

The Lyme Disease Association has "Reprinted from PEOPLE Weekly's June 16, 2003 issue by special permission; © 2003 Time Inc. All rights reserved.

People; 16 2003 J.D. Heyman Joanne Fowler in Frederick

### **Hidden Plague. Forget about SARS.**

#### **Lyme disease is spreading steadily, and some experts say it can elude the standard cure**

For months no one knew what was happening to Tom Coffey. In the spring of 2001 the then 34-year-old radio dispatcher was struck by high blood pressure and double vision. By summer's end he was suffering from facial palsy, crushing fatigue and joint pain so intense he walked with an old man's shuffle. Medical visits turned up nothing. By October his weight had plummeted 105 lbs., to 202. "My doctor was at the end of his rope," says Coffey. "He kept referring me to different people."

When he awoke unable to swallow his saliva, Coffey rushed to a hospital near his Frederick, Md., home and was given blood tests and brain scans. Doctors returned with a terrifying diagnosis: ALS, or Lou Gehrig's disease, a degenerative illness likely to kill him within six months. "Tom's dad said, 'I always thought he'd be burying me. Now I'll be burying him,'" says Coffey's wife, Tricia, 35.

Hooked to a feeding tube, Coffey waited to die. But a relative who thought his symptoms might have another cause suggested a trip to Dr. Greg Bach, a suburban Philadelphia Lyme disease specialist. The doctor found something everyone else had missed—a "bull's-eye" rash beneath his patient's hair. Coffey was suffering not from ALS but from a severe case of Lyme, which is spread to humans by tick bites. For most people, Lyme manifests in a rash and flulike symptoms easily treated with antibiotics. Left undiagnosed, however, it can invade the nervous system. "I always thought Lyme was no big deal," says Coffey, who rebounded after taking medication. "But it damn near killed me."

In fact, Lyme is rarely fatal, but as Americans head outdoors during the peak infection months of May to July, experts warn that it can be devastating—and that the threat is growing. In the past decade the disease has spread from the Northeast to every state except Montana. Last year the Centers for Disease Control reported 17,000 cases—more than double the number in 1990—but researchers like Joseph Piesman of the CDC say the actual incidence may be about 10 times higher.

The illness is also the subject of a growing debate. While most doctors believe that *Borrelia burgdorferi*, the tick-borne spirochete that causes Lyme, is quickly killed by medication, many patients complain of arthritis, irregular heartbeat, memory loss and motor-skill problems long after they have undergone the standard two-to-four-week treatment regimen. That has led some researchers to conclude that Lyme can return as a chronic illness in perhaps 10 percent of those thought to be cured. "Lyme is much more serious than the public recognizes," says Dr. Brian Fallon, director of Columbia University's Lyme Disease Research Center. "People can have severe cognitive problems for the rest of their lives." The medical establishment, however, remains unconvinced, and a few doctors have been penalized for their treatment of recurrent Lyme. Pat Smith, head of the Lyme Disease Association, a nonprofit group calling for greater research on the disease, thinks pressure not to recognize the chronic form comes from insurance companies: "They don't want to pay."

No one disputes that late-stage Lyme is little understood. Tests are often effective only in early-stage infection, and while sufferers usually get a rash, they don't always notice it. Worse, many Lyme symptoms mimic other diseases: fibromyalgia, multiple sclerosis, even mental illness. That means other diseases may be mistakenly treated as Lyme--the crux of mainstream objections to the chronic-disease theory. "People who test negatively for Lyme are still being given antibiotics to see what happens," says Dr. Gary Wormser, head of infectious diseases at New York Medical College.

But Fallon argues that a longer course of medication, given intravenously, may be needed for some patients. Coffey's doctor agrees. "Half the patients I see have been inadequately treated," says Bach. "These people thought they were cured by being treated only a little."

Coffey, now 37, is taking no chances: He has remained on antibiotics for 14 months to be sure that his Lyme is really gone. Still, he's grateful to have escaped his death sentence. "I'm starting over again," he says. "From here on out, the rest is gravy."

--J.D. Heyman --Joanne Fowler in Frederick