From: Sunset Advisory Commission
To: Janet Wood
Subject: FW: Lyme Testimony
Date: Monday, December 12, 2016 8:09:52 AM

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From:
Sent: Sunday, December 11, 2016 12:47 PM
To: Sunset Advisory Commission
Subject: Lyme Testimony

We are writing today to strongly encourage the Texas Medical Board to educate Texas doctors about Lyme disease and to include Lyme literate doctors on the Texas Medical Board.

Our son David was diagnosed with and began treatment for Lyme disease in 2012. Prior to that, we had taken him to see 10 different specialists in addition to his regular doctor and an emergency room visit over a 4 year period as the disease progressed. His symptoms included extreme exhaustion, debilitating headaches, severe bone and joint pain, heart pain, brain fog, dizziness, imbalance, phantom smells and tastes, urinary tract pain, and inability to concentrate.

Multiple blood tests were run on him over this three year period and well as an MRI, brain scan, and comprehensive examinations. The tests all came back normal. Lupus, Multiple Sclerosis and Brain Cancer, as well as any other illness or disease were all ruled out. The doctors all said they had no idea what was wrong. One or two even suggested that our son needed to see a psychiatrist as it was all in his head. Some of the doctors did not even give his symptom complaints serious consideration. We were told, ‘He is a teenager and teenagers are tired’. When asked how this would explain the other symptoms, our question was shrugged off. We started asking if David could have Lyme. Most of the doctors told us ‘No, there is no Lyme in Texas’.

We did much research online and started to believe that our son did indeed have Lyme disease, as all the other diseases with those symptoms had been ruled out. We took him to an internist and insisted he be tested for Lyme. The test came back negative, and the internist said he was “100% sure” that David did not have Lyme. We knew though our research that Lymes test show a false negative result approximately 33% of the time in chronic Lyme cases, and the more advanced the disease, the more likely to show a false negative. The internist denied this was the case. So we found a Lyme literate doctor through a referral from a Lyme advocacy group and traveled 400 miles to see him. He told us that our son most definitely had Lyme and he also suspected Bartonella. We were told that the Lyme/Bartonella infection was very advanced. He ordered another blood test but explained that the test may come back negative because the blood test tests for antibodies and in advanced cases the body stops fighting the disease so there are no antibodies. The test did come back negative, but the doctor began treating for Lyme/Bartonella. After David was on medication for 3-6 months the test was re-run and the test came back positive for both Lyme and Bartonella. Once on the medications, David's body was strengthened and was able to begin producing antibodies again. Because David was not tested and diagnosed early on, the treatment was expensive and lengthy. It took three years for David to get better. David is Lyme free at this point, and fortunately looks to have avoided some of the terrible long term consequences of Lyme. A year prior to the Lyme diagnosis, David was diagnosed with Narcolepsy. It is impossible to know if this is due to Lyme, but this symptom never went away.

David began college with undiagnosed Lyme/Bartonella and was able to still make a 4.0 his first year. As the disease progressed and the brain fog and pain worsened he was unable to maintain his grades or a full class schedule. His dream of being an occupational therapist is no longer feasible as grad school is very competitive. He is 24 and is still young, but is having to rethink his career plans. It could have been much worse. But it could have been a much better outcome if more of the doctors David had seen along the way were educated about Lyme disease.

Regards,

Mark and Denise Ferguson