

From: [Sunset Advisory Commission](#)
To: [Janet Wood](#)
Subject: FW: My Testimony for the Sunset Commission regarding the Texas Medical Board
Date: Thursday, December 08, 2016 12:27:17 PM

From: Erin Cottingham
Sent: Thursday, December 08, 2016 11:11 AM
To: Sunset Advisory Commission
Subject: My Testimony for the Sunset Commission regarding the Texas Medical Board

Dear Sunset Advisory Commission,

Thank you so much for listening to our many stories about the struggles we face in Texas relating to Lyme Disease. The Texas Medical Board has been negligent in addressing this pandemic through its unwillingness to acknowledge Lyme's prevalence in our state and by neglecting to train doctors and specialists to test, diagnose and treat.

My story begins 28 years ago in Colorado. I was 11 years old and suffered with paralysis, a very high unrelenting temperature, severely swollen joints and a systemic rash covering my entire body. This lasted months and I never felt the same once most symptoms resolved. I was misdiagnosed with Juvenile Rheumatoid Arthritis, as so many children in Lyme, Connecticut were in the 1970's.

I moved to Austin in 2000. I began having several concerning health issues which pointed to MS. In 2003, I visited a neurologist, and after listening to my history and symptoms, she included a western blot for Lyme along with the many other labs and tests she ordered. I did not know Lyme was controversial, and always trusted my doctors. While she did say I had a couple of bands show up on my western blot, she was dismissive of the significance, she failed to mention the controversy, and neglected to tell me my test was actually CDC positive.

I was referred to a rheumatologist who also reviewed and dismissed my positive test results. He told me to take baby aspirin daily to help with a disorder pointing to TIA (a common co-morbid condition in Lyme patients). He told me to stop searching for answers as I was young and he would not want a diagnosis to affect my ability to receive insurance as I would be saddled with a preexisting condition. I felt like my very real symptoms were downplayed and I was seen as a hypochondriac. I stopped listening to my body.

Fast forward 13 years...I am now married with 5 children. I have suffered years with arthritis, psoriasis, multiple chemical sensitivities leading to contact allergic dermatitis. My body is a host of autoimmune disorders and negotiating my way through everyday activities is challenging. The root of my symptoms is Lyme Disease.

I have one tested and obviously symptomatic child with congenital Lyme. In 2013, a pediatric rheumatologist tested her for many joint disorders, but neglected to test her for Lyme. When I asked my family doctor to test her in 2015, I was laughed at and denied. "Lyme is not in Texas. Lyme is not congenital." I asked a dear friend in the medical field to help us submit the blood work as my doctor would not help us. My daughter's test came back with 9 different bands on the western blot. Quite positive.

My daughter is suffering. There are very few doctors in Texas trained and adequately treating children in Texas, and my only choice at this point seems to be finding a practitioner out of state. She has had Lyme all 10 years of her life and symptoms include severe fatigue, swelling joints, muscle aches, vision problems, cognitive issues, and most severely suffering from an autoimmune condition, PANS. She has lost her childhood, and if she is not soon properly treated, I believe her future is uncertain. All treatment for Lyme is out of pocket, and I have yet to find the funds to test my 4 other children.

If only I had been correctly diagnosed and treated in 2003. This disease is ruining our family. Texan doctors need to be encouraged to be trained to recognize, test and treat tick borne diseases such as Lyme. Lyme knows no state borders, and thousands of Texans are being denied proper testing and treatment. Thank you again for listening. You can make a huge difference for thousands.

Sincerely,
Erin Cottingham