

FTR

CT General Assembly  
Insurance & Real Estate Committee Public Hearing

Testimony in Support of SB 37, AN ACT REQUIRING HEALTH INSURANCE  
COVERAGE FOR PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER  
ASSOCIATED WITH STREPTOCOCCAL INFECTIONS

By Carrie Jachimczyk, 950 Cove Road, Stamford, CT 06902  
Submitted February 17, 2016

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee. My name is Carrie Jachimczyk and I am the parent of a severely developmentally delayed child who has a dual diagnosis of Down Syndrome and Autism. My son contracted PANDAS in 2008 and I am offering you my testimony in support of SB 37.

In 2008 my son Daniel began exhibiting violent, self-injurious behaviors that his regular pediatricians were unable to diagnose or treat. At the suggestion of his developmental optometrist, we began seeing an allergist who diagnosed him with P.A.N.D.A.S. His health stabilized with long term antibiotic treatment until May of 2013 when he was hospitalized for five days at Yale Children's Hospital with anorexia, a common symptom of P.A.N.D.A.S. Despite displaying classic P.A.N.D.A.S. symptoms and having lost twenty percent of his body weight in three weeks, Daniel's doctors at Yale sent us home with instructions to try harder to feed him. Fortunately the feeding specialists at Alphabet Soup in Norwalk (also out-of-network and therefore not covered under our insurance plan,) were able to get him to eat again, and we avoided a catastrophic outcome.

Our experience has been that very few doctors have heard of P.A.N.D.A.S. or know how to treat it. The few specialists in the State of Connecticut do not accept insurance, and families are forced to pay thousands of dollars out-of-pocket while trying to deal with an absolutely horrendous, long term illness. P.A.N.D.A.S has been recognized as a disorder by the National Institute of Health for years, and I feel very strongly that mandating insurance coverage is necessary to prevent families from going bankrupt. One addition I would like to see added to this bill is to mandate Medicaid to pay for out-of-network coverage for P.A.N.D.A.S. because all of the specialists we spoke to do not accept Husky patients.

Daniel recently had his tonsils removed and he is doing so well that we have been able to discontinue the long term antibiotics. If P.A.N.D.A.S. coverage had been mandatory when he first became ill in 2008, he could have been treated by a specialist immediately, he would not have missed so many days of school, and we would have been spared this nightmare.

Thank you very much for your time and consideration.