



Patient Stories

Lyme disease is most often identified at its earliest stage when characteristic skin lesions are frequently present and an accurate early diagnosis is possible. With early diagnosis and appropriate antibiotic treatment, the prognosis for Lyme disease and other tick-borne infections can be excellent. In the majority of patients, early treatment can resolve the acute illness and prevent later manifestations that could occur without timely treatment. In contrast, Ruben Lee Sims' case illustrates what can go wrong when early diagnosis is missed. Such cases do not portray the typical course of most Lyme disease cases but do serve to emphasize the critical importance of accurate diagnosis and early treatment, as well as the complexity of chronic illness that can result from untreated Lyme disease.



Ruben Lee Sims

Disabled United States Vietnam Veteran
Lyme Disease Advocate
Moreno Valley, California

Ruben Lee Sims

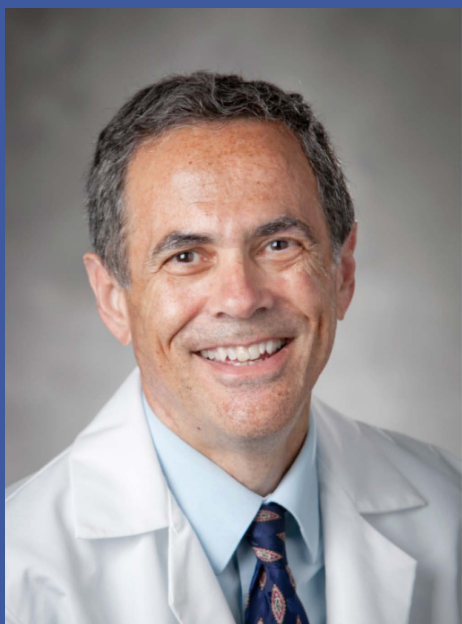
Ruben Lee Sims is a Vietnam Veteran who served our country, earned the Vietnam War Campaign Ribbon, and was recognized as the "USAF Comptrollers Top Enlisted Management Analyst of the Year" in 1977. Five years later, multiple tick bites, however, derailed his life. The U.S. Department of Veterans Affairs (VA) was not equipped to diagnose Lyme disease at that time. The military discharged Mr. Sims in 1984, citing "hypochondriasis with psychogenic pain disorder." In 1985, a non-military doctor in San Diego suspected Lyme disease. However, because Mr. Sims had not traveled to New England, the doctor decided that the symptoms could not be caused by Lyme disease. In the words of Mr. Sims, an American hero:

"I have had Lyme disease while under the direct care of both military and VA healthcare systems. 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, under-employed, disabled, and homeless populations that die by suicide and commit violent acts related to the psychological impact of Lyme disease. This is a treatable condition. Please review all emerging science and help prevent Lyme-disease-related deaths and suicides."

Mr. Sims' psychogenic pain is now confirmed as a symptom of Lyme disease, based on VA's diagnosis. With accurate diagnosis and appropriate treatment, Mr. Sims' physical and mental symptoms have resolved. He shares his story to reach and help other Veterans, especially homeless Veterans, who may be affected by tick-borne diseases.



Patient Stories



Dr. Neil Spector

Lyme Disease Survivor and Patient Advocate
Associate Professor of Medicine
Duke University School of Medicine
Durham, North Carolina

Dr. Neil Spector

Dr. Neil Spector's healthy outdoor lifestyle as a jogger and marathon runner increased his exposure to and risk for tick borne disease. In the late 1980s and early 1990s Dr. Spector lived in New England, which is a highly endemic area for Lyme disease. Dr. Spector first began to experience a bizarre constellation of symptoms in 1993, which included cardiac arrhythmias and profound fatigue ("I went from running 10 miles a day, six days a week to barely being able to walk 10 yards without feeling exhausted"). Doctors could find nothing wrong with him. In his own words,

"I was confused. 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."

