

LYME DISEASE

THE UNKNOWN EPIDEMIC

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.

BY D. J. FLETCHER AND TOM KLABER

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 achy"--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

All the other clinicians with whom the authors spoke agreed that Lyme has reached epidemic proportions. How is this possible? Obviously 25% of Americans haven't been bitten by one of a select few species of ticks. The answer is that Lyme is not transmitted just by ticks.

"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, reinfecting 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.

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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 spir o chete 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 can not 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. The photo on the bottom shows fully formed spirochetes emerging from a giant CWD form. 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 micronutritional status and also psychospiritual 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.

--JEFF KAMEN

ANTIBIOTIC TREATMENT

Every authority the authors spoke with considered antibiotics the primary treatment for Lyme, but that the accepted "standard" antibiotic therapies (of a duration and type acceptable to insurance carriers, HMOs, mainstream physicians, etc.) are insufficient. Lyme is sometimes classified as having different stages--early vs. chronic, or localized vs. disseminated. "The biggest distinction is between early-stage and chronic," says Dr. Whitaker. "In the beginning, many organ systems are invaded while the patient may experience no symptoms. As time goes on we see multiple system symptoms involving the whole body, especially the central and peripheral nervous systems, and the musculoskeletal, skin and circulatory systems. Many Lyme cases are diagnosed by psychiatrists. Dr. Brian Fallon is studying cognitive and other neuropsychiatric manifestations."

The problem, says Dr. Barkley, is that "There isn't an adequate treatment model. So if the physician says you have Lyme, and gives you the standard antibiotic therapy, and you aren't better, the thinking is that you must have something else wrong, such as an autoimmune problem, or else you didn't have Lyme disease in the first place. Short-term oral antibiotics are effective in treating localized Lyme, but with disseminated Lyme, the requirement for either intravenously administered antibiotics or long-term oral antibiotics becomes common."

In his regular practice, Dr. Bock has always tried to avoid antibiotics. But, he says, "If you go back to syphilis, the history of spirochetes is one of being able to hide out and then reappear, causing severe, devastating neurological illness. This isn't a risk I would recommend taking with Bb."

Most of the physicians recommended an immediate short course of antibiotics for anyone bitten by a deer tick, or who exhibits certain symptoms. "It takes a while for the immune system to produce antibodies," says Dr. Barkley. "So Lyme testing--other than by a skin biopsy from an active rash within 14 days following the bite--may yield inconclusive results. Symptoms of Lyme include fever, night sweats, fatigue or a flu-like illness that does not improve within three to five days." Other symptoms reported by physicians include stiff neck, prolonged joint and muscle pain, heart palpitations, brain fog or severe headaches.

"I tally all the initial symptoms and signs, and try to weed them out one by one," says Dr. Jones. However, he cautions, "Treatment duration varies with each individual. If one stops antibiotics prematurely, a more resilient Bb infection will develop that will cause more brain and body injury."

ADJUNCT THERAPIES

None of these physicians relied solely on antibiotics; they used immune system-strengthening protocols as well.

"The immune system may be less able to respond if the person is having a hard time clearing toxins," says Dr. Bock. "You're going to add to this overload by taking antibiotics. For general immune support, we've used maitake and reishi mushrooms, ginseng and astragalus.

This photo of a darkfield microscope image shows the Lyme spirochete (circled) in a patient's blood plasma. Many of the red blood cells are lemon-shaped, indicating an allergic reaction; their being somewhat clumped together is a sign of joint inflammation. The two larger, whiter bodies are a common kind of white blood cells called neutrophils. The two being in close proximity shows a response to infection.

"Natural medicine approaches include anti-inflammatory eicosanoids such as fish oil and borage seed oil; high-potency multivitamin and mineral formulas; CoQ10 and other mitochondrial nutrients; cognitive enhancement substances such as carnitine and certain herbal extracts. Acupuncture combined with physical therapy can often reduce pain. I have posted an article online that discusses these alternative approaches in more depth at my website, www.PatientsAmerica.com."

Dr. Cowden recited a litany of natural immunotherapy agents. His recommendations include the following: "Transfer factor--ImmuneFactor 2 and CellResponse are good products; Thymic Protein A; medicinal mushroom combinations such as ImmPower AHCC; glyconutrients like Ambrotose; arabinogalactan (Larix), an immune-enhancing polysaccharide; and Astragalus Supreme." Dr. Cowden also notes that "if you use a pharmaceutical antibiotic, you need to use an herbal antifungal to reduce stress on the liver and kidneys."

