

1 INTERIM RESOLUTION 2023-006

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3 REQUESTING THAT THE ARKANSAS LEGISLATIVE COUNCIL PROCLAIM OCTOBER  
4 2024 AS RETT SYNDROME AWARENESS MONTH.

5  
6 WHEREAS, Rett syndrome is a rare genetic neurological disorder that  
7 occurs almost exclusively in females and rarely in males; and

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9 WHEREAS, symptoms of Rett syndrome usually do not appear until six (6)  
10 to eighteen (18) months after birth; and

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12 WHEREAS, a period of regression follows in which acquired motor skills  
13 are lost, leading to lifelong impairments, including loss of speech,  
14 seizures, scoliosis, and irregular breathing patterns, with the hallmark sign  
15 of Rett syndrome being near-constant repetitive hand movements while awake;  
16 and

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18 WHEREAS, those diagnosed with Rett syndrome require maximum assistance  
19 with daily living activities; and

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21 WHEREAS, Rett syndrome is not degenerative, and biomedical research in  
22 mice suggests that neurological symptoms may be reversed even after decades  
23 of severe symptoms; and

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25 WHEREAS, with the discovery of the gene mutation that causes Rett  
26 syndrome in 1999, research in the laboratory that proved the theory of  
27 reversibility of the a mouse model of the syndrome in 2007, the discovery of  
28 breakthrough testing using in vitro models in 2010, and the launch of  
29 multiple disease-modifying human clinical trials recently, an unprecedented  
30 and historic moment in time has been reached when everything possible must be  
31 done to fund the truly life-changing research of Rett syndrome; and

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33 WHEREAS, in March 2023, the first treatment for Rett syndrome was  
34 approved by the United States Food and Drug Administration and was able to be  
35 used by patients; and

1           WHEREAS, currently, gene therapy trials are happening in the United  
2 States and Canada that are showing great promise for the future; and

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4           WHEREAS, current scientific research shows that Rett syndrome may be  
5 one (1) of the first reversible genetic disorders; and

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7           WHEREAS, efforts should continue to bring awareness to the medical  
8 community, therapists, teachers, caregivers, and the general public, and  
9 support should be given to researchers who are dedicated to finding a cure  
10 for Rett syndrome; and

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12           WHEREAS, the State of Arkansas supports this shared mission,

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14 NOW THEREFORE,

15 BE IT RESOLVED BY THE ARKANSAS LEGISLATIVE COUNCIL OF THE NINETY-FOURTH  
16 GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:

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18           THAT the Arkansas Legislative Council proclaim October 2024 as Rett  
19 Syndrome Awareness Month in Arkansas.

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24 Respectfully submitted,

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28 Senator Justin Boyd

29 District 27

30 Prepared by: JMB/JMB