

INTERIM RESOLUTION 2023-006

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

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

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

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

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

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

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

WHEREAS, in March 2023, the first treatment for Rett syndrome was
approved by the United States Food and Drug Administration and was able to be
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
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