

LYME DISEASE IN MINNESOTA

1. 1 in 3 black-legged ticks carry *Borrelia burgdorferi* (Bb), the bacterial cause of Lyme disease; they may also carry other bacteria and parasites (referred to as co-infections), complicating the clinical picture.
2. Once thought to be found only in wooded areas, black-legged ticks have expanded their range and are now found across Minnesota, including the 7-county metro.
3. Lyme disease has increased 450% in the past 10 years. The state ranks 8th in the nation for reported cases; in 2009, 1,546 cases were reported to the CDC. Due to under-reporting, the CDC estimates that the actual number of surveillance cases is likely to be 10 times more, meaning MN probably had over 15,460 cases.

IDSA

4. The Infectious Disease Society of America (IDSA) dominates the discussion on Lyme disease, controlling diagnosis and treatment via their 2006 guidelines. IDSA denies the existence of chronic, or persistent, Lyme disease, basing this claim on 4 small NIH-funded, randomized, controlled studies. These patients had been previously treated for Lyme disease but remained ill. Of these studies, 2 were fatally flawed while the other two found subsets of patients which improved with additional therapy. These results cannot be extrapolated to patients with late Lyme who have never been treated.
5. IDSA guidelines deny the benefits of long-term antibiotic therapy, although case reports in peer-reviewed journals document that this strategy can be beneficial and physicians who treat Lyme aggressively have had tens of thousands of treatment successes.
6. IDSA has blanketed the medical mainstream media with their recommendations, effectively suppressing conflicting evidence and gaining almost universal acceptance.
7. Insurance companies use the guidelines against doctors who don't adhere to them, reporting them to their state medical boards. Physicians in other states have had to defend their treatment protocols and some have been subject to sanctions. This has had a chilling effect on treatment as doctors are reluctant to treat outside the guidelines.
8. The Connecticut Attorney General investigated the IDSA over the 2006 guidelines, finding the process had serious procedural flaws; alternative opinions and evidence regarding chronic Lyme disease were ignored and several panelists had financial conflicts of interest. The settlement between the AG and IDSA required a complete review of the guidelines; the review process was controlled by the IDSA, including the selection of review panel members and presenters at the 1 day hearing.

TESTING

9. Lyme serology measures the level of antibodies directed against *Borrelia burgdorferi* (Bb); this is indirect evidence of exposure to the bacteria.
10. Antibodies develop 2-6 weeks after infection; tests done early in infection may be negative, even when Bb is present.
11. Antibiotics given early in the infection may turn off the antibody response prematurely. If the dose is inadequate, patients remain infected but their tests may be negative; this is called seronegative Lyme disease.
12. Available testing is insensitive and often irreproducible. The two-tier testing criteria adopted by the CDC – ELISA followed, if positive, by Western blot – is highly specific but misses many patients who have Lyme. The CDC developed this for epidemiologic purposes and never intended for it to be used to diagnose clinical cases.

13. Lyme should be a clinical diagnosis based on a patient's exposure to black-legged ticks, symptoms and exam findings. Testing can confirm a diagnosis but it cannot rule out Lyme disease.

TREATMENT

14. Bb can attack any system in the body, causing a wide array of symptoms which vary from person to person; treatment regimens differ based on stage of illness and the body systems involved.
15. Bb is an aggressive and adaptable bacterium that can persist despite antibiotic treatment; studies by Hodzic and Barthold have confirmed this.
16. Co-infections cause additional symptoms and complicate treatment.
17. Lyme and its co-infections require individualized care; physicians must use their clinical judgment.
18. The MN Board of Medical Practice moratorium on investigating long-term antibiotic use for chronic Lyme allows doctors and patients to make individualized treatment plans based on the specifics of each case without fear of reprisal for treating outside IDSA guidelines.
19. Adopting a narrow definition for what constitutes the standard of care goes against the scientific evidence, which is limited and weak.
20. Providing informed consent is a physician duty recognized by the AMA; it is one component of the AMA medical ethics principle of patient autonomy. Withholding information related to informed choice is unethical.
21. Limiting informed choice in the treatment of Lyme disease sets a dangerous precedent and may ultimately lead to limiting treatment choices in other diseases.