

Tamara Chauncey

*Note to members of the Sunset Advisory Commission: You patiently listened to many people the day I testified. You may remember that I was wearing sunglasses and noise cancelling headphones. I did not read this testimony and described the challenge I was experiencing in the moment because of sensitivity to light and amplified sound. I was unable to read my prepared statement at the time. So that you may understand more about how Lyme progresses when untreated, I have added part of my testimony submitted prior to the 2011 Legislative Session. Thank you for your commitment to helping citizens of Texas.*

9 December 2011

Thank you for this opportunity to speak today. My name is Tamara Chauncey. I was born in Lubbock and made Austin my home in 1975. I contracted Lyme 27 years ago. Despite knowing that I had a tick bite while I was vacationing near the Frio River, having classic symptoms of Lyme and positive blood tests for Lyme my doctor refused to prescribe antibiotics because it was his belief that there was no Lyme in Texas. After being denied care by several physicians in Texas, the illness progressed and I sought treatment from a Lyme specialist in New York. This delay in care allowed the disease to advance and leave me unable to work due to cognitive problems. Recent brain scans show evidence of changes consistent with Parkinson's Syndrome, one of the neurological diseases associated with Lyme.

Today is not the first time I have made a plea to members of the Texas Legislature on behalf of Lyme patients. In 2000, I spoke to a Special Committee Chaired by the Late Senator Chris Harris; in 2011, I spoke to a Legislative Committee regarding a bill that was intended to improve access to care for Lyme patients. I have also made a plea to the Texas Medical Board. In 2015, I spoke to the Texas Medical Board on two occasions, asking the TMB to use their platform to notify physicians that Lyme patients need educated and welcoming practitioners; I also asked that they post information about Lyme CMEs (that were developed at the behest of and paid for by the Texas Lyme Disease Association) on their website. We also asked that the TMB use their platform to physicians that they would be allowed to treat Lyme without fear of retribution. The TMB decided at their meeting last week to decline the request to list CMEs on their website.

At the TMB meeting, I was told that the TMB has no responsibility to educate doctors about treating any illness. I was also told that the TMB does not have any position for or against physicians treating Lyme patients. I specifically mentioned that patients were unable to access appropriate care and treatment in Texas. I was told that we (Lyme patients who spoke at the same meeting) were "in the wrong place". When I asked what the "right place" is, I was told that patients have no place in influencing the "standard of care", even when the current approach is inadequate and ineffective and people die from Tick Borne Diseases. A member of the Board noted that people die every day from many illnesses. Members of the TMB stated that they have no issue with treatment of Lyme and that no physicians have been disciplined recently. Since the legislation passed in 2011, it is my understanding that there has not been any investigation into physicians who treat Lyme patients. Checking that fact is not terribly difficult. There are only a handful of doctors who acknowledge treating Lyme.

Despite the declared change in attitude towards Lyme treatment, the perception of physicians across the state of Texas continues to be that they will be prosecuted for treating Lyme and Tick Borne Diseases. I facilitate a support group in Austin for Lyme patients. At almost every meeting new patients attend and share their stories. Of most concern to me are patients who are told by their physicians that they do not treat Lyme or that the patient must be diagnosed outside of Texas and have a Lyme specialist on their team before the local physician will participate in a treatment protocol. Often I meet parents who are traveling, at great expense, to take their child to specialists either to the west coast or east coast. I've met parents of young children and parents of adult children who moved back home after living independently. These are devastating circumstances that could be avoided if physicians were capable of and willing to identify and treat Lyme.

Recently I spoke with an Austin physician I met through the support group. He shared that the complex needs of Lyme patients becomes especially complicated when the insurance company suggests they will pursue action if the doctor continues treatment beyond what the insurance company deems as reasonable. He also shared that a patient may be well-informed and demand treatment that is considered

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standard in areas where Lyme is accepted as endemic. If the desired (and appropriately indicated treatment) conflicts with the insurance company's standard, the physician stands to have complaints filed by both or either party. If he follows what he believes is necessary, the insurance company may file a complaint and if he does not, the patient may file a complaint. His conclusion was poignant, and I paraphrase: "I believe that the needs of all my patients much be put before the needs of a single patient. If I lose my practice to satisfy one person, everyone stands to lose."

It is possible that since I was infected by Lyme in 1989 and denied care after five consecutive positive blood tests, that the climate has changed and there is more awareness and acceptance of Lyme. This is not my experience ,In my experience, patients do not have sufficient access to care, doctors have the perception that they will be prosecuted for treating Lyme patients as they see fit and there is no where for patients to turn for assistance except to the Texas Legislature. Please help us in whatever way that you are able.

*Possible solutions:* Appoint some board members who are knowledgeable about Lyme and Tick Borne Diseases and others who treat holistically or in the area of Complementary and Alternative Medicine. Provide information on agency websites about CME courses available to educate medical professionals about Lyme and Tick Borne Diseases. Encourage Texas Medical Educators to learn about Tick Borne Diseases from Lyme specialists who are helping patients return to wellness.

With great appreciation.

