

Re: Strange Illness For Over One Year, Please Help!

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- *From:* Susan <nevermind@xxxxxxxxxx>
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x-no-archive: yes

Robert wrote:

I was referring to relapsing fever Borrelia. Lyme Borrelia are found in ticks quite easily with phase microscopy.

Yes.

In humans that is of limited value. I did not say that was routinely done or practical for human diagnosis. I don't need a Medline search to tell me what I have been doing all these years.

I have been asked by ER doctors on how to diagnose Lyme disease and what tests to do. Not because they really didn't know what to do only that they are expecting something recent or cutting edge in finding a rapid test for it. None exists. I told them it is diagnosed clinically and serology takes a week to get back.

When possible, it can be useful to send a punch biopsy from the leading edge of any rash to a lab capable of culturing borrelia, but there are very few who do this competently, IIRC.

I am involved clinically. Research is research which means unproved and unevaluated in a clinical setting. Some research never finds it's way out of research. Only useful proven research makes it's way into clinical practice.

Not so. Much unproven research makes its way into clinical practice. TBD serology is one such thing. Nothing is proven, hence all the controversy.

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If I understand your stance on the state of affairs on Lyme research is that all tests are useless. That's a step back and not forward. Tell us something we don't know.

I wouldn't say all tests are useless. A positive test can confirm what can be a difficult clinical diagnosis. It's just not to be used as it so often is, and has been in the case we were discussing, to rule out disease.

Again you misquote him.

Were you in the room? I was, with about 20 other folks.

Are you telling me he would not do any serology testing at all?

He's not a clinician, so I doubt he would. His point was that the tests are not capable of meeting a *diagnostic* standard.

>There are diagnostic test out there that many people have been diagnosed with.

Tests which should have been used to confirm a clinical diagnosis, not rule it in or out on their own.

>A rise in titer is definitive for current infection along with Western blot for antigens.

A lack of rise in titer means nothing. Unless a doctor demands that all bands be reported (not just absurdly exclusive bands on the WB) one might miss useful, B.b specific bands. Thus, a confirmatory test is too often reported as non-reactive.

What he meant to say was there is no test that will pick up all cases of Lyme disease.

The exact, verbatim quote was, "there is no clinically meaningful diagnostic test for Lyme disease."

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>You can not depend on serology to always diagnose the disease.

Especially not TBDs.

If you have primary syphilis diagnosed with dark field microscopy and given antibiotics then you will never develop antibodies to syphilis. You will never have a positive serology test for syphilis. The same goes for Lymes disease.

Or you may mount an immune response that the FDA test kit isn't equipped to detect, for the approx. 75% of genetic strains that the kit doesn't look for. Abx can definitely abrogate immune response, and B.b is gifted at evasion, too, as mentioned earlier.

>Antibiotics interfere with antibody

production so if you suggest to treat all with classic disease then you might not get serological evidence in the future.

I'm disabled by long term undiagnosed mixed TBDs, my child was horribly ill with the same for 3 1/2 years, finally cured years ago my empiric trial of atovaquone/zithromax after good, not great results on abx; ask me if I give a rat's ass about test results, compared to early, curative treatment.

I just care about results.

That is what I am saying when it comes to the immune system and evidence via ANA RF titers which are antibodies. They are pumping out millions of antibodies some of which are directed and cross reacting else where. You are saying the bacteria is stealth and hides it's antigens by wrapping around itself with host tissue then you would not see millions of antibodies.

Yes, but that was one scenario. It's a known fact that B.b cloaks itself in host protein to evade detection.

I never said the test picks up all antibodies formed against borrelia. The antibodies formed against the bug have been established with clinical case studies and correlated with blood samples and proven to be of value.

Very limited value. There's a reason that the emphasis is on clinical diagnosis. What constitutes grounds for diagnosis is where the controversy is. Lyme is both over and underdiagnosed. The tests are of extremely limited value, and I disbelieve the reporting of the results.

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Maybe when we have some from those without a financial stake in the reported results...

All

serology testing has limitations. What he said is correct and also a given. We all know that. We deal with the antibodies that are known and the next generation can deal with what they find.

What he said was that there was no "clinically meaningful diagnostic test for Lyme disease." It was a verbatim quote. He disagreed with your assesment of the "proven" nature of the tests.

Anyway, we're way off topic for this group, and I think we can only repeat ourselves at this point.

Take care,

Susan

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