What’s Wrong with this Picture?

LYME STORIES
Told by Texas Patients

“This 'bug' destroyed my life. I feel as though I’ve been living in a waking nightmare ever since, and it is far worse punishment than I would ever wish on my worst enemy.” — Jessie
Healthy, active people like you get Lyme disease.

“In the year 2002 I was a very active mom with two young children. I volunteered at my son’s school, took my kids on play dates, the zoo, museums, parks, soccer and baseball practice. My only health issues at this time were irritating joint pain that seemed to migrate and lymph nodes in my neck that were constantly swollen . . . I was in excellent physical condition as I worked out at the gym 5 – 6 days per week and spent several hours in the cycling room per week. I was hoping to do the MS 150 marathon with some friends. In the year 2003, my health took a dramatic downturn. I was only 31 years old but found myself crawling up my stairs. I felt as if all the energy had drained out of every muscle in my body.” — Mary

“I used to be a bright, intelligent young woman with a 3.6 GPA in college. It’s now been nearly 5 years, and I’m a 28-year-old woman on disability who ‘looks fine,’ but who is secretly fighting for her life . . . just begging and praying for it to be over, so I can return to society and help give back.” — Jessie

“I grew up on a ranch in South Texas which bordered the King Ranch. I was a real tomboy, hunting and riding horses and spending hours at a time in the brush country of the Wild Horse Desert. Tick bites were a fact of life for all of us who lived on the ranch. We picked ‘seed ticks’ off of ourselves on a regular basis. I was bitten by at least 20 ticks per year and probably more since many bites go unnoticed. I can remember picking off up to ten ticks in a day after coming in from a deer hunt. I thought of ticks as an irritation but not a danger. Not once in my entire 45 years have I seen a warning from the Texas Department of State Health Services or any other government entity that would alert Texans or visitors of the dangers of infected ticks that can spread Lyme and other tick borne diseases.” — Alex

“I went from running a marathon to the ICU in 3 months.” — Jenny

“One day, while at work, I was listening to my voicemail and writing down the callers’ information when I had the biggest scare of my life. The handwriting on the paper was NOT mine. On my way home from work the next day, I began having symptoms of Bell’s palsy. I had a CATSCAN that day and they ran all sorts of blood tests and could not find a thing wrong. [After a positive test for Lyme disease] my regular doctor prescribed a 2-week dose of doxycycline. A month later, I was no better and had developed new symptoms. I could not talk without stuttering and was having trouble with my gait and lost total vision in my right eye.” — Anne

“I led a very active lifestyle which included caring for and riding horses each day, taking a full load of college classes, competing on the college rodeo team, and other extracurricular activities. I received scholarships for my active leadership in the community as well as competing on the rodeo team. I graduated in four years and moved to the Houston area to work as a teacher, being nominated for ‘Teacher of the Year’ several times. We occasionally pulled ticks off dogs and horses.” — Jordan

“I went to a physician in Lubbock where I was attending college. She told me that I had some strange disease and to call my parents immediately. My mom immediately flew up to Lubbock and I basically spent the rest of the summer in bed.” — Samantha
Lyme is sneaky. Patients do not always see a tick or know that they have been infected. Most cases begin with flu-like symptoms. Other symptoms can appear quickly or take months or years to develop.

“My sister and I lived in East Texas as children. We spent our days playing in wooded tick infested areas and we were always together. We were also both regularly and continually bitten by ticks during this time in our childhood and we now believe this is when we were both infected. My symptoms progressed very gradually. If fact, it was so gradual that I did not really recognize or pay attention to it for the first several years. I thought I was just getting older and my job was too physical. I eventually ended up in very severe pain most of the time.” — Virginia

“I remember the very day I got a bite, though I saw no bug. I quickly deterioriated and lost my job and could no longer afford those trips to doctors to find out why I felt sick. With no answers and no clues the symptoms set in further along with the worst one: insurmountable fatigue. I became immobilized . . . ” Christina

“Why is it so hard to get a true diagnosis? We should not have to be so far gone in order for us to get the treatment we deserve. I remember being bit by a tick when I was young and a few times as I was older but I can't recall when. I don't remember ever seeing a rash.” — Sharon

“I wish I could tell you when I contracted Lyme, but I can't. I had a tick bite when I was 12, and I had another when I was 24. Neither tick was a deer tick, and I’ve never in my life had a bull’s-eye rash.” — Nancy

“None of us remember a tick bite.” — Suzanne

“I developed a rash and it was the classic bull’s-eye rash. I went to a million different dermatologists and they never did a culture or biopsy. That is when I started developing strange symptoms. I had flu-like symptoms all of the time. I developed Bell’s palsy. My mom took me to the ER and they did a MRI and all sorts of tests and found nothing except white spots on my brain from the MRI. The rash never went away.” — Samantha

“I don't know where I got bitten. It could have been in Ukraine, Germany, Florida or Texas.” — Irene

The worst cases are often when a patient is infected by more than one kind of bacteria by the same tick.


“I also had Babesia, Ehrlichia, and Bartonella.” — Joanne

“We found a tick embedded in my daughter Amy’s arm. Weeks later she developed fully disseminated Lyme symptoms. During 3 years of treatment, her improvement was very slow. At the end she still had back pain and recurring fevers. Our neurologist learned that it was possible to be infected by more than one disease by the same tick. Amy tested positive for Babesia, a malaria-like disease. After treatment for Babesia, she finally became symptom-free. She has relapsed twice in the past 12 years.” — Betty
Lyme has been called the “New Great Imitator.”
It can affect every system in the body.

