

Statement from Pat Smith, President, Lyme Disease Association

Historic Move by CT Attorney General to Investigate IDSA Guidelines Process Gives Hope to Thousands of Lyme Disease Patients

HARTFORD, CT Nov. 16 — The national non-profit Lyme Disease Association (LDA), representing more Lyme disease patients than any organization in the United States, applauds Connecticut State Attorney General Richard Blumenthal for beginning an investigation into the Infectious Diseases Society of America (IDSA) Lyme disease guidelines development process. In an unprecedented move, the Attorney General's office filed a Civil Investigative Demand (CID) to look into possible anti-trust violations by the IDSA in connection with exclusionary conduct and monopolization in the development of the Lyme guidelines.

Although unprecedented, the LDA feels this action is vitally necessary to protect the welfare of chronic Lyme patients nationwide whose treatments have been impacted by the stance taken by the IDSA. Their guidelines deny the existence of chronic infectious Lyme disease and list as "not recommended" most of the conventional medical treatments prescribed by physicians as well as alternative treatments often chosen by patients for any Lyme manifestation. Even some nutritional supplements should not be an option according to IDSA.

Clinical guidelines now drive the standard of care, and these IDSA guidelines have already been published on the CDC website. They are being used to deny treatment reimbursement and will have a continued chilling effect on the small numbers of treating physicians, since clinical discretion is not recommended in the guidelines.

The October 2006 guidelines do not acknowledge that a complex bacterium such as the Lyme disease spirochete could possibly survive in the body and the brain, evading the immune system and short-term courses of antibiotics, nor do they take into consideration any other professional diagnostic or treatment guidelines such as those published by the International Lyme and Associated Diseases Society (ILADS), which discuss chronic disease diagnostic and treatment modalities. The IDSA also refused to allow patient or chronic disease-treating physician input into the guidelines process through the LDA and ILADS, respectively, although both organizations requested to be a part of the process.

The national LDA and its affiliates Time for Lyme (CT) and the California Lyme Disease Association and ILADS, a professional medical organization, had appealed to the Attorney General on behalf of patients and treating physicians, and we are encouraged by the issuance of the CID and we hope that this will lead to actions that will guarantee patients the right to be treated and support physicians' right to treat using clinical discretion.