



## International Lyme and Associated Diseases Society

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Title: Access to care for Lyme disease in Connecticut

Breakfast conference

Connecticut State Capitol Building, Harford, CT

Tens of thousands of citizens of Connecticut are at risk of developing chronic Lyme disease. In 2004, Dr. Hadler, Connecticut's Department of Public Health's epidemiologist and infectious disease specialist, testified before the State of Connecticut's Department of Public Hearing regarding the disturbing numbers of cases:

“34,000 people are getting a diagnosis of Lyme Disease in Connecticut each year”

“20 to 25 percent of all families have had at least one person diagnosed with Lyme Disease ever”

“three to five percent of all families have had someone diagnosed with Lyme Disease in the past year”

Equally disturbing are the findings that chronic Lyme disease patients suffer for years with a poor quality of life.

Onset of illness of 4.7 to 9 years (Klempner and Fallon NIH trials)

The Infectious Diseases Society of America (IDSA) dismisses chronic Lyme disease as nothing more than the aches and pains of daily living. Yet the both the Klempner and Fallon studies found that these patients have a quality of life worse than type II diabetes and a recent heart attack. The IDSA offers no effective treatment options for these patients, and, worse, denies these patient access to the only treatment option that we know is effective in treating Lyme, antibiotics. The IDSA does not tell doctors that the treatment studies are limited and their conclusions conflicting. As many doctors will tell you, randomized controlled studies do not always reflect reality. Patient populations in these studies are not like the patients that doctors see in their day to day practice.

The IDSA does not tell doctors that there is a genuine difference of opinion on the best approach to treating patients—that there are treatment options. Instead, it tells patients that they are untreatable and forecloses all treatment options for patients. There is not enough evidence to foreclose treatment options. Until we have more conclusive studies, we must give physicians the freedom to practice medicine to the best of their ability and we must allow patients to choose between treatment options.

I am speaking on behalf of the International Lyme and Associated Diseases Society (ILADS), a group of forward-thinking doctors who understand the complexities of Lyme disease and are pioneering a new standard of care focused on improving patient quality of life. Thousands of Lyme disease patients in Connecticut have been successfully treated using the second standard of care described in the published ILADS guidelines.

Standards of care should be explored and debated among physicians. State medical boards should promote treatment options and respect physicians and patient choices. It is too early in the science for the Connecticut's Department of Public Health's to select one treatment modality as the "best practice," particularly when we know many treatment failures occur under the IDSA guidelines and when the IDSA offers no viable treatment options. Yet that is what the DPH appears to be doing in its disciplinary hearings against Dr. Charles Ray Jones. ILADS is disturbed that Connecticut Public Health Commissioner Robert Galvin, who has stated that the department would not initiate cases against physicians who treat chronic Lyme disease allowed the case to proceed. The Department of Public Health's action leaves a chilling effect on Connecticut physicians considering treating chronic Lyme disease with antibiotics. Chronic LD patients in Connecticut could increasingly face difficulties finding access to care by a doctor experienced in the treatment of chronic Lyme disease.

I am appealing to the Department of Public Health to allow all reasoned positions on Lyme disease so that doctors would be encouraged to exercise their clinical judgment and patients be provided with treatment options. Dr. Jones is an 81-year-old physician with 30 years of experience treating children with Lyme disease in Connecticut. The Department of Public Health has the option to drop any case including the Dr. Jones case. Only by allowing the different points of view will the medical and scientific community reach a better understanding of controversial topics such as chronic Lyme disease.

Respectfully,

A handwritten signature in cursive script that reads "D. Cameron".

Daniel J. Cameron, MD, MPH

President, ILADS