“My symptoms continued to multiply until I was not only having pain in my joints, muscle fatigue and inflamed lymph nodes but also painfully swollen breasts, muscle twitching, numbness on the left side of my body from my face to my foot, feeling of electrical shocks through my feet, legs and hands, cramping causing difficulty in sleep, low grade fevers, chills, flu-like symptoms, pain and weakness in the back of my neck so severe that I had to support it with a pillow most of the time. Also, stiffness, body popping/cracking, rashes, burning skin, blurry vision, dizziness, vomiting, difficulty breathing, chest pains, migraines, very stiff and painful hands, numbness, lack of blood circulation in tip of some fingers and toes (Reynaud’s), paraesthesia, feeling of inflammation throughout entire body and a sharp decline in my ability to remember anything. Most concerning was that, often, I would only have pain on one side of my body from a migraine on the left side of my head all the way down to my left foot.” — Mary

“My first symptom was a circular rash around the tick bite, tingling in my neck, fever, ringing in my ears, random itching all over. After just a few weeks, I had heart palpitations, strange nightmares, insomnia, and paranoia.” — Diane

“I had severe migraines that caused black outs. I never found out why. In 2004 I was diagnosed with fibromyalgia. I had several years of extremely bad periods that produced a lot of blood clots and severe pain which later led to a hysterectomy. My arm was going numb and I had a lot of neck pain. I lost a lot of muscle and had to do physical therapy. I was diagnosed with degenerative disc disease. I have also been diagnosed with high blood pressure, anxiety, irritable bowel syndrome, migraines, depression, insomnia, muscle spasms, not to mention back pain and sore muscles for no reason. There are others but I can’t remember. I suffer a lot now with memory loss and confusion. I have problems with my vision although when I go in, the tests are not bad. I can’t remember the last time I woke up without any pain. I know my body and I know when something is wrong.” — Sharon

“I began to have strange health problems pop-up. Bladder infections, incontinence, interstitial cystitis, heavy and irregular menses, an acne-like rash along my jawline (never had acne before), migraines, tennis elbow, and bursitis of the hips. I began to get more fatigued and able to do less and less. I went to the doctor for all of these problems and they were each treated separately with pills, injections, antidepressants, but none of the issues were resolved, ever. I thought I was getting old and arthritic since I had just hit my 30s.” — Jordan

“The new symptoms began almost daily. They would migrate and some would stay. Extreme head pain that would come suddenly and then disappear . . . ear pain, motion sickness, nausea, extreme fatigue (like having the flu but no fever), constant feeling like I had a bladder infection, jaw pain (like TMJ), teeth pain, anxiety, unrelenting depression . . . and the list goes on. The problem I [had] a hard time explaining was what I describe as a spacey out of my body experience.” — Kathy
Lyme can infect whole families.

“When we received back the tests that showed 3 of the 5 family members were CDC positive, and the other two had [numerous] bands lit up, we were shocked on the one hand but almost felt a sense of relief on the other. After reviewing the symptoms characteristic with Lyme, we all had so many! I’m tired because I am burning the candles at both ends. My joints hurt because I never sit down and because I run. I have brain fog because I have too much to do. I am getting pneumonia 4 times a year because I do too much. My children act this way because they are tired, or it’s just their personality, I guess. We had lulled ourselves into thinking that this was our ‘normal’ and looking back—it was not a good normal. We were functional, but barely. And knowing how much better we feel now, after 1.5 years of antibiotic therapy, I hope never to go back to that old ‘normal.’” — Leslie

“We are identical twins, and we both have Lyme disease. My sister began having symptoms of Lyme disease just after she gave birth to her second child. This was the beginning of a nine-year struggle to find a cause and treatment . . .” — Virginia

“I am 68 years old, and am “The Matriarch” of a large family afflicted by Lyme disease. Most of my 6 children and 15 grandchildren have been diagnosed and tested positive.” — Lauren

“My three sons were born with Lyme disease and associated infections. I did not know that this was the case until my oldest child became extremely ill in the fall of 2009 when he was 10 years old. That year began a nightmare for our family from which we have yet to awaken. My son came down with the flu and he never recovered. His immune system had been dealt the final blow after having been at war with Lyme since birth.” — Alex

“As soon as my son was born I started having weird symptoms. I was very anxious, extremely tired, cried a lot, started having panic attacks, achy. Bell’s palsy came back—just a lot of weird symptoms. At first mom and my husband thought I had postpartum depression. I knew it was not postpartum.

“A couple of months ago I started noticing my two-year-old having the same symptoms. We found an LLMD (Lyme-literate MD) in Missouri that treats kids with Lyme and he tested positive. My worst nightmare had come true. I felt so much guilt for giving the precious little boy a disease. We started treatment on him right away. He is 4 and, happy to say, we caught it early enough and nearly all symptoms are gone.

“A couple of months after my son was tested we got my husband tested. He was having symptoms and we didn’t want to take chances. Again, another setback: he tested positive.” — Samantha

“All 3 family members were bitten by deer ticks on our family’s vacation property at Lake Possum Kingdom in Palo Pinto County, TX where deer come onto our property to drink water from the lake.” — Catherine

“Our whole family got tested and found that five of us (so far) have Lyme and I also had Babesia, Ehrlichia, and Bartonella. Since we have had it so long, we now have the chronic form of Lyme, which absolutely does exist because we live with it every day. We were greatly relieved to finally find out what was making us so sick, but we wonder why it took so long, in my case about 55 years just to get a diagnosis. Both of my children, as well as my husband, got it from me, so it’s a myth that it can’t be passed those ways.

“I am 60 now and I know that I will never be healthy, nor will four of my family members. This story is being played out over and over and now that there is a way to diagnose and treat early Lyme, then doctors need to be educated about it and know what to look for, when to test, which test to use, and how to treat it.” — Joanne
The spirochete that causes Lyme disease invades cerebro-spinal fluid. It crosses the blood-brain barrier and leads to mental problems.

“I did not socialize anymore and my son participated in after school sports, but I was unable to take him. I became more anxious and much less patient. I became angry easily. I began to lose vocabulary and short-term memory. It hurt to move my hands and it was hard to walk because of the pain in my soles. I had trouble sleeping, but I was so tired that I was exhausted all of the time.

