

Lyme blood tests should not be relied on to diagnose Lyme disease, says writer

Wednesday, 21 July 2010

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While it may be true that most doctors follow the Infectious Disease Society of America (IDSA) guidelines, there is little scientific evidence for doing so.

If physicians take the time to review the few studies the IDSA used to develop such influential guidelines, they will find they rely on scant evidence and faulty research.

Fortunately for Minnesotans menaced by a high risk of contracting Lyme disease, there are physicians who have taken the time to parse the few studies that exist and have determined them lacking.

Dr. Elizabeth Maloney is one such doctor. A family practitioner in Wyoming, Minn., Dr. Maloney came to realize that the multiple symptoms of Lyme disease — which often begins with severe fatigue, headaches, migrating muscle and joint pain and can progress to nerve, brain and neurologic problems — may persist after IDSA-recommended short course antibiotic treatment. She became concerned about the divide between patients' experience of Lyme disease and the medical description.

"Patients were saying, 'We're not getting better,' while doctors were hearing in lectures and reading in standard references that they should be cured, said Maloney.

There is ample evidence that calls into question the IDSA guidelines, and readers can find published challenges from the recent guidelines review on mlasg.com. However, I will focus on what the medical community takes for granted, that the standard blood tests are adequate to diagnose Lyme disease. They are not.

"Discussions on testing must take into consideration what stage of disease one is dealing with," says Dr. Maloney. "Testing, while appropriate for late Lyme, is not recommended when evaluating patients with known tick bites or early Lyme disease."

Lyme blood tests measure the level of antibodies directed against the bacterial agent of Lyme disease, *Borrelia*

burgdorferi (Bb); this is an indirect indication of exposure to the bacteria. Antibodies develop two to six weeks after infection, so tests done early in infection may be negative, even when Bb is present, Maloney said.

“With regards to late Lyme disease, available tests perform well if the patient has Lyme arthritis, but not if they have neurologic Lyme disease,” she said.

“For example, the first-step test, called an ELISA, misses many patients with Lyme. A study on the standard tests done by the CDC (Centers for Disease Control and Prevention) demonstrated that the C6 ELISA missed 40 percent of patients with disseminated, early neurologic disease and 27 percent of the patients with late neurologic Lyme.

The follow-up test, called the Western blot, misses late neurologic disease 28 percent of the time. Because the two tests are done in order and only ELISA positives have follow-up testing, this sequence can be expected to miss 47 percent of the patients with neurologic Lyme.”

So, it is wrong to suggest that a negative test result means a person doesn't have Lyme disease.

Lyme is a clinical diagnosis based on a patient's exposure to deer ticks, symptoms and exam findings, according to the International Lyme and Associated Diseases Society (ILADS). ILADS, unlike the IDSA, bases its recommendations on decades of research and thousands of case histories, not only from the U.S., but from around the world.

The fact that most physicians follow the IDSA guidelines is not a good reason to continue doing so. There are countless examples in history when the mainstream was slow to adopt evidence-based therapeutics.

“One of the most striking examples involved a physician in Austria who tried to convince his colleagues that hand-washing prevented death by ‘childbirth fever.’ In the decades that his evidence was scorned, women died needlessly,” Dr. Maloney said.

She also reminds readers that “science and medicine are not based on majority rule; they are based on evidence. Patients and their physicians should be free to examine the evidence and free to act on their conclusions rather than blindly trust restrictive guidelines which fail to serve a large number of patients with Lyme disease.”

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