

Re: Urgent notice on Congressional letter

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This is what LDF misrepresented as a "law". It was NOT. It never was. It was part of the language in a committee report. It was not identical to the report of the House nor to that of the conference which was created to resolve differences between language in the Senate appropriations LAW and that of the House (this is part of the legislative process, bills have to be passed indentially in both houses, conferences are used to resolve differences in language, see how a bill becomes a law recently posted here)

This language had no mandatory effect and little symbolic or salutary effect in that it is routinely ignored--look at the report in question it contains provisions about many many pet causes of congressmen or senators or both.

And Lyme patients ran around telling doctors, insurance companies and legislators about this great new "law" and LDF in some desperate attempt to prove that they still had some relevance to Lymeland and in an attempt to "win" the battle of the two bills raging between ldf and lda new jersey "the karen" vs "the pat"

Well so this is it.

You can probably tell from the language that there's nothing mandatory about it. And as I said as a practical matter in the real world of NIH and Congress this kind of stuff is routinely ignored.

LDFTF Jan 30 2002, 6:02 pm show options

Newsgroups: sci.med.diseases.lyme

From: l...@aol.com (LDFTF) - Find messages by this author

Date: 31 Jan 2002 02:02:18 GMT

Local: Wed, Jan 30 2002 6:02 pm

Subject: New Federal Law could help Lyme Docs and Patients

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Dear Friends

I am pleased to announce a new Federal Law (Public Law 107-116), that will have a major impact on the Lyme disease community, has passed the Senate and House, and was signed by President Bush on January 10, 2002. We and others have worked on the Lyme wording in this bill for over a year and know it will be of great benefit to physicians and patients across the country. This is another way we are helping our doctors in medical licensing hearings, insurance reimbursement, and other issues.

This law reinforces that the CDC's Lyme disease (LD) Case Surveillance Definition is not a standard of care for the diagnosis and treatment of Lyme disease. Sections of medical protocols that rely on the CDC LD Case Definition for diagnostic or treatment standards are misusing this protocol and should be invalid. A copy of the wording is on the lower part of this sheet.

This Public Law Appropriations wording states, along with other things about Lyme disease, that the CDC's case surveillance definition "is reportedly misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases." This reinforces that protocols misusing this case definition are inappropriate standards of care. The wording then instructs the CDC to correct this misuse. Other important wording includes concern about the Lyme vaccine, broadening of the Lyme Case Surveillance Definition, and development of an improved test.

I hope you join me in thanking Congress and the President for standing up for our rights and ask them to please help us with the next step....Sign onto the LIFT Act in the Senate (S969) and the House (HR 2118).

Sincerely,
Tom Forschner

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Executive Director
Lyme Disease Foundation

Excerpts from Public Law 107–116 Signed by President Bush 1/10/02
Departments of Labor, Health, and Human Services, and Education, and
Related
Agencies Appropriations Act 2002

Senate Appropriations Report Language – S.1536, SR.107–84.

This is the actual wording that was passed by the Senate (11/06/01,
12/20/2001)
and
House (10/11/01, 12/19/01) and included as part of the final bill that
was
signed
into Public Law by President George Bush on January 10, 2002.

Centers for Disease Control and Prevention

Lyme Disease – The Committee is deeply concerned about the safety of
the
Lyme disease vaccine (LymeRix). Over 1,000 adverse event reports were
filed
with the Food and Drug Administration from December 1998 to October
2000. The
Committee encourages CDC to work closely with the FDA to ensure that
all
adverse event reports are thoroughly and expeditiously investigated to
ensure
public safety as the vaccine is being distributed. Investigators should
pay
particular attention to patients' reports of arthritis when evaluating
these
reports.

The Committee recognizes that the current state of laboratory testing
for
Lyme disease is very poor. The situation has led many people to be
misdiagnosed and delayed proper treatment. The vaccine clinical trial
has
documented that more that one third (36 percent) of the people with
Lyme
disease did not test positive on the most sophisticated tests
available. The
ramifications of this deficit in terms of unnecessary pain, suffering
and
cost is staggering. The Committee directs CDC to work closely with the
Food
and Drug Administration to develop an unequivocal test for Lyme
disease.

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The Committee is distressed in hearing of the widespread misuse of the current Lyme disease surveillance case definition. While the CDC does state that 'this surveillance case definition was developed for national reporting of Lyme disease: it is NOT appropriate for clinical diagnosis,' the definition is reportedly misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases. The CDC is encouraged to aggressively pursue and correct the misuse of this definition. This includes issuing an alert to the public and physicians, as well as actively issuing letters to places misusing this definition.

The Committee recommends that the CDC strongly support the re-examination and broadening of the Lyme disease surveillance case definition by the Council of State and Territorial Epidemiologists. Voluntary and patient groups should have input into this process. Currently there is just one definition ('confirmed case') of seven possible categories. By developing other categories while leaving the current category intact, the true number of cases being diagnosed and treated will be more accurately counted, leading to improved public health planning for finding solutions to the infection.

The CDC is encouraged to include a broad range of scientific viewpoints in the process of planning and executing their efforts. This means including community-based clinicians with extensive experience in treating these patients, voluntary agencies who have advocacy in their mission, and patient advocates in planning committees, meetings, and outreach efforts.
Thomas E. Forschner
Executive Director
www.lyme.org