LIFESTYLE CHANGES

"Avoid sugars because they feed these bugs," advises Dr. Cowden. "It is most important to balance saliva pH between 6.7 and 7.0. Sufficient dietary minerals bring pH up if low. Reducing stress will raise pH; so will identifying and removing food, nutrient and inhalant allergies. You should identify your metabolic type and then follow the appropriate diet. Grapefruit seed extract and certain other substances, including vitamin C, can interfere with tissue uptake of the antibiotics and make them less effective. Take as few non-essential supplements as possible--consult with a physician knowledgeable about nutrition--and time them as far from the antibiotic as possible."

Dr. Bock reminds us that, "It's also important to support the endocrine system. In some cases, cognitive abilities improved when subclinical hypothyroid problems were treated. Chronic stress can cause suppression of the immune system. Manage the effects of stress on the body: Use relaxation techniques and biofeedback. Find a group for emotional support."

This is a scanning electron micrograph of the Lyme bacteria (*Borrelia burgdorferi*) isolated from human spinal fluid. The Lyme spirochete is genetically similar to the syphilis spirochete and they share important traits: Both can be transmitted by direct

contact through humans--through sexual intercourse, passage of the organism from mother to fetus, blood transfusions, etc. Infected individuals can also manifest no symptoms for years or, in contrast, have frequent relapses.

In his practice, Dr. Jones has found that, "Taking acidophilus and other probiotics is always important. [Antibiotics kill the intestinal flora necessary for digestion and immune functions; probiotics like lactobacillus re-inoculate the intestines.] Stay away from or severely limit alcohol intake. Develop a healthier standard of living. Rest is needed. We've found that a parent who has a child with Lyme is often feeling guilty. One has to work with these difficult feelings. I emphasize that it's not a parent's fault; you can't protect your child from Lyme exposure."

PRESENT LIMITATIONS

None of the experts the authors consulted claimed to completely understand Lyme or to be able to completely cure it in every case. Some people infected with Bb may never manifest the symptoms of Lyme. Others become seriously ill soon after they are infected. Treatment must be customized from patient to patient and can vary widely. "Certain people may clear Lyme without antibiotic therapy," says Dr. Barkley. "However, the other extreme is that even with antibiotics, some people with Lyme have died from this disease." Says Dr. Jones, "We have seen children from one day old to 18 years of age who have required from three months to six years of antibiotic therapy. We have had some patients on antibiotic therapy for very long periods, and we've done follow-ups for as long as 15 years post-treatment. The criterion for stopping therapy is that one must be totally Lyme disease-symptom free for two months, with no Lyme flare induced by another infection or menses and no 'Herx' [Jarisch-Herxheimer reaction of the body manifesting symptoms in response to dying Bb]."

"THERE ARE VERY FEW SYMPTOMS WHERE YOU SHOULDN'T CONSIDER LYME," SAYS DR. COWDEN. "MORE THAN 50% OF CHRONICALLY ILL PEOPLE MAY HAVE LYME CONTRIBUTING TO THEIR CONDITION."

The situation is quite difficult now. "It's sad where we are with this disease," says Dr. Cowden. "You're supposed to go through the 'standard' treatment first before turning to alternative treatments. We need to turn this around, into a logical, integrated approach." The impetus for this change must come not only from the patients who have been classically infected by a tick bite, but by those who suffer from "unexplained" muscle and joint pain, unrelieved fatigue and cognitive impairment--and by those who are afflicted with degenerative diseases that can be caused or aggravated by Lyme. Presently, such patients will find few doctors experienced in Lyme, because of the newness of the disease and lack of understanding about it--and because those doctors who take a comprehensive approach to diagnosing and treating Lyme are commonly harassed by state medical boards, insurance companies and HMOs.

It is up to patients to actually educate their doctors about the inadequacy of standard testing and the necessity for using techniques such as electrodermal screening and

darkfield microscopy. And it is up to patients to become politically involved with Lyme advocacy groups, such as those listed here, to fight for their right to proper medical care. The earlier Lyme is diagnosed, the easier it is to cure. For people with chronic Lyme symptoms, the road to recovery can be long. With comprehensive integrative treatment, however--a combination of the best of conventional and alternative medicine protocols--their health can be continually and dramatically improved.

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