

Chronic Lyme Disease: Liberation from Lyme Denialism

To the Editor:

The Review article by Halperin et al¹ concerning Lyme disease “misconceptions” is the latest in a series of Lyme denialist attacks by members and supporters of the Infectious Diseases Society of America (IDSA).¹⁻⁴ This series of copycat opinion pieces is disturbing from both a scientific and political perspective because the articles frame the complex debate over chronic Lyme disease in terms of “evidence-based medicine” on the one hand, versus “anti-science” on the other. Furthermore, the latest Lyme denialist attacks appear to be a concerted effort to offset recent political action aimed at helping the scores of untreated, undertreated, and mistreated Lyme disease patients around the globe.

The scientific problem with the copycat opinion pieces (including the Review article by Halperin et al¹) is that among the more than 25,000 peer-reviewed articles on tick-borne diseases listed in the PubMed database, there are literally hundreds that contradict the selective “evidence” that these opinion pieces are willing to acknowledge.⁵⁻¹⁰ In addition, to serve their purpose, these authors are now ready to discredit their own publications, such as the 1988 *New England Journal of Medicine* article on seronegative Lyme disease by Dattwyler et al.^{1,11} If this publication in a major medical journal should no longer be considered valid because it does not fit the authors’ Lyme denialist viewpoint, how much more “evidence” should we disregard in order to see the world through IDSA’s opaque prism? And why not discount studies that underpin Lyme denialism, such as the 2001 *New England Journal of Medicine* article by Klempner et al¹² repeatedly used to deny treatment of Lyme disease? The methodology and results of that study have been challenged recently,^{13,14} and studies in animals and humans with Lyme disease demonstrate failure of antibiotic therapy and persistent infection in many cases.^{8,15,16} In the absence of a test for cure of Lyme disease, which the authors acknowledge, the contention that patients with persistent symptoms should not receive further treatment amounts to no more than a value judgment that has left sick patients to suffer without treatment options.^{9,10}

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The political problem with this series of opinion pieces is that they gloss over the shortcomings of the shaky IDSA Lyme guidelines that have recently come under attack in scientific and legislative investigations.¹⁷⁻²² It is clear that the goal of opinion pieces such as the Review article by Halperin et al¹ is to counteract the growing political opposition to the IDSA denialist view of Lyme disease, and IDSA intends to achieve this goal by means of data selection and repetitive disinformation. Given the extensive suffering of Lyme disease patients⁵⁻¹⁰ and the ongoing legitimate controversy over the diagnosis and treatment of tick-borne diseases,¹³⁻²² the IDSA strategy of framing selective supportive data as “evidence” and dismissing volumes of contradictory data as “antiscience” is antiscientific, deceptive, and untenable. As the Lyme disease pandemic continues to grow, the plight of Lyme disease patients fostered by the tainted IDSA Lyme guidelines will continue to attract legislative attention until these patients are finally liberated from Lyme denialism.¹⁷⁻²²

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References

- Halperin JJ, Baker P, Wormser GP. Common misconceptions about Lyme disease. *Am J Med.* 2013;126:264.e1-e7.
- Auwaerter PG, Melia MT. Bullying Borrelia: when the culture of science is under attack. *Trans Am Clin Climatol Assoc.* 2012;123:79-90.
- Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Antiscience and ethical concerns associated with advocacy of Lyme disease. *Lancet Infect Dis.* 2011;11:713-719.
- Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Scientific evidence and best patient care practices should guide the ethics of Lyme disease activism. *J Med Ethics.* 2011;37:68-73.
- Cairns V, Godwin J. Post-Lyme borreliosis syndrome: a meta-analysis of reported symptoms. *Int J Epidemiol.* 2005;34:1340-1345.
- Stricker RB. Counterpoint: long-term antibiotic therapy improves persistent symptoms associated with Lyme disease. *Clin Infect Dis.* 2007;45:149-157.
- Stricker RB, Johnson L. Lyme disease diagnosis and treatment: Lessons from the AIDS epidemic. *Minerva Med.* 2010;101:419-425.
- Stricker RB, Johnson L. Lyme disease: The next decade. *Infect Drug Resist.* 2011;4:1-9.
- Johnson L, Aylward A, Stricker RB. Healthcare access and burden of care for patients with Lyme disease: a large United States survey. *Health Policy.* 2011;102:64-71.
- Stricker RB, Johnson L. The pain of chronic Lyme disease: moving the discourse backward? *FASEB J.* 2011;25:4085-4087.
- Dattwyler RJ, Volkman DJ, Luft BJ, Halperin JJ, Thomas J, Golightly MG. Seronegative Lyme disease: dissociation of specific T- and B-lymphocyte responses to *Borrelia burgdorferi*. *N Engl J Med.* 1988;319:1441-1446.

12. Klemmner MS, Hu L, Evans J, et al. Two controlled trials of antibiotic treatment in patients with persistent symptoms and a history of Lyme disease. *N Engl J Med*. 2001;345:85-92.
13. Delong AK, Blossom B, Maloney EL, Phillips SE. Antibiotic retreatment of Lyme disease in patients with persistent symptoms: a biostatistical review of randomized, placebo-controlled, clinical trials. *Contemp Clin Trials*. 2012;33:1132-1142.
14. Fallon BA, Petkova E, Keilp JG, Britton CB. A reappraisal of the U.S. clinical trials of post-treatment Lyme disease syndrome. *Open Neurol J*. 2012;6(Suppl 1-M2):79-87.
15. Stricker RB, Johnson L. Spirochetal 'debris' versus persistent infection in chronic Lyme disease: from semantics to science. *Future Microbiol*. 2012;7:1243-1246.
16. Stricker RB, Delong AK, Johnson L. Outpatient parenteral antibiotic therapy for Lyme borreliosis: a 'real world' view. *Q J Med*. 2013;106:201-203.
17. Johnson L, Stricker RB. Final report of the Lyme disease review panel of the Infectious Diseases Society of America: a pyrrhic victory? *Clin Infect Dis*. 2010;51:1108-1109.
18. Smith CH. Global challenges in diagnosing and managing Lyme disease — closing knowledge gaps. Testimony before House Committee on Foreign Affairs, United States Congress, July 17, 2012. Available at: <http://archives.republicans.foreignaffairs.house.gov/hearings/view/?1455>. Accessed April 16, 2013.
19. Barthold SW. Persistence of non-cultivable *Borrelia burgdorferi* following antibiotic treatment: critical need for further research. Testimony before House Committee on Foreign Affairs, United States Congress, July 17, 2012. Available at: <http://archives.republicans.foreignaffairs.house.gov/hearings/view/?1455>. Accessed April 16, 2013.
20. Stricker RB. Lyme disease: the hidden epidemic. Testimony before House Committee on Foreign Affairs, United States Congress, July 17, 2012. Available at: <http://archives.republicans.foreignaffairs.house.gov/hearings/view/?1455>. Accessed April 16, 2013.
21. Loudoun County (VA) Board of Supervisors. Ten point action plan to mitigate Lyme disease. Available at: <http://www.loudoun.gov/index.aspx?NID=2648>. Accessed January 22, 2013.
22. Pearson S, Huyshe-Shires S. Lyme borreliosis: the need for more research. *Q J Med*. 2013;106:203.