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Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee, my name is Lisa Williams. I am a parent and support SB 37.

The problem of not having health insurance for the coverage of PANDAS is twofold. First, families are forced to pay for treatment themselves with no insurance coverage. For many parents, this is a financial burden. A burden that many families cannot take on. Kids go without treatment because their families simply cannot afford treatment. Because PANDAS is often undiagnosed or misdiagnosed, children often go years with no treatment or the wrong treatment. The longer the child does not get the proper treatment, the harder and more expensive PANDAS is to treat.

The first line of treatment for PANDAS is an antibiotic. That is a prescription most parents, pediatricians and insurance companies are familiar with. With insurance, this treatment will not be financially onerous for parents or for insurance companies. It is the children that have not had treatment for PANDAS for a long time that would need the services of a specialist. The costs for the specialist and treatment like IVIG are exponentially more expensive than a supply of antibiotics.

For doctors, insurance coverage would provide them with the proper codes to diagnose and treat PANDAS children. As the insurance codes are communicated to the medical community, more doctors and educational professionals will be taught about PANDAS which would allow for quicker and more accurate diagnosis and treatment.

My son Brandt got PANDAS when he was two years old. He was not diagnosed with PANDAS but with Apraxia and autistic symptoms. He had both Birth to Three services as well as was in Special Education preschool for two years when he turned three years old. These two years were very expensive for the town of Wilton to provide and were a great waste of time, resources and money. As a parent, I also paid for supplemental speech

therapy through Norwalk Hospital. We spend money on a child therapist as well. Here are all the professionals that missed diagnosing my son properly.

2 Pediatricians, School Psychologist, Special Education Teacher, Head of Special Education, Summer School Special Education Teacher (Extended Year Services – EYS), 3 Speech Therapists, Vision Therapist, Preschool Teacher, Birth To Three Evaluator, Birth To Three Speech Therapist & Occupational Therapists, Special Education Aides in Preschool, School Counselor, Classroom teacher.

He suffered and our family suffered through those years. We cannot get that time back. We cannot get back money we spent on useless services that could be put away for his higher education. He could not talk, could not be potty trained, had frequent temper tantrums, rigidity, ADHD, OCD and severe anxiety. It is heartbreaking how much of my son's childhood was lost. He finally got diagnosed properly at age 11. And that is just by chance that I met another PANDAS mom whose child had some of the same symptoms as my son. By mandating that insurance companies pay for PANDAS, this disease will be more well known and considered when a child comes in to a doctor's office or a special education evaluation with PANDAS symptoms.

PANDAS is caused by a strep infection. No one knows why some kids who get strep get PANDAS and some do not. The reality is that research to show causation may never be done. The medical community and parents will never allow children to be given Strep to see which ones develop PANDAS. However, we do have some historical evidence that shows us that an infection can cause mental illness. Years ago, Syphilis was shown to cause mental illness. Antibiotics were the cure and the mental illness symptoms went away for Syphilis patients. The same can be said for Urinary Tract Infections (UTIs) in the elderly. As the National Institute of Mental Health (NIMH) acknowledges and addresses PANDAS and has done research for validation, I believe that CT should continue the NIMH's great work and provide support for families. That means having the insurance companies cover PANDAS treatment just like they do for other illnesses caused by an infection.