

## State of Missouri Governor's Proclamation

WHEREAS, Rett syndrome is a unique postnatal neurological disorder that is first recognized in infancy and seen almost always in girls, but can be rarely seen in boys; and

WHEREAS, Rett syndrome strikes all racial and ethnic groups, and occurs worldwide in 1 of every 10,000 female births; and

WHEREAS, early developmental milestones appear normal, but between 6-18 months of age, there is a delay or regression in development, particularly affecting speech, hand skills and coordination. A hallmark of Rett syndrome is repetitive hand movements that may become almost constant while awake. Other features may include seizures, irregular breathing, swallowing difficulties, deceleration of head circumference with age and curvature of the spine; and

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

WHEREAS, many individuals with Rett syndrome live well into adulthood. There is currently no cure; and

WHEREAS, with the discovery of the gene that causes Rett syndrome (1999), research in the lab that proves the theory of reversibility of the disease (2007), the discovery of breakthrough testing models (2010) and the launch of multiple disease-modifying human clinical trials (present), we now reach an unprecedented and historic moment in time where we must do everything possible to fund the truly life-changing research in front of us, and

WHEREAS, we must continue our efforts in bringing awareness to the medical community, therapists, teachers, caregivers, and the general public as well. We must have funding available for researchers who are dedicated in finding a cure for Rett syndrome. We support this shared mission now more than ever, and together, progress will continue until there is a world without Rett syndrome.

**NOW THEREFORE,** I, Michael L. Parson, GOVERNOR OF THE STATE OF MISSOURI, do hereby proclaim October 2018 to be

## RETT SYNDROME AWARENESS MONTH

in Missouri and encourage the residents of Missouri to become informed and aware of Rett syndrome.

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the City of Jefferson, this 24th day of September, 2018.

Michael L. Parson

ATTEST:

SECRETARY OF STATE