



Lyme Disease Association, Inc.

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To: Julia Turner Editor in Chief

By email: juliaturneratslate@gmail.com

Re: "Lyme Illiterate"

Picture an army of tens of thousands of people, sick, wasting away, many who have lost their homes, jobs, families, have no money, power or influence to use as weapons, and have few allied health care professionals who will treat their sickness. That is the picture of "the army of followers" Slate's Brian Palmer alluded to as following the Lyme Disease Association (LDA) in an article based on a multitude of unfounded assumptions.

Addressing the LDA's "army of followers," I say "followers" is a misnomer— the LDA is composed of volunteer patients and families of patients, the army is not following, but doing— helping to lead Lyme into the available technology of the 21st century, after almost 40 years of Lyme's mismanagement being left to the "experts" who continue to espouse tests and practices whose utility expired long before the turn of the century.

Currently, the LDA is working on its 16th physician CME conference on Lyme & tick-borne diseases, and in the 15 prior, world renowned Lyme researchers from places like Tufts, Columbia, NYU, Johns Hopkins, University of California, Tulane, Yale, Cornell, and Stony Brook have presented a representation of **all** the existent science, including that which supports chronic Lyme disease, not just science selected by bias. This LDA has sponsored hundreds of other Lyme education programs across the country to schools, corporations, governments, community groups and the general public and has provided \$250,000 to children without insurance coverage who desperately need help getting diagnosed and treated because of the continued misrepresentation by vested interest about Lyme being hard to catch and easy to cure. It has mailed more than 2.3 million pieces of prevention literature throughout the country. This army has been able to help endow a Lyme research center in New York, the one denigrated by Mr. Palmer, who obviously did not review any of the many published studies which have come from Columbia.

The LDA has supported research through 95 research grants, research which has appeared in 35 peer-reviewed journals including *JAMA*, *The Proceedings of National Academy of Sciences*, *Neurology*, *Emerging Infectious Diseases*, *Infection*, *Gene*, and *Genetics*. This altruistic army performs work to protect society as a whole, those infected and those yet uninfected. LDA is a non profit 501(c)(3) with no employees, and is characterized by IRS as a charity, with goals and objectives consistent with that characterization

Mr. Palmer does not characterize the other side as an army. However, I ask that you please picture the army on the other side, well funded, monies for extensive lobbying, vested interest abounding, powerful, healthy or the connections to make themselves healthy—self described experts in Lyme. It is no secret that medical societies are formed to promote the interests of members and are often no

stranger to political lobbying— one example mentioned by Palmer, the IDSA, is a 501 (c)(6), which is characterized by IRS as “creating conditions for the improvement of business conditions,” for example, “business leagues.” Palmer cites them as “the association of scientists and clinicians who study this sort of thing.” A check of the IDSA website by Slate would have revealed that not just the Lyme community advocates and lobbies— IDSA has a specific Policy & Advocacy Menu with 10 items under it, many of which are efforts to influence policies and laws, including its Comments on Medicare Program Revisions to Proposed Payment Policies under the Physician Fee Schedule for CY 2015— self interest? A check of IDSA’s 2012 990 online reveals almost 17M in revenues, 57 employees , and a VP for public policy and government relations who received almost \$1/4M in compensation, They are a business, they operate as one. An investigation of the production of the 2006 IDSA Lyme Guidelines by then Attorney General of Connecticut Richard Blumenthal, now a US Senator, uncovered a significant amount of undisclosed vested interest by IDSA in its Lyme guidelines panel.

A bit of research on a part of Slate critically examining the chronic Lyme evidence including ALL the science—not just one side— and all the stakeholders, before kicking mud on the already weary “David” and glorifying and idolizing an already powerful Goliath, would have shed much light on the controversy surrounding Lyme disease. But ignorance is bliss, and due diligence requires hard work and may unearth unpleasant realities some cannot or do not want to handle. Unfortunately, no one offers Lyme patients the opportunity to ignore reality, so the army of patients continues onward, its ranks growing by the CDC-reported 300,000 new cases annually in the US alone, and who knows how many more worldwide in 80+ countries.

Should the Governor of New York sign the bill? He should. But the tentacles of Goliath are integrated into the Lyme landscape, empowered by media such as Slate blindly trumpeting the cause of Goliath, so patients are relegated to marching with David, falling by the wayside due to disease, while Goliath has its way.

Patricia V. Smith



President

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