“I could not recall words. I lost most of my vocabulary and the ability to spell and form sentences. I could not pay enough attention to what people were saying to me to understand a conversation. I had trouble following directions that had more than one step. I began having extreme anxiety and panic attacks. I developed [cardiac] arrhythmia.” — Jordan

Mentally, I have brain fog, confusion, and dyslexia, short-term memory recall issues.” — Diane

“I also became so mentally ‘foggy’ as to not have the concentration to make budgets or do any kind of detailed planning in my life. Sometimes, it was even hard to complete a sentence.” — Nancy

“I started to have neck pain then it moved all over my body. Fatigue, neurological symptoms, brain fog, Bell’s palsy, anxiety, night sweats, insomnia, anxiety, heart problems, panic attacks, noise bothered me, odors bothered me, and a 40 pound weight loss in about 3 to 4 months. I would get lost going to places that I frequently went to all the time.” — Samantha

“My first symptoms were mood swings, brain fog. I haven’t worked since 2006.” [Does the disease affect you more physically, neurologically, or mentally?] “Neurologically/mentally.” — Abby

“I developed dementia as well during this time.” — Anne

Lyme patients look normal, but their symptoms are severe.

“The tipping point was when I started having difficulty walking through the grocery store long enough to get everything I needed. Then I would go home and literally curl up in a ball in excruciating pain.” — Virginia

“I remember one visit telling my rheumatologist, ‘I feel like one day my symptoms will become so severe and debilitating that the cause of my illness would be apparent but by then it might be too late to treat it.’” — Mary

“I was feeling sick all the time with different things, tired during the day, insomnia at night, arthritis, the left side of my body was numbed to the point that I went to the emergency room thinking I was having stroke.” — Maria

“Symptoms would wax and wane over the years. Stress makes everything worse. At one time I felt like I was dying from the inside.” — J.B.

“I had lost mobility in my arm and my elbow was two times bigger than my knee. The doctors were sure it was rheumatoid arthritis or lupus, but my bloodwork never showed positive.” — Brittany
Lyme robs children of their childhood.

“My son has Lyme disease. He became sick in 1988 after he had gone on a camping trip with his Sunday School peers. He came down with a very bad case of the flu and never really recovered. He was recommended to go into Shoal Creek Hospital for mental issues that [his primary care doctor] was not specialized in. He was put on Zanax, and Hydrocodone for his mental issues and for pain. He was nine years old. He is now in his 30s and is still having symptoms. We had to send him to Washington, DC for testing of Lyme disease since no one in Texas would test him. He tested positive for Lyme and two co-infections.” — Janet

“I’m now 34 yrs. old, and my life doesn’t look exactly how I pictured it. Growing up I wasn’t sick very often, but around the age of 16, weird stuff started to happen. First came the panic attacks, generalized anxiety, and depression. At 19 yrs old I was hit with my first round of Bell’s palsy. Then came the severe reflux disease that left me with stomach fluids coming from my nose. By the age of 22 the mitral valve prolapse set in, and my heart continues to be a concern. Then came strange cysts, dizziness, loss of sense of smell, dry eyes, nystagmus, swollen glands, popping knees, shoulders, and jaw, and bulging disk issues. What’s been the hardest has been the extreme fatigue, depression, brain fog, insomnia, and the feeling of unreality at times. What makes me sad is that I spent so many years feeling defective. This disease has broken my heart and the hearts of those that love me.” — Melissa

“[My] daughter had a tick bite in 1973 at age 8 with an onset of chronic symptoms (migraine, loss of bowel control and severe chronic symptoms preventing regular school attendance throughout elementary, jr. high and high school. She had to take the GED to graduate from H.S. She was not diagnosed until 25 years later in 1988 at age 33.” — Catherine

“I got tick-borne diseases when I was 14 years old in Edna, TX, on the river two hours from Houston. I was diagnosed with juvenile rheumatoid arthritis. In my 20’s I was diagnosed with chronic fatigue syndrome and fibromyalgia. In my 30s I was diagnosed with MS and RSD [reflex sympathetic dystrophy]. I was diagnosed with Lyme, Babesia and Bartonella on my 40th birthday.” — J.B.

“Now I have to put my life on hold because of ignorance! What 22 year old wants to miss out on life?” — Brittany

“I am a mom to a 17 year old who has been sick for 4 years now. He was a very active, smart, popular boy. He was a start 1st baseman, played basketball, soccer goalie and was top of his class. He had many friends and now he has 0. In the 7th grade, he was forced out of the public schools. I’m fighting for my son’s life and there is nothing more I would rather do than to find relief for him.” — Susan

“My little boy lost much of his childhood to this disease. This is the third year in a row that we had to withdraw him from school because he just couldn’t continue. He is gifted intellectually and was one of the top two students in his grade level before he had to leave school. He is naturally athletic and used to hike long distances and run on the school track team. He can’t remember a time when he felt completely well and he has become depressed, sad and deeply discouraged about the state of his life. He asks why we can’t go to Disney World or go on a cruise or do a real vacation like some of his friends enjoy. We tell him that when we beat this illness and don’t have to travel so far for medical care and treatment, we will be able to afford some normal family vacations.” — Alex

“Now I have to put my life on hold because of ignorance! What 22 year old wants to miss out on life?” — Brittany

“I am a mom to a 17 year old who has been sick for 4 years now. He was a very active, smart, popular boy. He was a start 1st baseman, played basketball, soccer goalie and was top of his class. He had many friends and now he has 0. In the 7th grade, he was forced out of the public schools. I’m fighting for my son’s life and there is nothing more I would rather do than to find relief for him.” — Susan

