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The Mounting Toll of LYME DISEASE

By JOHN PEKKANEN

What you need to know
about this strange and
frightening disorder
whose symptoms mimic
those of other ailments

ON AN AUGUST DAY in 1986, Stanley Staron's knees suddenly swelled like balloons. Staron, 29, assumed he had sprained the knees while jogging. His doctor drained fluids and prescribed anti-inflammatory drugs and therapy, but the swelling persisted. When surgery brought no improvement, Staron consulted a rheumatologist.

As Staron gave the specialist his medical history, a true picture of his illness emerged. Staron's Bolton, Conn., home was in a rural, wooded area where deer roamed freely. The previous spring, he had developed a mysterious ankle rash that

disappeared after a few days. Four months later, a flu-like illness had confined him to bed. He had also suffered unexplained fatigue, even though he had been sleeping ten to 12 hours a night.

An analysis of Staron's blood confirmed the rheumatologist's suspicion: Staron had Lyme disease. Although he was relieved to find the cause of his symptoms and begin antibiotic treatment, his troubles were far from over.

THE LYME DISEASE story began with Polly Murray, an artist in Lyme, Conn. For years she had suffered from unexplained fatigue, pain, stiffness and a rash on her hands. She had to stop painting. Murray had consulted many doctors, but not one could diagnose her illness.

She searched the medical literature for clues, but found none. Other members of her family became ill, and in 1975 her 11-year-old son

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PHOTO: BERNARD FURNIVAL

was diagnosed as having juvenile rheumatoid arthritis. She and Judith Mensch of nearby Old Lyme, whose daughter also had the disease, notified the state health department after learning that a number of area children had developed the illness.

Soon Dr. Allen C. Steere, a post-doctoral fellow in rheumatology at Yale University, was called in to head up a team investigation. He and his colleagues determined that the problem was a tick-borne syndrome, and named it Lyme disease. The evidence became conclusive in 1981, when Willy Burgdorfer, an internationally recognized expert in tick-borne diseases, discovered in a deer tick the corkscrew-shaped bacterium that causes Lyme disease. The bacterium, called a spirochete, now bears his name, *Borrelia burgdorferi*.

Difficult to Detect. Today the disease is reaching epidemic proportions. It has spread to 43 states, with 90 percent of all cases in Connecticut, Rhode Island, Massachusetts, New York, New Jersey, Wisconsin and Minnesota. It is also found in Europe, Asia and Australia.

The total number of its U.S. victims is unknown, but everyone, including the Centers for Disease Control, agrees that the roughly 5700 new cases reported to the CDC last year was a fraction of the true count. With several thousand people infected every year, Lyme disease now surpasses Rocky Mountain spotted fever as the most prevalent tick-borne disease in the country.

The riskiest period for Lyme

disease infection is late spring and summer, when people spend a lot of time outside. That's also when the deer tick is in its nymph stage and about the size of a poppy seed, making it difficult to detect.

Though the deer tick's name comes from the white-tailed deer, the tick's wintertime adult habitat, ticks become infected by biting the white-footed mouse—nature's major reservoir for the Lyme disease bacteria. Explains Andrew Spielman, professor of tropical public health at Harvard: "The deer keep the ticks going, and the mice keep the disease going." It is estimated that one-fourth to one-third of nymph deer ticks carry the Lyme disease spirochete. The western black-legged tick is the major carrier on the West Coast, and other types of ticks may also carry the spirochete. The common dog tick, however, is not believed to be a threat.

About half of the people infected develop a rash. It may be light red to nearly purple; it often expands into an oval, triangular or round shape with a white center and red border; it may even include blisters. If a person is treated when the rash first appears, the risk of later complications is sharply reduced. A flu-like illness that may include fever, nausea, soreness, head, neck and backaches and profound fatigue can occur before, during or after the appearance of the rash.

The disease may also involve arthritic-like symptoms in the knees or other large joints as the

bacteria attack the joint lining, causing inflammation and swelling. A New York State Department of Health survey found that 65 percent of 600 patients with advanced Lyme disease developed arthritis days or months after the original tick bite.

Greatest Worry. The arthritic symptoms wax and wane. Antibiotic treatment can usually control them, and for most people they eventually fade away. But for others, the symptoms may recur for years, unpredictably, and permanently damage joints.

In eight percent of the survey's cases, Lyme disease led to serious heart complications, the most common of which was an interruption of the heart's rhythms. Other patients need a temporary pacemaker. On occasion, the disease can also attack the liver, eyes, kidneys, spleen and even the lungs.

But the greatest worry is damage to the brain and other parts of the nervous system. The survey found that 23 percent of the patients developed neurological complications, and many experts believe the actual percentage is higher.

For most, the symptoms are relatively mild and controllable with antibiotics. But those who go too long without treatment, or who don't respond to antibiotics, can suffer a recurrence of limb numbness, facial palsy, seizures and excruciating headaches. Some, like Stanley Staron, face even worse.

Last summer, more than two

years after his initial infection, Staron began to experience depression, mood swings and memory loss. "I began to blow my top at the littlest thing," he says. "Once, after I washed the car, I became uncontrollably angry at my wife because she drove it. Then I noticed I didn't remember what had been said at meetings at work."

