

Re: In Praise of Lyme Activists

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GregGerber@hotmail.com wrote:

> *a_weisman@yahoo.com* wrote:

>> *Why not say that we AGREE with Steere's studies*

>> *(when he did studies rather than opinion pieces with no new data for*

>> *years now) which show that MOST people do well—but also document*

>> *treatment failure rates even higher than 10–20%, some show treatment*

>> *failure rates of 35%.*

>>

>> *Our real quibble should be that treatment failure rates of 10–35%*

>> *are demonstrable, real, really tragic and unacceptable.*

>

> *Weisman, I'm confused --I really never have heard an activist in a*

> *leadership position say anything but this –what you suggest. THIS IS*

> *what they say. It is what they say publicly and in their official*

> *handouts and position papers.*

Greg instead of asking me to prove the negative, why don't you prove what you say?

Incidentally, I HAVE heard the "leaders" say exactly what I have said.

I do NOT keep their "position papers" nor their handouts and I have exactly zero interest in digging around the internet.

In fact, what "position papers" are you talking about?

In fact, what "organized leadership?"

Seriously.

"Organized" leadership? Which Lymeland have you been hanging out in?

>*You have seen official positions saying otherwise?*

I have heard self proclaimed "leaders" say otherwise, yes. And ALL of them are "self proclaimed."

There's no "organization" with a voting membership. Tom & Karen head LDF because, well because they started it.

"The pat" took over lida new jersey in one of her coups. Because "she" (and honestly, I'm REALLY not sure, reminds me of the SNL character "its pat") is the pushiest battleaxe around and apparently doesn't have Lyme so it is not a fair fight between "the pat" and anyone else.

And, once in "power" none of the "leaders" has sought or welcomed input from others (when "the pat" has minions who do her bidding that is NOT the same as "seeking input"). They have not asked for the support of Lymeland for any action (issuing "action alerts" is NOT the same thing; "action alerts" are like papal edicts or executive orders, they are not susceptible to discussion debate or dissent they are calls, actually DEMANDS for action). What I mean is they have never tried to build a consensus; they have simply DEMANDED one. And when I say "Demanded" I mean that they tolerate no discussion debate input much less dissent. There is no decision making process involving others; there is simply decisions issued.

> *Where? I am not talking about random patients without an
> official voice, but the organized leadership.*

Well greg who has an "official voice"

How does one go about getting an "official voice"

The way I've seen it work is that one proclaims oneself a "leader" whether or not one demonstrates any qualities of what might fairly be called "leadership" and then begins to issue "action alerts."

"Organized leadership" what does that MEAN in the context of Lymeland?

Seriously. Please give us some details on this process; share with us your insights where you differ.

> *Where is your evidence
> that they say the flakey stuff you contend?*

I've heard it repeatedly. But I'm sure that isn't enough "evidence" for you (though you saying you haven't heard it will surely suffice?)

> *I have never heard it,
> never seen it written anywhere, not once. Of course, if some crazy
> patient on a bulletin board says something well, that is true in any
> disease, believe me, if you bother to pay attention.*

Many of the "crazy patients on bulletin board[s]" ARE amongst the self proclaimed "leaders" greg.

- > *The internet is*
- > *rife with health misinformation across the spectrum of diseases and*
- > *disorders and conditions.*

The PRIME example being LymeNUT, which, if there were an award for health misinformation would win hands down.

Hey LDA new jersey owns LymeNUT. So when their "leaders" speak there, they speak with the apparent authority of the organization. And I don't see why, even absent Ida new jersey "official" authorization, why the self proclaimed "leaders" there are any less legitimate than "the pat."

Explain to me the difference? The LymeNUTTERS declare themselves "leaders." Some of them purport to have organizations or run support groups. Some consider the FLASH board to BE their support group. They issue action alerts, engage in lobbying and legislative efforts. They are urged to call and speak for "the cause" by people like "the pat" (well she doesn't deign to post there but has other people post her messages, I don't know if she is too important or doesn't want to associate herself?).

- > *BTW, most of the Lyme outcome studies with rash entry requirements*
- need*
- > *to be thrown out, period,*

I don't agree that they need to be "thrown out." I would agree if you more reasonably suggest that they speak only to the limited group which they study and describe.