“My little boy lost much of his childhood to this disease. This is the third year in a row that we had to withdraw him from school because he just couldn’t continue. He is gifted intellectually and was one of the top two students in his grade level before he had to leave school. He is naturally athletic and used to hike long distances and run on the school track team. He can’t remember a time when he felt completely well and he has become depressed, sad and deeply discouraged about the state of his life. He asks why we can’t go to Disney World or go on a cruise or do a real vacation like some of his friends enjoy. We tell him that when we beat this illness and don’t have to travel so far for medical care and treatment, we will be able to afford some normal family vacations.” — Alex

“My now 14 year old is the one most affected by Lyme. When she was 6, she had a bull’s-eye rash. The doctor said ‘we don’t have Lyme in TX.’ I looked up the symptoms and was looking for joint pain. A few months later, she started not feeling well, having headaches, and raging, but no joint pain. She said, ‘Something doesn’t feel right.’ The doctors said it was ‘anxiety.’ She was diagnosed with migraines and put on Elavil for that and her
anxiety. A few years later, her headaches were not controlled by the Elavil any more. She had a nonstop headache for over 3 years that she rated a 9 on the pain scale. Before her illness, she was ahead in school, popular with her peers, and doing gymnastics 15 hours a week. She ended up spending 4 years in bed, disabled from her headache, and unable to learn when we home-schooled. She couldn’t keep track of a conversation, never mind a lesson.” — Ellen

Lyme robs people of their jobs and careers.

“I have a full-time job, but I am barely able to keep it.” — Irene

“I worked full-time as an occupational therapist as long as possible, then part-time. I was disabled for Social Security in 2009.” — Evelyn

“I had to quit my full-time job and get on disability.” — J.B.

“I was fired from my job of 15 years (on contract, no disability) because I simply could not get to work on time. I have become a ‘shut in.’ I think of things I could do around the house, but it hurts to move, so I just sit here. We are fighting for our life here. Lyme is death by a thousand cuts.” — Julie

“Lyme took an incredible toll on my health, family, and finances. I have been unable to return to work since [the] Bell’s palsy incident. I’ve been told that I will probably never be able to work again. I had a career that I loved and I think that was the hardest part emotionally for me. Losing my career was like processing a loss of a loved one. I still have days where I feel like a burden upon my whole family.” — Anne

“I went to my primary doctor in tears who suggested immediately that I go out on disability. I then went to my specialist who confirmed and ordered intravenous antibiotics to begin immediately. It was one of the hardest things I have ever had to do because as a teacher, you never want to leave the children with no teacher, but it had to be done. I could no longer work. I could hardly care for myself let alone my family; I was crushed.” — Jordan

“I had to take a leave of absence from my job that I had for 15 years. I eventually lost my job that I loved. They kept me on for a year before they let me go.” — Samantha

“I had to quit a 6-figure salary professional job. I have been on disability 3 years.” — Lily

Lyme can destroy marriages.

“I was bitten by a tick in Mexico the day my husband proposed . . . it was also my 23rd birthday. The bite went away, but I grew weaker and more sick. I am now 28, my husband has separated from me and is considering divorce.” — Jessie

“My formerly happy marriage of 22 years is for all intents and purposes over. My husband won’t touch me. He blames me for spending every penny I made to try to get well, because, hey, it didn’t work.” — Julie
Lyme is isolating. It puts stress on families.

“I work full time but it is a huge struggle. It controls my life. I must rest in the evenings and on weekends. I have to work to maintain my health insurance and the insurance for my family. I could qualify for disability, but I’m only 48.” — Diane

“She had no idea what was wrong with her. For nine years she suffered alone, and I mean completely alone. During this time she saw countless doctors who gave her no relief. No one knew what was wrong with her. She was told she was depressed, she was a stressed-out mother, she needed antidepressants, she needed psychiatric help. No one believed she was sick. She was ridiculed and humiliated by the medical community. Even her family could not truly understand.” — Virginia

“My condition deteriorated to the point that I was spending most of my day in my chair or in bed. I was no longer able to cook, clean, grocery shop, exercise and had very limited involvement in my children’s school and other activities.” — Mary

“It’s embarrassing if anyone could see how collapsed I was when I wasn’t forcing myself to go do something as simple as grocery shopping. I had no internet life or even the simple act of a phone call and I was alone.”

— Christina

“I was basically bedridden with a new baby. My husband had to do everything and work full time. My life was falling apart right before my eyes. Finally, in April 2008 I went to a neurologist that treats Lyme. He took one look at my rash and said you have chronic Lyme disease.” — Samantha

“I had to stop working in July 2011. I am disabled and currently fighting for my disability since the insurance companies don’t recognize chronic Lyme. This disease affects me in every way possible. It has given me over 70 different symptoms, has caused other diseases, and is greatly affecting my ability to think and concentrate.”

— Elise

“I cannot do much. My mom has to take care of my kids. Neuro-headaches, word confusion, short-term memory loss, mentally depressed, low self-esteem, suicidal thoughts.” — Lily

“I could not even muster the energy to take a shower most days. If I walked upstairs I had to stop half way up and lay down. I was too weak to lift a sack of groceries. I did not think I would ever get back to the person I once was. I literally wished my heart would just stop because it would have been easier than dealing with the misery and effects that Lyme had on my life.” — Jordan
Lyme disease is hard to diagnose.

