbjohnson@lymedisease.org). On Twitter, follow her [@lymepolicywonk](https://twitter.com/lymepolicywonk).*



# Advocates Call on CDC to Remove Expired Lyme Guidelines from all Publications

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CDC has failed to protect the public health and has made matters worse by endorsing outdated treatment guidelines that misrepresent science and restrict access to care for chronically ill patients.

*KB:* After a decade of controversy, the Infectious Diseases Society of America (IDSA) [guidelines for treatment of Lyme disease](#), first posted in 2006, have lapsed and been removed from the National Guideline Clearinghouse (NGC). Lyme patients and advocates are calling on the CDC to follow suit and remove references to the IDSA guidelines from all CDC publications.

During a January 26-27, 2016 telethon, Lyme patients and advocates from more than 45 states called on their representatives and senators in Congress to compel CDC to end its preferential treatment of the IDSA guidelines and investigate how conflicts of interest have influenced Federal policy on Lyme disease.

*KB:* The [position paper](#) for the telethon describes how CDC provides preferential treatment to IDSA by promoting IDSA's 2006 guidelines for Lyme disease while withholding information

from the public about the more current and more comprehensive 2014 Lyme guidelines from the International Lyme and Associated Diseases Society (ILADS).

J.B.: According to Allison Caruana, co-founder of the Mayday Project Lyme patient advocacy group, "It has been 40 years since Lyme disease was identified, yet CDC has failed to protect the public health and has made matters worse by endorsing outdated treatment guidelines that misrepresent science and restrict access to care for chronically ill patients."

Unlike the ILADS guidelines, the IDSA guidelines do not comply with the Institute of Medicine (IOM) Standards for Developing Trustworthy Clinical Practice Guidelines or with the Grading of Recommendations Assessment, Development and Evaluation (GRADE) Working Group standard for rating evidence and recommendations.

J.B.: "What's more troubling," says Caruana, "is that CDC officials who provide the preferential treatment are also members of IDSA, the organization receiving the preferential treatment—a glaring and long-standing conflict of interest."

Caruana points out that CDC's preferential treatment of IDSA violates the Standards of Ethical Conduct for Employees of the Executive Branch, which states: "Employees shall act impartially and not give preferential treatment to any private organization or individual."

In response to CDC's refusal to end its preferential treatment of IDSA, The Mayday Project has scheduled a solidarity rally May 19-20 at CDC headquarters in Atlanta.

### **About the Mayday Project**

The Mayday Project was formed by a group of volunteers who have been touched by Lyme disease. Mayday advocates for more accurate tests, better guidelines, improved access to treatment, improved education for physicians, and more funding for research.