



Doll Lane, 96th Medical Group laboratory technician, reviews sample through microscope November 19, 2015, at Eglin Air Force Base, Florida, after recently discovering rare spirally twisted bacteria, known to cause tickborne relapsing fever, and cultured by Centers for Disease Control (U.S. Air Force/Ilka Cole)

The Myths of Lyme Disease

Separating Fact from Fiction for Military Personnel

By Montgomery McFate

I love everything in the world. Except for ticks.

—DALAI LAMA

No one is immune to, and there is no cure for, tickborne diseases. Just one tick bite can destroy a person's career. At age 43, Air Force Colonel Nicole Malachowski was found unfit for duty due to neurological damage resulting from a tickborne disease. Colonel Malachowski was the first woman to fly with the Thunderbirds and then commanded the 333rd Fighter Squadron. She also served as the deputy director for U.S. Air Force Readiness and Training in the Office of the Under Secretary of Defense for Personnel and Readiness and as the executive director of the White House "Joining Forces" Initiative (2015–

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2016).¹ While she was commanding an F-15 fighter squadron, Colonel Malachowski began experiencing a rapid onset of multiple symptoms. She wrote that she suffered from

*intractable pain, insurmountable fatigue, cognitive dysfunction and major problems with my speech and short-term memory. I endured disorientation, confusion, anxiety and even moments of temporary paralysis. I was unsafe to be left alone. I could not play with my children, care for myself, or interact with my husband. . . . There were times I would have welcomed death. I thought I was tough as a combat-proven fighter pilot but tickborne illness destroyed me. It brought me to my knees and ruthlessly broke me.*²

Servicemembers are particularly at risk for Lyme disease; they live, work, and play on bases where Lyme is rampant. Some 75 percent of all U.S. military installations are located in states where 99 percent of the approximately 500,000 tickborne disease cases reported to the Centers for Disease Control and Prevention (CDC) from 2004 to 2016 occurred.³ Moreover, training drills often take place in woods and fields that harbor a variety of tick species. In their leisure time, many Servicemembers and veterans, and their families, also enjoy hunting, fishing, camping, and hiking in the great outdoors, which increases their risk of encountering ticks.⁴ Lyme disease is most prevalent in rural counties with relatively high socioeconomic status, abundant forestation, wet conditions, and mid-range temperatures. These American counties tend to be exactly the sort of places where veterans like to retire, and indeed, “Lyme disease incidence rates were higher in counties with greater military veteran population compositions.”⁵

Commonly referred to as Lyme disease, *Lyme borreliosis* was first discovered in the United States in Lyme, Connecticut, in 1976. More than 20 children developed what doctors initially mistook for a juvenile form of rheumatoid arthritis. Strangely, each of these children had exhibited a rash resembling a bull’s eye, which led the doctors to see a

link between the arthritic symptoms and the bite of an insect. In the early 1980s, Dr. Wilhelm Burgdorfer discovered that the causative agent of Lyme infection was a spirochete type of bacteria, subsequently named *Borrelia burgdorferi* in his honor. After extensive field investigations, *Ixodes scapularis*, commonly referred to as the deer tick or blacklegged tick, was identified as the main vector of Lyme infection east of the Rocky Mountains. In areas west of the Rocky Mountains, *Ixodes pacificus*, also known as the western blacklegged tick, was the primary vector.

Lyme disease is now a serious epidemic in the United States, with positive lab tests reported from all 50 states and Washington, DC.⁶ The CDC calculates annual U.S. incidence at more than 300,000 cases; however, true incidence is certainly higher.⁷ Although the majority of cases have been reported from the northeastern part of the country, infected ticks can be found in about 50 percent of U.S. counties.⁸ An increase in both temperature and humidity as a result of climate change is predicted to increase the number of Lyme cases by more than 20 percent in the coming decades.⁹ In short, Lyme disease has already reached epidemic proportions in the United States, and the situation will certainly get worse. As the disease spreads, military personnel, veterans, and their families will be at even higher risk for contracting the disease.

