
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 1029 Session of
2020

INTRODUCED BY KINSEY AND MADDEN, SEPTEMBER 29, 2020

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
SEPTEMBER 29, 2020

A RESOLUTION

1 Recognizing the month of October 2020 as "Rett Syndrome
2 Awareness Month" in Pennsylvania.

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

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

7 WHEREAS, It is estimated that Rett syndrome occurs in
8 approximately 1 in every 10,000 to 15,000 female births
9 worldwide and affects an estimated 15,000 girls and women in the
10 United States and 350,000 girls and women globally; and

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

15 WHEREAS, Rett syndrome may also be characterized by a child's
16 inability to perform motor functions, the inability to
17 communicate, seizures, scoliosis, sleep disorders, microcephaly,
18 irregular breathing and the loss of functional use of hands

1 which results in the development of compulsive hand movements;
2 and

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

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

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

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

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

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

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

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

29 WHEREAS, Although there is no cure for Rett syndrome, well-
30 designed treatment plans may slow the loss of abilities, improve

1 or preserve movement and encourage communication and social
2 contact; and

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

8 RESOLVED, That the House of Representatives recognize the
9 month of October 2020 as "Rett Syndrome Awareness Month" in
10 Pennsylvania; and be it further

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