“I began having horrible panic/anxiety attacks and severe TMJ that was very debilitating. I went to see an oral surgeon that specialized in TMJ and they did a CAT scan that showed inflammation of the right TMJ. I became so ill, I lost a lot of weight, and my scalp, lips and tongue ached and burned daily for about seven months. I also developed frozen shoulder syndrome and had to go through physical therapy. At night, my body would get these weird sensations like what you feel when you hit your funny bone. I went to see a neurologist, rheumatologist and massage therapist for therapy, labs and testing. Everything came back negative. I complained to my primary doc, but she thought it was my hormones. She put me on bio-identical hormone therapy, but it didn't relieve these symptoms.” — Suzanne

“I developed a hugely swollen knee. The assumption was that I had somehow injured it, and as my overall health and mobility rapidly declined, I eventually sought out treatment for a presumed tear in my knee. However, the surgery proved that there was, in fact, nothing structurally wrong with my knee. The surgeon removed a LOT of ‘inflammatory fluid’ and recommended I see a rheumatologist instead. I saw a prominent rheumatologist and he diagnosed me with rheumatoid arthritis and fibromyalgia.” — Nancy

“I was recently clinically diagnosed with Lyme by my life-long family doctor. I have been chronically ill for 20 years plus. Many specialists later and being diagnosed with multiple syndromes: fibromyalgia, Sjogren’s, Hashimoto’s, chronic fatigue, irritable bowel, vertigo of unknown origin, muscle twitches and cramps, heart palpitations with high blood pressure and on and on . . . .” — Margaret

“I went to several doctors, had lots of tests done, and I have never found a definite answer to what the problem was. Only their best guess based on symptoms. I have spent a lot of money on MRI’s, CAT scans, ultrasounds, upper GI, physical therapy, chiropractors, and so on. It’s really frustrating not having an answer and feeling like no one believes me.” — Sharon

“I saw ENT’s (six or seven, can’t remember how many), internal medicine, family doctor, OB-GYN, infectious disease doctors, oncologists, neurologists, dentists, endocrinologists, naturopathic doctors . . . . I have been tested for lupus, MS, fibromyalgia, brain tumor, cancer, diabetes, thyroid issues and [more].” — Kathy

“I diagnosed myself with Lyme disease Christmas of 2010 and got medical test confirmations 2 months later. The previous 5 years of seeing multiple doctors essentially turned out to be a control group for what was a process of elimination. By going to many, many doctors who knew nothing of my symptoms and who also, being so stumped by them, in turn implied that I was either mental or menopausal, did I come to know what I did not have. Theirs is an example of sheer waste and my limited ability to tolerate bullying.” — Christina

“Finally the accidents added up to disability. This is when I was enabled by my disability medical coverage to start going to every kind of doctor there is AND I went. None of those medical dollars spent on my behalf by the State of Texas or any Federal assistance for the disabled got me a doctor with any Lyme disease literacy.” — Christina
Texas doctors do not have the training needed to diagnose and treat Lyme or other tick-borne diseases.

“Our local pediatrician said it couldn’t be Lyme Disease since the rash was not in a bull’s-eye shape. I trusted him. Michael’s health continued to deteriorate with many other neurological issues (intermittent blindness, severe headaches, spinal pain, balance problems, depression, anxiety, mood swings, etc). We pursued neurologists, psychologists, neuro-ophthalmologists, ocular immunologists, psychiatrists, etc. They all either had their own theory or no clue as to what the problem was. Our pediatrician shouted over the phone to me that ‘He doesn’t have Lyme disease’ when I finally begged him to test for it after one year of watching my son decline into a mere shadow of his former self. He insisted, ‘We don’t have Lyme disease in Texas.’ I had to keep reminding him that we now have engines that can take us out of state and that my son was bitten in Arkansas!” — Michele

“If you do not have a doctor that really understands this complicated disease, they will not look at the full clinical picture to make a diagnosis.” — Virginia

“I was misdiagnosed by 15 doctors in the Houston area.” — J.B.

“After seeing over 15 doctors, (rheumatologists, neurologists, psychiatrists, psychologists, family doctors, allergists, ENT, OB/GYN, internal medicine, endocrinologists) I stumbled upon a doctor who decided to test me for Lyme. The only reason she thought to test me was because she was from New Jersey and had experience testing Lyme. Sure enough I tested positive. I was sent to a new rheumatologist to make sure it wasn’t a false positive and he assured me I had Lyme. He acted like it was no big deal and I would be better in no time. I was given a prescription for an antibiotic for a month and then dropped as a patient. That was 4 months ago and am I better? No, because one month of antibiotics does nothing for chronic Lyme.” — Brittany

“My primary physician and any specialists that I need to see are all located at the Houston Medical Center. I do not try to tell any of them that I have Lyme disease, because when I have tried that in the past, they have either rolled their eyes or told me, ‘Oh yes, I know about Lyme disease. I used to live back east.’” — Lauren

“I found moving [to Texas] that many doctors here are unfamiliar with Lyme or unwilling to treat it.” — Nancy

“I went to about 30 plus doctors. One of the very first doctors I went to was a neurologist and she said it sounds like Lyme. Of course, she used the standard test instead and it came back negative. So, we continued to go to doctor after doctor and they would run a million tests and never get the right diagnosis.” — Samantha

“I was diagnosed on October 31, 2011. I had been seeking diagnosis for 14 years.” — Elise

“I saw 8 doctors in 3 months.” — Jenny

“I saw 27 doctors before I got the proper diagnosis and it took 10 years.” — Irene

“I have been sick most of my life off and on. By 2008, I had seen 28 doctors, and now it is close to 47.” — Lily

“I tested positive for Lyme on 5 consecutive tests, and still my doctor said he didn’t think I had Lyme disease.” — Lisa

“I saw 100+ doctors before getting diagnosed. I had a bull’s-eye rash.” — Evelyn
Texas patients must go out of state to be treated for chronic Lyme.

“I have learned that Lyme literate doctors in Texas are afraid to treat patients in Texas for fear of losing their license to practice. I have seen this fear first hand.” — Virginia

“I had to travel outside of Texas to get treatment for chronic Lyme disease. Convenient? Not at all. No one seems to understand that I have to leave the state in order to get treatment despite our ‘wonderful’ medical center. Are people going to have to wait around to stumble upon doctors who actually know about Lyme? It’s not right.” — Brittany

“I have gone to Connecticut and Louisiana for treatment. The doctors here in Texas are having a hard time with the [Texas Medical Board]. The public is not being told about the tick-borne diseases here. The doctors keep telling us there is NO Lyme in Texas.” — J.B.