Similarly, the Klempner study used an absurd set of entry criteria which produced a completely unrepresentative group of Lyme patients (much less "chronic Lyme patients") and the results of that never fully recruited study apply only to those in the study and the tiny percentage of patients similarly situated. And some of the conclusions extrapolate from a limited and unrepresentative data set inappropriately to a population that they can't reasonably or rationally be applied to. In addition to that the extrapolations are simply unreasonable in many respects, overbroad, overreaching and ultimately without a rational basis. Nor should the Klempner study be considered anything more than a single study; often times nearly identical medical studies will produce different results, sometimes dramatically different, so the very notion that the Klempner study was in way "definitive" is facially ridiculous. It is one study; it was never fully recruited; it was halted early; the statistics were methodologically flawed; the conclusions were overbroad and to a large extent unjustified; there are certainly concerns and even allegations about manipulation of the data that I have heard raised, and basically the group studied was so unrepresentative that there is no basis for extrapolating conclusions to the world of Lyme writ large.

And by the way Phyllis, THANKS for signing off on this predictable disaster. Do you still think that we should ask her for her feedback, greg, or follow her "leadership" given this as a big part of her track record?

- > *because they didn't differentiate between*
- > *disseminating and non-disseminating clones of b burgdorferi.*

Also those with a rash may have a very different illness. The fact of the rash may signify a different strain[s] of infection; different immune responses ("better" immune responses in many cases); those w rash were by definition diagnosed early and many other problems.

Of course, if the studies didn't have other methodological flaws, they may have SOME validity as far as they go and for the groups they study but YES I would agree there is a real concern about misinterpreting the data and extrapolating it to others with "Lyme" (or a diversity of borrelial infections) and/or coinfections (most studies haven't even attempted to control for this HUGELY SIGNIFICANT factor).

- > *Look, the*
- > *treatment failure rate for disseminating clones is far higher than*
- > *studies indicate and the non-disseminating clones can be cured with*
- > *water: They do NOT disseminate and cannot by definition cause late*
- > *stage disease.*

What do you mean by "clones" here? Do you mean other strains? Please clarify.

- > *Don't be so fast to believe a study has been done well or*
- appropriately*
- > *because it comes from said academic.*

Well thanks for the tip. :-)

- > *Steere and many others have made*
- > *plenty of big time research faux pas due to poor and misleading*
- > *methodology --failure to take the clonal situation into account in*
- > *their early Lyme studies a prime example.*

LOL Listen, Steere's seminal article "The Overdiagnosis of Lyme Disease"

Steere AC, Taylor E, McHugh GL, et al. The overdiagnosis of Lyme disease. JAMA 1993;269:1812-6. was one of the most absurd things I have EVER encountered.

Just as a matter of "logic" it doesn't work. False positives are essentially defined in two ways: one, people were positive at some other lab but NOT at Steere's lab which assumed the correctness of his lab and made no attempt to control for or take into account the differences in timing of the serologies where we know the vagaries of

the testing and immune response in Lyme, so that is all kinds of wrong; and two, a false positive was defined as someone who was diagnosed with Lyme but didn't get better with an arbitrarily determined course of treatment which was never and never has been established as "adequate" other than by Steere and his ilk calling it "adequate" It was bad science and even worse logic; in fact, what someone I admire called "triumphantly circular reasoning."

Sure that study SUCKED.

Nor did the study account for the fact that the "adequate" course of treatment simply was not "adequate" in previous studies for an unacceptably large segment of the patients studied (up to 35% treatment failures and THAT using a very "generous" definition of "success" vs failure, and a relatively short term follow up notwithstanding the incidence of relapse seen to occur. And a very limited definition of symptoms in the first place, typically symptoms that may resolve on their own but ignoring other sequelae that now were arbitrarily determined to be "post Lyme syndrome" or thrown into garbage can diagnostic categories like Fibromyalgia (sic) (and I'm using "sic" there because I think that FMS IS a mistake period—perhaps that is what zip zip meant earlier? or CFS, which is too often a garbage can diagnosis, and both diagnoses being diagnostically inappropriate because, on their own terms, they REQUIRE ruling out any known disease etiology which in this case was done only peremptorily and/or arbitrarily using the "triumphantly circular reasoning."

Disturbing that this study was accepted by the medical community at large rather than critiqued and rejected by JAMA in the first place!

> *This fills the research with*
> *incredible noise, and often raises it to a level of sloppiness that*
is
> *astounding and unbelievable.*

Well, moreover, Steere and some of the others long ago stopped worrying about the pretense of "studies" and have gotten away with writing what amount to opinion pieces for years now, disseminating old "wisdom" without discussing nuance, discussing the real segment of chronic patients, without discussing or encompassing newer findings and science etc. It is if the world stopped with the publication of that paper in JAMA.

Amazing!