Tamara Chauncey

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Testimony submitted in 2011 (with a few updates):

My battle with Lyme Disease began in 1989. Despite having five consecutive positive blood tests for Lyme Disease, the doctors in Texas would not prescribe antibiotics, insisting that the tests were "false positive" because, "There is no Lyme Disease in Texas".

Because I was not treated in a timely way, I developed a systemic illness with numerous complications. I now have neurological issues caused by Lyme that left me unable to work. Before I conceded and applied for disability, I participated in the Texas Department of Assistive and Rehabilitative Services program for job retention. I also completed over 80 hours of cognitive rehabilitation therapy. At the end of each program I was advised to stop working and file for Social Security Disability. Two years ago an MRI and DaTscan of my brain revealed changes consistent with Parkinson's Syndrome and my neurologist believes this is secondary to Lyme. It has been necessary for me to prepare for the eventuality of moving to a long-term care facility and depend on others for support in ways I never imagined.

I received a tick bite while vacationing near Concan, Texas, by the Frio River. My first symptoms were about three weeks after I removed the tick. Symptoms resolved and returned repeatedly until I saw the partner of my family physician (my doctor was out of town). I specifically requested a Lyme test and he reluctantly agreed. He insisted that there was no Lyme Disease in Texas. His nurse called a few days later to tell me the test was positive and when I asked what the treatment was, she said they would not be prescribing antibiotics at that time- I was to return to the office for a second test. The second blood test, taken to the Texas Department of Health, was also positive. I was again told it must be a false positive and denied antibiotic treatment.

When I was refused antibiotic treatment, I consulted a homeopathic clinic in Nevada and yet another blood test was conducted; it was positive. Homeopathic remedies provided some relief, but the illness did not resolve. One internist in Dallas reviewed my medical records and stated that she was sure that I had Lyme and needed IV antibiotic treatment. She ordered more lab work and scheduled a second visit. After traveling to Dallas a second time, I was told that she was unable to take me as a patient because physicians in Texas were being investigated by the Texas Medical Board for treating Lyme Disease and she

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was no longer taking new Lyme patients. Five Texas doctors told me that I did not have Lyme and one denied treatment, after telling me that I did have Lyme.

After researching my options, I traveled to East Hampton, New York, to see one of the top Lyme physicians in the country. I saw Dr. Joseph Burrascano about three times a year until his retirement in 2006. Dr. Burrascano ordered yet another Lyme test that was also positive. He prescribed IV antibiotic therapy. By the time I saw the New York physician, the infection had become systemic, impacting my health in numerous ways. He also tested for co-infections, something that no Texas doctor had mentioned. I tested positive for three co-infections and was treated by Dr. Burrascano. In addition to weakness, fatigue and joint pain and a heart arrhythmia, a significant neurological impairment was evident. The New York physician ordered a SPECT scan of my brain which indicated blood flow to my brain had been reduced, resulting in a reduction of oxygen uptake. This explained the neurological symptoms I experience. The SPECT scan was done at Columbia Hospital in New York. After treatment, he ordered a follow up of the same test, but my insurance refused to approve the test, insisting I get a second opinion.

For a second opinion, I saw a physician who specializes in Lyme Disease and practices near White Plains, New York. He agreed with the Lyme Diagnosis and suggested that I continue treatment as ordered by the New York physician. My insurer insisted that my records be reviewed by an Austin physician. The Austin physician disagreed with the opinions of the doctors in New York. He questioned the validity of the test completed at Columbia Hospital. When I asked him if he had treated any Lyme patients, he noted that he had not. He also said he had never read a SPECT scan (normal or atypical) for a woman of my age and that his specialty was age related dementia. He restated the opinion of other Texas physicians, "There's no Lyme Disease in Texas". Even after seeking care from a specialist, I struggle to access care in my home state of Texas.

I see a neurologist on a regular basis due to the serious cognitive problems that I experience. He manages medication that is typically prescribed for patients with Alzheimer's disease. I have completed over 80 hours of neuro-cognitive rehabilitation training and the cognitive problems continue to worsen. Neither my neurologist or the cognitive therapists with whom I have worked have further treatment options to recommend and the progressive nature of this illness is well known.

I graduated from Austin College with an M.A. in Education. I completed additional coursework at the University of Texas in order to obtain credentials as an Educational Diagnostician. My work involved diagnosing learning problems that qualify students for special education services. I administer and interpret cognitive and academic assessments and make recommendations for programming in school. I was forced to retire at least seven years before I planned to do so and ultimately stopped working completely a few years ago.

I am unable to afford to travel out of state for care at this time and do not have a Lyme physician. Recently I found an Austin physician brave enough to accept Lyme patients and have started treatment again. He does not participate in any insurance program; this is consistent with other practitioners who accept Lyme patients. Medical expenses not covered by insurance have drained my financial resources. The tragedy of my situation is that if the physician that first read a positive Lyme test had prescribed a course of antibiotics, I would most likely be a healthy and looking ahead to an active retirement. Even when changes are made regarding medical treatment, those of us who have endured this catastrophic illness will not recover the years lost to illness. Please do everything you can to ensure that others do not have to live this nightmare.

It is my hope that the Texas Legislature will take appropriate action so that Lyme patients are able to access the medical care we deserve. Thank you for taking time to read my story.

Tamara Chauncey

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Austin, Texas

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