
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 498 Session of
2019

INTRODUCED BY KINSEY, MADDEN, BIZZARRO, SAINATO, BURNS,
LONGIETTI, HILL-EVANS, McCLINTON, ROTHMAN, SONNEY, KORTZ,
DIGIROLAMO, BOBACK, FREEMAN, MILLARD, THOMAS, HARKINS,
KOSIEROWSKI, KIM, READSHAW AND MURT, SEPTEMBER 18, 2019

REFERRED TO COMMITTEE ON HEALTH, SEPTEMBER 18, 2019

A RESOLUTION

1 Designating the month of October 2019 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 one 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,

1 irregular breathing and the loss of functional use of hands
2 which results in the development of compulsive hand movements;
3 and

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

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

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

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

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

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

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

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

30 WHEREAS, Although there is no cure for Rett syndrome, well-

1 designed treatment plans may slow the loss of abilities, improve
2 or preserve movement and encourage communication and social
3 contact; and

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

9 RESOLVED, That the House of Representatives designate the
10 month of October 2019 as "Rett Syndrome Awareness Month" in
11 Pennsylvania; and be it further

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