

JOINT RESOLUTION NO. 4

A JOINT RESOLUTION designating the third Tuesday in October of each year as “Rett Syndrome Awareness Day.”

WHEREAS, Rett Syndrome, or RS, is a neurological disorder that is seen almost exclusively in girls, and is one of only four diseases that occur only in females; and

WHEREAS, RS was first described by Dr. Andreas Rett in 1964 and received worldwide recognition after the first English language publication by Dr. Bengt Hagberg in 1983; and

WHEREAS, RS is attributable to a defective regulatory MECP2 gene found on the X chromosome, and becomes apparent from six to 18 months of age; and

WHEREAS, RS leads to physical handicaps, delays in intellectual development, and impaired expressive language, all of a severe nature, and also causes loss of functional hand use and commonly features abnormal hand movements, epileptic seizures, and curvature of the spine, with additional problems that may include breathing irregularities and teeth grinding; and

WHEREAS, The most severe handicap that a child with RS has is apraxia, which means that the child has the will to move but is unable to carry through with that movement; and

WHEREAS, There is currently no known treatment or cure for RS; and

WHEREAS, There are likely between 8,000 and 10,000 young girls with RS who are undiagnosed, or are misdiagnosed as having autism, cerebral palsy or a non-specified developmental delay, since many health care professionals are not familiar with RS; and

WHEREAS, Most girls with RS need assistance with all their activities of daily living, including feeding, dressing, and toileting; some 25% of all girls with RS may never walk at all, and about half of those who do walk will lose the ability at some point; and

WHEREAS, The families of those girls with RS who are struggling to cope with the ravages of this disease and bear the physical, financial and emotional burdens of caring for their loved ones merit recognition for their efforts; and the medical community and the public at large need to be made aware of the symptoms and impact of RS on those subjected to its cruel and unrelenting force; now, therefore,

BE IT RESOLVED *by the Senate and General Assembly of the State of New Jersey:*

C.36:2-90 “Rett Syndrome Awareness Day,” third Tuesday in October; designated.

1. The third Tuesday in October of each year is designated as "Rett Syndrome Awareness Day" in the State of New Jersey.

2. The Governor is hereby requested to issue a proclamation calling upon public officials and the citizens of this State to observe this day with appropriate activities and programs.

3. This joint resolution shall take effect immediately.

P.L. 2007, Joint Resolution No. 4

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Approved January 29, 2007.