

## “Straight Talk About Chronic Lyme Disease ”

Four years ago, we noted an example of irresponsible reporting on Lyme disease by the investigative or I-Team of NBC4-NY-TV (1). Consequently, when we learned that this same group was airing a new five part series entitled, “The Lyme Wars: Investigating a Public Health Crisis”, we were most interested to see if they had done a better job this time in providing the public with more accurate and reliable information about Lyme disease. Sadly, that was not the case (2). Once again, the I-Team failed to act responsibly and in the best interest of the public health.

To date, there are more than 12,000 publications dealing with virtually every aspect of Lyme disease (3). Since its discovery in the U.S. in the mid-1970s, we know a great deal about the nature, diagnosis, and treatment of Lyme disease which has been defined historically as a tick-borne infectious disease caused by a bacterial spirochete, *Borrelia burgdorferi* (4). Lyme disease is not the strange and mysterious disease that some imagine it to be. Any physician who is board certified in the specialty of infectious diseases certainly will know how to diagnose and treat Lyme disease; one does not need to have “special training” in medical school, just to learn how to diagnose and treat this particular infectious disease.

Although the I-Team falsely asserts that the scientific community is deeply divided on issues related to Lyme disease, there is wide-spread agreement among international and national experts on all major issues related to the prevention, diagnosis, and treatment of Lyme disease (5). Unfortunately, the issue receiving the most attention in the media -- and on the internet-- is the condition called “chronic Lyme disease” that has yet to be defined unequivocally as a distinct clinical entity. This is due mainly due to the large amount of misinformation being disseminated by a small -- but vocal—minority of Lyme disease activists and “Lyme literate physicians” (LLMDs) who, when it comes to understanding the peer-reviewed scientific literature on Lyme disease, do not appear to be at all “literate”.

Annual surveys by the Centers for Disease Control and Prevention (CDC) indicate that about 15% of women and 10% of men in the U.S. felt exhausted or extremely tired (fatigued) either every day or most days of the preceding 3 months (6), and that about 16% of men and 22% of women experienced pain in the past 3 months (7). It is estimated that unspecified irritable bowel symptoms effects about 11% of the global population (8). Also, the Institute of Medicine reports that acute and unspecified chronic pain affect 116 million Americans, about 30% of the general population; such individuals often go from one physician to another, unable to find anyone who can either identify the cause of their pain or suggest a remedy (9). Data for a U.S. National Health Interview Survey, 2014-2016, revealed that “5.1% of adults  $\geq$  45 years were limited in any way because of difficulty remembering or periods of confusion” (10). Since such symptoms are often viewed as “hallmarks” of “chronic Lyme disease”, it is quite possible that individuals who believe that they have “chronic Lyme disease” are represented in the cohorts just described. LLMDs, who “specialize” in the treatment of Lyme disease, base their diagnosis of Lyme disease simply on the presence of these widely prevalent symptoms. Obviously, under such circumstances, one should rely on the results of objective laboratory blood tests to make a valid diagnosis of Lyme disease; it makes no sense to treat a patient for Lyme disease when they may not have it in the first place. Since the vast majority of individuals who believe that they have “chronic Lyme disease” are negative by 2-tier blood testing procedure and criteria recommended by the CDC, LLMDs claim that these tests must be unreliable, instead of considering other possible causes for their patient’s symptoms.

There is abundant evidence that 2-tier testing is in fact very reliable for the diagnosis of Lyme disease in patients who have had symptoms for a month or longer (11). Even a perfect diagnostic test will not give a positive result if a patient does not have Lyme disease. However, it certainly is possible to get a falsely positive test result using an unapproved, non-validated test procedure performed by a laboratory that specializes in the diagnosis of Lyme disease as is often the case in patients with “chronic Lyme disease” (12). The tragedy in all of this is that these individuals are suffering from chronic debilitating symptoms for which they should receive appropriate medical treatment and care; however, it is clearly not Lyme disease and other possibilities must be considered as recommended in the multidisciplinary program on chronic pain advocated by the Institute of Medicine (9). That makes good sense and the failure to accept such a reality results in the pursuit of countless unorthodox approaches for the treatment of Lyme disease, as well as extended antibiotic therapy using various antibiotics for months or years at a time, at great expense and with no benefit beyond a placebo effect (13, 14). Astonishingly, a patient described in one episode of the Lyme wars TV series was said to have been treated with more than 70 pills per day! Getting all of these medications ready for use appeared to be what was called an elaborate “assembly line process” (2). This hardly inspires confidence in the competence of the treating physician. All this is being done at great expense to the patient, who then wonders why health insurance companies would not cover the costs of these unproven and often expensive “remedies”.

The solution advocated for another patient in the TV series was dietary supplements and the use of nutraceuticals, none of which have been found to be beneficial for the treatment of *B. burgdorferi* infection. Obviously, it would be wise for patients, before allowing themselves to be subjected to such unorthodox and potentially harmful treatment regimens, to insist on seeing the results of peer-reviewed publications, proving that such remedies indeed are beneficial for the treatment of Lyme disease. Testimonials from former patients are no substitute for rigorously reviewed published data derived from carefully controlled studies and, it is especially important to keep in mind that testimonials are often used selectively. Usually, one only is told about those who responded favorably, not about the many more who failed to derive any benefit whatsoever from the treatment regimen in question.

It should be noted that the recommendations made by the Infectious Diseases Society of America (IDSA) in its guidelines for the treatment of Lyme disease (15) and disputed in the TV series are in agreement with those of the European Federation of Neurological Societies, the European Union of Concerted Action on Lyme Borreliosis, the American Academy of Neurology, the Canadian Public Health Network, and the German Society for Hygiene and Microbiology (16). They also are in agreement with recommendations made by expert panels from 10 European countries, i.e., The Czech Republic, Denmark, Finland, France, The Netherlands, Norway, Poland, Slovenia, Sweden, and Switzerland (16). Therefore, it is reasonable to conclude that the IDSA guidelines are universally accepted by experts on Lyme disease throughout the world, and that the treatment recommended is indeed beneficial and safe for patients who have been correctly diagnosed as having Lyme disease. It should be noted that, in contrast to the costs of many of the unorthodox treatment regimens proposed and/or implemented by LLMDs, the cost of the IDSA recommended treatment for Lyme disease (10-28 days of oral doxycycline, a generic antibiotic) is about \$40. Most, if not all, health insurance companies will cover such a modest and reasonable expense.

In May of 2008, the IDSA entered into an agreement with Connecticut Attorney General (AG) Richard Blumenthal to voluntarily submit the 2006 Lyme disease guidelines to a special expert review panel to determine if they were based on sound medical and scientific evidence, and whether

the guidelines should be modified or revised. To avoid conflict of interest issues, all members of the expert panel were selected through an open application process. An ombudsman was jointly selected by the IDSA and the AG to screen all applicants to ensure that each panel member was without any beneficial or financial interests related to Lyme disease, any financial relationship with an entity that has an interest in Lyme disease, and any conflict of interest; the chairperson as well as all panel members met the required criteria. After multiple meetings, a public hearing, and extensive review of more than 2,000 research publications and other information submitted by all parties involved, the expert panel concluded, in a full report issued in 2010 (17), that the recommendations contained in the 2006 guidelines were medically and scientifically justified on the basis of all available evidence and that no changes in the guidelines were warranted. No other set of guidelines has been subjected to such independent scrutiny and critical review -- and survived the process intact with no revisions recommended.

(Updated 12/5/17)

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