

LYME DISEASE FOUNDATION

P.O. Box 332, 384-z Merrow Road, Tolland, CT 06084

860-870-0070 Fax: 860-870-0080 www.Lyme.org 501(c)(3) Est. 1988

Protecting people and pets from Lyme disease and *other* vector-borne disorders.

Babesiosis, cat scratch disease,
Colorado tick fever, ehrlichiosis,
anaplasmosis, Master's disease, tick
paralysis, tularemia, Powassan
encephalitis, Rocky Mountain spotted
fever, dengue/dengue hemorrhagic
fever, West Nile virus, yellow fever,
Eastern equine encephalitis, plague, Q-
fever, relapsing fever, and tularemia.

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Educator

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5018

Feb. 3, 2009

Dear Insurance and Real Estate Committee:

I started the Lyme disease movement 20 years ago when I cofounded the *first* Lyme disease organization in the world - the Lyme Disease Foundation ("LDF"). I and my baby son were suffering from Lyme disease and needed answers. Since then, our growing team have been advocating regarding prevention and improved health care for the public, businesses, government, and patients. While Jamie died in 1991, during a Lyme relapse when his brain was so inflamed it crushed itself. I continue to volunteer my time at the LDF.

Despite 20 years of scientific research, there is still no perfected test that can prove who is infected and who is Lyme bacterium-free. Therefore, doctors rely on an imperfect immune system test. Unfortunately, that test will only capture, at best, 64%¹ of the positive cases. Despite the test's failures, insurance coverage guidelines depend on the test as its hallmark for diagnosis and treatment - leaving thousands of Lyme patients with unpaid medical treatment bills or without access to treatment, *except* for Connecticut residents. In our state, we have a Lyme treatment mandate that provides patients with coverage.

H.B. 5018 threatens Connecticut's Lyme disease treatment mandate and any future mandate that we and others may need for tick-spread diseases, cancer, or any other health issue.

I am asking that every Connecticut Legislator vote against Conn. H.B. 5018 for the following reasons.

1. The bill creates a disfavored status for individuals seeking state health mandates to correct health insurance coverage abuses.
2. The bill attempts to repeal insurer-disfavored mandates, such as coverage for Lyme disease treatment, as well as place a post-statute block to the implementation of ALL future healthcare mandates.
3. The bill's "independent working group" violates the state's legislative process and possibly the Connecticut Constitution because it abrogates a portion of the legislative process to a non-elected, non-Legislative, non-Executive branch committee that is being vested with the authority to place a temporary to indefinite hold on the implementation of new state statutes.

Worse yet, this "working group" has no: terms or conditions for selection of members, reporting authority to the legislature, budget for expenses

¹ Source: SmithKlineBeecham's Scientific Director largest Lyme clinical trial in history.

incurred, legal council for the group, statement of the criteria to be used for the cost-benefit analysis, method for public or legislative input into the group's process, transparency of action, parameters for where the analysis is to be submitted, maximum time frame for the group's hold on a new statute (while the committee completes its work), and any logical connection to why such a group is actually necessary after a bill has passed.

4. The bill is unnecessary and fiscally irresponsible because the legislature can obtain the same analysis during the legislative process through the existing transparent and already funded legislative offices such as the *Office of Fiscal Analysis* and the *Office of Legislative Research*.
5. The bill is unnecessary because outside groups, such as those that would theoretically make up the "independent working group," are *already able* to provide their views and cost-benefit analysis to legislators, allowing those concerns to be aired during the process of a bill becoming a law. Why should just health mandates be subjected to a discriminatory post-statute extra-regulatory process when no other bills are?
6. Even if the bill is modified to exclude the current Lyme disease mandate, the bill's significant flaws still stand. In addition, any future tick-borne disorder legislation will still be discriminatorily burdened by H.B. 5018's post-statutory process.
7. The bill's "working group" may have troubling anti-trust implications if it were not otherwise statutorily created by the state. If this is true, then that fact alone should prohibit the passing of the legislation.
8. If some group wants to change the existing statutes, they should do it just like every other group and individual in the state, without favored access being legislated just for them.

It is clear that this bill's intent is to offer insurers/businesses one last chance to thwart the legislative intent of a new statute, so that they can lobby for the statute's reversal prior to implementation. At its worst, this committee provides a secretive nontransparent post-legislative review process.

I urge you to vote against this legislation because it is unnecessary, burdensome, expensive, and possibly unconstitutional.

Sincerely,



Karen Vanderhoof-Forschner