

**Testimony of Rachel Penna-Scheer 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 Insurance and Real Estate Committee, my name is Rachel Penna-Scheer and I'm here to speak in support of SB 37.

I'm an 18 year old Freshman at the University of Hartford, and I have PANDAS. My sudden onset was at age 10, and no one knew what was wrong with me. I was a high achieving, happy kid that had a lot going for me, including music and playing the viola. But all of the sudden, I had so much OCD, anxiety, depression, fatigue, fear that I could barely attend school. This went up and down throughout middle school. But the time I was in 9<sup>th</sup> grade, I was suddenly very, very sick and had to go on special education, having been an honor student. I could no longer play my viola or keep up with any extra activities, because I could not even attend normal school. I lost a lot of friends, and I could not keep up with family relationships. My grades plummeted, and I was afraid that I might not be able to get through high school, or attend college. It was intensely scary, and no one could put a finger on what was really going on.

I was put on numerous psych meds and tried a variety of therapies but these only made me worse. I was giving up hope that I would ever be myself again. I had long periods that I could not even remember what I was doing, and what was happening. It was frightening for me, as well as my family, and especially my little sister. I was sick way more than I was healthy.

Finally I was diagnosed with PANDAS by a neurologist and also with an immunologist, from different medical practices. I was given the same exact diagnosis. My psychiatrist and therapist not only agreed with the diagnosis, but fully supported it. I was put on antibiotics to help my body get rid of the active infections, but my immune system was so depleted that I was flaring from anything and everything that I came into contact with. So, my doctors were able to get me off of all psych meds, and put on prophylactic antibiotics, and I remain on them to this day, unfortunately.

The treatment that all of my doctors wanted me to have – both the PANDAS specialists and my general pediatrician, therapist, and psychiatrist – was IVIG. However, my family could not afford IVIG treatment because insurance would not cover it. It feels like the insurance companies want to tell my doctor, who knows me best, what is the best medical protocol for me – and this is just not right. And, it negatively impacted my ability to heal. The lack of proper treatment has caused me

to have all sorts of secondary issues, because I'm not on the right medications to get my body fully healed. I want more than anything to have a normal life, to be fully healed, and to put this horribly illness aside for good. But, the insurance companies don't seem to agree.

We paid out of pocket for an IVIG in March of 2014. The results were tremendous and almost miraculous. I've never been as sick as I was before, again. In the year after IVIG, I was able to attend school as a normal student, get my work done at a level that reflects my intellectual abilities, and pursue my musical interests. I was able to have friendships, attend normal high school activities and events, and really focus on developing myself. I got my GPA up from a 2.7 before IVIG to a 3.7 after IVIG. Because of this, I was able to get into all 8 colleges I applied to, and received scholarship and grant offers from almost all of them. I chose the Hartt School and I'm very happy there. However, I have this constant worry in the back of my head (as does my family) that I could, at any time, have a huge flare up which will take all of this away from me.

Right now, I've just been denied IVIG again from my insurance company. We are appealing this for the 5<sup>th</sup> time, which is time consuming and stressful. In the meantime, I cannot get the proper medication and I still have flare ups and frequent illnesses. This isn't right. IVIG is covered for more than 80 illnesses, and even if certain agencies don't believe IVIG works for enough PANDAS patients, I know that it worked for me - this is undisputed.

I want to offer up the fact that my medical groups have acknowledged PANDAS, my school acknowledged PANDAS (in fact it is my diagnosis on my IEP and on my 504 plan for high school), and University of Hartford also acknowledges my illness as PANDAS and provides ADA accommodations for me as a safety net. It seems that the one group that does not acknowledge and want to help kids like me are the insurance companies, and I think this is a huge conflict of interest.

Thank you.