

From: [Sunset Advisory Commission](#)
To: [Janet Wood](#)
Subject: FW: LISA TODD'S TESTIMONY
Date: Wednesday, December 14, 2016 2:58:22 PM

From: Lisa Todd
Sent: Wednesday, December 14, 2016 1:55 PM
To: Sunset Advisory Commission
Subject: LISA TODD'S TESTIMONY

I've had 2 tick bites that I know of right here in the state of Texas, and have been battling it out with Lyme disease and some very serious viral and parasitic infections for almost a decade.

- It's estimated that there are at least 1 to 2 million new cases of Lyme disease per year.
- These numbers do not reflect late stage Lyme disease cases like myself, nor does it reflect the thousands and thousands of people going undiagnosed.
- There are over 700 peer-reviewed studies showing that Lyme disease can persist in the body and turn into a very serious chronic illness.
- Lyme disease is twice as common as Breast Cancer and six times as common as AIDS.
- THERE ARE THOUSANDS AND THOUSANDS OF PEOPLE IN TEXAS WITH LYME DISEASE. I didn't make that very clear in my speech to you all, but it's the biggest vector-borne epidemic in Texas.

Lyme disease can be debilitating and fatal if left untreated, even for those of you who are in the medical field, you cannot escape the wrath of Lyme disease. For example, one of the nation's leading oncologists who has developed 2 cancer therapies in his career, went years bouncing from specialist without being diagnosed and it almost killed him due to Lyme related heart failure.

No amount of money can rid you of Lyme disease. Perfect examples of this are Ally Hilfiger, America's favorite Ashley Olsen from the full house, Bella Hadid America's top supermodel, Yolanda Foster, Rob Thomas's wife, Avril Levine, etc.

Before I start telling you my story, I want you to take a moment to imagine that I am your daughter.

MY STORY

I've been battling late stage Lyme disease and some really serious coinfections for almost a decade. Unfortunately, my story is all too common here in Texas....there are thousands and thousands of people in the state of Texas that are just like me. I am not sure if you read some of our stories, but I know that hundreds of us have written you our story.

My story began with me pulling a tick out of the back of my head and actually showing that tick to my doctor. I asked my doctor that day if I should take some antibiotics so that I don't get Lyme disease. He told me that there is No such thing as Lyme disease in Texas, and that there is no possible way that I could have Lyme disease. He told me that I would not need any antibiotics unless I started showing symptoms later and to come back to his office if I do.

Because he did not give me antibiotics that day, I went on to develop Late stage Lyme disease which is almost impossible to get rid of. Had he been educated in Lyme disease, I might not have spent the last decade being sick.

Can you imagine living like this every single day all because your doctor didn't give you antibiotics? This experience has been so terrible that I can honestly sit here and tell you that there have been days where I literally wanted to give up and die.

It took me seeing well over 10 top specialists in the state of Texas before finally getting the right diagnosis. Not once did any of those doctors think to test me for Lyme disease. Not once did they think to test me for coinfections. Not once did they recognize the symptoms of Lyme.

Again and again, I was continually misdiagnosed with a myriad of illnesses without being given the proper test for Lyme disease. Year later, I FINALLY got my positive diagnosis.

SO WHY AM I HERE TODAY? Because all of this could have been prevented. If my doctor had been properly trained in Lyme disease and immediately given me antibiotics, I could have eradicated the infection before it progressed into late stage Lyme disease.

WHOLE PURPOSE:

My question to you is, if there is a very simple solution to this problem, why aren't we taking action.

If the TMB's whole purpose is to educate doctors and to protect the public, why don't they fulfill their duty to educate doctors just as it is written in bill 1360 in order to help those that are suffering? Why not go ahead post a permanent link to educational CME courses for Lyme disease on your website so that doctors can get the proper education in Lyme disease? Why not include this information in every single newsletter that you send out? Why not make this a requirement? Why not inform them that Lyme is in Texas. Why not send a clear message to doctors that it's okay to test and diagnose Lyme disease and that they do not need to be scared.

By doing this the TMB and TMA can prevent a lot of heartache and suffering and can prevent years of misdiagnosis and misery. They can prevent unnecessary death.

