



Feb. 21, 2020

Madam Chair, Mr. Vice Chair, Members of the Committee:

I write to provide written testimony about the experiences of our Maryland families impacted by Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Autoimmune Neuropsychiatric Syndrome (PANS). My wife and I have become involved with Maryland's statewide family support group, Maryland PANDAS Support. We first began this journey as parents whose three oldest children were diagnosed with PANDAS after a sudden onset of anxiety, sleep disturbances, eating disturbances and motor issues. Subsequently, two more of our children were diagnosed with post-infectious neurological complications of strep, and we now have five children who have seen our PANDAS specialist for one-time or ongoing treatment and evaluation. We are fortunate in that our children have healed and are healthy now as a result of early diagnosis and prompt treatment.

Having become involved along with my wife with our statewide support efforts, I would like to share with you some facts about the impact of PANDAS and PANS generally and the impact of these debilitating disorders among Maryland families.

As reported in a survey by the national PANDAS Network advocacy group, most families of children with PANDAS report seeing multiple medical providers in search of the correct diagnosis (PANDAS Network, 2018). Almost half of PANDAS/PANS patients reported one or more "incapacitating" episodes (Calaprice et al, 2017). Nursing researchers in the state of Michigan described the experience of PANDAS families seeking medical treatment with these three phrases: "Fear, frustration, not being heard" (McClelland et al., 2015). Stanford University researchers have found that the caregiver burden for parents of children with PANDAS or PANS exceeds the burden experienced by parents of pediatric cancer patients (Theinemann, 2016).

This year, Maryland PANDAS, our community support group for PANDAS and PANS families, surveyed statewide PANDAS families about their own experiences. Here is what we found from the families that responded:

- 60% of our Maryland PANDAS families have spent over \$10,000 out of pocket on their child's medical treatment since receiving a PANDAS or PANS diagnosis.
- 15% percent spent over \$50,000 since diagnosis.
- A quarter (over 25%) of our families report spending 40 hours or more per year--the equivalent of a full workweek--communicating with insurance.
- 70% reported that lack of insurance coverage had prevented them from providing doctor-recommended care to their child.
- 67% of our parents have taken unpaid time from work to address their child's medical needs.
- 70% of our parents have liquidated savings to pay for their child's treatment. More than 70% have delayed or foregone major purchases to pay for treatment, money that is not being spent at Maryland businesses as a result.

We asked our families to describe how lack of insurance coverage has affected them, and here is what some of them said.

- We have to travel to faraway states to have medical care for my children. We haven't been able to get treatments that are recommended because insurance won't pay.
- We've had to empty our savings and charge some on credit cards to see a specialist that would even take his illness seriously. We live paycheck to paycheck so having no savings is horrible.
- It's crippling. Our entire family is suffering from the incredible debt. We can't afford basic things. Even our water bill hasn't been paid in a year.
- My son was prescribed IVIG last summer but hasn't been able to get it, because 6 months later we are still battling insurance with no end in sight.
- Lack of immediate insurance coverage adds an additional stress on the already paper thin time we have as parents to take care of our children, do our jobs well, manage our household affairs, take care of our own health and well being.
- Two of my three children would not have the debilitating autoimmune conditions they have today if they had been able to receive the IVIG treatment protocol recommended by specialists that was denied by insurance. My children lost their childhood because insurance companies do not view PANDAS/PANS as autoimmune encephalitis, an acute, life-threatening illness.

- We delayed getting an appointment with the one specialist in our area who treats this disease for almost two years because she doesn't take insurance. That delay meant we didn't treat it early, when we had a better chance of recovering faster and with less invasive measures.
- We spent little time arguing with our insurer because we knew it was hopeless.
- We have been denied medical procedures that can bring my little girl back.
- We are both self-employed, and while we have the immediate finances to pay for treatments and appointments, our businesses are suffering as we have to spend time away from work.
- Without extra funds, all specialists do not accept any insurance. Therefore we have only kept our son in a bubble and have only treated to the bare minimum with antibiotics and steroids. Hoping for change.

Members of the committee, our families, here in Maryland, are suffering. Like that last parent respondent, we respectfully request your support for SB475 because we, too, are hoping for change for our children and our families.

Thank you for your time.

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