

# Destroying the Village in Order to Save It: Collateral Damage in the Battle Over Lyme Disease

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A federal court recently dismissed the case against the Infectious Diseases Society of America (IDSA) brought by a group of patients with Lyme disease. While the outcome represented an important victory of the IDSA, I argue that it should also serve as a turning point in our approach to patients with “chronic” Lyme disease, many of whom experience substantial symptoms and suffer an emotional burden due to the uncertainty of their diagnosis. As the incidence of Lyme disease continues to increase and the geographic range of the vector expands, infectious disease specialists—experts in history taking, physical examination, and diagnosis—should play a leading role, not only to combat pervasive misinformation, but more importantly to benefit patients.

**Keywords.** Lyme disease.

On 20 September 2021, a federal judge in Texas dismissed all claims against the Infectious Diseases Society of America (IDSA) brought by a group of patients with Lyme disease [1, 2]. The lawsuit alleged that the IDSA and other defendants had “engaged in a decades-long conspiracy to deny the existence and prevent treatment of chronic Lyme disease.” In his dismissal, the judge held that the IDSA guidelines—as most clinicians are aware—represented a summary of current medical knowledge and adherence to the recommendations was voluntary.

The outcome represents a clear and important victory for the IDSA in the decades-long contentious debate over

Lyme disease, and more specifically chronic Lyme disease—a catch-all term that now encompasses residual symptoms after treatment of a documented infection (also known as posttreatment Lyme disease syndrome) as well as the presence of nonspecific symptoms without objective evidence of infection—spurred by a range of activists and advocacy groups [3]. At the most extreme, these groups have peddled antiscience tropes and conspiracy theories, occasionally propagated by high-profile leaders of questionable character [4]. Despite the lack of evidence, many of the ideas espoused are now well-established in the public square and are ubiquitous on the internet.

While the decision brings the legal matter to a close, the fundamental challenges remain. The incidence of Lyme disease continues to increase as the geographic range of the vector expands to new areas [5, 6]. Surveillance for ticks and tick-borne pathogens is uncoordinated and underfunded and there are few effective strategies to control tick populations [7, 8]. On the clinical front, existing diagnostic assays and testing algorithms, which rely on the development of host antibodies in response to infection, are of limited utility early in the course of infection and are frequently misapplied and misinterpreted [9, 10]. Meanwhile, there

is a substantial patient population that perceives their symptoms, suffering, and experiences—Lyme-related or not—are being dismissed, even as researchers rush to tackle “long COVID,” another incompletely understood, postinfectious syndrome that shares many similarities with posttreatment Lyme disease.

At the same time, physicians and scientists are reluctant to even speak on record about the topic, let alone aggressively refute misinformation [11]. More worrisome, clinicians may be wary of seeing these patients due to uncertainties regarding the diagnosis and treatment of posttreatment Lyme disease syndrome, concerns about unaddressed mood and psychiatric disorders, and even fear of confrontation. For example, I practice in a state at the leading edge of the epidemic, but one that is historically classified as low incidence. While the epidemiological data show a substantial rise in cases, many infectious diseases practices in my area, both academic and private practice, refuse to accept referrals for Lyme disease. A large proportion of the more than 100 referrals I see each year are on their second or third attempt at getting an appointment. Many patients, frustrated with the inability to see a specialist, pursue care with self-professed “Lyme-literate” providers who

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frequently administer invasive and, at times, harmful interventions of dubious effectiveness [12].

So where are we now? I am generally cautious in my use of battlefield metaphors, having spent 2 years at war in Iraq; nevertheless, considering the recent history of Lyme disease, I keep returning to the concept of collateral damage. In counterinsurgency warfare, collateral damage frequently becomes the source of propaganda and misinformation that can spread quickly through the population and ultimately may influence so-called fence-sitters to turn against the larger campaign. At that point, attitudes become fixed and the war is lost.

While the comparison is a bit extreme, I do worry that we may in fact be contributing to the spread of misinformation through our inaction. When patients are told that their condition does not “meet criteria” nor otherwise warrant an evaluation, we are often telling them—intentionally or not—that their symptoms are not real. In doing so, we are not only feeding the narrative of the conspiracists, but also ceding the ground to the profiteers and charlatans. Policies that deny “chronic Lyme” referrals are particularly harmful because many of these referrals are not driven by patient demands, but by providers themselves. In my own practice, I see very few patients with epidemiological risk factors for or symptoms typically associated with Lyme disease. Instead, most patients have had testing for Lyme ordered as part of a workup for nonspecific symptoms like fatigue, chronic pain, or poor concentration, often described to me as “brain fog.” Testing seems to take place well into the diagnostic course after other, more common causes have been considered and both patients and providers are searching for clues. Thus, when a Western blot is performed after a negative enzyme immunoassay and 1 or 2 immunoglobulin G bands return positive, there is often a reflexive response to diagnose and treat, even though such a result should be interpreted as a negative test. When a course of doxycycline

predictably fails to resolve the symptoms, patients may receive another course of antibiotics and the descriptor “chronic” gets added to the diagnosis.

When I see these patients, most could be described as fence-sitters. In other words, they are not anchored to the diagnosis, but they are concerned, especially if they have spent time searching for information on the internet. They have come to see an infectious disease specialist because they are seeking reliable information from what is (thankfully) still considered a trustworthy source. By taking a complete history, performing a thorough examination, and then walking patients through the basics of immune response in relation to their test results, I have found that the overwhelming majority are simply relieved. On occasion, I am able to identify an alternative cause of a patient’s symptoms. In North Carolina, where Lyme is emerging, but not yet seen at rates similar to states in the northeast, the clinical manifestations of ehrlichiosis, spotted fever rickettsiosis, and alpha-gal syndrome are frequently misattributed to Lyme disease [13–15]. In circumstances where patients are still uncertain, and particularly in cases where testing algorithms have not been followed, I will repeat tests, including Lyme serologies. Of course, on more than a handful of occasions, my “pretest” assessments have been wrong and in those cases I have treated patients.

Overall, my experience with chronic Lyme referrals has been professionally fulfilling. While these visits usually require 45 to 60 minutes—and I am fortunate to be at an academic institution that affords me this time—the encounters allow me to apply my knowledge to the differential diagnosis and evaluation of unexplained symptoms, one of the very reasons I was originally drawn to the field. Furthermore, multiple studies have shown that infectious diseases providers are frequently able to identify other causes of patients’ symptoms, which almost certainly contributes to better health outcomes and satisfaction

[9, 16, 17]. Even when I do not have a clear answer, patients generally feel reassured that their symptoms are not attributable to an incurable spirochete and, where appropriate, I am often able to steer patients to colleagues in fields such as rheumatology and neurology. Yes, I have had a patient throw her medical records in my face and curse at me, but these events are very rare. I feel more defeated when I am unable to convince someone that they don’t need a central line and antibiotic cocktail, let alone things like ozone or colloidal silver. Still, as a field that has published many, many papers demonstrating improved outcomes for conditions like bacteremia and candidemia with our involvement, we should not raise the white flag on patients referred for chronic Lyme disease. Undoubtedly there has been collateral damage, but we have an important role to play in developing better diagnostics and management pathways and we should not be afraid to lead from the front.

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