

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 Barbara Rudini
Trumbull, CT
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Dear Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee,

My name is Barbara Rudini, I am a mother of a daughter who has PANDAS in support of SB 15. My daughter has been suffering from this horrific disorder since January 2013. In addition, our entire family has been suffering mentally, emotionally, physically and financially.

In order for a PANDAS child to get the proper treatment you must have a team of doctors which include neurologists, immunologists, psychologists, psychopharmacologists, behavioral optometrists and integrative health doctors just to name a few. There is unfortunately a minority of these doctors who treat children with PANDAS. There is a several month wait for an appointment and these doctors don't take insurance. (Note that my daughter's pediatrician is not on this list.) A diagnosis code does not exist for PANDAS, therefore, insurance companies can't be billed. As a result, parents like me are paying out of pocket for doctor appointments and treatments. Since January 2013, I have paid over \$50,000 for doctors and treatments. This figure does not include the cost of supplements, prescription medicines, travel, etc.

My daughter is unfortunately a severe case that has not responded with antibiotics alone. In addition to antibiotics, she receives monthly IVIG treatments. So far she has received 13 treatments and was doing well until a recent exposure to two siblings who contacted strep. She suffered a severe setback in December 2014 and now is waiting to get approved for a treatment called Plasma Exchange. I don't know yet if insurance will approve and pay for this procedure. She will eventually need inpatient cognitive behavioral therapy. I don't know yet if insurance will approve and pay for this procedure.

My daughter is fortunate that her father makes a decent salary which enables me for now to self pay for the doctors and treatments she needs and then fight our insurance company for which we receive only partial reimbursement. We will only be able to sustain this approach until the savings account is depleted. Many families

are not so lucky and as a result their children do not get the correct diagnosis and treatment.

My daughter also unfortunately suffers from Lyme Encephalopathy but this additional diagnosis has allowed her to be approved for treatments that are also the same treatments used to treat PANDAS. Without these treatments she would not stand a chance of getting well and would have eventually been institutionalized.

If insurance coverage existed for children with PANDAS:

- The amount of doctors who treat children with PANDAS would increase.
- A child experiencing an acute onset of symptoms, can actually get immediate proper treatment at a hospital or inpatient psychiatric hospital. Unfortunately, there is no hospital that exists that provides both mental (Cognitive Behavioral Therapy etc) and medical treatment for PANDAS patients (Antibiotics, IVIG, Plasma Exchange, Biofeedback therapies, Behavioral Optometrist therapies, etc) which are both needed in order for these children to get well.
- Children would not have to wait months or be forced to travel far to an appointment.
- Children would receive the correct diagnosis because there would be more doctors who treat PANDAS.
- Children would receive a diagnosis and treatments in a timely manner.
- Children's families would be able afford to get their child well and not end up hopelessly, needlessly institutionalized and on psych drugs.
- Families wouldn't be torn apart from the psychological effects and financial stress of this horrific disorder.

I urge you to give my daughter and all children with PANDAS a chance to get well. Even with insurance coverage, the road to recovery is brutal and not straight forward one for these children and their families. I have not included any details of the unbelievable devastating symptoms that continue to physically and mentally impair my daughter every day. If I shared them, the decision to provide health coverage for PANDAS would be a no brainer.