> *Hey I could call it sleight of hand if I*
> *weren't such a trusting soul but I would NEVER call it that, never*
say
> *such errors are intentional, that is how nice I am.*

Some might call that insufficiently skeptical or even naive. Because honestly I don't always find you to be so "nice" though I can give and get without a big concern or emotional breakdown. But I'm sure it isn't being "nice" so much as giving them the benefit of the doubt particularly where their positions are demonstrably absurd even given that benefit of the doubt. You don't NEED to say they are IIARS to make your points so you don't. Whereas I might if I thought that was it. And I'm not sure whether they really believe the nonsense (in some cases they have admitted they don't believe it in all cases but proceed to blithely gloss over the exceptions anyway) or if they are simply BAD doctors and scientists (often times doctors are NOT good scientists and scientists are NOT good doctors).

>When I see this

> kind of error I assume it is an honest error unless I have evidence to

> the contrary, and I do not.

In some instances there may be. But it might not be necessary to call it a LIE. I guess it depends on context and your purpose. Which isn't clear. I don't know WHO you are greg gerber. You have a good and wide ranging knowledge of the science and medicine (though sometimes not as good as you think) and grasp of the underlying concepts of science and medicine writ large, you claim to be the ultimate observer on the sidelines but then say you have been at lobbying sessions and meetings and claim a real inside knowledge of Lyme "politics" internal and external but claim not to take positions or be involved. You remove your posts so they won't (god forbid) be archived. Yet you have a fairly innovative notion for potentially effective Lyme research and inherently advocacy with the business model you propose. You claim to not be an expert in business but have some business experience. You are critical of some of the efforts by lyme "activists" "leaders" and "advocates" but have what appears to be some streak of loyalty in defending some of their least defensible actions, or at least their integrity and good intentions (and I really don't question their good intentions, I am SURE they mean well BUT I do question their actions and tactics and integrity, realizing that often times people who think their cause is righteous act as if the ends justify whatever means and if there is a group of "true believers" in the righteousness of their cause, it is the group in Lymeland for sure). You claim that your only "agenda" here is to watch the watchers so you are also a self appointed arbiter of THE TRUTH.

So I really don't know WHO you are. And I don't think it is necessary for you to say either but you certainly are an international man of mystery and in many ways enigmatic in your positions, frequently a moving target.

To me it doesn't matter WHO you are (though at times you do put it at issue when you claim inside knowledge, it is fair to ask, HOW do you come by it and ask you to establish bona fides with respect to such

statements).

I try to respond to what you say rather than WHO I or anyone else thinks you are. And seriously I don't care and honestly I do not have a single clue.

>*But on the other hand I wouldn't become a
> cheerleader for the perfection of Allen Steere's studies just yet if
I
> were you. You might be surprised.
>
> GG*

Well, again, thanks for the tip greg.

I do have one question, greg.

WHERE DID I EVER BECOME A CHEERLEADER FOR THE "PERFECTION" OF ALLEN STEERE'S STUDIES?

Your entire argument here is nice and well put and I really don't disagree.

WHERE DID YOU GET THE IDEA THAT I FELT OTHERWISE?

It sure wasn't from any reasonable interpretation implication or inference from ANYTHING I said.

And YOU get really annoyed when you think people are responding to arguments that YOU NEVER MADE "strawman" arguments (though it is harder to tell with you because you delete your posts to avoid god forbid them being archived).

So where did I make the arguments that you're attributing to me and responding to?

You say it is a "nasty habit" of mine or Sir Der but from my perspective I see YOU doing it all the time. And it IS annoying.

But to be clear and for the record (my posts ARE archived) I NEVER said anything different, I do NOT admire Allen Steere's "work" I think he's a LOUSY scientist, a WORSE doctor and I have no comprehension as to how what he has done has allowed him to rise to the prominence or acclaim that he has. I don't understand how better doctors and scientists haven't critiqued him and said the emperor steere has no clothes.

Of course I really don't "get" the election of George W Bush either, so perhaps I have a blind spot or perhaps I'm TOO demanding or bring too much skepticism and scrutiny to the table.

So bottom line, thanks for the argument, whoever and whatever you were responding to, I really don't and never did say otherwise or disagree except to the small extent that I state herein (e.g., I wouldn't "throw out" rash studies; I would take them for what they're worth).

I'll look forward to your comments in reply. PLEASE try to respond to what I said, not some "strawman" and if you have to respond to something I didn't say, well please don't attribute it to me.

And really and sincerely greg I hope you have a happy holiday and healthy and happy new year and I mean that to ALMOST everyone here! :-)