



Fact Sheet

Rett's Disorder

What is Rett's Disorder?

Rett's Disorder is one of the five disorders classified as a Pervasive Developmental Disorder (PDD). Other PDDs include Autism, Asperger's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Rett's Disorder is included as a Pervasive Developmental Disorder (PDD) because there are some autism-like characteristics, particularly when the disorder is first recognized in a child; however, the course and onset of Rett's is very different from any other PDD.

What are the Characteristics of Rett's Disorder?

Children with Rett's Disorder most often appear normal at birth but after a short period of typical development, usually 5-18 months, there is a deceleration of head growth resulting in cognitive impairments, loss of socialization and communication skills, and toe walking or an unsteady gait. A hallmark sign of Rett's Disorder is the loss of all purposeful hand movements and the development of repetitive hand wringing or hand washing. Additionally, individuals with Rett's Disorder are at a higher risk for seizure activity, scoliosis, irregular sleep patterns, poor circulation, and constipation. It affects mainly girls and is a rare disorder, occurring only once in every 10,000-20,000 births.

How is Rett's Disorder Diagnosed?

Rett's Disorder is diagnosed by genetic testing and use of the DSM-IV criteria. Initially, children with Rett's disorder based upon the autism-like characteristics they display. Upon the onset and additional regression of skills, parents are typically referred on for genetic testing. A mutation on the MECP2 gene on the X chromosome confirms a diagnosis of Rett's Disorder.

It is important to have a full diagnostic evaluation when considering a Rett's Disorder diagnosis. As with any Pervasive Developmental Disorder, a comprehensive evaluation including a thorough medical, social, adaptive, motor skills and communication history are imperative. A geneticist, pediatric neurologist, and a developmental pediatrician are a few of the professionals who may diagnose Rett's Disorder. When seeking a diagnosis, it is important to include a team of specialists when considering a Pervasive Developmental Disorder to be present.

Is There Treatment?

While there is no known “cure” for Rett’s Disorder there *are* strategies that have a positive impact. As with other pervasive development disorders, it is believed that early, intensive use of evidenced based practices and interventions can improve the outcomes of individuals with Rett’s Disorder. Most of these interventions fall under the category of special education. In the educational setting, specialized instruction and individualized educational plans should be developed to meet the individual’s specific needs. Some of the more common therapies and services include:

- Visual and Environmental Supports, visual schedules (Hodgdon, 2002)
- Applied Behavior Analysis
- Discrete Trial Instruction
- Social Stories and Comic Strip Conversations (Gray, 2000)
- Speech and Language Services
- Physical and Occupational Therapy

Although there are not any medications specifically developed for the treatment of Rett’s Disorder, medications may be an option to treat some of the symptoms of Rett’s (i.e., seizure activity). The best outcomes can be achieved when a team approach amongst supporting individuals is utilized.

Additional Resources

Books

Lindberg, Barbro (2006). *Understanding Rett’s Syndrome: A Practical Guide for Parents, Teachers, And Therapists*. Hogrefe & Huber Publishers.

Kerr, A. & Ingerstrom, I. (2001). *Rett’s Disorder and the Developing Brain*. Oxford University Press.

Websites

www.illinoisautismproject.org

www.Rettsyndrome.org

www.ninds.nih.gov

www.kennedykrieger.org

www.autismspeaks.org

Illinois Autism/PDD Training and
Technical Assistance Project
International Rett’s Syndrome Foundation
National Institute of Neurological Disorders
and Stroke
Kennedy Krieger Institute
Autism Speaks



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