

Senate Bill 360 An Act Concerning P.A.N.D.A.S.

Paula J Penna
36 Leo J Lane
Manchester, CT 06042
(860) 707-0107

Thank you for hearing the PANDAS stories today. I look forward to the Informational Forum on March 1, 2013.

Since you've already heard testimony from others telling their stories of how their children and families have been affected by PANDAS, I'm going to just share with you some statistics:

My daughter is 15 ½ years old, a Sophomore in high school.

Her onset of PANDAS/PANS seems to have been 5 years ago, in the autumn of 5th grade. However, we believe it started much earlier, probably with less symptomatic manifestations, and it was missed then, as well.

Prior to her 5th grade year, my daughter was a normal, highly functioning child being considered for Gifted and Talented programs, attending scholarly programs at Manchester Community College, enjoying her school orchestra, playing viola and piano, loving her school and her friends, going to birthday parties, eating normally, participating in Yearbook Club, and going to art school and summer camps.

That all stopped in November of her 5th grade year. Her life (our lives) have never been the same; what you'll hear from ALL of the PANDAS parents and children's testimony is one common theme: suddenly their child was not the same, the family was held hostage by an invisible demon, and no one could help them.

Now for the statistics:

Physical Symptoms:

- 34 Upper Respiratory Infections
- 5 urinary tract infections
- 8 diagnosed strep infections
- 10+ bothersome mystery rashes
- 12 Incidents of joint pain, back pain, stiffness
- 20 "virus" diagnosis with no other explanation
- Numerous diagnosis of pharyngitis
- Numerous "croup" visits to the doctor and ER
- Reflux requiring medications 5 times per day
- Bedwetting/enuresis
- Chronic fatigue, exhaustion
- Trouble hearing, with no reason
- Dilated, fixated pupils
- Weight loss

Total: over 100 incidents of physical symptoms

Mental Health Symptoms (since 5th grade):

- Obsessive Compulsive Disorder
- General Anxiety Disorder/Severe Anxiety
- Irrational Fears
- Compulsivity
- Intrusive thoughts
- Rages
- School refusal
- Age regressive behaviors
- Nightmares
- Agoraphobia
- Rituals
- Trouble sleeping and waking up
- Depression
- Severe separation anxiety
- Cutting behaviors
- Suicidal thoughts

Total: 14+ mental health symptoms

Neurological/Cognitive Symptoms (since 5th grade)

- Cognitive decline; CMT scores plummeted in some areas at least two categories
- Handwriting/Art decline – went from drawing full detailed pictures and being a talented art school student, to drawing in stick figures
- Holding utensils and scissors backwards
- Trouble holding onto items
- Severe headaches
- Trouble concentrating
- Trouble focusing

Total: 7+ possible neurological/cognitive symptoms.

YET NO ONE COULD CONNECT THE DOTS.

Why?

They simply didn't have the information, never heard of PANDAS/PANS, or didn't keep up with the research well enough to see it as a credible, real illness.

With whom did we consult/seek out for help?

Medical Professionals

- 3 therapists
- 2 psychologists
- 2 psychiatrists
- 1 nurse practitioner
- 2 pediatricians

- 1 ENT
- 1 GYN
- 2 eye doctors
- 1 audiologist
- 1 rheumatologist
- 1 urologist
- 1 trichotillomania specialist
- 1 support group led by a psychologist
- 3 hospitals
- 2 mental health clinics
- 3 school psychologists
- 3 school social workers
- 3 school nurses

Total: 33 professionals and organizations, not including walk in clinics and urgent care facilities had seen my daughter and MISSED the diagnosis, misdiagnosing her wrongly and wasting time and money.

Psychotropic Drugs

- Prozac
- Celexa
- Abilify
- Ativan
- Clonopin
- Visteral

Total: 6 psychotropic drugs used in various dosages, protocols, and at various times of day. NOTHING helped. NOTHING worked. SHE WAS WORSE (common for PANDAS children due to receptors in the brain not responding well to these drugs, making them even more dangerous for pediatric use)

My daughter was finally diagnosed with PANS/PANDAS in November, 2012.

We were told about PANDAS at a mental health clinic in Philadelphia in February, 2012. It was missed by every other professional!

But that wasn't the end of the story.

What has happened since we heard about PANDAS?

- 8 months of finding the right doctors who knew what to look for and run tests
- 6 more months wait to get into one of only THREE immunologists in the USA that know how to diagnose and treat PANDAS/PANS
- 32 very telling blood tests revealed many answers to my daughter's illnesses, and many mysteries finally have been solved.

Where is she now?

- 1 pediatrician
- 1 therapist
- 1 pediatric neurologist
- 1 immunologist (April 2013 – made the appointment in Oct 2012 – long wait)

- 1 gyn
 - 1 antibiotic
 - 3 vitamins
 - 1 supplement
 - 1 pepcid
 - occasional advil for inflammation of the brain when flaring
 - 0 (**ZERO psychotropic drugs**)

Most importantly: ONE HAPPY GIRL! (and mom)

Economic Costs:

- Tens of thousands of dollars spent on the wrong diagnosis, the wrong treatments, and doctor visits with doctors who were ignorant to this disease.
- Inability to return to work due to child being “unstable” and in need of constant care
- Leaves of absence from work with no pay
- Loss of economic streams, due to the inability to work
- Mother having to drop her own health insurance in order to pay for child’s medical appointments (most of which were useless, as we had the wrong diagnosis)
- Possible bankruptcy

In conclusion:

Had it not been for the Philly clinic mentioning PANDAS, my daughter would have been in at least one psychiatric hospital, destined to a life long mental illness diagnosis. Many teens who have gone undiagnosed this long end up with drug addiction to psych drugs, troublesome and dangerous side effects from those drugs, co-morbidity and more complex emotional problems, school drop outs, etc. I believe my daughter has been saved from that, or at least we are on the road to recovery.

SHE IS NOT OUT OF THE DARK.

There is still a lot more work to be done on her behalf, including seeing the immunologist finally, genetic testing, mitochondrial testing. Right NOW it looks as if she does not need IVIG, but that can change in a moment.

**I'm asking you to please support and put your full weight behind the PANDAS bills.
Our children and our families are depending on CT to pave the way to
getting help for these kids in this state and across the nation.**

Thank you for your consideration.