Il am going to end with this....Let's say that your daughter ends up dying from heart failure due to Lyme disease or committing suicide due to Lyme disease pain....would you have the heart to tell your daughter (who is up in heaven) that you were on that board making those life or death decisions for thousands of families in the state of Texas AND YOU CHOSE NOT TO EDUCATE DOCTORS.

I hope that my story is compelling enough for you to recommend that the TMB and the TMA to permanently promote Lyme CME training on your website and in your newsletters, and eventually make this a requirement.

Please remember Senator Chris Harris who wasn't lucky enough to survive Lyme disease. Please I beg you, make the right decision and start educating doctors by posting to your website.

REQUESTS:

Have CME training links highly visible on both the TMA and TMB websites at all times. Have them listed on the bulletin and in every single email that is sent out.

Send a clear message to doctors that it is okay to diagnose and treat Lyme disease.

Require insurance companies to pay for long-term treatment. It's obvious at this point that a lot of us are not healed in 4 weeks!

Stop the TMB from punishing Lyme doctors and our alternative health doctors because they are the only people who can help us!

Stop allowing for private complaints on doctors because we all know that they are coming from the insurance companies who don't want to pay for treatment. Stop using that as an excuse to go in and investigate our doctors.

Stop allowing the TMB to subpoena our private information form our doctors without our permission, especially when it has nothing to do with our case.

Please require up-to-date (ILADS based) CME training in Lyme disease for ALL doctors in the state of Texas.

Lyme Literate doctors should be on the TMB

Alternative Healthcare practitioners should be on the TMB.

Read the below for the rest of my requests.

"Additionally, there are at least two, maybe three, Lyme

FaceBook groups in our state for a combined membership of probably a couple of thousand members. Most of our members are late-stage, chronic Lyme patients whose numbers are never represented in the Texas Department of Health (TDH) statistics for Lyme disease because TDH is assigned to report only just early-stage cases of Lyme disease.

In spite of passing protective legislation for our Lyme specialists back in 2011, nothing has changed in the last five years since then. Lyme patients are still having an extremely difficult time finding Lyme-literate doctors capable of diagnosing and willing to treat them because of the perception that they will be prosecuted/persecuted (take your choice) by the Texas Medical Board (TMB) if they accept chronic, late-stage Lyme patients into their practices. Something needs to be done to reassure doctors that it is safe and OK for them to treat Lyme disease, without fear of prosecution by the TMB.

For example, I know of three cases of early Lyme disease in young Boy Scouts who got tick bites with rashes at Boy Scout camp – classic cases of early Lyme which should have been very easy to recognize and diagnose – a no-brainer! Their young lives have been devastated as a result of their failure to receive a timely diagnosis and adequate treatment before their cases progressed into late-stage Lyme which is much more difficult to treat. What's even worse is that in two of these cases, their astute parents filed complaints with the TMB – valid complaints which were dismissed as “non-jurisdictional.” What's going on here?

This situation is inexcusable, especially when we consider that our Texas Constitution (Article 16, Sect. 31) guarantees that the state medical board cannot discriminate against different “schools of medical thought”. That Constitutional clause was the basis of our protective legislation for Lyme specialists when HB 1360 was passed back in 2011.

Perhaps a partial answer to this question is that our Lyme doctors look around them and see that other doctors who specialize in Complementary Alternative Medicine (CAM) are still being unfairly persecuted by our TMB. This persecution of CAM doctors continues still, despite Chapter 200 of the Medical Practice Act (MPA) which was originally designed to protect CAM doctors in Texas – all no avail though, because of extraneous legalese written into the MPA, which subverted the

original intent of that law.

It seems to me that the majority of members of our TMB hold a paternalistic attitude towards Texas citizens, as if we need protection from “medical charlatans” because we are not smart enough to discern for ourselves what is best for us concerning our own health care needs. This overly protective attitude is ridiculous because patients today have access to the internet, including authoritative websites such as PubMed and Medscape, to do our own research on medical topics. We do not need Big Brother looking after us by discouraging doctors from practicing medicine in innovative ways. Texas patients should be assured of exercising their right to “informed consent” without worrying that their CAM doctors will be run out of business by an over-zealous medical board.

