

Re: How Odd Again

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- *From:* itsybitsyone@xxxxxxxxx
 - *Date:* Thu, 31 Jan 2008 14:00:46 -0800 (PST)
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I am troubled by what appears to be a willingness of ILADS to associate itself with members who may be of more questionable professional qualifications and what I perceive to be questionable (financial) motivations.

This is a huge problem for me as well. Also, the association with doctors that have some pretty far out there ultra alternative ideas. Or the ones who are simply criminals. I feel bad for the ones trying to treat Lyme who get the witch hunt.

I also think that the two faces of Lyme, Striker and Steere, two ends of the spectrum, BOTH use data to their own ends and both seem to think numbers are rather, well, up for interpretation.

But the larger issue is the lack of an adequate base of documented studies supporting their very hands-on empiric observations. The simple fact is that the IDSA position is better-researched and referenced. ILADS desperately needs supporting peer-reviewed research. Don't think this is a big secret.

You don't have to be around long to pick up on that. BUT...try saying something about it.
You read Lyme Europe lately? Its like three of us against the rest. And I LIKE the people I am fighting with about this kind of thing, or, at least most of them.

I would like to be able to have the references, have the data, quit fighting about it, and get to a place where Lyme patients could actually be taken

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seriously.

OK...more seriously, anyway.

It took two more years to come to a diagnosis. The diagnosis was reached, in classic clinical terms, by the lucky happenstance of my consulting a neurologist who had recently moved here from the east. He observed that Lyme disease could cause what was happening to me...myoclonus...convulsing. Neuro symptoms. Heart trouble also.

Only two years? Sissy! lol

Took them over 30 years to accidentally diagnose me...and I grew up on the NJ shore!!!

Moved away about 12 years ago.

Damn lucky I didn't take the prednisone after the sarcoidosis misdiagnosis, huh?

Or the Sjogren's diagnosis.

If I told you all the 'clinical diagnosi' I have had each time I had to change doctors and they went "E-Gad!"

Then there were times I was actually looking to find out what was wrong and couldn't get help.

Last year, I got sick, and I told my country bumpkin doc to run an arthritis profile on me because if he was going to catch RA or Lupus, he was going to catch it then. He happens to run an elisa as part of his arthritis profile. LMAO...there it was. And bizarre too...cause my dog died of this in the early 90's and I had NO IDEA that's what was wrong with me. I'm walking proof that people shouldn't ever self-dx. I grew up around Lyme, my dog, people I knew...was bit several times, had a rash with the deer tick bite in 74 ish...I don't know if the bad one in the 80's got a rash, it was on my back. It never really occurred to me because rankly, it was slow slowly progressive until '97 that it never occurred to me...even though I suffered joint and neuro problems almost as long as I can remember. Last 5 years has been the worst.

So...despite the diagnosis...no iv, even though the then-existing IDSA Guidelines would have recommended it. I got in touch with Dr. "D", and he very graciously consulted with my doc...went on the Dr. Sam plan. After that, more followup with abx until the symptoms seemed no longer responsive to antibiotics.

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I haven't had an IV either. And because I am such late stage and a oral treatment failure, technically I should probably go there. BUT...that's a long story. Right now I have a bad fungal infection in my throat from the minocycline. She wants to start me on avelox in addition to the mino...yikes. I'm a little hesitant, to be honest. I hate antibiotics. Yes, I use an ILADS doc. What choice do I have?

So...long story short...yes, I absolutely DO believe that longterm abx therapy may be beneficial in some cases, and that the doctor and patient should be allowed to pursue that course, without fear of disciplinary repercussion. I would be a hypocrite to suggest otherwise, and don't think I ever have. I am less confident that multiple courses of ivs are beneficial or necessary and may be a result of "LLMD" personal enrichment schemes, shall we say?

There are always people very willing to take 'care' of the sick, no?

