
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 177 Session of
2023

INTRODUCED BY KINSEY, HILL-EVANS, GREEN AND NEILSON,
JULY 18, 2023

REFERRED TO COMMITTEE ON HEALTH, JULY 18, 2023

A RESOLUTION

1 Recognizing the month of October 2023 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 female births; and

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

13 WHEREAS, Rett syndrome may also be characterized by a child's
14 inability to perform motor functions, the inability to
15 communicate, seizures, scoliosis, sleep disorders, microcephaly,
16 irregular breathing and the loss of functional use of hands
17 which results in the development of compulsive hand movements;
18 and

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

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

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

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

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

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

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

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

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

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

6 RESOLVED, That the House of Representatives recognize the
7 month of October 2023 as "Rett Syndrome Awareness Month" in
8 Pennsylvania; and be it further

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