

Re: In Praise of Lyme Activists

Source: <http://sci.tech-archive.net/Archive/sci.med.diseases.lyme/2004-12/0998.html>

GregGerber_at_hotmail.com

Date: 12/29/04

Date: 29 Dec 2004 07:39:07 -0800

I will make my answer to these posts relatively brief. I consider Pat Smith, president of LDA, to have an official leadership position and true power. I have never heard her say that everyone who gets Lyme disease gets desperately sick, but she has addressed the issue of the treatment failures many times in many official speeches and statements. If you are saying she said something YOU need to prove it—you need to prove the positive, don't ask me to prove the negative, it doesn't exist. I am not gonna clutter this newsgroup with statements and speeches lacking the claims you say are made—that would be all of them. No I do not consider Lisa or Kathleen to be leaders or people with any official role. I do not want to continue with this argument, I consider it ridiculous.

Finally, you are not understanding what I am saying about the clones—the fact is that a significant percent of strains are proven never to disseminate in the human host, ever, meaning they cannot, by their nature, cause anything but the rash. When you count these people in a Lyme study (and say that treatment worked for them) and do not quantify their number or differentiate between them and patients infected by the true disseminating strains, you have a study rendered meaningless by noise, not a study that "has meaning for those in it." Instead, you have a study without any real meaning for how a particular individual with a known, particular strain will respond to treatment in the future. The study is telling patients that their treatment efficacy amounts to the toss of a coin, and not any biological reality. It is as if I tested those with either Lyme disease or freckles and failed to distinguish between the two groups but counted all of them as having potentially disseminating Lyme disease and said the treatment was great because those with the freckles did not develop late stage Lyme disease. The study becomes statistically ludicrous and cannot tell us what is going on.

I am happy to explain this in more detail—but the response you gave was in many parts irrelevant to this and not understanding of what I meant.

GG