Dr. Spector's symptoms worsened with time: cardiac rhythm disturbances, migratory muscle pains, weight loss, malaise, insomnia, brain fog, severe fatigue, and more. In 1997, doctors prescribed him antibiotics for an unrelated condition and, unexpectedly, many of his symptoms, including arthritis, improved. It was also in 1997 that he was diagnosed with third-degree heart block and ventricular arrhythmias requiring a permanent pacemaker/defibrillator. A diagnosis of Lyme disease was confirmed in late 1997 and despite an aggressive

course of antibiotic therapy, the heart block and ventricular arrhythmias did not resolve. He then progressed to a dilated cardiomyopathy.

Dr. Spector was undiagnosed and misdiagnosed for years. Even as a well-trained, academic physician-scientist with access to the best medical resources in the United States, Dr. Spector's symptoms were dismissed as "stress" related. As a result, Dr. Spector's heart suffered irreversible damage. Lyme carditis when Lyme disease bacteria enter the tissues of the heart is considered rare yet serious and potentially fatal. This manifestation of Lyme disease brought Dr. Spector to the brink of death. He needed a heart transplant to save his life.



Patient Stories



David Roth

Retired, Senior Managing Director
Finance Industry
New York, NY

David Roth

In May of 2010, I was a healthy 43-year-old businessman living with my family in New York City. One morning, I awoke with symptoms consistent with a sinus infection that evolved into what felt like the flu. A week later, I visited my internist, who told me I had a viral infection. I mentioned that I had been in areas endemic for Lyme disease, but my doctor did not consider nor test for the illness.

My symptoms worsened in the following weeks. I experienced stomach pain that migrated throughout my body, involuntary twitches in my limbs, joint and tendon pain, difficulty concentrating and memory loss, shortness of breath, difficulty speaking, and insomnia. I revisited my doctor who once again told me it was a virus. This time I requested a Lyme disease test, but the result was negative. As my condition worsened, with new symptoms piling onto the old ones, I saw six more doctors, but none mentioned Lyme disease.

Four months into my illness, I went to a doctor who considered my symptoms and suspected Lyme disease. He ordered a western blot test (my third), and the result showed all three IgM bands and four of the ten IgG bands. I also sought a second opinion from a "Lyme-literate doctor," who treated me for Lyme disease and later clinically diagnosed me with babesiosis. With extensive, prolonged treatment for the illness

and its myriad symptoms, I slowly recovered to where I am now, about 85 percent of the person I was before I became sick.

During 2010 and 2011, I was tested several more times for Lyme disease. One test came back positive, several equivocal (negative by CDC standards but showing multiple bands), and one indicated I had never been exposed to Lyme disease. I have since learned that the diagnostics used today were developed before most modern technology.

My experience demonstrates that tick-borne diseases are not properly diagnosed and treated in the United States. We need better diagnostics, better treatments, safe and effective vaccines, as well as better medical training and public awareness to combat tick-borne diseases.



Patient Stories



Colonel Nicole Malachowski (USAF, Ret.)

Career Officer, Leader, Fighter Pilot
First Woman Pilot, USAF Air Demonstration Squadron ("Thunderbirds")
Springfield, VA

Nicole Malachowski

My name is Nicole Malachowski. I am a mother, wife, and retired U.S. Air Force (USAF) colonel and F-15 fighter pilot; and I have neurological tick-borne disease.

In the summer of 2012, while still serving in the Air Force, I went to see a doctor about a growing rash on my right hip and was given 10 days of doxycycline and a topical cream. However, my condition worsened despite the treatment. Within a month, I began experiencing fevers, malaise, and burning sensations. A few months later, I began experiencing neurological symptoms. One day while leading a formation of F-15E fighter aircraft back from a training mission, I was overcome by an overwhelming sense that my aircraft was turning left, though it was not; and I could not get my hands to activate the switch that I had activated thousands of times. After I finally managed to activate the switch, I realized that I could not speak. Fortunately, my experienced wingman led us home, and the instructor pilot in my jet performed backseat landing.

However, that day marked the beginning of my medical odyssey. In the following four years, I saw more than twenty doctors across eight specialties. My neurological symptoms continued to worsen, but none of the doctors knew why and some suggested it was all in my head. I was suffering from intensifying fatigue, joint and muscle pain, vestibular issues, ocular manifestations, sensory problems, cognitive dysfunction, and the list goes on. I was misdiagnosed with everything from possible multiple sclerosis, to autoimmune disease, to fibromyalgia. Eventually I could no longer work in the military as a fighter pilot, and the military began steps to medically retire me. At

the age of 43, I was permanently, medically retired from the career I loved, after having served in the military for more than 21 years.