“I currently see a Lyme specialist (internationally known cardiologist) who comes to the Dallas area one week per month.” — Evelyn

“I have to go to [Missouri] for proper treatment.” — Lily

“Both of my doctors are out of state, one in Louisiana and one in North Carolina.” — Irene

“[Our Houston Pedi Infectious Disease specialist] indicated she had done all she could do and would not prescribe any more antibiotics. As my son was not back to 100%, we returned to Louisiana . . .” — Michele

“We traveled to CT, VT, MO, LA, and CA to find the right LLMD. We spent a year with each one.” — Ellen

Delayed diagnosis and the need to travel for treatment lead to heavy financial burdens.

“I’m so tired of all these doctors. I’ve seen around 40 by now, and spent around $75k.” — Jessie

“I’ll never satisfy any insurer for IV antibiotics. And I will have to amass some small fortune in order to pay for it in cash. Or go to Germany where they successfully treat Lyme disease every day. Either way I am in a trap that I can’t get out of.” — Christina

“Between myself and my insurance I have mounted probably close to $150,000 in medical bills. I have been tested for lupus, MS, fibromyalgia, brain tumor, cancer, diabetes, thyroid issues and [more].” — Christina

“Now we have to spend money to travel and money for treatment because insurance doesn’t cover it! If they would have tested me in the first place, eight years ago, I probably wouldn’t have been such an expensive patient!” — Brittany

“I do not have the funds to go out of state for proper treatment.” — Jenny

“Our 2010 medical expenses out of pocket were almost $50,000. All 5 of us have been in treatment but our policy has had to be ‘sickest first’ when guiding treatment because we can’t afford to do more at this point.” — Alex
Patients are treated with skepticism and scorn.

“I have had to travel five hours from home to the doctor’s office. Even though I was immediately diagnosed by two doctors, I have had ID doctors tell me I was crazy. I’ve had my family doctor deny treatment all together. I’ve had my insurance company deny additional treatment.” — Diane

“I went to several doctors who ordered dozens of blood tests and asked me questions like how much does my husband work, how many kids do I have and do I have any help at home. The solution was a prescription for antidepressants. It did not help with pain or muscle fatigue.” — Mary

“When I made my best attempts to go visit a doctor, my appearance at an office seemed to be more proof that I was ‘well’ enough to get to a doctor’s office and not sick from the symptoms I was relating. And this was all of them with no exceptions.” — Christina

“It has been a curse because we are the ‘walking sick.’ We do have bad days—we just keep those quiet. Everyone says, ‘but you look so healthy. You aren’t sick. Are you sure you have Lyme?’ And when they ask questions, most are skeptical, thinking we are hypochondriacs.” — Leslie

Patients know: Chronic Lyme requires long-term treatment.

“We returned to Louisiana again and started a new course of the proper antibiotics for Bartonella in combination with IM Bicillin injections for his type of neuroborreliosis. After several months, he became symptom free.”

— Michele

“What I will tell you is that after seeing this doctor he has gotten me to a more normal way of life. I can get 8 hours of sleep now and get up in the morning, and the everyday of depression hell is now down to about 2 days a month. I’m able to work out (when my back isn’t giving me trouble), and the other numerous symptoms are tolerable.” — Melissa

“My daughter was treated continuously for 10 years. Finally she reached successful remission in 2008 after 4 yrs. treatment with the Marshall Protocol. She is completely well now without relapse, symptom free and medication free since 2008.” — Catherine

“Around the sixth week of antibiotics and the glutathione/ATP injections I noticed an increase in energy levels and after about one year improved to around 80%.” — Mary

“I had my [PICC] line in for 3 months. I made great improvement, but because of the delay in diagnosis and treatment today at 36, I have been left with devastated body and mind.” — Anne

“As my treatment progressed, I slowly began to see and feel improvements. After several months of IV treatment, I noticed that I could go a little farther without losing my breath. I could do a little bit more than I could before. After about 7 months of IV treatment, I was able to go to my first [horse riding] competition. I don’t know if it’s reasonable to hope that I will be in remission when the doctor and I decide that I’ve had enough.” — Taylor

“I went from barely being able to hobble through my house or a grocery store to spending all day at the local theme park with my kids AND being able to ride roller coasters.” — Nancy
Thoughts and Wishes for the Future

“I will beat this, but it would be so helpful if people realized the truth about Lyme disease. Eyes need to be opened about this debilitating disease. It exists. It is chronic. It is spreading. It needs to be recognized.”

— Brittany

“I do wish that there was more knowledge about Lyme disease and that there were resources for doctors and patients on how to successfully treat it. I do feel at times like it’s a guess and check. I also don’t think it’s right that I have to wonder whether my treatment will be covered by insurance or not next week. I know that I am one of the fortunate ones who has had the resources to receive IV treatment for 12 months. If I had received it for only one month like most people do because of the guidelines available to most physicians, I am sure I would be dead or close to it.” — Jordan

“At this time in my life I was under the notion that doctors knew it all and took all that they said as fact. I believed they were all brilliant. NOW I KNOW THAT BRILLIANCY DOESN’T COME WITH THE DEGREE BUT IS EARNED long after they have tossed the hat.” — Kathy

“My son’s suffering for 2 years is due to the ignorance of Houston physicians regarding Lyme disease and the adherence of other Houston physicians to the IDSA [Infectious Diseases Society of America] protocol. My son’s health and happiness is due to the ILADS [International Lyme and Associated Diseases Society] protocol followed by our out-of-state LLMD [Lyme-literate MD]. I know this since we tried both.” — Michele

“Knowledgeable or more Lyme-literate doctors could very easily have shortened my length of suffering.” — Christina

“I have learned that the CDC and IDSA’s guidelines for the treatment of Lyme disease are utterly and completely wrong. It has probably cost the lives of many people with Lyme disease. It is the reason insurance companies are able to deny coverage to treat this disease.

