

A Lyme Disease Dichotomy: Public Health vs. Public Knowledge

Controversy over Lyme disease flared last spring when *WDSE* of Duluth, Minnesota and other public broadcasting stations began pulling a documentary on the illness, *Under Our Skin*, off May broadcast schedules. A firestorm of complaint spread across the nation, with charges of censorship leading the fray. While many stations did air the film, activists believe the removal of the scheduled program is part of a concerted effort to keep the public from seeing a Lyme disease viewpoint that opposes the way the infection is perceived by mainstream medicine.

During an interview with Tom Grier of the Duluth-based Minnesota Insect Borne Disease Education Council he pointed out, "In the beginning the medical experts not only got things wrong, they got nearly everything important about a new disease wrong."

By MJ

When a new disease is found one of the first questions asked is, Can it be transmitted from person to person? Other questions follow: Is this an isolated incidence? Is it isolated in the body? What type of organism causes the illness? Can it be contracted through blood transfusions or organ donations? And, to what other known diseases could it be related?

For Lyme disease, important questions remain unanswered more than thirty years after an outbreak of the illness in Connecticut. Physicians sent by Yale University to investigate that outbreak didn't know what caused the swollen, painful joints and odd rashes they were seeing, but they guessed it was a bacterial infection because some patients responded to antibiotics. These physicians . . .

- *Called* the malady *Lyme arthritis*, although early on in the Yale investigations the illness was known to also cause neurological and cardiac irregularities.
- *Proposed* short-term antibiotic treatment for Lyme disease equal to that for strep throat, even though treatment failures with that protocol were noted in the early days of the Yale team's investigations.
- *Disregarded* what was known about other diseases caused by bacteria called spirochetes after a spirochete was found to cause Lyme arthritis. Medicine already knew then that relapsing fever and syphilis spirochetes infected multiple organs and tissues, evaded treatment, and relapses often followed periods of wellness.
- *Dismissed* the potential for brain and spinal cord infection by the spirochetes that cause Lyme disease. Since then, the bacteria have been photographed entering human brain cells.
- *Believed* Lyme disease was found only in the Northeastern U.S. It has now been reported in every state.

- *Decided* Lyme disease infection was transmitted by *Ixodes dammini* ticks, a species that does not exist. Lyme disease is transmitted by tiny black-legged ticks, commonly called deer ticks (*Ixodes scapularis* or *Ixodes pacificus*) in the U.S.
- *Maintained* that the illness caused by the "southern" Lone star tick, which often produces a bull's-eye rash, is not really Lyme disease. However, the *Yale Journal* and *Science Magazine*, in 1989, reported that the Lone star tick had been found as far north as New Jersey, and that the New Jersey Health Department had proven the Lone star tick transmitted Lyme disease.

Grier explains the Yale investigators "got off on the wrong foot in the 1970s" and have never corrected their mistakes, though somehow they are, to this day, considered experts. The bulk of Lyme disease research is still performed with their names attached to the outcomes, while important questions such as sexual transmission have not been answered.

Person to person transmission of Lyme disease *can* occur between an infected pregnant mother and her fetus, although maternal/fetal transmission was proven, not by the Yale doctors, but by pathology findings made public by others.

Erroneous assumptions presented as facts created controversy that to Grier seems more about protecting the public from the truth about Lyme disease than the disease itself. He laments that many PBS stations pulled *Under Our Skin*, a documentary chosen by the America Library Association as one of fifteen Notable Videos for Adults for 2011.

Treatment Controversy

In 2000 and 2006 medical guidelines for the treatment of Lyme disease were published by several of the same physicians who got so much wrong in the preceding three decades. Those guidelines from the Infectious Diseases Society of America (IDSA) state Lyme disease is cured with a short course of an antibiotic. For symptoms that persist after treatment the authors recommend no more antibiotics be prescribed.

Patients followed in the film *Under Our Skin* receive longer antibiotic therapy and regain active lives after having been devastatingly ill with Lyme disease. Of interest, the majority of the 2000 and 2006 IDSA *Guidelines* writers do not treat or no longer treat patients who suffer from Lyme disease.

