

2013-K1357

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim October 9, 2014, as PANDAS/PANS (Pediatric Acute-onset Neuropsychiatric Disorders) Awareness Day in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official days that are set aside to increase awareness of serious illnesses that affect the lives of citizens of New York State; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, this Legislative Body is justly proud to memorialize Governor Andrew M. Cuomo to proclaim October 9, 2014, as PANDAS/PANS (Pediatric Acute-onset Neuropsychiatric Disorders) Awareness Day in the State of New York; and

WHEREAS, PANDAS, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections, is the sudden onset of OCD often displayed as severe anxiety and emotional disturbances plus two or more of the following symptoms: tics or other abnormal movements; severe separation anxiety, generalized anxiety; irritability, emotional lability, aggression, personality changes; ADHD, inability to concentrate; sensory sensitivities; deterioration in learning abilities and school performance; developmental and age regression (including deterioration in handwriting); sleep and nighttime difficulties; and/or urinary frequency or daytime/nighttime secondary enuresis; and

WHEREAS, The onset of symptoms is corresponding to an infection, usually strep; PANDAS children may have moderate to dramatic improvement with antibiotics within one week of treatment, however, further interventions may be needed; and

WHEREAS, How to stop the entire syndrome is still debated, but many parents and doctors report prolonged antibiotics (two months to one year) and/or IVIG (intravenous immunoglobulin) treatment or plasmaphore-

sis; and

WHEREAS, PITAND, Pediatric Infection-Triggered Autoimmune Neuropsychiatric Disorders, is similar to PANDAS in terms of presentation; however, it consists of a broader list of possible triggers, not only strep; triggers may include Mycoplasma Pneumonia, Mono, Lyme, viruses, and more; and

WHEREAS, PANS, Pediatric Acute-onset Neuropsychiatric Syndromes, is a new classification introduced in the 2012 research paper FROM RESEARCH SUBGROUP TO CLINICAL SYNDROME: MODIFYING THE PANDAS CRITERIA TO DESCRIBE PANS; and

WHEREAS, PANS is broader than PANDAS and PITAND as it includes not only disorders associated with a preceding infection, but also acute-onset non-infectious triggers, such as environmental and metabolic; no treatment plan for this syndrome has been defined at this time, but treatment plans similar to PANDAS should be attempted; and

WHEREAS, The three criteria for PANS are: abrupt, dramatic onset of obsessive-compulsive disorder or severely restricted food intake; concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset; and symptoms are not better explained by a known neurological or medical disorder; and

WHEREAS, A conservative estimate of the prevalence of PANDAS/PANS cases in the United States alone is 162,000; however, the true prevalence of PANDAS/PANS is not known; and

WHEREAS, PANDAS/PANS is likely as common as illnesses like Pediatric Cancer, Pediatric Diabetes, and ALS, and can seriously affect the healthy outcome of a child's life; and

WHEREAS, Approximately 500,000 children are diagnosed with OCD in the United States; and roughly 148,000 children are diagnosed with Tourette Syndrome in the United States; and

WHEREAS, Founded in 2009, PANDAS Network.org is a non-profit organization that raises awareness of PANDAS onset and course of illness by

providing: an ongoing database of new PANDAS cases (over 1,000 tracked thus far); parent referrals to support groups and physicians; a conduit for new researchers to navigate collaborations and new treating physicians to find information; online newsletters to parents and physicians about latest research; and information that is medically accurate and reviewed by our Scientific Advisory Board; and

WHEREAS, It is imperative that there be greater public awareness of this serious health issue, and more must be done to increase activity at the local, State and national levels; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim October 9, 2014, as PANDAS/PANS (Pediatric Acute-onset Neuropsychiatric Disorders) Awareness Day in the State of New York; and be it further

RESOLVED, That copies of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York, and PANDAS Network.org.