What I remain confused about, though, and am still trying to remain open-minded about, is WHY antibiotics make people feel better. Certain classes have known anti-inflammatory properties. It may well be that BOTH sides are right, in essence, that antibiotics do kill the infective organisms, but are also effective against continuing inflammatory symptoms.

There are some studies showing a neuro protective quality...I'll see if I can find the link. You've probably seen it.

I did NOT see the armageddon-apocalyptic aspects of the IDSA Guidelines that others saw. I thought some of it was very badly worded. I really still do NOT understand what all the fuss was about, or how the new GUIDELines changed things terribly dramatically.

The didn't change anything. Nothing is different. I think they ARE too stringent, but I keep telling people that in their own minds, they may actually be trying to protect us from ourselves...or from quacks. However, it is always possible that there is a conflict of interest. I think its good that it is supposedly being investigated. Only because there are studies that DO indicate possible persistent infection. To deny that possibility when there isn't proof one way or the other is wrong...problem is, we don't HAVE a real answer. If we did have proof one way or the other 100%, there wouldn't BE a controversy anymore.

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And I understand what you're saying, but I hope you realize that you are suggesting that she just be allowed to dominate this board and others simply without opposition.

No, I do not think I am saying that. I just look at it a little differently. I haven't been here dealing with the frustrations about this, granted. So, a fresh perspective on Kathleen's role here might be called for is what I am saying. I would love to have a conversation about Lyme with Kathleen. I'd be very pleased if she could prove everyone wrong about her and have an intelligent conversation about Lyme with me.

At this point I am SURE she doesn't trust me and probably doesn't trust anyone. But rather than beat up on the girl, I have no desire to fight with her. If people (not only Kathleen) are posting stuff that I feel I have the shield my kid from 100%, I find NONE of the carrying on to be acceptable. BUT I am not going to feed it, either. I'm not here to sling mud. And, unless I have a migraine and am in a really bad mood, I probably won't sling it.

That's NOT acceptable. Sane voices need to speak up. Differing opinions should be expressed.

That's what intelligent conversation is for. You see, its words. Just words. Its not like we are dealing with a national disaster here. Its not like people are dying at the hand of Kathleen. I'm tired, I tend to save my outrage for stuff that really really is action oriented. This is just a woman who was sick and emotinally hurt enough to crack. Sci.Lyme.Med will get spammed by others on other topics (BUY A RIFE MACHINE, BUT THAT IS NOT ALL...GET A BLENDER FREE), other people. It can be rebuilt anyway. Maybe even Kathleen can be rebuilt, who knows? Do we scream at the spammers? NO, its a waste of time. We can discuss that we don't agree with something that is posted without cussing and carrying on more than necessary can't we?

She knows that what she posts here is picked up by Google. She is deliberately trying to dominate.

When I worked for Studyweb, Suite101 and a few others (back in the

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90's when sites actually paid for content!!) one thing I learned about web writing. People scan, and then read what is important to them, quickly, on the web. We had to keep articles and review short and sweet. Because people do not READ. So, just because google provides a lot of clicks, people looking for happy crappy stuff on lyme that is easy to read and tells them they will get well soon will not get past the first page.

I read. But I am guilty of scanning till I find what I want. I have read a lot of her site because she has a lot of the studies I was looking for all in one place.

I am very interested in the cystic stuff, myself. There have been some interesting developments with that...observation in tissue ex vivo.

You have a link for that? I am interested in the bugs myself. On Lyme Enigma's little board (a small group of questioners like myself) I started a thread called the bugs. I don't get a lot of input on it, but I add to it when I find new stuff. I want to know:
How long do they live?
What's the maximum lifespan in cyst form?
What's the maximum lifespan period?

I want to know, why some insisit on this toxin theory and where is the evidence?

I want to know more about OSP's. I just want to know more about the life cycle of the bug in general.

Yep. Cool. No problem. But also please understand that this battle has been going on for a long time. There are others who are more or less reflections of Kathleen to a greater or lesser degree. And there are emotions, too...

I have to split...maybe more tomorrow...gotta go home...we'll talk more later.

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