

Lyme Disease: The Unknown Epidemic

by D. J. Fletcher and Tom Klaber

Millions of people who are diagnosed with multiple sclerosis, fibromyalgia, Alzheimer's, chronic fatigue syndrome and other degenerative diseases could have Lyme Disease causing or contributing to their condition.

Forget just about everything you think you know about Lyme disease.

It is not a rare disease, it is epidemic. It is not just tick-borne; it can also be transmitted by other insects, including fleas, mosquitoes and mites -- and by human-to-human contact.

Neither is Lyme usually indicated by a bull's-eye rash; this is found in only a minority of cases. And, except when it is diagnosed at a very early stage, Lyme is rarely cured by a simple course of antibiotics. Finally, Lyme is not just a disease that makes you "tired and achey" -- it can utterly destroy a person's life and ultimately be fatal.

Lyme disease, in fact, might be the most insidious -- and least understood -- infectious disease of our day. **"If it weren't for AIDS,"** says Nick Harris, Ph.D., President of IgeneX, Inc., a research and testing laboratory in Palo Alto, California, **"Lyme would be the number one infectious disease in the United States and Western Europe."**

Lyme disease was first recognized in the United States in 1975, after a mysterious outbreak of arthritis near Lyme, Connecticut. It wasn't until 1982 that the spirochete that causes Lyme was identified. It was subsequently named *Borrelia burgdorferi* (Bb), in honor of Willy Burgdorfer, Ph.D., a pioneer researcher.

Many now see the disease, also called Lyme borreliosis, as more than a simple infection, but rather as a complex illness that can consist of other co-infections, especially of the parasitic pathogens *Babesia* and *Ehrlichia*.

Animal studies have shown that in less than a week after being infected, the Lyme spirochete can be deeply embedded inside tendons, muscles, tissue, the heart and the brain.

"Of the more than 5,000 children I've treated, 240 have been born with the disease," says Dr. Jones, who specializes in Pediatric and Adolescent Medicine. **"Twelve children who've been breast-fed have subsequently developed Lyme."**

Bb can be transmitted transplacentally, even with in vitro fertilization; I've seen eight children infected in this way. People from Asia who come to me with the classic Lyme rash have been infected by fleas and gnats."

Gregory Bach, D.O., presented a study on transmission via semen at the American Psychiatric Association meeting in November, 2000. He confirmed Bb DNA in semen using the PCR test (Polymerase Chain Reaction).

Dr. Bach calls Bb "a brother" to the syphilis spirochete because of their genetic similarities. For that reason, when he treats a Lyme patient in a relationship, he often treats the spouse; otherwise, he says, they can just pass the Bb back and forth, reinfesting each other.

Dr. Tang adds other avenues of infection: "Transmission may also occur via blood transfusion and through the bite of mosquitoes or other insects." Dr. Cowden contends that unpasteurized goat or cow milk can infect a person with Bb.

Unreliable Testing

What is the reason for the discrepancy between the government's statistics and the experience of front-line physicians? Says Dr. Jones, "The CDC criteria was developed only for surveillance; it was never meant for diagnosis.

Lyme is a clinical diagnosis. The test evidence may be used to support a clinical diagnosis, but it doesn't prove one has Lyme. About 50% of patients I've seen have been seronegative [blood test negative] for Lyme but meet all the clinical criteria."

Most of the standard tests used to detect Lyme are notoriously unreliable. Explains Dr. Harris, "The initial thing patients usually get is a Western Blot antibody test. This test is not positive immediately after Bb exposure, and only 60% or 70% of people ever show antibodies to Bb."

Dr. Cowden favors two tests developed respectively by Dr. Whitaker and by Lida Mattman, Ph.D., Director of the Nelson Medical Research Institute in Warren, Michigan. However, both of these tests have yet to win FDA approval for diagnostic use.

Explains Dr. Whitaker, "We have developed the Rapid Identification of Bb (RIBb) test. A highly purified fluorescent antibody stain specific for Bb is used to detect the organism. This test provides results in 20 to 30 minutes, a key to getting the right treatment started quickly."

Dr. Mattman's culture test also uses a fluorescent antibody staining technique which allows her to study live cultures under a fluorescent microscope. "When a person is sick," says Dr. Mattman, "antibodies get tied up in the tissues, in what is called an immune complex, and are not detected in the patient's blood plasma.

So it's not that the antibody isn't there or hasn't been produced; it just isn't detectable. Thus, the tests which are based on detecting antibodies give false negatives." The tests of Drs. Whitaker and Mattman do not look for antibodies but look for the organism, in the same way that tuberculosis is diagnosed.

When Dr. Jones treats a Lyme patient who's in a relationship, he often treats the spouse as well; otherwise, he says, they can just pass the Bb back and forth, reinfecting each other.

There are several reasons why Lyme is so difficult to test for -- and difficult to treat. Take, for instance, the bull's-eye rash -- called Erythema migrans -- that is supposed to appear after being bitten by a tick carrying the Lyme spirochete.

Every doctor with whom the authors spoke said that this rash appears in only 30% to 40% of infected people. Dr. Jones said that fewer than 10% of the infected children he sees exhibit the rash.

A Master Of Elusiveness

More importantly, Lyme can disseminate throughout the body remarkably rapidly. In its classic spirochete form, the bacteria can contract like a large muscle and twist to propel itself forward: because of this spring-like action it can actually swim better in tissue than in blood.

It can travel through blood vessel walls and through connective tissue. Animal studies have shown that in less than a week after being infected, the Lyme spirochete can be deeply embedded inside tendons, muscle, the heart and the brain. It invades tissue, replicates and destroys its host cell as it emerges. Sometimes the cell wall collapses around the bacterium, forming a cloaking device, allowing it to evade detection by many tests and by the body's immune system.

