



International Lyme and Associated Diseases Society

P.O. Box 341461 • Bethesda, Maryland 20827-1461

www.ilads.org

E-mail: lymedocs@aol.com

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Committee on Public Health
Connecticut General Assembly
Legislative Office Building, Room 4005
Hartford, CT 06106-1591

Dear Committee Members,

I am writing in response to the letter of February 3 from Dr. Anne Gershon, President of the Infectious Diseases Society of America (IDSA). That letter urged you and other governors to turn your backs on patients with Lyme disease. I would like to offer a more positive approach from my organization, the International Lyme and Associated Diseases Society (ILADS).

Dr. Gershon states correctly that she represents a group of 8,000 doctors who specialize in treating infectious diseases. However, only a small fraction of that group knows anything about the diagnosis and treatment of tick-borne illnesses such as Lyme disease. Unfortunately that small faction has hijacked the IDSA policy on Lyme disease and created guidelines that severely limit the treatment of patients with tick-borne illnesses. As proof of this statement, an investigation by the Attorney General of Connecticut uncovered significant conflicts of interest and suppression of data arising from the exclusionary process that led to the IDSA guidelines formulation (<http://www.ct.gov/ag/cwp/view.asp?a=2795&q=414284>).

In contrast, ILADS is an international organization of healthcare providers who specialize in the treatment of Lyme disease and associated tick-borne disorders. The members of our multidisciplinary society care for some 50,000-100,000 patients with tick-borne diseases, and we have published evidence-based guidelines for the diagnosis and treatment of Lyme disease (available at www.ilads.org). Our guidelines are flexible and inclusive. They allow practitioners to treat patients in a more pragmatic fashion, especially if those patients are suffering from chronic Lyme disease.

A major problem is that Dr. Gershon and IDSA refuse to acknowledge the existence of chronic Lyme disease, stating that there is "no convincing published data" to support the existence of this serious chronic illness. IDSA has repeated this mantra despite evidence gleaned from more than 21,000 peer-reviewed scientific articles that chronic Lyme disease does in fact exist. The problem is that IDSA does not accept this evidence and buries its head in the sand every time the evidence is brought up. In fact, IDSA refused to meet with ILADS to discuss our concerns before the IDSA guidelines were adopted. It is certainly hard to convince an organization that doesn't want to listen to the opposing side.

Dr. Gershon employs two lines of reasoning to discredit treatment with longer courses of antibiotics for patients with chronic Lyme disease: First she states that "carefully designed and conducted studies of Lyme disease treatments have failed to demonstrate benefit from prolonged antibiotic therapy". This statement ignores the fact that there have been only four published studies that fit this description. Three studies showed benefit of longer treatment, and one did not. Thus Dr. Gershon's statement is both inaccurate and misleading.

Dr. Gershon also makes the point that "long-term antibiotic therapy may be dangerous, leading to potentially fatal infections in the bloodstream as a result of intravenous treatment". What she fails to tell you is that long-term antibiotic treatment is used routinely in patients with serious infectious diseases, such as the case of Andrew Speaker, the attorney with resistant tuberculosis who led the CDC on a global chase before he was quarantined and treated for his disease. Nobody would argue that Mr. Speaker should not receive the full course of antibiotic treatment necessary to eradicate his infection (up to two years of therapy). However when it comes to Lyme disease, such treatment is branded as "dangerous", despite the fact that antibiotics are generally well tolerated by patients and regarded as safe by the Food and Drug Administration.

And why does IDSA consider this treatment dangerous? Because they refuse to look at the facts. For example, a homecare company with extensive experience in treating patients with intravenous antibiotics for chronic Lyme disease submitted a study to IDSA for presentation at their annual meeting. The study showed that in patients who received intravenous antibiotic treatment for an average of four months, the mortality rate was zero, and the rate of side effects was less than 1%. The IDSA response to this report? They rejected the study for presentation and refused to look at the data. Once again, there is no convincing an organization that refuses to listen to the opposing side.

It is particularly sad to see that the sources cited at the end of Dr. Gershon's letter in support of her views are not articles from the peer-reviewed medical literature but rather misleading reports from Forbes Magazine, the Washington Post and Newsday. Perhaps Dr. Gershon and IDSA should stop reading the supermarket tabloids and start paying attention to scientific facts about Lyme disease.

ILADS urges legislators to support federal and state legislation intended to protect doctors who specialize in treating Lyme disease against the misleading and uninformed views of IDSA. ILADS urges you to support adequate treatment for patients suffering from chronic Lyme disease, and we urge you to consider the research information that has been suppressed and ignored by IDSA. If we continue to ignore this information, the Lyme epidemic will continue to spread with no end in sight.

Sincerely,

Raphael Stricker, MD
Past President, ILADS