Part of the Lyme disease treatment controversy stems from medicine's efforts to stop "over-prescribing" antibiotics. The anti-antibiotic campaign at present rests on the assumption that methicillin-resistant *Staphylococcus aureus* bacteria (MRSA) result from physician and patient reliance on antibiotics. However, study results released last May call that assumption into question:

Roughly 70% of the antibiotics available in the U.S. are fed to livestock to compensate for their unsanitary living conditions and to promote growth, so researchers from the

University of Arizona decided to test food for antibiotic-resistant bacteria. They found *Staphylococcus aureus* contaminated 47% of beef, chicken, pork, and turkey products collected from 26 retail grocery stores in 5 US cities. And 52% of the *S. aureus* samples proved to be resistant to *multiple* antibiotics.

An anti-antibiotic campaign, limited research from medical experts, and limited public knowledge of all aspects of Lyme disease—such as maternal/fetal transmission—pose difficulties for those infected. In addition, some health insurers cite IDSA guidelines as the reason for curtailing coverage of antibiotic treatment of Lyme disease infection. Grier contends,

"I don't think the insurance industries see the long-term economic impact of Lyme disease. Companies are so concerned with quarterly returns and dividends [that] they don't look at 10 or 20 year projections. But not covering treatment leads patients to multiple medications for disorders the disease causes such as depression, fibromyalgia, arthritis, chronic fatigue, heart arrhythmias, or conditions that mimic MS, ALS, Alzheimer's and senile dementia."

Testing Controversy

From the time Lyme disease became a Centers for Disease Control-reportable infectious disease in 1991 testing and reporting practices have changed:

- To compensate for Lyme disease tests that produced "too many positives" a two-test system was instituted in 1994. The first step test (ELISA) proved to be seriously flawed—50% accurate, although it still constitutes the first hurdle the infected must surmount.
- At the same time the two-test system was instituted laboratory directors decided which second-step test (Western blot) markers would be counted for reportable Lyme disease cases. Horrified with the new parameters for diagnosis, Dr. Paul Fawcett explained that under those Western blot test requirements 46 of 66 pediatric patients (69%) in his care with bull's-eye rashes (confirmed Lyme disease) would no longer be counted as positive cases.
- Later, Yale's researchers proposed that the peculiar bull's-eye rash produced by Lyme disease should not be considered indicative of the infection for reporting purposes.
- And now, for reporting purposes, some Western blot markers are considered positive for Lyme disease only if those markers are evident on tests within thirty days of the onset of symptoms.

Steering Another Path Through Pathology

Together the two flawed tests miss approximately 75% of people who have Lyme disease, so the first priority for scientific inquiry into *what is and what is not Lyme disease* should be direct detection tests, insists Grier.

"Right now, today, we have to start training pathologists to look for spirochetes. It's a lost art, and in a time of budget cuts we don't expend the time, care, and money it takes to look for them. *Borrelia burgdorferi* [the Lyme disease spirochete] is invisible. Samples must be stained to find it."

He further proposes, "We have to train pathologists and researchers outside the CDC, NIH, and the University system because for twenty years we have seen poorly-conceived studies done over and over again."

Scientific inquiry has proven Lyme disease bacteria can withstand blood storage practices, but no proven transfusion-acquired infection has been recorded. Nonetheless, other tick-borne disease infections that may accompany Lyme disease infection have been transfused into unsuspecting patients. These transfused pathogens include Babesia and Anaplasma, both of which are on the rise in Minnesota and Wisconsin. In Minnesota reported Babesiosis infections rose from 31 in 2009 to 56 in 2010, and Anaplasmosis infections more than doubled from about 300 cases to 721 for 2010. How many of these infections were transfusion-acquired has not been made public.

Questions about Lyme disease and other tick-borne infections can't be answered with suppositions; progress demands reliance on what can be observed and proven, Grier tells us. To him an "old boy" network in medicine and a public health system that doesn't want to "alarm the public" have placed our collective health in jeopardy:

"We now have a medical system so corrupt with conflicts of interest, egos, and personal gain that we can no longer trust the system to work. It is now a game where friends and colleagues support each other, but not in the interest of public health. Therein lays the Lyme disease dichotomy."