More than 40 years after children in Connecticut began getting sick from tick bites, there is still no cure for many of the people who have been bitten. A bitter political battle has ensued in the United States among professional medical organizations, patient advocates, and even the CDC concerning the origin, diagnosis, and treatment of the disease. Mainstream medical opinion has been that there is no such thing as *chronic* Lyme because the bacteria could not survive treatment with antibiotics, evade detection, and cause ongoing symptoms.¹⁰ However, individuals who suffer from the disease and patient advocacy organizations point to their own experiences as evidence that the disease may linger for years. (Indeed,

many of the most recent medical studies indicate that Lyme *can* evade detection and cause severe chronic symptoms.) As a result of the so-called Lyme wars, the disease itself has become shrouded in a number of myths. Separating fact from fiction is critical for military personnel and their families since members of the Armed Services could face a heightened risk of contracting Lyme disease based on their occupations, locations, and recreational activities.

It Is Not That Severe: False

Lyme disease can produce a wide variety of symptoms, but typical signs of infection are a round red rash at the site of the tick bite, fatigue, swollen joints, headache, fever, night sweats, cognitive impairment, and sensitivity to light.¹¹ Many medical professionals in the United States tend to minimize the dangers of Lyme and may mistakenly believe that the symptoms of the disease are not severe. For example, in the words of Dr. Katerina Silverblatt of Heights Pediatrics in Brooklyn, “We’ve never had a complication from Lyme that would be of any consequence.”¹²

On the contrary, many complications from Lyme disease are severe indeed. For example, the spirochete bacteria of Lyme disease can penetrate the heart, even causing death.¹³ Dr. Neil Spector, who taught medicine at Duke University, began experiencing muscle pain, fatigue, and irregular heartbeat.¹⁴ Doctors who treated him could find nothing wrong and dismissed his symptoms as stress related. “I was confused,” recalled Dr. Spector. “Should I believe a team of doctors assuring me that nothing was wrong? Or follow my gut instinct exhorting me to unearth the mystery responsible for my downwardly spiraling health? I was beginning to question my sanity.” Left undiagnosed and untreated, the Lyme bacteria entered his heart. Only a heart transplant initially saved Dr. Spector’s life, but he lost his battle with Lyme disease in June 2020.¹⁵ His experience was not unusual: Cardiac manifestations of *Borrelia burgdorferi* infection occur in up to 8 percent of patients,¹⁶ with most of the severe cases occurring in men of military age.¹⁷



Technical Sergeant Jessica Roofe, 86th Aerospace Medicine Squadron NCO in charge of epidemiology, prepares tick to be sent for testing, September 9, 2016, at Ramstein Air Base, Germany (U.S. Air Force/Tryphena Mayhugh)

In addition to heart problems, Lyme can affect the brain. Lyme bacteria can cross the blood-brain barrier, infecting the central nervous system. This manifestation of the disease—called Lyme neuroborreliosis—occurs in up to 15 percent of patients bitten by an infected tick.¹⁸ Symptoms include meningitis, facial palsy, encephalitis, and stroke.¹⁹ When Lyme disease infects the central nervous system, it may also cause severe psychiatric symptoms such as psychosis, schizophrenia, hallucinations, and dementia.²⁰ In 2011, researchers at the International Alzheimer’s Research Center in Switzerland found evidence of spirochetes (the type of bacteria that causes syphilis and Lyme disease) in the brains of Alzheimer’s patients,²¹ confirming that Alzheimer’s disease may have a bacteriological component and that *Borrelia burgdorferi* may play a role.²²

Those who suffer from Lyme disease have an increased risk of suicide. Of course, depression and chronic pain

might play a role in the suicide risk for Lyme patients, but scientists also believe that biological effects of Lyme on the nervous system (including brain inflammation, neuronal dysfunction, and white matter encephalopathy) could be a factor.²³ One study demonstrated 33 percent of late-stage Lyme disease patients were suicidal, and by conservative calculations, about 1,200 people infected with Lyme commit suicide each year.²⁴ The risk of suicide is highest in children. One study demonstrated 41 percent of children who had been diagnosed with Lyme disease had suicidal thoughts and 11 percent had made suicidal gestures.²⁵