By August 2016, my condition had deteriorated so much that I was having extreme difficulty with speech and memory, and I could barely walk. Determined to find out the cause of my medical issues, my husband and I poured through my medical records, and all signs pointed to the rash from 2012 and a tick bite I got the following year while I was stationed in Rhode Island.

Out of sheer desperation, I reached out to a group of doctors specializing in tick-borne disease in Boston. They ordered tests that confirmed neuroborreliosis (*Borrelia hermsii*), neurobartonellosis, babesiosis, and anaplasmosis, confirming severe neurological tick-borne disease. The doctors immediately started treating me with IV antibiotics. Within 10 days, my daily fevers, chills, sweats, and sleep disturbances were gone. Within a few weeks, my ability to find words improved, and I could communicate again. However, I was not able to speak fluently for several more months.

Because my illness went undiagnosed for so long, it is challenging to say how long I will need treatment and how long my recovery will last. But I can tell you this: I went from someone who literally could not get out of bed to someone who can take her seven-year-old twins to their soccer games. While I have not recovered completely, I now have a life worth living. I would never have gotten to this point without the accurate diagnosis made by competent, experienced physicians who knew how to recognize and treat the devastating tick-borne illness that so many other doctors missed.



Patient Stories



Julia Bruzzese

High School Sophomore
Pediatric Lyme Disease Patient and
Lyme Disease Advocate
Brooklyn, New York

Julia Bruzzese and Family

Julia Bruzzese was a lively nine-year old when she was bitten by a tick and contracted Lyme disease, associated coinfections, and other types of tick-borne diseases ("Lyme"). Although she was brought to the pediatrician with a bull's eye rash after the tick bite and for many subsequent sick visits, Julia went undiagnosed for more than two years. She is now 15 years old and bound to a wheelchair due to her ongoing battle with Lyme. After Julia received extensive serological workups for every possible diagnosis on numerous occasions, and despite Julia's suffering from early signs of Lyme and increasingly worsening symptoms, doctors failed to make an accurate diagnosis and provide her with timely treatment. Because of a lack of reliable diagnostic testing, doctors and hospitals did not diagnose or treat Julia for Lyme disease, and insurance companies refused to pay for the expenses. As a result, Julia eventually lost her ability to walk, among many other things, and nearly died at age 11.

While Julia's health was declining, other members of the Bruzzese family (Julia's parents, older brothers, and little sister) realized they were all suffering from many symptoms similar to Julia's. However, the family's focus and dwindling financial resources were allocated to Julia, the sickest one. They were determined to save Julia's life, to get her childhood back, and to seek an answer and hope.

Hope came after Julia met Pope Francis in 2015. The Papal Blessing drew international attention and increased awareness. Love and support began pouring in. Julia was subsequently diagnosed with Lyme, bartonellosis, and babesiosis. All Bruzzese family members were diagnosed with Lyme as well.

With the financial support raised by her community and people in other parts of the world, Julia and her family received treatment from physicians experienced with Lyme disease. The family saw tremendous improvement after proper treatment, and Julia's symptoms gradually improved. Because treatment was delayed for so long, Julia, however, still suffers from the chronic effects of Lyme and remains in a wheelchair.

"It is not fair that many share my story of suffering and a life being lost. I am determined to bring about change, and bring hope to those who have forgotten the meaning of the word." - Julia Bruzzese, age 15

"My friends don't understand. When I leave school today, by the time I come back tomorrow, I feel as though years have gone by. It feels as though seconds are years at home." - James Bruzzese, brother, age 22

"One day, I'll have my sister back."
-Sofia Bruzzese, sister, age 9

"Where medicine fails, love for my children will prevail." - Josephine Bruzzese, mother

"We are all being put to the test, pushed to the limit to reveal how far we go." - Adam Bruzzese, brother, age 17