Staron went to Dr. Steere at the New England Medical Center in Boston, where a spinal tap revealed evidence that Lyme disease bacteria had invaded his brain and central nervous system. Staron underwent yet another round of antibiotic treatments, and his problems abated.

Although Lyme disease is not regarded as fatal, it is responsible for at least two deaths, one heart-related, the other involving the lungs. And one patient, a man in his 30s, nearly died from neurological complications.

Unfortunately, the symptoms of Lyme disease—sometimes called "the great imitator"—may mimic those of other neurological illnesses, such as multiple sclerosis, Alzheimer's disease and amyotrophic lateral sclerosis (Lou Gehrig's disease). But doctors say Lyme disease can usually be distinguished from other neurological illnesses with a thorough medical examination.

One fear among experts is that some people with relatively mild cases may yet experience serious neurological problems long after the initial infection. Such cases fuel the "time bomb" theory that some

Precautions to Take

1. When walking in tick-infested areas, wear light-colored clothing, a hat, long-sleeved shirt, and pants tucked into your socks.
2. Use insect repellents. Permanone, very effective against ticks, can be sprayed on clothes, but not on your skin. Other insect repellents can be applied to the skin, and those containing Deet are considered best.
3. It takes at least a few hours, and perhaps up to two days, before a tick can infect you. If a tick does attach itself, use a fine-bladed tweezer to pull it directly out by the head. Don't squeeze the tick's body when extracting it, as this may inject the spirochetes into your bloodstream. Do not use alcohol or any other antiseptic on the tick before you pull it out. Keep the tick in a container with a blade of grass for later identification.
4. Children and pets should be checked for ticks every day.
5. If you notice a rash or flu-like symptoms, consult your physician. For more information, send a stamped, self-addressed envelope to: Lyme Borreliosis Foundation, Inc., P.O. Box 462, Dept. RD, Tolland, Conn. 06084.

bacteria remain latent for years in the brain, thereby escaping antibiotic therapy.

The good news, however, is that antibiotics now available, particularly the third-generation cephalosporins, can cross the blood-brain barrier and usually reverse neurological problems. And even more promising drugs are being tested.

"It can't be stressed too much that early diagnosis and treatment will prevent the progression of Lyme disease in the overwhelming majority of cases," says Steere.

Mystery at Birth. Karen Vanderhoof-Forschner was bitten by a tick near her Stamford, Conn., home during her third month of pregnancy. She developed a rash, but did not realize she had Lyme disease, and received no treatment. In July 1985 her son, Jamie, was born prematurely and a few days later

developed a bright, red rash and severe neurological problems. Over the next few years, the Forschners were told that their son suffered from four different metabolic or neurological disorders, all of them fatal. The couple consulted more than 100 doctors before Dr. Robert Spector, a neuro-ophthalmologist at New York's Albert Einstein College of Medicine, solved the mystery.

"Jamie was terribly small and underweight," Spector says. "He had a facial palsy, his head hung limp, he had serious eye and ear disorders, and he was unable to swallow or speak."

Spector surmised that nothing but an in utero infection could explain Jamie's symptoms, and he concluded it was Lyme disease. The strongest evidence, Spector says, is that antibiotics have improved the child's condi-

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tion, although a full recovery remains uncertain.

Spector has examined 18 other children born to mothers who suffered untreated Lyme disease in pregnancy. One of the children is blind, and all have problems similar to Jamie's, although not as acute. "From what I've seen, Lyme disease in pregnancy can pose a serious risk, and any pregnant woman who suspects she has Lyme must consult her physician," Spector says.

Most researchers are convinced, however, that if the disease is treated in pregnancy, the risks to the fetus are minimized, if not eliminated. "If Lyme is detected during pregnancy," says Dr. Raymond Dattwyler, director of Clinical Lyme Disease Services at the University Hospital in Stony Brook, N.Y., "my recommendation is to get appropriate antibiotic therapy and continue with the pregnancy. And that's the advice I would give my own wife."

Search for a Vaccine. Studies have shown that tests for Lyme disease can be inaccurate, and most doctors use them only to confirm clinical diagnoses. Scientists are now looking hard for better tests.

Researchers are also seeking a vaccine, but that appears farther off than an improved test. Says Russell C. Johnson, a microbiologist at the

University of Minnesota: "We've patented a vaccine that produces protective antibodies in hamsters, but I don't think we're going to have a human vaccine against Lyme for several years."

On a different tack, there have been promising experiments with a product called Damminix, a small, cardboard cylinder containing about 30 balls of cotton treated with the pesticide permethrin. When the cylinder is laid on the ground, the white-footed mouse uses the treated cotton to build its nest. Though the pesticide is harmless to rodents, it kills the deer ticks that feed on them. But the cost is high: over \$350 a year to treat an acre of land.

STANLEY STARON's life is nearly back to normal now. "I'd say I'm 80 percent of my old self. My knees still give me problems, but I'm not tired like I was, and although my memory isn't completely restored, it is much better. I'm calmer now. What scares me is a recurrence of the neurological problems, losing control of my thinking.

"Because this disease has come back so many times, I'm resigned to the idea that there may be no cure for me. I'll probably have to return for more antibiotic treatments. Whatever it takes, I'll do it."

Reprints of this article are available. See page 230.

THE BIGGEST MISTAKE you can make is to believe you're working for someone else.

—Quote Magazine