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AT THE WILLIAM & MILDRED LEVINE RANCH

Disability Of The Week: Rett Syndrome

What is Rett Syndrome?

Rett syndrome is a rare non-inherited genetic neurological disorder that affects 1 in 10,000 females (and even more rarely in males) and begins to display itself in missed milestones or regression at 6-18 months. Rett syndrome leads to severe impairments, affecting nearly every aspect of life: ability to speak, walk, eat and breathe easily. The hallmark of Rett syndrome is near constant repetitive hand movements while awake. Cognitive assessment in children with Rett syndrome is complicated, but we know that they understand far more than they can communicate to us, evidenced by their bright and attentive eyes, and their ability to express a wide spectrum of moods and emotions.

What are the stages of Rett syndrome?

Stage I – Early Onset Stage
Age: 6 months to 1.5 years
Duration: Months

Stage II – Rapid Destructive Stage
Age: 1 to 4 years
Duration: Weeks to Months

Stage III – Plateau Stage
Age: Preschool to adulthood
Duration: Decades

Stage IV – Late Motor Deterioration Stage
Age: When ambulation is lost (those who never ambulate move from Stage II to IV)
Duration: Up to decades

Learn more: https://www.rettsyndrome.org/about-rett-syndrome/

Glossary of Terms: https://www.rettsyndrome.org/about-rett-syndrome/glossary-of-terms/


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