The Lyme spirochete (Bb) is pleomorphic, meaning that it can radically change form. The photo on the left shows a colony of Bb both in spirochete and round cell wall deficient (CWD) forms.

In the CWD form, the Lyme organism can lack the membrane information necessary for the immune system and antibiotics to recognize and attack it. Dr. Lida Mattman states that cell wall deficient organisms are more properly called cell wall divergent.

The Lyme spirochete cannot only change from the classic spiral into a round form, but can change back again into a spiral. The middle photo shows this process occurring in the area shown by the arrow.

But the main reason that Lyme is so resistant to detection and therapy is that it can **radically change form** -- it is pleomorphic. Explains Dr. Whitaker, "We have examined blood samples from over 800 patients with clinically diagnosed Lyme disease with the RIBb test and have rarely seen Bb in anything but a cell wall deficient (CWD) form. The problem is that a CWD organism doesn't have a fixed exterior membrane presenting information -- a target -- that would allow our immune systems or drugs to attack it, or allow most current tests to detect it."

As a CWD organism, says Dr. Mattman, Bb is extremely diverse in its appearance, its activity and its vulnerability. Adds Dr. Cowden, "Because Bb is very pleomorphic, you can't expect any one antibiotic to be effective. Also, bacteria share genetic material with one another, so the offspring of the next bug can have a new genetic sequence that can resist the antibiotic."

Clinical Diagnosis

The doctors the authors interviewed all had their own testing preferences, but each insisted that Lyme was a clinical diagnosis, only supported by testing -- and retesting.

"We look at the patient's history and symptoms, genetic tendencies, metabolism, past immune function problems or infection," explains Dr. Bock, "as well as history and duration of antibiotic treatment, co-infection, nutritional and micro nutritional status and also psycho spiritual factors."

Dr. Tang uses all of the above, but also analyzes the blood using darkfield microscopy -- although she cautions that not spotting the spirochete doesn't mean that the patient does not have Lyme disease.

Dr. Cowden also employs muscle testing and electrodermal screening. Dr. Burrascano has developed a weighted list of diagnostic criteria and an exhaustive symptom checklist.

"In pediatric screening especially," says Dr. Jones, "we ask about sudden, sometimes subtle, changes in behavior or cognitive function -- such as losing skills or losing the ability to learn new material; not wanting to play or go outside; running a fever; being sensitive to light or noise.

If one has joint phenomena, we know that an inflammatory or infectious process is present. A hallmark of Lyme is fatigue unrelieved by rest."

For women, Dr. Barkley has found that testing around the time of menses **increases the probability of discovering the presence of Bb**. "Women with Lyme have an exacerbation of their symptoms around menses," she explains.

"The decline of both estrogen and progesterone at the end of the menstrual cycle is associated with the worsening of the patient's Lyme symptoms."

Government Persecution Of Lyme Disease Doctors

Physicians who treat Lyme disease in ways other than the established standard of care -- which means a course of antibiotics lasting no more than 30 days -- risk invasive, exhausting, time-consuming investigation by state licensing agencies, leading to possible loss of their right to practice medicine.

Activists report that 50 physicians in Texas, New York, Oregon, Rhode Island, New Jersey, Connecticut and Michigan have been investigated, disciplined and/or stripped of their licenses over the past three years because of their approach to healing Lyme disease.

This past November 9th, 500 patients who got well after their doctors used alternative or complementary methods joined in a protest rally in New York City. They rose to defend Dr. Joseph Burrascano, who has treated an estimated 7,000 cases.

As this story was heading for publication, New York's Office of Professional Medical Misconduct was engaged in what activists call an unjustified fishing expedition that will probably last for months and will allow state bureaucrats to hunt for any irregularity that could be used to damage Dr. Burrascano.

State medical boards seem to be trying to protect the medical insurance industry rather than patients.

In most cases, effective alternative/complementary treatments require much more doctor time per patient and often include a broad range of medicines and supplements consumed over a much longer period of time, costing much more money than the current standard of care accepted by medical insurers.

But at the rally, patients angrily rejected the medical board's suggestion that their cases demonstrated anything negative about their physician. In fact, they all insisted, it was Dr. Burrascano whose knowledge, patience and care finally freed them from the pain and debilitation that had been ruining the quality of their lives.

Lyme Disease Cases Up 70% in the 1990s

Lyme disease appears to be on the rise, with the majority of cases occurring in the northeastern and north central US, according to the Centers for Disease Control and Prevention (CDC), in Atlanta, Georgia. There was a 70% increase in the number of reported cases of the tick-borne illness between 1992 and 1998, from about 10,000 cases per year to almost 17,000. Ninety-two percent of the cases occurred in only ten states - New York, Connecticut, Pennsylvania, New Jersey, Wisconsin, Rhode Island, Maryland, Massachusetts, Minnesota and Delaware.

Most cases occur in June, July and August, when ticks in the immature nymph state tend to feed, and outdoor activities are most common among children and adults. In the nymph stage, the tick is about the size of a poppy seed, and may easily stay attached to the body long enough to transmit the bacteria.

To avoid contracting Lyme disease, CDC officials suggest wearing tick repellents and light colored clothing to make the ticks more visible, or avoiding tick-infested areas altogether. However, because these protective measures "can be inconvenient," researchers are currently working to develop new ways to reduce the risk of Lyme disease. Vaccination should be considered for "persons aged 15-70 years who live in areas of moderate to high risk for Lyme disease and have frequent or prolonged contact with tick habitat," according to the report.