Statistics on suicide often seem abstract, but the experience of one veteran might help illuminate the psychiatric dangers of Lyme disease:

I woke up on a beach out of the country with a bottle of scotch in one hand and my handgun in the other. I did not remember driving there. My doctor said I was in a

psychogenic fugue state. My life was being destroyed by Lyme disease and no one had a clue. At work, I had been highly awarded throughout my career, but it became a real struggle and I did not understand why. When I went to work that morning, I was tired, frustrated, and in a state of dread and fear, and I drove 100 miles past the base. I only drank a small amount of the scotch; the bottle was still nearly full. I have never been a big drinker and as a result I fell asleep on the beach. I woke up the next day wondering how I got there and why and drove back to the base and turned myself in for Away Without Leave. After being diagnosed, treated and having recovered, I can relate to other veterans living with undiagnosed and untreated Lyme disease.²⁶

Another severe complication of Lyme disease is the transmission from a pregnant woman to her unborn baby. In a systematic review of the medical case studies from the United States, Europe, and Asia between 1969 and 2017,

scientists identified negative outcomes for the fetus or newborns in 61 percent of pregnancies, including spontaneous miscarriage, stillbirth, and death shortly following birth. Babies who survived experienced a variety of congenital irregularities and health issues, including jaundice, respiratory distress, and heart abnormalities.²⁷ Autism spectrum disorders are also associated with Lyme disease.²⁸ Interestingly, states' prevalence of autism spectrum disorder correlate with their prevalence of Lyme.²⁹

Many people—including many medical professionals—discount the severity of Lyme disease. Yet scientists who study Lyme disease recognize that the closest biological analogy to Lyme is syphilis. Like syphilis, Lyme disease is caused by a highly invasive pathogen with a unique form called a spirochete. Like syphilis, the Lyme disease spirochete can invade the central nervous system and other major systems of the human body. Also like syphilis, Lyme disease begins with a localized infection, spreads throughout the body, and may result in chronic degenerative disorders and possible mortality.³⁰ Indeed, the bacteria that cause syphilis and Lyme are so similar that scientists who study syphilis use Lyme bacteria as a surrogate in the lab.³¹

It Is Easy to Diagnose: False

Ruben Lee Sims enlisted in the Air Force and served in Vietnam. While serving in the military, Sims was bitten by a tick and contracted Lyme disease. Military doctors neither diagnosed nor treated Sims appropriately and instead discharged him after 14 years of service in 1984, citing “hypochondriasis with psychogenic pain disorder” (meaning pain from psychological factors rather than a physical cause). After his discharge from Active duty, Sims entered the care of the Department of Veterans Affairs (VA). He suffered from multiple symptoms common to late-stage chronic Lyme: vision problems, night sweats, joint swelling, heart palpitations, and depression. Despite his classic Lyme symptoms, the VA refused to perform the tests that could have confirmed the disease and instead referred him to a

psychiatrist. “Just ask any VA doctors whether or not they understand Lyme disease,” Sims wrote in a letter to his Member of Congress. “The likely response is either no or just take the CDC tests. Surely, they are doctors, but, they have not been trained to clinically diagnose Lyme disease. . . . They are visibly shaken and uncomfortable with Lyme disease. Consequently, veterans with Lyme disease are misdiagnosed and mistreated.” In 2015, Sims wrote to President Barack Obama for help. The VA responded to the Presidential inquiry and hired a Lyme disease specialist, who finally diagnosed Sims with the disease after 33 years of misdiagnosis. Sims wrote:

I was misdiagnosed for over three decades and left untreated for Lyme disease. This led to homelessness. Survived attempted suicides. Untreated patients can lose everything, as I did, and become part of the unemployed, underemployed, disabled, and homeless populations that die by suicide and commit violent acts related to the psychological impact of Lyme disease.³²

Why is Lyme disease so difficult to diagnose? In the early stage of the disease, approximately 50 percent of patients develop an *erythema migrans*, or bull's-eye rash, at the site of the bite.³³ The other 50 percent do not develop a rash but experience flu-like symptoms, including fever, headache, and joint swelling. Many people simply assume that they had a case of the flu, never suspecting that their symptoms were caused by an infected tick.

