



IRSF INTERNATIONAL RETT SYNDROME FOUNDATION

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Facts about Rett syndrome

- Rett syndrome is the leading genetic cause of impairment in girls
- Rett syndrome is caused by mutations in the gene *MECP2*. 95% of girls diagnosed with Rett syndrome in the United States have this mutation
- Rett syndrome is the only autism spectrum disorder with a known genetic cause
- Girls and women with Rett syndrome have unusually bright eyes and seem to understand more than they can express
- A girl is born every five hours with Rett syndrome
- The amazing breakthrough in science is the ability to reverse Rett symptoms in an animal model
- Thousands of girls and women world-wide are undiagnosed or misdiagnosed with cerebral palsy or autism
- Rett syndrome affects all ethnic, racial and socio-economic groups; every parent is at risk for having a child with Rett syndrome
- Rett syndrome is often characterized as a "Rosetta Stone" disorder that can give insight into a host of other late onset neurological disorders such as autism

Medical Facts

- Rett syndrome is 1 of 4 diseases primarily affecting females
- The American medical community did not recognize Rett syndrome until 1983
- 20% of all girls and women may never walk at all, and about one-fourth of those who do walk will lose the ability
- 80% of those affected by Rett syndrome will experience at least one seizure in their life
- Approximately 90% are at risk for some degree of curvature of the spine
- The most severe handicap in Rett syndrome is apraxia, which means the will to move is present but there is an inability to carry through with movement
- Most girls and women also live with near constant repetitive hand movements while awake, irregular breathing and sleep patterns as well as gastrointestinal issues



Rett syndrome has taken away the future that many parents have dreamed for their daughters. IRSF is working to give it back. **Join us in our mission.**