Stalking Dr. Steere Over Lyme Disease

By DAVID GRANN, The New York Times

In the late 1970's, as Steere's team fanned out along the Connecticut River, about 50 miles away in Westport, Conn., my 11-year-old sister woke up with tingling in her joints. My father, a cancer specialist, thought she had some sort of flu, but 24 hours later she couldn't walk. As my mother and I looked on, my father carried her out to the car and took her to Stamford Hospital. When he returned with her several hours later in a wheelchair, I could hear him talking to my mother in hushed voices in the bedroom. The next day, he took her to a specialist at Yale, who said that despite negative tests, she probably had an acute form of juvenile rheumatoid arthritis and might die. He recommended that my father admit her to the hospital and treat her with high dosages of steroids. But still unsure why her tests were negative, my father decided to wait. That night, he searched his medical books, trying to find out what she had. I could see him in the study, hunched over his desk, folding the pages in half. Medicine, he always believed, was like a language: each disease has its own meaning. But what was a disease that had no name?

While my father conducted his own search, Steere homed in on four country roads, where one in 10 children appeared to have the sickness. Though he could not find the source of the outbreak, his team found several important clues: first, the apparent infection was more prevalent in heavily wooded areas and in the summertime; second, it was sometimes preceded by a skin lesion that resembled the red bull's-eye from a tick bite.

Based on these and other observations, Steere, at the age of 33, hit the holy grail of medical research: he announced that his team had discovered a new disease in the United States. Transmitted in all likelihood by a tick, it was, as his later studies uncovered, one of the great impostors of medicine, taking on the form of other diseases depending on where the infection was in
the body. As a result, the symptoms varied wildly: one person might suffer headaches or joint pain while others, with severe cases, might endure cardiac and neurological abnormalities, including memory loss and facial paralysis. In most cases, he and his team concluded after subsequent studies, the illness could be effectively treated with one or two courses of antibiotics.

Though many in the medical establishment remained skeptical -- a researcher wouldn't find proof of the new bacterial agent for another five years -- the public already hailed Steere as a kind of Magellan of medicine. Known for his quiet and reserved nature (he liked to dress up in protective suits and walk through the forest with a blanket, trailing for tick specimens), he appeared in Time magazine and The New York Times. When my father stumbled upon his findings in the Annals of Internal Medicine in 1977, my sister's disease had already subsided on its own, as it would in many, but her affliction now had a name -- Lyme," after the town in Connecticut in which it was discovered.

By the end of the 1980's, 15 years after Steere documented the first 39 known cases in a cluster of children, the disease had become the most common vector-borne infection in the United States. Between 1982 and 1992, there were nearly 50,000 cases reported nationwide, but because there was still no perfect test, diagnosis remained a notorious problem, and the disease stayed shrouded in mystery. Blood tests, especially in the early stages of the infection, frequently came back negative, even though the spirochete was present. As a result, patient advocacy groups put the real number of infected closer to one million. The explosion made Steere one of the most powerful forces in medicine