Suspecting that their symptoms might be Lyme disease, some individuals go to their primary care doctor and get tested. The only type of test currently available for Lyme disease is a serological assay, or blood test, that detects whether the body has developed antibodies in reaction to the presence of the bacteria. Antibodies may not develop immediately, so if the test is taken too soon after a person is bitten by a tick, the results will be negative. Moreover, individuals with compromised or weak immune systems may not produce detectable levels of antibodies in response to an infection, and so they will

test negative when in fact they are actually infected.

Most doctors use a two-tier blood test for Lyme diagnosis, which was developed by the Food and Drug Administration, CDC, and others in 1994 and adopted by the Infectious Diseases Society of America as a standard protocol. The first step is an enzyme immunoassay (enzyme-linked immunosorbent assay, known as ELISA) followed by an antibody test (known as the Western blot). Not only is the accuracy of these tests a dismal 50 to 60 percent,³⁴ but requiring a positive result on two different tests for a diagnosis excludes many patients who actually do have Lyme disease. A 2005 survey of patients by the California Lyme Disease Association revealed that 73 percent of patients were denied a diagnosis for Lyme disease at least once due to a negative ELISA test result according to the CDC criteria.³⁵

This two-tier diagnosis system was never intended to be used for the diagnosis of Lyme disease. Rather, it was developed by the CDC as a “surveillance case definition,” which is “a set of uniform criteria used to define a disease for public health surveillance.”³⁶ Only patients who test positive according to the surveillance case definition for any particular disease are counted in epidemiological reporting. For Lyme disease, the surveillance case definition is an acknowledged tick bite, the appearance of a bull's-eye rash, and, for those who do not live in a region where Lyme is common, laboratory evidence of infection.³⁷ Medical doctors generally use the CDC surveillance case definition to diagnose patients, and insurance companies often require patients to meet these criteria before they will cover medical care. However, as the CDC notes, “Surveillance case definitions are not intended to be used by healthcare providers for making a clinical diagnosis or determining how to meet an individual patient's health needs.”³⁸ In short, the misinterpretation and misapplication of CDC epidemiology guidelines by the medical community make Lyme disease even more difficult to diagnose because it excludes a vast number of patients through the use of excessively narrow criteria.³⁹



Colonel Nicole Malachowski, USAF (Ret.), former commander of 333rd Fighter Squadron, first female pilot selected to fly as part of Air Force Air Demonstration Squadron “Thunderbirds,” and ambassador for Wounded Warrior Project, shares her story with base personnel during visit to Schriever Air Force Base, Colorado, December 19, 2019 (U.S. Air Force/Katie Calvert)

Lyme disease is also difficult to diagnose because ticks may transmit multiple pathogens in addition to *Borrelia burgdorferi*, many of which have symptoms that are similar to Lyme and occur in conjunction with it. Lyme disease is bacterial, but other tickborne diseases can be parasitic or viral. One common coinfection of Lyme disease is babesia, which is caused by a parasite that infects red blood cells and causes headache, nausea, mood changes, and in some cases kidney or heart failure. Viral tickborne infections, such as the Powassan virus, cause swelling in the brain and have a 10 percent mortality rate. No treatment exists for Powassan virus. In the past few years, the Asian longhorned tick has been discovered in the United States. These ticks can transmit a type of hemorrhagic fever as well as an enzyme that causes an allergy to red meat. These pathogens cannot be detected by the standard Lyme disease blood tests, and antibiotics used

successfully for Lyme patients may not effectively treat these coinfections.

