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Testimony re: TMB for Sunset Commission Dec. 2016

PROBLEMS:

1. The TMB is not being effective in helping to safeguard Texans who have Lyme disease or doctors who treat Lyme. Because the TMB has disciplined doctors who treat Lyme with long-term antibiotics in the past, doctors are afraid to test or treat for Lyme. Some doctors say "there is no Lyme in Texas." I repeat – DOCTORS ARE AFRAID OF THE TMB.

2. The TMB rules against Lyme patients who file complaints against MDs who missed their diagnosis saying they are non-jurisdictional. This discrimination needs to change to prevent worsening of illness and further death of Lyme patients.

3. The TMB has not fulfilled their mission statement, which includes to "educate" physicians.

4. The TMB has not fulfilled their mandate from 2011 -- SB1360 and HB 2975 -- which outlined that they need to encourage CME for physicians who treat Lyme disease. Well, ALL physicians could potentially test for, diagnose and treat Lyme if they were educated because Lyme can manifest as cardiomyopathy, skin rashes, arthritis, schizophrenia, Bell's palsy, chronic fatigue, irritable bowel, Alzheimer's, Parkinson's and more. Whether one is a GI doctor, a cardiologist, a family practice physician, psychiatrist, rheumatologist or other type of doctor, Lyme has probably been missed because doctors do not think Lyme is in Texas and don't know to test for it.

5. The TMB only has infectious disease doctors on their expert panel to make decisions regarding complaints dealing with Lyme. The problem is infectious disease doctors only follow the Infectious Disease Society of America (IDSA) guidelines which only allow for 28 days max of antibiotics. These guidelines are out of date and have been taken down from the National Guideline Clearinghouse and replaced with the International Lyme and Associated Disease Society's (ILADS) guidelines which were recently updated and have proven more effective in treating Lyme patients. Here is an article: https://www.lymedisease.org/idsa-guidelines-removed-ngc/

6. The TMB is most likely not aware of the anti-trust investigation of the IDSA and all of their conflicts of interest – http://www.ct.gov/ag/cwp/view.asp?Q=414284

7. At a recent TMB meeting, they said they did not think there was much Lyme in Texas, so there was not much need to put any information in their bulletin or on their website, although they have promoted Ebola CME on their website. Actually, there is a lot of Lyme in Texas, but it is so underreported by doctors to the Health Dept, that we don't have an accurate count. There are thousands of patients who

> have contacted the Texas Lyme Disease Association, and there are several FB groups made up of Lyme patients. www.txlda.com

This scenario I am going to describe is what it's like for Lyme patients in Texas -- Imagine if you had some signs of cancer, a bleeding mole, or a lump in your breast or groin. You suspect skin cancer or breast cancer, for example. But the doctor tells you, "There is no breast cancer in Texas. There is no skin cancer in Texas. I'll refer you to a psychiatrist."

Ridiculous isn't it? This is the situation that many Lyme patients have gone through in Texas, and continue to go through on a regular basis….because I have been hearing these stories since 1998 when I got diagnosed with Lyme.

I got sick with fatigue and pain in 1994. For four years, several doctors missed my Lyme diagnosis and I went out of state, continuing to search for answers, and finally got a test and diagnosis. Why do we have to go out of state? What is wrong with our doctors that they cannot or will not test, diagnose, and treat?

I learned many others had gone through the same nightmare, so I helped start the Texas Lyme Coalition in 1999 and later co-founded the Texas Lyme Disease Association (and was the first president of the Board). We approached Senator Chris Harris because he had Lyme and was aware of the problems patients were having getting tested, diagnosed and treated in Texas.

Senator Harris chaired the 2000 Senate Hearings on Lyme and many of us testified. The committee had some great recommendations, for example encouraging the TMB to take a more active role in education and that they also develop guidelines for doctors treating tick-borne illnesses so they could treat without fear of undue reprisal.

This was not done and the fear and lack of education continues to this day. To my knowledge, the TMB has not disciplined a Lyme doctor in the past 4 years, <u>yet the FEAR REMAINS.</u>

When my husband got Lyme in 2013, the general practitioner did not recognize his bull's eye rash and said the TMB persecutes doctors who treat it. My friend took her daughter who started having symptoms after a tick bite to a well-respected family practice here and they refused to test for Lyme because they said "**<u>the TMB are Nazis</u>**." I hear these stories all the time. **<u>Nothing has changed in the past 16 years.</u>**

Many doctors continue to miss the diagnosis, <u>including infectious disease doctors</u>. A woman recently filed a complaint with the TMB since the infectious disease doctor told her she did not have Lyme even with a POSITIVE Western Blot test, and referred her to a psychiatrist. <u>The TMB responded and did not even open an investigation because they said it did not fall below the acceptable standard of care.</u>

What kind of standard of care do we have if an infectious disease doctor misses the diagnosis, disagrees with a lab report which says CDC POSITIVE and doesn't make a clinical diagnosis based on her symptoms? Four other doctors said this patient had

Lyme, that her test was positive, including a doctor from the NIH, one at Columbia U, her family practice physician and a leading Lyme infectious disease doctor on the East Coast. Yet, the TMB chose not to investigate. They are biased in favor of infectious disease doctors and against patients and Lyme-literate doctors who know how to read a Western Blot test, and who know that some patients need long term antibiotics to get well.