My first recommendation to the Sunset Commission therefore is for you to ask the Governor to appoint new TMB members, whenever vacancies arise, who are knowledgeable about and supportive of late-stage, chronic Lyme disease and also about CAM in order to create a better balance of medical viewpoints among the TMB itself. Likewise, whenever Expert Panels are called upon to review complaints against CAM doctors or Lyme specialists, then these experts should be selected from among those same medical societies, instead of being restricted only to practitioners of mainstream allopathic medicine.

Furthermore, please review Chapter 200, Sect. 190.8 of the MPA and fix it so that it is unambiguous that CAM physicians are welcome to practice freely here in Texas, according to the tenants of their various CAM associations’ practice guidelines, without fear of unjust persecution by an over-reaching TMB.

(By the way, lawyers with our TMB frequently refer to “standard of care” which is outdated medical terminology. The current medical term for this basic concept is “Clinical Practice Guidelines,” according to the National Clearing House for Treatment Guidelines and also our National Institutes of Medicine. “Standard of care” implies something very legalistic and rigid; whereas, “Practice Guidelines” implies broader flexibility because guidelines are constantly changing as new research emerges.)

I concur whole-heartedly with what Rep. Bill Zedler said in his

testimony. I would like to see us go back to the earlier composition of the TMB when an MD was the Chief Medical Director of the TMB who supervises the legal team, who must answer to the Medical Director in the chain of command. "Why?" you ask. That's because MDs have all taken the Hippocratic Oath about "First, do no harm." It's an entirely different mindset altogether! TMB lawyers, on the other hand, should lend their expertise by insuring "fair due process" to physicians whenever they must defend themselves during ISC hearings.

I also want to emphasize Rep. Zedler's comment about the importance of getting rid of the current anonymous, confidential complaint process – with rare exceptions of course, such as when hospital nurses fear reprisal by their employer for filing a legitimate complaint against a bad doctor, or perhaps when a patient seeks anonymity because of embarrassment about sexual abuse by a physician. The reason for the importance of this revision is that surrogates of the insurance industry who do not want to pay for treating complex chronic health conditions can easily take advantage of the confidentiality clause by filing frivolous complaints against CAM doctors, which then allows the TMB to go on a "fishing expedition" by seizing patient records without that patient's express consent to use them against the doctor being investigated.

Similarly, doctors who desire an open public hearing should be allowed to request it, as is done in other states across the country. What we have now is secret kangaroo court proceedings, without any expectation whatsoever of fair due process for physicians. This has a very intimidating and chilling effect on the readiness of other doctors to dare to treat chronically ill patients, including Lyme patients.

The Texas Legislature has already gone a long way in the past with tort reform, but the pendulum has now swung too far in the wrong direction, by empowering the TMB with too much authority over doctors, but without assuring patients of their right to "informed consent" and without assuring doctors of their right to fair due process in defense of their medical licenses. All of these proposed changes will go a long way in making Texas one of the very best states in the country for receiving first class medical care."

In Lyme disease is the largest vector borne illness in Texas, and yet doctors here in Texas are being taught that you cannot contract Lyme disease in Texas, they haven't the slightest clue how to recognize symptoms, they are giving outdated tests that are missing the majority of cases, and furthermore they are misdiagnosing thousands of patients. The majority of doctors here in Texas still think that you need to have a bullseye rash to start treating for Lyme to eradicate an early infection. Most doctors in the state of Texas are not aware that Lyme disease has over 300 rotating symptoms, and often mimics things like ALS, MS, Fibromyalgia, chronic fatigue, Lupus, Bells Palsy, alzheimers, etc. Most doctors are not aware that Lyme is typically never just Lyme... it's almost always accompanied by parasites and viruses like chronic Epstein Barr Virus, Chronic Mycoplasma, babesia, bartonella, hhv6, shingles, cytomegalovirus, parvovirus,

As you can see, this is a huge problem in Texas!

Please do the right thing, and help us resolve some of these issues.

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***Kind Regards,
Lisa Todd***