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THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 1032 Session of 2018

INTRODUCED BY KINSEY, HILL-EVANS, READSHAW, BURNS, ROTHMAN, DONATUCCI, DiGIROLAMO, BIZZARRO, HENNESSEY, MURT, LONGIETTI, NEILSON, SAINATO, RYAN, BOBACK, STAATS, DRISCOLL, KIRKLAND, B. O'NEILL, SCHLOSSBERG, BARRAR, MILLARD, PHILLIPS-HILL AND CALTAGIRONE, SEPTEMBER 5, 2018

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, SEPTEMBER 5, 2018

A RESOLUTION

Designating the month of October 2018 as "Rett Syndrome Awareness Month" in Pennsylvania.

WHEREAS, Rett syndrome was first identified in the 1960s by Austrian physician Dr. Andreas Rett; and

WHEREAS, Rett syndrome is a rare, genetic neurological disorder occurring almost exclusively in girls; and

WHEREAS, It is estimated that Rett syndrome occurs in approximately one in every 10,000 to 15,000 female births worldwide and affects an estimated 15,000 girls and women in the United States and 350,000 girls and women globally; and

WHEREAS, A child with Rett syndrome suffers from developmental regression after 6 to 18 months of normal development following birth, including severe impairments that affect the child's ability to speak, walk, eat and breathe; and

WHEREAS, Rett syndrome may also be characterized by a child's inability to perform motor functions, the inability to

communicate, seizures, scoliosis, sleep disorders, microcephaly, irregular breathing and the loss of functional use of hands which results in the development of compulsive hand movements; and

WHEREAS, Researchers have determined that the primary cause of Rett syndrome is linked to a random mutation in the MECP2 gene; and

WHEREAS, Researchers have developed a genetic test to complement a clinical diagnosis of Rett syndrome; and

WHEREAS, Although less than 1% of recorded cases of Rett syndrome are due to genetic inheritance of the MECP2 mutation, some families of individuals with Rett syndrome have been found to have other female family members with an MECP2 mutation who have not shown any clinical symptoms; and

WHEREAS, Prenatal testing is available for families with a daughter affected by Rett syndrome; and

WHEREAS, The risk of a family having a second child with Rett syndrome is less than 1%; and

WHEREAS, Early developmental intervention is crucial for those who have been diagnosed with Rett syndrome, as children can receive the necessary therapy and services to help them reach their full potential; and

WHEREAS, Rett syndrome is often undiagnosed or misdiagnosed due to sharing similar symptoms with autism, cerebral palsy and nonspecific developmental delay; and

WHEREAS, Rett syndrome can present in an array of disabilities which result in complex and varied treatment options for those individuals who are diagnosed with Rett syndrome and often require the coordinated efforts of a team of specialists; and

WHEREAS, Although there is no cure for Rett syndrome, well-designed treatment plans may slow the loss of abilities, improve or preserve movement and encourage communication and social contact; and

WHEREAS, Great strides in understanding the cause of Rett syndrome have been made in recent years allowing researchers to develop better methods of diagnosis and new therapies to manage specific symptoms and to identify biochemical manipulations that may prevent the progression of the disorder; therefore be it

RESOLVED, That the House of Representatives designate the month of October 2018 as "Rett Syndrome Awareness Month" in Pennsylvania; and be it further

RESOLVED, That the House of Representatives recognize "Rett Syndrome Awareness Month" to raise awareness, acknowledge families and individuals living with Rett syndrome and to recognize the importance of finding a cure.