This is something most doctors, including the TMB, do not know ---- In a Lyme Western Blot test, the CDC requires that five specific antibody bands are needed to REPORT the disease, but not to diagnose. **Lyme is a clinical diagnosis**. If one has symptoms, tick exposure and only two highly specific bands, such as 23 (the Outer Surface Protein) or 39 (the Lyme spirochete's tail), (41 is a more general spirochete tail), it's very likely they have Lyme, but because they don't have five bands for reporting, the doctor will say, "You don't have Lyme. We don't know what you have, but it's not Lyme."

It's very scary to me that some of these infectious disease doctors missing the diagnoses are teaching at the medical schools and perpetuating wrong information. The devastating ripple effect cannot be emphasized enough.

Doctors need to be educated on how to read a Western Blot and make a clinical diagnosis of Lyme. ALL doctors need to be encouraged to take up-to-date CME because for example, a dermatologist and a GP thought a bull's eye rash was a spider bite. New treatment guidelines have been posted on the National Guideline Clearinghouse, but there is no news about this. Probably because the latest guidelines are written by ILADS and the TMB give preferential treatment to the IDSA. Those are the types of doctors are their expert panel. They need to have a Lyme specialist on the infectious disease panel for investigations about Lyme.

I've gone to four TMB meetings in the past year and a half asking them to alleviate doctors' fear of them by encouraging Lyme CME on their website and bulletin, as outlined in SB1360 and HB2975, and help get out the word that there is Lyme in Texas. And so far, they have not done so.

I would like to ask that the Sunset Commission get the TMB to fulfill their mandate from the 2011 legislation, be proactive in educating doctors, reminding them there is Lyme in Texas, there is free CME on the TXLDA website (txlda.com), which is approved by the AAFP (American Academy of Family Physicians). By raising awareness like this, they will be sending the message to doctors to not be afraid to test and treat.

People are dying. Someone I know in Austin who was 32 years old and had Lyme, died in his sleep like the other 3 people in their 30's the CDC recently reported on – except they didn't even know they had Lyme, died suddenly and the pathologist doing the autopsy and organ transplants noticed the hearts looked like Lyme cardiomyopathy, and sure enough he was right.

Please help stop this loss of life and waste of life, by getting the TMB to do what they were tasked to do in SB1360. What good is legislation if the TMB does not comply with it? Please get them to promote awareness and education of Lyme in Texas, promote ILADS education, because this is the education that is science based and most up-to-date, while the IDSA guidelines are old.

There are 700 articles outlining the persistence of Lyme infection in patients. Infectious disease doctors need to know this. Insurance companies need to pay for longer term antibiotics if a Lyme doctor thinks it's necessary, and the physicians should be able to do so without fear of disciplinary action from the TMB.

To answer Representative Flynn's question, why are doctors being persecuted? This is the conclusion I have come to -- the IDSA doctors are affiliated with the insurance companies who do not want to pay for more than 28 days of antibiotics. The infectious disease doctors affiliated with IDSA are paid as consultants by the insurance companies. **For more info, go to this link: http://www.ct.gov/ag/cwp/view.asp?Q=414284**

SOLUTIONS:

1. Have the TMB include ILADS (International Lyme and Associated Diseases Society) guidelines in the standard of care for treating Lyme patients.
2. Have a Lyme-literate doctor on the Expert Panel. We have one or two to suggest.
3. To help alleviate doctors' fears, have the TMB promote ILADS CME or the CME on the Texas Lyme Disease Association website written by Dr. Elizabeth Maloney. If the TMB would promote Lyme CME on their website and in their bulletin, doctors' fears would be diminished and they would start to treat.
4. Ideally, make it a requirement for all doctors to take Lyme CME, but I heard the TMA has already opposed this suggestion, and that's why the 2011 legislation is watered down.

What good is legislation if there are no consequences to the TMB for not following through?

If you have any questions, please let me know. I have traveled to Germany for a CDC sponsored conference and met Dr. Willy Burgdorfer (Lyme is Borrelia burgdorferi named after this researcher who identified the organism). I've attended Lyme conferences in the States, and stay in touch with Lyme practitioners, so I have lots of information I would be happy to share with you.

Thank you.

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