“Education will slowly eat away at the old misconceptions related to the diagnosis and treatment of this disease. It will open the eyes of doctors who would have never before even considered the possibility of Lyme disease because they thought it did not exist in [our] state. Education will save the lives of countless people in Texas who have yet to find someone who will treat them, and education will prevent many more people from contracting this terrible disease.” — Virginia

“I pray that our state will come to terms with the ever expanding infection rate and will do the right thing by her people. We, who boast the ‘medical mecca’ that is Houston should not have to travel to Missouri or California or Pennsylvania or New York to get proper treatment. It’s tragic. But the other Texans who have borreliosis and other tick-borne diseases have stories very similar to ours. Many have seen at least ten specialists and still couldn’t get a diagnosis or treatment in our state.” — Alex

“As long as the CDC continues to spread inaccurate information to our physicians, patients will continue to suffer needlessly. It is this inaccurate information that led me down this long 9-year road in a struggle to find a cause, treatment or cure for my illness. It is this inaccurate information that has turned my curable Lyme disease into an incurable chronic illness. This is what has to change.” — Mary
This patient’s story is here in its entirety, because it perfectly illustrates the journey so many Lyme patients experience. How many more people in Texas are living like this because they have not yet discovered they have Lyme disease?

LYME NIGHTMARE

Writing a simple story about Lyme disease is difficult—there is nothing simple about Lyme disease. Even though I have watched friends and family suffer with chronic and terminal illness, nothing could have prepared my family and me for the journey of discovering I had Lyme, as well as what it would take to recover from it. I am still in that journey now, and I beg God to help me reach remission and get my life back.

I think I have had Lyme for about 25 years. I never saw a tick on me, or had the expected bull’s-eye rash. One could say I tired easily after my son was born 23 years ago, but what mother isn’t tired when caring for a non-sleeping, active child? When my son was about 6 years old (1995), I went back to work full-time during the school year. Within months, I began having chest pain, my arms were often weak, I had extreme fatigue, and pain all over my body. My family doctor said pneumonia was to blame and that a week of antibiotics would have me feeling great soon. When I didn't get well and the chest pain remained, I saw a cardiologist, who quickly diagnosed me with mitral valve prolapse, and he really didn’t take most of my symptoms seriously.

As time went on, more odd and unexplainable symptoms developed. My skin hurt, and my scalp hurt and burned when I brushed my hair. I came down with a lot of upper respiratory infections that were hard to overcome. Fatigue was always my chief complaint, but the chest pain and other aches were pretty prominent as well. I even had a bout with TMJ – temporomandibular joint inflammation. A specialist helped me get past that problem. The next medical professional I sought was a rheumatologist, and he said he felt I had an autoimmune issue, but that the labs were just not consistent. Three doctors did not seem concerned with any of my symptoms.

The pain increased, and my life was slowly and negatively being changed. I had to plan all activities around how I felt and if I would have the strength to do them. Rest seemed to help, but I could never get enough. I decided to see another rheumatologist, and she immediately diagnosed me with fibromyalgia and said there was no cure. I told her of my “brain fog” issues—memory lapses, speech issues, and not being able to think clearly at times. She assured me it was not life-threatening and to just get as much rest as possible.

Time went on, and because years ago nothing much was done to “treat” fibromyalgia, I just adjusted my life around the old symptoms, as well as some new, strange symptoms. I accepted that I just wouldn’t be as strong or have the stamina that was normal. It seemed my annoying symptoms were all blamed on fibromyalgia and/or mitral valve prolapse.

About 7 years ago (2005), my health really took a decline. The chest pain was awful—varied in intensity and form, and it hit randomly. The fatigue was miserable. Pain was in my joints and muscles, and even felt like it was in my bones. I saw a new cardiologist, and he could find nothing wrong besides the mitral valve prolapse, but I did fail a stress test. He had no explanation for the failed stress test, and he admitted he didn’t know why I felt so bad, but he was not concerned. I moved on to more doctors: a doctor of osteopathy and an internist, and others. An internist told me I had depression and that I was just under too much stress, and I went along with that for over a year. The depression medication only made me think I wasn’t suffering quite so badly, but eventually, I
began having difficulty walking and intense digestion problems started.

In 2007, I moved on to a gastroenterologist and a new rheumatologist. A variety of digestion tests were done, even repeating an endoscopy, only to reveal inflammation and to be told I had irritable bowel syndrome. The rheumatologist said I had lupus and Sjögren’s syndrome, as I had autoimmune blood markers. Those markers had come and gone over the last 16 years. The rheumatologist offered me no help with pain and acted like having these illnesses equated to having a cold virus.

Because of the 3rd rheumatologist’s indifference, I moved on to my 4th rheumatologist, and she said I had inflammatory arthritis. She prescribed Prednisone, and some symptoms waxed and waned, and I even had some temporary relief. When numbness, swallowing issues, waking up in the night gasping for air, and feelings of faintness persisted, I was sent to a neurologist. I was told I had pinched nerves. My jaw line was sore, and the skin was red in that area around my glands. I was told to see an ENT specialist, and no medical problem was found. All kinds of vision problems came and went, including the loss of vision in the center for about 20 minutes one day. I was told by an ophthalmologist that I probably had a migraine, even without head pain. My menstrual cycle became irregular, and I kept getting painful ovarian cysts. Because my mother died young of breast cancer, I sought help at the top cancer hospital and had numerous exams related to female cancers. No cancer was found and there was no medical reason determined why I was having difficulties.

