

Public Health Committee Public Hearing

Wednesday, February 27, 2013

Testimony in Support of

SB 360 AAC Pediatric Autoimmune Neuropsychiatric Disorder Associated With Streptococcal

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Senator Gerratana, Representative Johnson and members of the Public Health Committee. My name is Jim Carson and I am a parent of a 10 year old diagnosed with PANDAS 18 months ago.

My son has had a history of OCD and anxiety issues that has had a profound impact on his school and home life enough to have him placed into a special education program that required services from the town for speech, occupational therapy, psychological and social skills. He has also required outside services that duplicate what the school system provides. We have been following that regiment for 6 years now as he is in the 5th grade.

Since my son was 5, we have been seeking answers to his anxiety and have worked through many doctors and therapists seeking answers to his body tics, anxiety, OCD and anger issues. It wasn't until last fall where a dietician suggested we have him screened and treated by an immunologist who specializes in PANDAS did we turn a corner. There is a definite need for wide-spread information on identifying, screening/testing and treatment of this disorder.

A simple throat culture swab for strep may or may not test positive. In this case it did not and the immunologist then ordered several blood tests that taken together proved positive for PANDAS. I am lucky enough that Anthem covered those tests but I understand that other plans do not cover them and that is coverage denials on the screening for the diagnosis.

As a result of those tests, the immunologist put him on antibiotics for 4 weeks. He anticipated we would see dramatic changes and he was correct. After just 8 days on antibiotics it was like a switch was thrown. He got all his homework done without asking, cleaned his room and seemed to mature several months over just a few days. We took him off the antibiotics to see if there was a change and he reverted back to his old self. He was then put back on the medicine and has seen progressive improvement to such an extent, we are in the process of cutting back on the anxiety medicines and seeing many new sides to my son that had been masked by the PANDAS and OCD and anxiety.

In my son's case, the cost of one round of blood work and inexpensive antibiotics pales in comparison to the costs over the years for medical appointments, therapists, psychiatric prescriptions and special education services to the town. This issue is very similar to Lyme Disease 20 years ago when there was no "test" and some doctors treated the condition and others said it was not a real disease.

Had he been screened and diagnosed for the disorder years earlier, there may not have been a need for any special education services that would have saved thousands and thousands of dollars. Had the PANDAS been treated, he may also not have been given an autism diagnosis and been treated for OCD and ADHD with anti-anxiety medications for the past several years.

Thank you.