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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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HOUSE RESOLUTION

No. 464 Session of  
2024

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INTRODUCED BY MEHAFFIE, BARTON, BENNINGHOFF, CABELL, COOK,  
CUTLER, DAVANZO, DIAMOND, FLICK, JOZWIAK, KAUFFMAN, KINSEY,  
KRUPA, KUTZ, LABS, M. MACKENZIE, MALAGARI, MARCELL, MERCURI,  
MOUL, MUSTELLO, NEILSON, E. NELSON, SCHEUREN, SCHLOSSBERG,  
STEHR, STRUZZI, TOPPER AND WATRO, JUNE 4, 2024

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REFERRED TO COMMITTEE ON HEALTH, JUNE 4, 2024

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A RESOLUTION

1 Designating the month of July 2024 as "MECP2 Duplication  
2 Syndrome Awareness Month" in Pennsylvania.

3 WHEREAS, MECP2 duplication syndrome is usually caused by  
4 duplication of DNA on the Xq28 region of the chromosomes; and

5 WHEREAS, Despite MECP2 duplication syndrome being a  
6 neurodevelopmental disorder, it causes multisystemic health  
7 problems, such as severe gastrointestinal symptoms, frequent  
8 respiratory infections and treatment-resistant seizures; and

9 WHEREAS, MECP2 duplication syndrome is a condition that  
10 occurs almost exclusively in boys; and

11 WHEREAS, Some boys have large duplications which include many  
12 other genes, and the full extent of phenotypes due to  
13 duplication of other genes is not completely understood at this  
14 time; and

15 WHEREAS, Recent studies have shown a link between MECP2  
16 duplication syndrome and autism, and most boys with this

1 syndrome do have distinct features of autism; and

2 WHEREAS, Patients with MECP2 duplication syndrome are highly  
3 responsive to proper stimulation such as schooling, exercise,  
4 music, age-appropriate social interactions and related  
5 activities; and

6 WHEREAS, MECP2 duplication syndrome can cause significant  
7 anxiety, depression and emotional exhaustion on caregivers; and

8 WHEREAS, MECP2 duplication syndrome was not formally  
9 recognized until 2005; and

10 WHEREAS, MECP2 duplication syndrome is most commonly  
11 inherited in an X-linked manner, with affected males most  
12 commonly inheriting the MECP2 duplication from the carrier  
13 mother, but spontaneous duplications have been reported; and

14 WHEREAS, To date, no cases of a father transmitting the  
15 duplication have been reported; and

16 WHEREAS, MECP2 duplication syndrome research, which has shown  
17 that symptoms of the disorder can be reversed in mice using a  
18 small antisense oligonucleotide, gives hope for the future  
19 development of effective treatments for humans with this  
20 disorder; and

21 WHEREAS, Clinical readiness studies have been done to  
22 identify ways to monitor response to therapy and ensure safety  
23 as a preparation for future clinical trials; and

24 WHEREAS, Natural history studies are ongoing to define the  
25 natural course of MECP2 duplication syndrome over the span of 12  
26 to 18 months to prepare for the start of clinical trials;  
27 therefore be it

28 RESOLVED, That the House of Representatives designate the  
29 month of July 2024 as "MECP2 Duplication Syndrome Awareness  
30 Month" in Pennsylvania.