



PANDAS Resource Network™

Pediatric Autoimmune Neuro-psychiatric Disorder Associated with Streptococcus

Public Health Committee Public Hearing

Wednesday, February 27, 2013

Testimony in Support of

SB 360 AAC Pediatric Autoimmune Neuropsychiatric Disorder Associated With Streptococcal

Lynn Johnson, Executive Director

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Senator Gerratana, Representative Johnson, members of the Public Health Committee, my name is Lynn Johnson, Executive Director PANDAS Resource Network. I am submitting testimony on behalf of myself and Dr. Denis Bouboulis medical advisory board director for the Pandas Resource Network and an immunologist from Darien Connecticut and speak in support of SB 360. In the last three years in practice I have treated more than 2,000 PANDAS/PANS patients from across the United States and literally from around the world.

In very simple terms, antibodies created to fight an inciting strep infection and/or other infections become misdirected against a small area of the brain known as the basal ganglia. This autoimmune reaction results in a host of neuropsychiatric symptoms that are both difficult to endure and difficult to manage. There are also case reports in the medical literature of infections besides strep, such as mycoplasma pneumonia, Lyme disease and common childhood viruses such as Epstein Bar Virus (mononucleosis) and parvo (Fifth's disease) that also can cause an autoimmune response. PANS is a newer term used to describe the (larger enable to encompass) class of acute-onset obsessive compulsive disorder (OCD) cases. PANS stands for Pediatric Acute-onset Neuropsychiatric Syndrome and includes all cases of abrupt onset OCD, triggered by infections, not just those associated with streptococcal infections (Swedo et al., 2012).

The symptoms of PANDAS/PANS include: (Episodic Presentation)

Acute Onset	Obsessive Compulsive Disorder	Motor/Vocal Tics
Choreiform Movements	Separation Anxiety	Hyperactivity/Impulsivity
Nightmares	Personality Changes	Rage episodes
Psychotic Symptoms	Oppositional Behaviors	Urinary Frequency
Learning disabilities		

THE DEVASTATING EFFECTS OF PANDAS/PANS ON THE FAMILY:

Frequently PANDAS/PANS has an extremely sudden onset. One day these children are perfectly normal, and the next day they may suddenly be unable to get out of bed without performing innumerable rituals. Or perhaps they cannot bear to hear laughter, erupting in explosive rage if anyone does laugh; or they cannot go through a doorway without touching the threshold; or they cannot bear the feeling of most clothes. Math savants suddenly may no longer be able to do simple arithmetic and handwriting may become illegible. Formerly, highly independent children can no longer stand to be separated from their parents and refuse to go to school, raging at all attempts to deposit them there. The change can be very extreme; and quite often immediately fragments entire families.

PANDAS IS OFTEN MIS-DOAGNOSED OR UNDIAGNOSED:

The first encounter parents have with their pediatrician is highly unsatisfying and frustrating for the parent. In many cases, the pediatrician is completely mystified and passes the child on to a psychiatrist, or if tics are

prominent, a neurologist. A new patient appointment with one of these pediatric specialists can take weeks or months. In the meantime, the family has to rearrange the entire household to accommodate all the bizarre behaviors their child is presenting. Some parents may believe—and outsiders are likely to judge—this has all come about from a lack of discipline. They attempt to bring the behaviors under control through discipline, which serves only to escalate the anxiety, that the child is already experiencing. Parents find themselves distraught with no place to turn; in a land they did not know existed with neither map nor compass. After a long awaited appointment with the neurologist or psychiatrist, parents are told their child has obsessive-compulsive disorder (OCD) and needs an SSRI (antidepressant) or has Tourette's syndrome and placed on psychotropic drugs. Frequently they are also told their child has "late onset autism," a medically dubious diagnosis for which little treatment is available. PANDAS children are often very sensitive to the psychotropic drugs typically prescribed and frequently experience a worsening of symptoms while undergoing this treatment.

THE IMPORTANCE OF SUPPORTING PANDAS/PANS ADVOCAY GROUPS:

Feeling failed by the medical profession and desperate for answers, parents turn to the internet, researching for hours late at night after their insomniac child has finally fallen asleep. Some fortunate parents will run across references to PANDAS on advocacy sites and quickly learn they are not alone and that their child should be tested for strep and other infections like mycoplasma pneumonia, Lyme disease and a host of other possible infection triggers. They will learn that their child may actually need antibiotics to treat an infection instead of psychotropic drugs. Primary physicians rarely associate Neuropsychiatric symptoms with a infection driven autoimmune neuropsychiatric syndrome regardless if the parents find reference to such a phenomenon exists.

THE PHYSICAL, EMOTIONAL AND FINANCIAL IMPACT ON THE FAMILY:

Parents become confused and angry; their household has been thrown into total chaos by their child's behaviors, and the doctors they have trusted for years refuse to administer common blood tests or give a prescription for simple antibiotics that could bring a modicum of relief and perhaps even possibly cure their child. They then look into finding a doctor who understands this disease entity and are able to offer definitive, curative treatment. As there are only a scant few physicians that have experience in this disease entity, it makes access to medical care for these families difficult. In certain circumstances, they may require immune modulation therapy with intravenous immunoglobulin (IVIG) in addition to antibiotic therapy. Many are also left wondering if they can possibly come up with the thousands of dollars for IVIG, which insurance currently rarely covers for PANDAS because they believe the scant research on IVIG for PANDAS/PANS is insufficient to support this treatment option.