After an insurance change and over a year of being sent to specialists for anything outside of rheumatology, I decided to go back to my 2nd rheumatologist who had diagnosed me with fibromyalgia years earlier. She is one of the top docs, and she is involved in clinical drug trial studies. For the last 15 years, I had endured multiple MRIs, CT scans, x-rays, blood tests, heart tests, cancer tests, and other medical diagnostic procedures. Many new symptoms, including very strange ones, were coming and going, and all were disconcerting, as no medication could relieve them for more than a short time. The rheumatologist ran more tests and gave me the clinical diagnosis of rheumatoid arthritis to go along with the fibromyalgia. A Sjögren’s antibody kept popping up, so it was determined that I must have Sjögren’s syndrome. I was put on drugs to suppress my immune system. Each drug gave some or a decent amount of relief, but then symptoms would return. I took Prednisone, Methotrexate, Arava, and Cimzia injections at different times and different amounts, during 2007–2011. In 2011, I began the Cimzia injections—a powerful drug to suppress the immune system and block the tumor necrosis factor. The stiffness in my joints was almost completely gone, but other symptoms increased, including fatigue. My cognitive skills deteriorated after a couple of months of taking Cimzia, and I had to quit driving. I told my doctor all of these things, and she asked me how much of my symptoms were stress! My stress was the physical hell my body was going through, so I was surprised by her thought. She did have me wear a 24-hour heart monitor when I began experiencing heart palpitations. A new cardiologist thought my symptoms were from medication. For the hundredth time, I researched my symptoms online, and Lyme disease came up. When I asked my rheumatologist about Lyme, she replied that Lyme was NOT in Texas. I told her I traveled, and she asked about the bull’s-eye rash—I had not ever had one. Her conclusion was that I did not have Lyme.

By fall of 2011, I could not drive due to concentration difficulties, I was in constant, debilitating pain all over, I could not sleep through the night without waking multiple times, I was losing my balance and having cognitive problems, digestive issues were regular, my hair was falling out, I had trouble writing, and then my foot pain began. A podiatrist diagnosed me with plantar fasciitis. More annoying and scary symptoms popped up—it is a long list. Oddly, I was having severe teeth pain for about 20 minutes at a time, but my dentist could find nothing wrong. My health was rapidly declining, and I was on the verge of complete collapse. Working was stressful, as I had to repeatedly check my work and take naps on my lunch just to get through the work day. A good friend insisted I try just one more doctor. I was sick of being sick, and I did not have any faith that a new doctor could help me, as I had seen at least 14 doctors in 15 years, and many of those doctors were considered top doctors in their fields.
With little hope, I went to see the recommended doctor, and she literally saved my life. At my first appointment, she told me something was very wrong and that she would test me for several illnesses, including Lyme. I didn’t think twice about Lyme, as my rheumatologist said I didn’t have it, especially since I didn’t see a tick and had no bull’s-eye rash. In about 2 ½ weeks, I got a phone call from the Harris County Health Department—I had Lyme, and I had more than enough bands to satisfy the Centers for Disease Control’s criteria. Wow! Would my health nightmare be coming to an end?! What a shock it was to our family to realize that I had been seen by so many specialists who never thought to test me for Lyme, and the worst part was that I had been taking medications for the last 4 years to suppress my immune system—the worst thing for a Lyme victim. The Lyme took over and invaded everything from my skin to my bones. Unfortunately, my central nervous system was included in the infection.

It has only been 6 months since I got the diagnosis of late-stage chronic Lyme disease, and I got worse before I got better, even with an immediate 6 weeks medical leave from my job. To add insult to injury, I also have multiple co-infections. I sought medical help from a Lyme specialist out of state, as he was the closest, experienced Lyme specialist. I am still not able to work 5 days a week, and working is difficult. I work because I have to—there is no other way. I carry the medical insurance for my family, and we need the income. Lyme treatment is terribly expensive, and traveling to see a specialist has added extra financial burden. Thankfully, I have an understanding boss regarding my plight, and I am forever grateful.

Nothing about Lyme is simple, as there is such a variety of symptoms, variables in treatment, and no 2 people heal and recover in the same time or way. The treatment itself adds and magnifies symptoms and can be disabling. Because I had Lyme for so long, only time will tell what symptoms and cognitive problems will be permanent. My brain involvement has been harsh. Tasks that were automatic were not that way for months. I had to (and still do at times) focus to be able to dress myself, to get on the right bus for work, to do my job, to count, to run errands, and to do basic household tasks, etc. Some of my memory is gone, and at times, both short and long-term can be a problem. I look at my Christmas card list and cannot remember some of the people on it. I no longer see memories in my head. My speech problems are still very present when I am fatigued. I take nothing for granted, as each day is different.

My suffering from Lyme has seemed unlimited, and there were many times I prayed for God to take me, and I even thought of suicide. Yes, someone who is very spiritual, relishes life, and loves enjoying life with others, thought of suicide. It is a devastating illness that can remove all hope because of the intense physical, emotional, and mental suffering. Lyme stole my time, my health, my money, and my dreams. For years, I have been less of the person I was meant to be. All of my relationships have been affected and mostly in a negative way. I was once a confident woman, but Lyme reduced me to someone who has to think about how to walk and fears just about everything, especially my future. I have come such a long way in my Lyme journey, but I have a long way to go to wellness and peace. Each day is difficult to face, as my future is unknown, and getting Lyme disease into remission is hard work. I keep thinking that I will wake up one day, and all of this hell will have been a horrible nightmare. It is hard to believe that such a tiny bug bite can do so much harm, but it can, and it did. I am grateful to be alive, but I am not living . . . yet.

Cheri Stine
Mar. 2012
The Texas Lyme Disease Association wishes to thank the people who shared their stories. A special thanks goes to Teresa Lucher, our Support Group Liaison and the leader of the Houston Lyme Disease Support Group, for collecting most of these from members of her group, the Greater Austin Area Lyme Council, and the Txlyme Yahoogroup.

The names of the contributors were changed in the interest of privacy.

Readers will notice that all of these stories were contributed by women, which may give a false impression that only women suffer from Lyme disease. Men of all ages are equally vulnerable to tick bites, and Texas has hundreds of male patients with Lyme and other tick-borne diseases. It is simply a fact that men are more reluctant to share information about their physical and mental ailments. Men, too, are more often afraid that they will lose their employment if their employer discovers they have a chronic illness.