Given the difficulty of diagnosing Lyme disease due to coinfections, exclusionary diagnostic criteria, inaccurate testing, and lack of clear symptoms, patients must often rely on luck. In June 2019, the *New York Times* published an article titled “My Son Got Lyme Disease. He’s Totally Fine,” which recounted how the author’s son developed a swollen knee. After a magnetic resonance imaging scan showed inflammation on the boy’s knee and ankle, an orthopedist suggested it might be juvenile arthritis or an autoimmune disorder. Treatment for inflammation was not effective, so other causes for the strange symptom were sought. The mystery was solved only after the author’s husband had a chat with his squash partner—who happened to be a doctor.⁴⁰ This lucky little boy got a quick diagnosis and was prescribed antibiotics. But imagine if the father of the family

had not played squash regularly with a doctor. In the absence of a bull’s-eye rash, it might have taken years to get a correct diagnosis and even longer to get adequate treatment.

It Is Easy to Treat: False

Standard medical practice is to prescribe 28 days of antibiotics for treatment of Lyme disease, and many medical professionals believe that this is sufficient to cure it. In the words of Dr. Eugene Shapiro, professor of pediatrics and epidemiology at Yale, for example, “It’s baloney that you can’t cure Lyme disease; it’s eminently curable.”⁴¹

Unfortunately, in more than 50 percent of cases, Lyme disease is not cured by a single round of antibiotic therapy.⁴² These cases are designated as *chronic Lyme* or *post-treatment Lyme disease (PTLD)*. Individuals may appear to respond well to the initial treatment with antibiotics and experience a relief of symptoms, but



Dr. Willy Burgdorfer inoculating *Ornithodoros* ticks, May 1954 (Rocky Mountain Laboratories Historical Collection/Nicholas J. Kramis)

then relapse either months or years later. A subsequent round of antibiotics may lead to the same results. In some cases, this pattern of response and relapse continues for decades. A recent study estimates that the number of people in the United States suffering from PTLTD will exceed 2 million by the end of 2020.⁴³

Many scientists who study Lyme disease have struggled with the question of why 20 percent of patients fail to respond to treatment with antibiotics. One of the first avenues of exploration has been to determine whether Lyme, like other bacteria such as staph and tuberculosis, could develop a resistance to antibiotics. The bacteria that cause Lyme disease, however, do not develop antibiotic resistance. According to one study, “Given that antibiotic resistance has not been observed for *B. burgdorferi*, the reason for the recalcitrance of late-stage disease to antibiotics is unclear.”⁴⁴ With that line of inquiry shut down, scientists have proposed and tested different theories, including the possibility that chronic Lyme is actually the result of coinfections from the original tick bite⁴⁵ or that it is simply an autoimmune response.⁴⁶ Some

members of the medical establishment have dismissed the existence of chronic Lyme altogether on the grounds that it “includes a broad array of illnesses or symptom complexes for which there is no reproducible or convincing scientific evidence of any relationship to *B. burgdorferi* infection.”⁴⁷

From a diagnostic perspective, the problem with chronic Lyme is that the standard diagnostic tests for infection are often negative and, thus, there is no evidence of actual infection. As Dr. Marcelo Campos at Harvard Medical School noted:

*Conventional medicine has a hard time treating something we cannot see or isolate. However, we cannot ignore that people’s lives changed after the diagnosis of Lyme disease. Their suffering is real. And the frustration is widespread. On one side, we have distressed patients tired with the lack of answers; on the other side, we have doctors who cannot find a biological proof of what is happening.*⁴⁸

One reason that biological proof of an existing infection cannot be found—as

scientists have recently discovered—is that Lyme bacteria are actually shape shifters: When exposed to a hostile environment of antimicrobial drugs, the bacteria change from a spirochete to a round body or “cyst” form.⁴⁹ The most common treatment for Lyme disease—a course of doxycycline—kills 98 percent of the Lyme bacteria but actually induces the surviving 2 percent of Lyme bacteria to shape shift to cyst form.⁵⁰ In other words, when a tick bite is treated with doxycycline, the antibiotic can force the Lyme bacteria to shift their shape into a form that can evade the immune system and resist treatment with antibiotics.

Lyme “doesn’t stay in the bloodstream for long,” according to Richard Ostfeld, a biologist who studies the ecology of Lyme. “Instead,” Ostfeld continues, “*Borrelia* manages to insinuate itself into parts of the body that have fewer circulating antibodies, where it is harder for antibiotics to reach.”⁵¹ According to one article, the “defensive morphological forms of *Borrelia burgdorferi*” such as cysts and biofilms make it difficult to detect the bacteria in the blood of infected patients and also allow the Lyme bacteria to evade the patient’s immune system and resist even the most aggressive antimicrobial treatments.⁵² In short, Lyme disease is not always easy to treat.

