

CT General Assembly  
Insurance & Real Estate Committee Public Hearing

Testimony in Support of SB 15, AAC Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections.

By Carrie Jachimczyk  
Submitted January 26, 2015

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee. My name is Carrie Jachimczyk, I am the parent of a child with P.A.N.D.A.S. and I am in support of SB 15.

My 13 year old son Daniel was born with Down Syndrome, has been diagnosed with Autism and is now also suffering from P.A.N.D.A.S. He is significantly delayed, non-verbal and has had complex medical issues all his life. In 2008 Daniel began exhibiting violent, self-injurious behaviors that his regular pediatricians were unable to diagnose or treat. At the suggestion of Daniel's developmental optometrist, we scheduled an appointment with an allergist who diagnosed him with P.A.N.D.A.S. Daniel's health stabilized with long term antibiotic treatment until May of 2013 when he was hospitalized for 5 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 20% of his body weight in 3 week, Daniel's doctors at Yale sent us home with instructions to try harder to feed him.

Our experience with P.A.N.D.A.S. has been very few doctors have heard of it or know how to treat it. My husband lost his job a few years ago and Daniel is now covered by Medicaid. There are only a few P.A.N.D.A.S. specialists in the state and not a single doctor in our area will accept HUSKY insurance. Dr. O'Hara does not accept any insurance and charges \$1,000 for just the initial visit. Dr. Bouboulis' office does not accept HUSKY and will not even accept a self-paying patient. Daniel continues to be followed by our allergist who is not a P.A.N.D.A.S. specialist. Over the last few years, we have been forced to go into debt and borrow money from family members to pay thousands of dollars for his treatment.

I strongly feel mandating insurance coverage for P.A.N.D.A.S. is necessary to prevent families from going bankrupt. Mandating coverage would also lend legitimacy to doctors who treat our children. Even though P.A.N.D.A.S. has been recognized as a disorder by the National Institute of Health for years, many doctors are not comfortable with either the diagnosis or treatment. If P.A.N.D.A.S. coverage was mandated, perhaps more doctors would be encouraged to go into the field and better treatment options would be developed.

One addition I would like to see added to this bill is to mandate Medicaid to pay for out-of-network coverage. Many doctors will not accept Husky or will not accept new Husky patients.

I would hope to see the opportunity for families to be reimbursed for the thousands of dollars charged by the specialists.

Thank you very much for your time and consideration

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