

# LDA Support for MN Bill – HF 2597

The Honorable John Ward  
533 State Office Building  
100 Rev. Dr. Martin Luther King Jr. Blvd.  
Saint Paul, Minnesota 55155

Dear Representative Ward,

I was pleased to have the opportunity to speak with you when I traveled to Minnesota last summer to take part in the Senator briefing hosted by Senator Marty on the Lyme disease physician protection bill. I am writing now to express the support by the Lyme Disease Association for HF 2597, of which you are Chief Author.

As you may already know, the Centers for Disease Control and Prevention (CDC) reported numbers which show that confirmed cases from Minnesota represented close to 4% of the total reported confirmed cases for the US for 2008, a startling statistic indeed. The 1,046 confirmed cases in Minnesota for 2008 translate into 10,460 actual cases in Minnesota, as the CDC indicates reported cases numbers are about 10% of actual cases that meet their surveillance criteria—neither of those numbers include clinically diagnosed cases by the way.

According to an IDEXX Reference Lab (veterinary) survey over a roughly 6 year period ending early in 2007, 15,782 canine cases of Lyme disease occurred in Minnesota with over 500 cases in dogs found in each of 14 counties, and many other counties with lesser numbers of cases. During the same period, 15,153 Minnesota dogs were positive for anaplasmosis, a disease transmitted by the same deer tick that transmits Lyme disease.

The military is obviously concerned about Lyme disease in the State. To monitor the prevalence of tick-borne diseases such as Lyme, Camp Ripley has implemented a Lyme Disease Risk Assessment Survey partnering with the Mayo Clinic, the U.S. Army Center for Health Promotion and Preventative Medicine, the University of Minnesota and the Minnesota Department of

Health. The Camp has the largest database on tick infestation in the State of Minnesota.

It is imperative that those who develop a Lyme disease infection get diagnosed and treated early to avoid chronic Lyme disease. Congress has recognized the seriousness of Lyme and its chronic nature in the recently enacted "Fiscal Year 2010 Labor, Health & Human Services, Education Appropriations bill." Report language in the appropriations in the area of the CDC includes "Lyme Disease- The Committee encourages CDC to expand its activities related to developing sensitive and more accurate diagnostic tools and tests for Lyme disease, including the evaluation of emerging diagnostic methods and improving utilization of diagnostic testing to account for the multiple clinical manifestations of acute and chronic Lyme disease; CDC was also given an additional \$3.6 million toward its work on Lyme disease including the above language."

In the section on the National Institutes of Health, NIAID, "The Committee encourages the NIAID to sponsor a scientific conference on Lyme and other tick-borne diseases that would represent the broad spectrum of scientific views on Lyme disease and include input from individuals with Lyme disease. The Committee also encourages NIH to intensify research that will increase understanding of the full range of Lyme disease processes and the physiology of *Borrelia burgdorferi*, including the mechanisms of persistent infection, and research that may lead to the development of more sensitive and accurate diagnostic tests for Lyme disease capable of distinguishing between active and past infections."

It is clear that Congress, including, US House of Representatives Appropriations Committee Chair Dave Obey of neighboring Wisconsin, recognizes the seriousness of Lyme disease, the chronic and persistent nature of the disease, and the problems associated with the current tests. The testing is precisely why this physician protection bill is necessary – physicians need to treat based on clinical judgment.

As the national patient organization which serves as an umbrella for 34 organizations, one in Minnesota, LDA strongly supports this legislation and the benefits it will provide for patients, who have had the "deck stacked against them" from the beginning of this disease by those with

vested interests.

Lyme patients have the right to be treated with the standard of care they choose. Over 41,000 people have signed the LDA petition against the Infectious Diseases Society (IDSA) guidelines, which have become de facto law and prevented patient diagnosis, treatment, and clinical judgment by physicians. The Guidelines process was investigated by the Attorney General of Connecticut (AG), a settlement was reached by the IDSA and the AG, with IDSA agreeing to review the guidelines with a new panel. Now it appears from documents "FOIAed" (Freedom of Information Act) on behalf of patients, that the IDSA has violated the terms of the settlement agreement and substituted its own panel voting arrangement for that found in the settlement agreement. The example of improper voting given by the AG concerns the testing guideline, the one which holds so much power over patient lives.

Right now, you have an opportunity to level the playing field, prevent development of chronic disease, and help those who already suffer from chronic Lyme disease lead productive lives. It's a win-win situation.

Thank you on behalf of patients in Minnesota and everywhere.

Sincerely,

*Patricia V. Smith*

Patricia V. Smith

Lyme Disease Association, Inc.

PO Box 1438, Jackson, New Jersey 08527

888-366-6611 [Lymeliter@aol.com](mailto:Lymeliter@aol.com) 732-938-7215 (Fax)

LymeDiseaseAssociation.org

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(i) <http://www.dogsandticks.com/>

(ii)

[http://www.minnesotanationalguard.org/campripley/envir/overview/extras/es\\_award1.pdf](http://www.minnesotanationalguard.org/campripley/envir/overview/extras/es_award1.pdf)