

Lyme Disease Physicians and Patients Expose Research Group's Ploy to Silence Them

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Already caught up in an anti-trust investigation, IDSA opposes research bill in order to maintain monopoly over Lyme diagnosis and treatment options

Washington, DC – Physicians specializing in treating chronic Lyme disease and a national coalition of Lyme disease patients and their families today accused a medical research group of trying to exercise monopoly control over research on Lyme and tick-borne diseases.

"We're very disappointed," said Pat Smith, president of the national Lyme Disease Association (LDA), responding to a letter to Congress by the Infectious Diseases Society of America (IDSA) that seeks to deny patients a voice regarding the research needed to better understand the disease.

Lyme disease is a serious bacterial infection that develops from the bite of an infected tick. The disease is often misdiagnosed or goes untreated, causing many patients to suffer persistent health problems, including neurological disorders, crippling muscle and joint pain, disabling fatigue, psychological disorders, and even death. Even when Lyme disease is caught early and treated with a short course of antibiotics, the debilitating symptoms can persist and require additional longer-term treatment.

In March, IDSA wrote Congress attacking the Lyme and Tick-

Borne Disease Prevention, Education and Research Act of 2007, introduced by Chris Smith (R-NJ) and Bart Stupak (D-MI) in the House, and Christopher Dodd (D-CT), Charles Schumer (D-NY) and Chuck Hagel (R-NE) in the Senate. The broadly supported bipartisan bill calls for acceleration of Lyme disease research and creates a new federal advisory committee made up of the full range of scientific viewpoints on Lyme, including a seat for patient advocacy groups.

The IDSA is currently under investigation by the Connecticut Attorney General for abuse of monopoly power and exclusionary conduct in formulating its Lyme disease guidelines, which were developed by a panel that held significant commercial interests in diagnostic tests, vaccines, and consulting arrangements. In its letter to Congress opposing the Lyme Bill, the IDSA failed to mention this ongoing investigation.

IDSA researchers have virtually controlled Lyme disease research for the past 30 years amidst ongoing controversy surrounding its guidelines, which deny patients the right to treatment options and undermine the ability of physicians to use their clinical discretion in treating patients. IDSA provides private health insurance companies with the basis for denying long-term treatment for chronic Lyme disease.

The California Lyme Disease Association (CALDA), national Lyme Disease Association (LDA) and Time for Lyme (TFL) are non-profit organizations that were founded by individuals who had personal experience with Lyme disease, in order to address the lack of research, education and support services available for this newly emerging infection.