

February 17, 2016

**S.B. No. 37 (RAISED) AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL INFECTIONS.**

The American Academy of Pediatrics does not endorse treatment of PANDAS and does not consider evidence for benefit of antibiotics or IVIG to be sufficiently compelling to recommend such treatment. Antibiotic use contributes to antibiotic resistance in the community and IVIG is very expensive and is associated with serious side effects, such as serious allergic reaction, irritation of the lining around your brain, kidney problems, blood clots, liver problems or a blood problem, serious heart or lung problems, or infection.

While there are individual parents who feel they have been helped by these treatments there is no information about the children who have not improved. The backbone of scientific evaluation for new therapies are double-blind randomized controlled trials. Trials of sufficient size have not shown significant benefit for PANDAS as yet.

The national leaders in streptococcal disease have not included PANDAS in reviews and recommendations for treatment of streptococcal illnesses. Neither the Pediatric Infectious Diseases Sections at Yale nor at Connecticut Children's Hospital are willing to make the diagnosis of PANDAS nor will they treat children labeled with this disorder.

*The Red Book* which is the most authoritative source for treatment recommendations for Pediatric infectious diseases does not endorse this diagnosis nor recommend treatment for PANDAS as an infectious disease. (Attached, please find the actual position from the *Red Book*.)

Neither the AAP section on ID, the ID committee of AAP, The Red Book nor recent IDSA and American Heart Association Guidelines have recommendations for diagnosing or treating PANDAS. The concept of PANDAS being caused by other organisms (now called PANS), treatment with antibiotics, or use of IVIG are used by physicians who practice outside of the mainstream and are not part of mainstream and were endorsed by practitioners with major conflicts of interest. PANDAS treatment is not demonstrated to be better than placebo. Some doctors diagnose PANS/PANDAS by used of what are called the Cunningham laboratory tests. This has not been demonstrated outside of the single lab that has major conflict of interest.

**In sum, support for PANDAS treatment by the Connecticut legislature would at this time be support for a diagnosis that is outside the mainstream of US pediatric practice.**

**We do not support mandating insurance coverage for the treatment of PANDAS.**

A Statement from the CT Chapter of the American Academy of Pediatrics on:

Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcus

From *Pediatrics*, Vol. 123 No. 1 January 1, 2009 , pp. e171 -e173 (the official journal of The American Academy of Pediatrics) the conclusion of an article titled "Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcus: Comparison of Diagnosis and Treatment in the Community and at a Specialty Clinic" was:

"Our results support our hypothesis that pediatric autoimmune neuropsychiatric disorders associated with streptococcus are frequently diagnosed in the community without the application of all working diagnostic criteria. This phenomenon has resulted in unwarranted use of antibiotic treatment for tics/obsessive-compulsive disorder without evidence of laboratory infection."

Unnecessary use of antibiotics can result in the "heightened medical risks associated with unwarranted antibiotic treatment, including diarrhea, pseudomembranous colitis, yeast infections, and, most importantly, increased rates of antibiotic resistance, a major public health concern. To this effect, the intent of our study was not to criticize community physicians but, rather, to emphasize the need for strict adherence to diagnostic criteria and appropriate management of treatment (eg, evidence based if available), abiding to "*primum non nocere*" (first do no harm), particularly when treating patients such complex conditions."

The policy from the AAP's *Red Book*\* is:

"An association between GAS (group A streptococcal) infection and sudden onset of obsessive-compulsive or tic disorders—pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS)—has been proposed but is unproven."

The CT Chapter of the American Academy of Pediatrics believes that the CT State Legislature is not justified in its proposed language until there is more information available.

\*The Red Book is written by the Committee on Infectious Disease (COID) of the American Academy of Pediatrics and that committee is responsible for developing and revising guidelines of the AAP for control of infectious disease in children.