

Bull's eye: *Unraveling the medical mystery of Lyme disease*

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Book Review

Scientists, clinicians, and the general public have become so habituated to the idea that we live in a world of emerging and resurging infectious diseases that we forget how recently this notion has taken root in medical terminology and the public consciousness. Of the numerous infections that have confronted the biomedical and public health communities during the past two decades, two, AIDS and Lyme disease, have done more than any others to foster the concept that infectious diseases are rapidly evolving entities. Though vastly different in etiology and manifestations, both afflictions have transcended the public health and scientific arenas to become major sociological phenomena. However, while the remarkable advances in the science and management of HIV disease have united all but the most ardent AIDS activists, controversy rages on between the mainstream medical community and a small, but vociferous, alliance of nonprofessionals and practitioners over the very definition of Lyme disease — not to mention its medical management — despite impressive gains in our understanding of the most prevalent arthropod-borne infection in the United States. In *Bull's eye: unraveling the medical mystery of Lyme disease*, Jonathan Edlow attempts to explain this enigma by chronicling events from the disorder's emergence in the affluent suburbs of eastern Connecticut in the 1970s to its current state of political and medical polarization. Edlow's book [...]

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BULL'S EYE Unraveling the Medical Mystery of Lyme Disease



Bull's eye

Unraveling the medical mystery of Lyme disease

Jonathan A. Edlow

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London, United Kingdom. 2003.

xviii, 304 pp. \$29.95. ISBN 0-300-09867-7 (hardcover);

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Scientists, clinicians, and the general public have become so habituated to the idea that we live in a world of emerging and resurging infectious diseases that we forget how recently this notion has taken root in medical terminology and the public consciousness. Of the numerous infections that have confronted the biomedical and public health communities during the past two decades, two, AIDS and Lyme disease, have done more than any others to foster the concept that infectious diseases are rapidly evolving entities. Though vastly different in etiology and manifestations, both afflictions have transcended the public health and scientific arenas to become major sociological phenomena. However, while the remarkable advances in the science and management of HIV disease have united all but the most ardent AIDS activists, controversy rages on between the mainstream medical community and a small, but vociferous, alliance of nonprofessionals and practitioners over the very definition of Lyme disease — not to mention its medical management — despite impressive gains in our understanding of the most prevalent arthropod-borne infection in the United States. In *Bull's eye: unraveling the medical mystery of Lyme disease*, Jonathan Edlow attempts to explain this enigma by chronicling events from the disorder's emergence in the affluent suburbs of eastern Connecticut in the 1970s to its current state of political and medical polarization.

Edlow's book consists of two parts. At the outset, the author creates an entertaining narrative that weaves together convergent subplots and observations, some more than a hundred years old and spanning continents, that culminated in the discovery of the Lyme disease spirochete, *Borrelia burgdorferi*, and its principal vector, *Ixodes scapularis*. The endeavors he describes are part of Lyme

disease lore and, hence, are familiar to most workers in the field. Nevertheless, Edlow provides new information that illuminates the tale even for those, myself included, who thought they knew it well. Though his account is tedious at times for physicians and scientists, the author goes to great lengths to ensure that his nonmedical readers are not left behind by providing detailed explanations of the scientific method and the actual techniques researchers use to study infectious diseases. The power of this portion of the book, however, resides in his dramatization of the human dimensions of the Lyme disease story — the uncertainty and disagreements among the physicians who treated and investigated the first cases and, most notably, the heroism of two Connecticut women, Polly Murray and Judith Mensch, who forced the Centers for Disease Control and local public health authorities to take seriously the disorder (misdiagnosed as juvenile rheumatoid arthritis) that was afflicting their families and community. Edlow thus exposes a root cause of the forces that gave rise to what he calls the "conventional" and "alternative" camps. Lyme disease was really discovered by patients; their intimate involvement in the drama from the outset has empowered nonprofessionals to challenge the judgments of medical and scientific experts to this very day.

The second half of the book focuses on two questions: "Why did the incidence and geographical range of Lyme disease continue to expand" and "Why did public concern and the sociopolitical profile of Lyme disease remain intense?" Edlow correctly attributes the expansion of Lyme disease to the reforestation of endemic areas, the consequent explosion of local deer populations, and demographic trends that have placed humans, accidental hosts for the spirochete,

in the midst of the enzootic cycles that perpetuate the bacterium. For the second question, Edlow delves into the thorny issue of chronic Lyme disease. He divides the Lyme disease medical community into a "conventional" camp, which believes that *B. burgdorferi* infection is readily diagnosed under most circumstances and responds well to relatively short courses of antibiotics, and an "alternative" camp, which holds that chronic Lyme disease patients suffer from persistent *B. burgdorferi* infection that can be eradicated only with prolonged courses of antibiotics. Unfortunately, his apparent sympathies for the alternative camp cause him to deviate from the scientific tenor established earlier in the book. A central tenet of the alternative camp's viewpoint is that mainstream practitioners adhere inflexibly to unreliable Lyme disease tests. To support this viewpoint, Edlow engages in a tortuous dissertation on medical diagnostics without seriously examining the corpus of clinical studies that have yielded serviceable diagnostic assays and criteria for Lyme disease. He also relies heavily on Thomas Kuhn's theory that scientific fields advance via paradigmatic shifts; based upon Kuhn's landmark treatise, he proposes that the schism in the Lyme disease field represents a stalemate between competing but equal paradigms. Along the way, he implies that the conventional camp has used its superior political and economic power to stifle efforts by the alternative adherents to garner evidence in their favor. Unfortunately, Edlow overlooks the fact that a field advances precisely because the weight of scientific evidence eventually favors one paradigm over another. By failing to carefully and objectively evaluate the scientific and medical evidence that support these two viewpoints, rather than scoring a bull's eye, Edlow's analysis ultimately misses the mark.