

An Open Letter to Members of the Infectious Diseases Society of America

October 10, 2014

Dear IDSA Members,

Lyme disease patients from around the world are calling upon you to help revise the IDSA's diagnostic and treatment guidelines for Lyme disease. The current guidelines are outdated, do not reflect current research, and are harming patients who are unable to receive proper care.

We realize that most of the over 9,000 members of your organization are not involved in creating the Lyme disease guidelines. Nevertheless, as members of this society, you are part of a group that is dedicated to, "improving the health of individuals, communities and society by promoting excellence in patient care, education, research, public health and prevention." We are therefore calling on you to intervene on our behalf with those on the Lyme disease committee to help rectify the guidelines in the interest of patient care.

The IDSA guidelines have significantly increased the illness burden for patients with Lyme disease. The guidelines strongly influence physician decisions with regard to diagnosis and treatment of Lyme disease, and empower insurance companies to deny coverage for evidence-based treatment options that patients should be entitled to.

Large numbers of Lyme patients remain seriously ill despite receiving the IDSA recommended 2-to-4 week course of antibiotic treatment. A recently published [study by John Aucott of Johns Hopkins University](#) shows that over 30% of early diagnosed and early treated cases of Lyme disease continue to have ongoing illness and 11% of that number will continue to have severe, debilitating symptoms. Debilitation can include being homebound, bedbound, or wheelchair dependent. We desperately need care that is more effective.

Whether *Borrelia* spp. are capable of persistence after the recommended treatment is the primary question that must be answered in order to determine proper care for those with ongoing illness. Top Lyme researchers recently discussed this question during a May 2014 HHS webinar convened by Ben Beard of the CDC and moderated by Joseph Breen of the NIH and NIAID.

From the microbiology perspective, the most likely hypothesis to explain why a significant proportion of Lyme patients experience persisting symptoms is that *Borrelia*, like its spirochete cousins *Leptospira* and *Treponema*, are remarkable survivors. [Research by Kim Lewis](#) of Northeastern University presented at the recent Boston Bacteriological Meeting (BBM), shows that *Borrelia* spp. are one of many types of bacteria that have a "[persister](#)" phenotype.

The persister state is a long-term survival strategy that is increasingly recognized as the reason why other infectious diseases, such as tuberculosis, MRSA, and

Pseudomonas infections require extended periods of antibiotic treatment, often without full resolution of the disease.

Additionally, Jin Zhang at Johns Hopkins University has demonstrated that many antibiotics, including the two frontline drugs, doxycycline and amoxicillin, used to treat Lyme disease, do not kill the bacterial persister cells.

Another explanation for persisting symptoms after antibiotic treatment is co-infection with other microorganisms that do not respond or respond poorly to treatment with antibiotics. One such tick-borne agent that is increasingly identified as a co-infecting organism is Babesia, which is an apicomplexan protozoan, putting it in the same group as Plasmodium (malaria) and Toxoplasma (toxoplasmosis). As a eukaryotic protozoan, and not a bacterium, the antibacterial antibiotics used to treat Lyme disease have little effect on Babesia.

The current IDSA guidelines do not reflect this research. As a result, untold numbers of patients are suffering because physicians are relying on outdated diagnostic and treatment standards.

We are also concerned about widespread conflicts of interest among the authors of the guidelines and the exclusion of panelists with divergent viewpoints.

As you may know, in 2008 Connecticut Attorney General Richard Blumenthal, now a U.S. Senator (D-Conn), conducted an antitrust investigation of IDSA based on allegations of abuses of monopoly power and exclusionary conduct. In a May 2008 press release, Blumenthal said:

“The IDSA's 2006 Lyme disease guideline panel undercut its credibility by allowing individuals with financial interests -- in drug companies, Lyme disease diagnostic tests, patents and consulting arrangements with insurance companies -- to exclude divergent medical evidence and opinion. In today's healthcare system, clinical practice guidelines have tremendous influence on the marketing of medical services and products, insurance reimbursements and treatment decisions. As a result, medical societies that publish such guidelines have a legal and moral duty to use exacting safeguards and scientific standards.”

After reviewing the current science, we ask that you make some strong recommendations to the Lyme committee such as: the inclusion of independent experts from the Lyme disease community; the addition of some new members of the committee who can see this issue with fresh eyes; and a focus on finding the answer to the question, “If this large group of sick patients does not have chronic Lyme, what exactly do they have?”

As Lyme disease has reached epidemic proportions worldwide, it is imperative that a national action plan be implemented. We call on the IDSA to begin this process by acting with a sense of urgency to revise the guidelines for Lyme disease.

Sincerely,

Lyme disease Patients and Supporters from Around the World