Conclusion

The majority of doctors in the United States believe that Lyme disease is easy to diagnose and easy to treat and is severe only in rare cases. However, both the scientific evidence and the experience of patients demonstrate that Lyme disease can often be challenging to diagnose and difficult to treat. In many cases, the symptoms can be debilitating and, in rare cases, lethal. “What we’re dealing with is way more sophisticated bacteria than any other bacteria we know,” according to Ginger R. Savely, a Lyme disease specialist at Union Square Medical Associates in San Francisco. “The more you really study the bacteria and how it works, the more you become incredibly impressed by how many mechanisms this bacteria has for survival and how difficult it is to get rid of it.”⁵³

Lyme disease is the most widespread vector-borne disease in the United States, and it has reached epidemic proportions.⁵⁴ Thus, it is surprising that there is neither a reliable diagnostic test nor an effective treatment for it. In 2018, the Tick-Borne Disease Working Group—composed of representatives from a variety of Federal agencies— noted in a report to Congress that “progress has been hampered by a lack of attention at the Federal level and by divisions within the field.”⁵⁵ Despite the epidemic proportion of Lyme disease in the United States, Federal funding for tickborne diseases is drastically less per new case than for other diseases. The National Institutes of Health, for example, spends on average \$77,355 for each new case of HIV/AIDS and \$36,063 for every new case of hepatitis C virus, yet only \$768 for each new case of Lyme disease. In the same report to Congress, it was noted that “Federal funding for tick-borne diseases today is orders of magnitude lower, compared to other public health threats, and it has failed to increase as the problem has grown.”⁵⁶

Lack of attention to Lyme disease— despite its epidemic proportions and debilitating symptoms—has led many patient advocacy groups to begin funding their own research. The Global Lyme Alliance, for example, has funded much-needed basic research, including mapping the genome of *Borrelia burgdorferi* and identifying the antibiotic cocktail most effective against biofilm colonies. In some cases, private foundations have picked up the slack where the Federal Government has fallen short and committed significant funding to cutting-edge Lyme research. The Steve & Alexandra Cohen Foundation, for example, has provided \$60 million to support more than 25 Lyme disease research projects. Privately funded research may have identified a drug capable of killing Lyme in all of its forms: disulfiram, which has been used for more than 70 years in the treatment of alcoholism.⁵⁷ The drug is now undergoing a pilot clinical trial at Columbia University, and a few physicians are prescribing it to patients willing to try experimental approaches.

New basic research into Lyme disease and the repurposing of old drugs such as disulfiram provide some hope for Lyme patients. At the moment, however, there is no cure and no easy treatment for this serious and debilitating disease. Given the dire health consequences, the poor diagnostic tools, the effects of climate change in increasing tick habitats, and the endemic nature of the disease in geographical areas where the military lives, works, and plays, Lyme should be a serious concern for the entire joint force. At the moment, unfortunately, the Department of Defense (DOD) has dedicated scant resources to fighting Lyme and associated diseases. As noted above, DOD participates in the U.S. Government Tick-Borne Disease Working Group, and Lyme is one of the congressionally directed medical research programs.⁵⁸ However, DOD has dedicated only \$900,000 in fiscal year 2020 to supporting basic research on Lyme and other tickborne diseases.⁵⁹ In terms of Lyme prevention, beginning in 2013, the Army began issuing Army combat uniforms (ACUs) treated with permethrin (an insect repellent),⁶⁰ which is an important step in the prevention of tick bites. However, any comprehensive program to counter tickborne diseases must also include chemical pest control, testing ticks for pathogens, landscape management, public education, and targeting reservoir hosts such as deer and mice. To date, there is no comprehensive tickborne disease education and prevention program that targets the entire joint defense enterprise, and there definitely should be. JFQ

Notes

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