

**Testimony of Paula Penna of Manchester, CT**  
**Before the Insurance and Real Estate Committee**  
**On S.B. 37**  
**An Act Requiring Health Insurance Coverage for Pediatric Autoimmune**  
**Neuropsychiatric Disorder Associated with Streptococcal Infections**  
**February 18, 2016**

Senator Crisco, Representative Megna, Members of the Ins and Real Estate Committee, my name is Paula Penna and I'm here to speak in support of SB 37.

My daughter, Rachel Penna-Scheer, was diagnosed with PANDAS in late 2012, after having been sick since 2008. The lack of insurance coverage for her diagnosis and treatment resulted in years of her childhood and adolescence lost, which she cannot get back again. My daughter will be speaking more to her experience in her personal testimony before you today.

I'm aware that there are large groups such as the American Academy of Pediatrics speaking against mandatory insurance coverage for this horrible illness, and this absolutely petrifies me for all of the kids out there who suffer with this. However, a broad brush opposition is not even accurate - although they may say that institutions such as CCMC do not treat or acknowledge PANDAS illness, we have had the opposite experience. When my daughter had her tonsils and adenoid surgery, her ENT fully acknowledged her illness and worked with her Immunologist and Neurologist before and after surgery to protect her fragile immune system. The staff in the ENT surgical department understood the anxiety and OCD symptoms a PANDAS patient will have, and assigned a patient care hospitality volunteer to her so she was more comfortable.

The lack of insurance coverage and acknowledgment of her illness has caused major financial crisis in our family. My daughter started on psych meds, which interestingly enough the insurance companies have no problem paying for, but these meds made her worse. At one point she was on more than 6. The numerous doctors visits and emergency visits were highly expensive to my family, and I'm sure to the insurance companies. When she was diagnosed properly with PANDAS, a simple round of antibiotics had a 180 turn for the better for her health, and yet agencies opposing this bill state that antibiotics do not work.

Since my daughter could not get the proper treatment soon enough, due to the costs of treatment, her condition worsened, affecting her school work and performance. Her friendships, her development as a teen, and her role within our family and household. She was put into the special education program and had to have home tutors and online school for 9<sup>th</sup> and 10<sup>th</sup> grades, when she could attend (which was not often).

Friends and grants paid out of pocket for the IVIG she was finally able to get in March of 2014. Within 10 days, my daughter was "back" to her "normal" self again. We were fortunate that, in the year following, she had such an impressive outcome that she was able to attend school regularly, and she pulled her grade point up from a 2.7 to a 3.7. She graduated with honors, whereas prior to IVIG and proper treatment, we were told she may not graduate on time, if at all. She was a candidate for a lifetime of mental illness, and luckily we were able to avoid that. She's now on the honor society at University of Hartford and started her own health business.

The impact of this on our family, however, has been tremendous. In order to pay her outstanding medical bills, we lost our family home. I was unable to work at the business I had built up since before Rachel was born, and as a result, my income declined dramatically. We used up money put away for retirement, and money put away for college. If she had not had the IVIG, if she were able to go to college, I'm not sure how we would have paid for it. But, since she improved so dramatically at school, she earned numerous scholarships.

My daughter is not out of the dark - she needs at least another IVIG, but with a \$12k out of pocket price tag, we cannot afford it. Therefore, she is still on medications and still has flare ups from time to time, which interrupt her life. And, they interrupt my life and the life of her little sister, who is in the process of being screened for PANDAS, as well. With Round Two occurring, I cannot impress upon you just how important having insurance coverage is for families like mine - hard working, industrious, good parents, with great kids, but cannot afford to get these kids treated and healthy and also put food on the table.

Thank you.