International Rett Syndrome Foundation

Accelerating Research. Empowering Families.

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

WHEREAS: Every 2 hours, a child is born with Rett syndrome, but its symptoms usually do not appear until age 6 to 18 months; and

WHEREAS: A regression period follows where acquired motor skills are lost, leading to lifelong impairments, including loss of speech, seizures, scoliosis, and irregular breathing patterns. More than half of those affected lose their ability to walk. The hallmark sign of Rett syndrome is near constant repetitive hand movements while awake; and

WHEREAS: Those diagnosed with Rett syndrome require maximum assistance with daily living activities for their entire lives; and

WHEREAS: The disorder is not degenerative[1] and biomedical research in mice suggests that neurological symptoms may be reversed[2] even after decades of severe symptoms; 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 in vitro models (2010) and the launch of five disease-modifying human clinical trials and more in the pipeline (present), we now reach an unprecedented and historic moment in time where we must do everything possible to advance research that creates truly life-changing solutions for all with Rett syndrome; and

WHEREAS: International Rett Syndrome Foundation is one of the world's largest private sources of funds for Rett syndrome research addressing the full spectrum of this developmental disorder while advocating to improve the quality of life for the patients and their families; and

WHEREAS: We must continue our efforts to bring awareness to the medical community, pharmaceutical industry, researchers, therapists, teachers, caregivers, and the general public as well. We must have funding available for researchers who are dedicated to 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.

[1]Armstrong DD. Neuropathology of Rett syndrome. J Child Neurol. 2005;20(9):747–753. doi: 10.1177/08830738050200090901. [PubMed],
[2]Guy J, et al. Reversal of neurological defects in a mouse model of Rett syndrome. Science. 2007;315(5815):1143–1147. doi: 10.1126/science.1138389. [PubMed]