THE IMPACT OF PANDAS/PANS ON THE CHILD:

When PANDAS/PANS strikes, children themselves are deeply confused about what is happening to them. They no longer feel in control of their minds or bodies. They are afraid to attend school because of their severely debilitating neuropsychiatric symptoms or disturbingly violent motor or vocal tics. Those who are able to make it to school may be failing math and marked off for illegible writing, undermining their self-confidence. Children with PANDAS/PANS find it hard to concentrate on studies as their mental rituals or tics take over. Former honors student may find themselves in special education classes. Formerly socially accepted children may now they find their friends no longer wish to associate with them. They may become bullying victims. Trying to spare their child the frustration and failure of school and the possibly hostile school environment, parents fight for at home-tutoring or funding for a private school or, if they are able to have one parent leave the work force, they simply give up on the educational system and home school instead. Children who have gone undiagnosed and untreated for a prolonged period may find themselves admitted to a psychiatric ward, perhaps multiple times. As they enter their teens, they may find themselves in trouble with law and end up in the juvenile detention system. Or they may turn to drugs and shuttle in and out of rehabs, which are ill equipped to deal with the underlying causes of the symptoms of the PANDAS child, who has turned to illicit substances as a way of self-medicating and coping. Tragically, some of these children will die from an overdose or other drug-related complications.

THE HIGH COST OF MISDIAGNOSING PANDAS/PANS:

While the human costs of missed diagnoses and insufficient treatment are enormous, so are the dollar costs. Many children, promptly identified as having PANDAS, could have their symptoms resolved fairly easily with a course of inexpensive antibiotics for a three to six week period. Others may require the boost of a steroid burst or perhaps an antiviral, as well as a prophylactic antibiotic regime, all low cost treatments. These medications are far less costly than the psychotropic drugs that are frequently given to treat the symptoms but which nonetheless are usually ineffective. There are the more severe cases, which may require sinus surgery or a tonsillectomy to eradicate chronic bacterial infections. Other children may be found to be susceptible to PANDAS-triggering infections because of a deficient immune system and require IVIG, an expensive treatment option. Even after proper treatment with medications, some children may require a round of exposure and response prevention therapy (ERP) to deal with residual OCD symptoms. The costs associated with these more intensive treatments still are far less than those associated with just one stay at an acute psychiatric ward or a stint in juvenile detention or drug rehab facilities, or the cumulative costs of special education, home tutoring, or publicly funded private schooling.

MORE RESEARCH INTO PANDAS/PANS IS NEEDED AND AWARENESS NEEDS TO BE ONGOING:

The doctors and other practitioners who have stalwartly treated PANDAS children are all too familiar with the devastation this disorder brings to children and their families. At least one experience PANDAS/PANS physician, has noted that PANDAS/PANS families often experience symptoms akin to those seen in post-traumatic stress disorder. These practitioners, work long hours to deal with these children other doctors have “abandoned” by failing to recognize this disorder or treat it correctly. Even though they devote inordinate amounts of time fighting for insurance coverage for their patients, they often fail to get treatment covered. Insurance companies repeatedly deny coverage for immune modulating therapy based on the paucity of clinical studies showing the benefit of IVIG for treating PANDAS/PANS.

The lack of ongoing research limits the ability of these practitioners to serve those children most in need of their help. They understand that much of the suffering the disorder brings is unnecessary; if every physician looked for evidence of infection in children who suddenly present with OCD, tics, or emotional lability and treated them promptly with proper antibiotic, the anguish of this disorder could be eliminated. Proper treatments would obviate the need for mis-directed referrals to psychiatrists and the prescribing of dangerous psychotropic medications. Therefore educating the school system and physicians to consider PANDAS as a potential cause of neuropsychiatric symptoms is imperative to facilitate proper referral practices and definitive treatment for this disorder.

To begin mitigating all the human and financial costs of PANDAS/PANS several steps should be taken.

Recommendations:

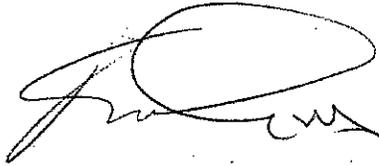
It is imperative that research and awareness into this disorder take place simultaneously.

- Development of clinical awareness programs for physicians and public awareness programs for educators and community. (i.e: sponsored grand rounds presentations and/or conferences)
- Development of effective epidemiological studies within the state of Connecticut.
- Development outcome studies of clinical intervention strategies including all treatment options for children meeting current PANDAS/PANS classification of post-infection sudden onset symptoms.
- Development of clinical effectiveness studies of Cognitive Behavior Therapy and SSRI therapy in particular.

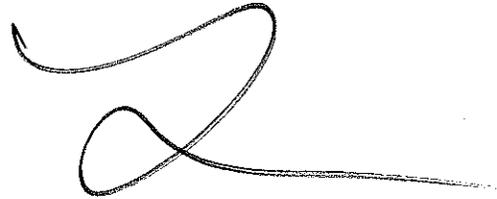
- Development of clinical effectiveness of antibiotic alone vs. IVIG therapy vs. a combined approach therapy
- Establishment of a State of Connecticut liaison with the NIMH and CDC to help develop science-based guidelines for identification and treatment.
- Establishment of “blue ribbon” panels of experts from within the clinical and basic research communities, internationally, to help draft practice guidelines for the State of Connecticut.
- Development of liaison between government, community, clinical stakeholders, and the insurance industry in developing practice guidelines for identification and treatment. These can include representative members of panels from other States and countries (e.g. Canada) that have already developed effective practice guidelines.
- Design and develop patient databases to connect patient populations with researchers, clinicians and scientists.

By implementing these recommendations, over time, no child with an infection will be misdiagnosed with a psychiatric disorder. Mental health costs for children and adolescents will diminish significantly as will the associated costs to the community, even as many more children experience complete relief from their neuropsychiatric symptoms.

Sincerely,



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Director – Medical Advisory Board



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