

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.

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Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee. My name is Gabriella True; I am Board Member of New England PANS/PANDAS Association and a mother of a ten-year-old boy with PANDAS in support of SB 15.

New England PANS/PANDAS Association holds educational conferences throughout New England in which nationally respected doctors give lectures on PANDAS/PANS. This Fall we held a conference in Connecticut in which roughly 200 parents with children who have PANS attended. Not one of those families has Health Insurance that covers PANDAS. The four doctors that gave lectures cannot write a prescription or charge for appointments and code them properly for PANDAS. Doctors can occasionally find a code that works under another diagnosis so that some appointments and prescriptions are covered but not always. As there is no PANDAS coverage, parents too often either have to struggle financially to pay out of pocket or simply can't treat their child properly so their condition only gets worse. But it does not have to be this way. If PANDAS was covered by insurance, doctor appointments and appropriate treatments, such as antibiotics and immune-modulating therapy, would be provided which would positively alter the course of PANDAS/PANS; the condition would be a treatable condition with periodic flares rather than a lifelong illness.

My family's story is not that different from the 200 families that attended the Connecticut conference. So, I want to share my family's story as an example. My son was diagnosed with Autism at age 3. We had been working with doctors and therapists for many years to help him with his Autism. But one day he was suddenly different; he presented with anxiety, obsessive thoughts, tics, aggression and cognitive regression. I fortunately knew about PANDAS and was able to suspect that this might be the cause of this change in him. I took him to a pediatrician who practices integrative medicine. After running several tests and going through the diagnostic criteria, my son was diagnosed with PANDAS at age 6. Many children with Autism who present with PANDAS are too often dismissed and told, "It's just the Autism." So we were lucky to find a doctor that did not ignore his symptoms. He was treated with one round of antibiotics and all behaviors except the tic disappeared but shortly after they came back. So he was treated with several rounds of antibiotics and then put on a prophylactic dosage for almost a year after that, his behaviors improved greatly, his tic disappeared and his cognitive skills increased. Labs indicated that he would improve greatly if he had IVIG but there was no way that insurance was going to cover it and there was no way I could ever afford it out

of pocket. None of the appointments were covered by insurance. The antibiotics were covered by insurance but coded under something other than PANDAS. However there was lots of fighting with the insurance over coverage of prophylactic antibiotics so several doses were missed. Fast forward two years and my son had another PANDAS flare. Once again I was faced with having to pay for a doctor out of pocket and getting antibiotics covered for something other than PANDAS and still wishing IVIG would be covered. At this point, if he has another flare I really don't know what I will be able to do because I simply can't afford any more out of pocket expenses. I fear for his future; I fear that his symptoms will present more often and more intensely. I fear not being able to have him treated. I have to choose putting food on the table and putting a roof over our heads over appropriate treatment. This is not an easy thing to swallow.

I don't have time to describe how devastating PANDAS is for my child and our family as a whole but I will give you a small snapshot. My child, due to his autism is non-verbal with minimal communication skills, low-functioning, can never be left alone not even for a minute, has zero concept of danger, and has low cognitive skills. So life is not easy to begin with but he is a loving, sweet-tempered boy who lights up a room, loves going to school, loves to go on walks and has lots of kids wanting to play with him. But when he is in a PANDAS flare that all changes. He is obsessive about eating, he has a couple tics, he will not sleep, he regresses in school and every goal falls below baseline, he loses almost all his ability to communicate, he pees everywhere, he bites himself and tries to bite other people, he screams and sobs for hours at a time, he walks around the room in a panic and none of his self-soothing techniques work, he hyperventilates and the list goes on. I don't want him to have another flare. I don't want the flares to no longer be flares but turn into a chronic condition. I don't want to know I can no longer afford to take him to the doctor to be treated.

In Massachusetts, legislators are voting on refilling a similar insurance related bill (Docket Number HD 343: An act relative to insurance coverage for PANDAS/PANS). Due to the success in the previous legislative session, a CHIA (Center for Health Information Analysis) review has been guaranteed; it is in progress but has yet to be published. As per the CHIA website (<http://chiamass.gov/mandated-benefit-reviews/>), *"CHIA evaluates the impact of health benefit mandate bills referred by Massachusetts legislative committees for review. These evaluations provide a medical efficacy analysis, an actuarial estimate of the effect that the proposed benefit mandate would have on the cost of health insurance, and an estimate of state responsibility to defray the cost of additional mandated benefits. CHIA produces reports on each reviewed benefit mandate proposal and performs a comprehensive retrospective review, typically every four years, of all mandates in effect."* If SB15 does come out of committee, I would hope that at the very least something similar could be done so as to better inform legislators such as yourselves and the community what the scope of insurance coverage for PANDAS/PANS would look like.