Lyme disease antiscience

Paul Auwaerter and colleagues' Personal View[1] outlines an extremely uncomfortable situation in the USA, but this report should not lead anyone to believe that the situation in the UK is the same. Dissection of this opinion piece only adds to the divisiveness. Instead it should be pointed out that, in the UK, doctors rather than patients are misusing science.

Two Lyme disease charities exist in the UK: Borreliosis and Associated Diseases Awareness UK (BADA-UK) and Lyme Disease Action (LDA). BADA-UK focuses solely on raising awareness; its attendance at county shows has increased awareness, early recognition of symptoms, and safe removal of ticks. LDA produces leaflets used by the National Health Service (NHS), many employers, and countryside organisations. Online, LDA provides unbiased, evidence-based information for clinicians and patients and points to independently researched sources of information, such as Clinical Knowledge Summaries and the Map of Medicine.[2] All this action is funded by donations, not the UK Government.

The Health Protection Agency, however, provides guidelines based on a biased selection of papers,[3] such as a recent position statement by the British Infection Association that would not pass NHS evidence guidelines accreditation. In this statement, which specifically assesses UK patients, the British Infection Association states it is particularly concerned that patients with a range of disorders (eg, multiple sclerosis and malignant disease) have been misdiagnosed with chronic Lyme disease. How many clinicians reading this nodded their heads wisely and agreed? Did any check the references supporting this statement and discover that none of them refer to cases in the UK? That commercial companies will deliberately mislead consumers to increase sales is unsurprising, but what about professional associations? Undoubtedly, some members of the public do not have access to good-quality articles and have based their understanding and beliefs on little information. However, many clinicians will also uncritically read opinion articles written by their peers, and implicitly believe them.

The British Infection Association has listened to criticism of the position statement and is now collaborating with LDA and a Department of Health funded body, the James Lind Alliance, on documentation of the uncertainties in treatment and diagnosis of Lyme disease. Despite the prevailing view that patients do not understand the issues, some clinicians are prepared to work with patients. We might have had greater clinician participation in this project had it not been for reports such as Auwaerter and co-workers', but, in the end, evidence will triumph over institutional bias.

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1 Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Antiscience and ethical concerns associated with advocacy of Lyme disease. *Lancet Infect Dis* 2011; **11:** 713–19.
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3 Health Protection Agency. July 11, 2011. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/LymeDisease/Guidelines/lymGuidelines/ (accessed Aug 26, 2011).

Paul Auwaerter and colleagues[1] compare some Lyme disease activists who use non-evidence-based arguments with anti-HIV or antivaccination extremists. Their Personal View shows that unscientific thinking and malpractice occur in many specialties. Such a focus has unfortunately resulted in suppression of legitimate and necessary scientific debate about the management of syndromes of unclear aetiology, which sometimes occur after a previously proven episode of Lyme disease or tick bites. Public health recommendations should rely on strong evidence-based data and not on expert opinion, as Lee and Vielmeyer's review[2] of the Infectious Disease Society of America guidelines shows is the case with Lyme disease.

Recommended serological tests for Lyme disease vary greatly in sensitivity. Since no reliable reference standard exists—such as a specific clinical score, culture, or PCR—the cut-off levels of such tests are decided with healthy donors and calculated arbitrarily. Several studies have shown that seronegative Lyme disease cases can be proved with culture or PCR. Seronegative patients have been included as Lyme disease cases in a major clinical trial.[3]

For the **James Lind Alliance** see http://www.lindalliance.org/

Another difficulty is that, although many variants and new species of *Borrelia* are regularly discovered, most commercial tests rely on the original Massachusetts B31 isolate of *Borrelia burgdorferi*, used since 1982. However, Scottish experts were able to improve the sensitivity of their tests with local strains of *Borrelia* spp.[4] In Brazil, a Lyme-like syndrome has also been described that is due to a non-cultivable spirochete—not a *Borrelia* species—and is therefore undetected by current serological tests.[5]

Additionally, peer-reviewed studies show that other bacterial, viral, or parasitic infections might contribute to syndromes associated with Lyme disease or its mimics. Microbial involvement is being actively investigated in other well known but poorly understood conditions. For example, the possible role of spirochetes, including *B burgdorferi*, has become the subject of research into the pathophysiology of Alzheimer's disease.[6]

Syndromes without a clear cause or objective evidence should no longer be called chronic Lyme disease. These syndromes are probably

caused by several factors; therefore, both infectious and non-infectious aetiologies should be considered. To limit the debate to Lyme disease alone is highly unproductive, because this disease is unlikely to be the universal explanation of our patients' persisting ailments. These syndromes with possible microbial involvement should be investigated with the best available tests and with a fresh and open-minded scientific approach.

I declare that I have no conflicts of interest.

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Paul Auwaerter and colleagues[1] are among the handful of individuals who have controlled the Lyme disease research agenda for decades and ultimately which data have been reported. Why is it that, in my experience, many people in New Hampshire have been severely debilitated by Lyme disease or know someone who has, whereas Auwaerter and co-workers claim that the disease is easily diagnosed and treated with a short course of antibiotics? Seven states have now passed legislation to protect clinicians who treat late-stage Lyme disease with long-term antibiotics (CT, MA, MN, NY, NH, RI, and TX) and support groups exist in nearly every state, with 19 in Pennsylvania alone.

The ELISA first-line screening test produces false-negative results and patients are told they do not have Lyme disease. A follow-up western blot test that is much more sensitive is not allowed when the ELISA test is negative. In a two-tiered testing algorithm, western blots can only be used after a positive ELISA test to rule out a false-positive result. Therefore, we have no way to rule out a false negative. Clinicians who exclusively treat Lyme disease no longer use the ELISA test.[2–4] The German Borreliosis Society has recognised that the two-tier system we presently use for Lyme disease testing is inadequate.[5]

Misinterpretation of laboratory results is the main reason why the medical community is dismissive of patients with Lyme disease and their symptoms. Faulty diagnostic tests create confusion, causing physicians to miss the small period in which they can give successful short-term treatment. As a result, many patients have late-stage Lyme disease. Since we only test for antibodies against the infection and not the bacteria itself, we have no way to rule out active, continuing infection.

If the Infectious Diseases Society of America and the Centers for Disease Control and Prevention are correct with their single-treatment approach for all stages of Lyme disease and two-tier method of testing, why do we have so much legislation involving Lyme disease?

I declare that I have no conflicts of interest.

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Authors' reply

Although we support efforts to educate clinicians and the public alike with high-quality, evidence-based information about infection with *Borrelia burgdorferi*, the comments from Stella Huyshe-Shires regarding our Personal View misleadingly suggest that the UK is untainted by antiscience concerns. A report by Cottle and colleagues[1] showed that most patients referred to an infectious diseases unit in Liverpool, UK, for Lyme disease (n=115) did not have the disorder. Of 38 patients with chronic fatigue syndrome, 45% were incorrectly labelled as having chronic Lyme disease by alternative practitioners. These patients had received unnecessary antibiotics instead of other targeted management strategies, supporting the case that overdiagnosis and inappropriate management of Lyme disease also occurs in the UK and reinforcing concerns cited by the British Infection Association.

Both Christian Perronne and Carl Tuttle believe that present serological testing for *B burgdorferi* is inaccurate. Although the human immune system can take 2–3 weeks to produce detectable concentrations of antibodies in the early phases of Lyme disease, this delay is also reported in many other bacterial infections. This delay in no way negates the usefulness of two-tier