

## 2013-K716

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to declare December 4, 2013, as Pallister-Killian Syndrome 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 health-related issues 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 declare December 4, 2013, as Pallister-Killian Syndrome Day in the State of New York; and

WHEREAS, Pallister-Killian Syndrome (PKS) is an extremely rare chromosomal disorder occurring for no apparent reason; it is clinically a mosaic tetrasomy of 12p which means people with PKS have 4 copies of the short arm of chromosome 12 rather than the normal 2 in some, but not all, of their cells; and

WHEREAS, Selecting December 4th as the day of recognition for PKS is derived from chromosome 12, 4 copies of the short arm; and

WHEREAS, Children born with this syndrome suffer from low muscle tone, global developmental delay, seizures beginning in infancy, lack of speech development, and intellectual disability; they may also have hearing and vision loss; and

WHEREAS, There are fewer than 300 known cases of PKS worldwide; however, medical experts believe the actual incidence is higher and that there remain undiagnosed cases; and

WHEREAS, Jay Wood is a kindergarten student at Peru Central School who has been diagnosed with PKS; Jay works extremely hard every day to complete tasks other children his age take for granted; he can now sit momentarily unassisted, is learning to feed himself and greets his

classmates with a "hi"; he loves life, has a wonderful laugh, eats anything chocolate and is one of SUNY Plattsburgh's biggest hockey fans; most of all Jay is a loving son and brother to his sister, Emma; and

WHEREAS, Research, education and understanding of PKS will aid in the early diagnosis of children and will benefit the families and individuals facing the many challenges affected by the disease; 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 declare December 4, 2013, as Pallister-Killian Syndrome Day in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York.