Ivory Tower Coverups Impede Progress Toward Cure

Frontline physicians knew about persistence and how to treat it 20 years ago

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Lyme Disease is not a new illness. It has been recognized in one form or another for over a hundred years. In unraveling its history, one can see many instances of missed opportunities, unrecognized patterns and outright mistakes by scientists, physicians and government officials.

Over time, a divide has developed between the frontline Lyme-treating physicians and scientists and physicians at major university and government institutions throughout the U.S.

How did this come to be? What are the consequences? Could any of the troubles we now face in the Lyme Wars have been prevented?

What follows is a brief history of Lyme as seen through my eyes. It includes as yet unpublished and largely unknown but important facts and stories that need to be told. So read and enjoy!

In the beginning...

Skin rashes now associated with Lyme were recognized and described as long ago as the late 1800s.

- 1883 - Dr. Alfred Buchwald described a skin lesion he names acrodermatitis chronica atrophicans (ACA).
- 1909 - Arvid Afzelius described an expanding ring-like skin rash, later named Erythema Chronicum Migrans (ECM); in 1990. Dermatologist Bernard Berger, MD, recognizing that the rash is not chronic, renamed it Erythema Migrans (EM).
- 1934 - The appearance of ECM or ACA was associated with benign cutaneous lymphocytomas.

The tick connection was made over ninety years ago!

- 1921 - Arvid Afzelius connected the disease with joint problems, which he speculates are somehow related to the bite of a tick.
- In 1922 the disease was found to be associated with neurological problems and in 1930 with psychiatric problems.
- 1934 - arthritic symptoms are reported in association with the disease.

What did we learn? That Lyme is not new. By the early 1930s, we had the basic framework for Lyme (acute and chronic skin lesions), plus constitutional, neurologic and arthritic symptoms associated with a tick bite. Why was this crucial history ignored by American researchers in the 1970s?

Lyme before Connecticut

In 1965, Dr. Sidney Robbin, semi-retired internist in Montauk, NY, described expanding circular rashes that responded to penicillin treatment. He also described a peculiar monoarthritis that he named "Montauk Knee."

In 1970, Dr. Rudolph Scrimenti, a Wisconsin dermatologist, published the first report of ECM rash in the U.S. Like Dr. Robbin's observations, Scrimenti reported that the rash responds to penicillin.

What did we learn? That, as in many illnesses, it is the front line physician who makes and reports important observations.

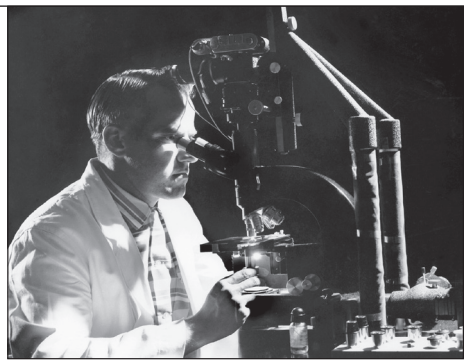
Lyme, Connecticut

In 1975, after many calls from local residents led by artist Polly Murray, the CDC sent Dr. Allen Steere, a Yale rheumatologist and epidemiologist, to Connecticut to study a cluster of unusual rashes and painful swollen joints, especially in children.

Dr. Scrimenti, hearing of the findings in Connecticut, called Steere and his contacts at Yale and related his experiences with the ECM rash and the use of penicillin. It is unclear whether Yale paid much attention to these observations.

In 1977, Dr. Steere published a study of 51 cases describing a new clinical entity and calls it "Lyme Arthritis." He recommended treatment with aspirin and steroids; considering it self-limited, he saw no benefit from treatment with antibiotics. After all, he was a rheumatologist and not an infectious disease specialist. This newly described entity, Lyme arthritis, seemed to be associated with the bite of an Ixodes tick. Dr. Steere suspectsed a virus.

What did we learn? That from the very beginning, the CDC and academic "Ivory Towers" ignore important observations from front line physicians. This delays the use of antibiotics for nearly a decade. Important work spanning the prior 90 years was ignored. Somebody is not reading the literature! Big mistake!



In 1982, Willi Burgdorfer, Ph.D., seen here inoculating ticks, discovered the spirochete that causes Lyme disease in ticks from Shelter Island, NY . The spirochete was later named Borrelia burgdorferi in his honor. *Photo: NIAID/RML*

Along comes Willi

In 1982, Dr. Willi Burgdorfer, NIH entomologist and specialist in relapsing fever *Borrelia*, examined ticks from Shelter Island, NY, and published his finding of a spirochete as the causative agent of Lyme.

Instead of assigning the study of this new entity to the infectious disease branch of the NIH, however, immunologists and rheumatologists were given the job, thus setting the stage for the current divide perpetuated by this same group who still insist on the immune-based theory of persistent symptoms in the chronic Lyme patient. Another big mistake!

What did we learn? 1983 - Based on regimens used for syphilis, antibiotic trials began with mixed and generally poor results.

- 1985 - In Southampton, NY, Dr. Bernard Berger, a dermatologist, and pathologist Dr. Alan MacDonald biopsied the periphery of the EM rash, cultured spirochetes from the skin, and did antibiotic sensitivity studies.
- Discovered that amoxicillin is superior to penicillin, and that erythromycin worked great *in vitro*, but was nearly useless in real people. The first of many treatment surprises began!