

LDF LYME DISEASE FOUNDATION

GREAT NEWS! LYME DISEASE IN THE FEDERAL BUDGET!

Dear Friends:

I am pleased to announce the LDF's success in having Lyme disease addressed in the House and Senate Federal Budget Report that accompanies Federal Law (Public Law 107-116) that was **signed into law by President Bush** on January 10, 2002.

Why is this Report important? Charles W. Johnson, Parliamentarian, United States House of Representatives, (House: How are Laws are Made, 1/31/00, <http://thomas.loc.gov/home/lawsmade.toc.html>) answers the question:

“Committee reports are perhaps the most valuable single element of the legislative history of a law. **They are used by courts**, executive departments, and the public as a source of information regarding the purpose and meaning of the law.” Elsewhere Johnson wrote, “The *report describes the purpose and scope of the bill* and the *reasons for its recommended approval*. Generally, a section-by-section analysis is set forth explaining precisely what each section is intended to accomplish.”

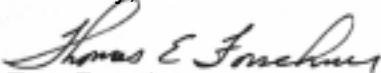
This is another way we are helping doctors in medical licensing hearings, patients receive insurance reimbursement, and continue to work towards improving the standard of care patients of tick-borne disorders receive!

This report states that the CDC's case surveillance definition is **“misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases.”** This reinforces that protocols are not to be based on the case definition. **The wording also instructs the CDC to correct this misuse!** Other important wording addresses concerns over the *Lyme vaccine, broadening the Lyme Case Surveillance Definition, and encouraging development of an unequivocal (perfect) test*. While the agencies may choose to ignore the *Will of Congress*, they do so at their own peril and risk repercussions.

The LDF, Lyme Society, New Jersey and Illinois Task Forces, and others worked on the law's Lyme-related wording for over a year and are confident it is of great benefit to physicians and Lyme disease patients nationwide. Because this language could have been altered before the President signed it into law, the LDF remained silent about this. Now it is time to celebrate. As of April 2002, this language has been used by doctors in licensing board hearings, courts cases, and by patients to successfully obtain insurance benefits.

I hope you join me in thanking Congress and the President for standing up for our rights.

Sincerely,


Tom Forschner

Departments of Labor, Health, and Human Services, and Education, and Related Agencies Appropriations Act 2002 Report

Explaining Congressional Intent on How the Budget Money is to be spent.

[Senate Appropriations Report Language](#) - S.1536, SR.107-84.

This is the 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 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

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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 than 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.

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.*

[National Institutes of Health - Office of the Director](#)

Lyme disease - The Committee recommends that the NIH improve its communication across Institutes in order to better coordinate Lyme disease research and outreach to public and private scientists with the goal of stimulating research interest in this field. The Committee encourages the Office of the Director to involve NIAID, NHLBI, NINDS, NEI, NIMH, and NCCAM in promising areas of research.

The Committee urges NIH officials to identify appropriate NIH advisory committees for Lyme disease representation and ensure the appointment of qualified persons. ***The NIH is encouraged to include a broad range of scientific viewpoints in the process of planning and executing these efforts, including community-based clinicians with extensive experience in treating these patients,*** voluntary agencies who have advocacy in their mission, and patient advocates.

[Social Security Administration](#)

The Committee understands that some patients with Lyme disease and other tick-borne disorders have encountered some difficulty when applying for assistance through SSA offices, due to SSA employees' unfamiliarity with these illnesses. SSA is encouraged to work on developing educational materials for SSA employees to facilitate a better understanding of the potential debilitating effects of these disorders. The Committee suggests that SSA collaborate with clinicians who have expertise on the multi-system chronic effects of Lyme, as well as patient and voluntary communities, to accomplish this goal."

Please distribute a copy of this to as many places as possible, including doctors offices, state medical licensing boards, insurers/HMO's, state attorney generals, health departments, and hospitals.