



Disability Awareness Begins With You: Rett Syndrome

Rett Syndrome is a neurological disorder occurring primarily in girls, in which individuals exhibit reduced muscle tone, autistic-like behavior, stereotyped hand movements consisting mainly of wringing and waving, loss of purposeful use of the hands, diminished ability to express feelings, avoidance of eye contact, a lag in brain and head growth, gait abnormalities and seizures. Hypotonia (loss of muscle tone) is usually the first symptom.

The Syndrome was first recognized in 1966 by Dr. Andreas Rett, however it was not until a paper was published by Dr. Bengt Hagberg in 1983 that the disorder was made widely known in medical circles.

The Syndrome affects approximately 1 in every 10,000-15,000 live female births, with symptoms usually appearing in early childhood.

Diagnostic Criteria:

- A period of normal development until between 6 - 18 months
- Normal head circumference at birth followed by a slowing of the rate of head growth with age (starting between 6 months and 4 years)
- Severely impaired expressive and receptive language
- Intellectual development appears to be severely delayed, but true intelligence is difficult to measure
- Loss of purposeful hand skills at age 1-4 years
- Repetitive hand movements including hand washing, hand wringing, hand clasping and hand mouthing which can be almost constant while awake
- Shakiness of the torso, which also may involve the limbs, particularly when the child is upset or agitated
- Unsteady, wide-based, stiff-legged gait, and

sometimes toe walking

Supportive Criteria:

- Breathing dysfunctions which include beeath holding or apnea, hyperventilation and air swallowing which may result in abdominal swelling
- EEG abnormalities which include slowing of normal electrical patterns, the appearance of epileptiform patterns and a reduction in REM sleep
- Seizures
- Muscle rigidity/spasticity/joint contractures
- Scoliosis
- Teeth grinding (bruxism)
- Small feet
- Growth retardation
- Decreased body fat and muscle mass
- Abnormal sleep patterns and irritability
- Poor circulation of the lower extremities
- Decreased mobility with age

Source: The International Rett Syndrome Association.

See www.pc2online.org for more disability awareness pages concerning:

Attention Deficit Hyperactivity Disorder
Autism
Down Syndrome
Asperger's Syndrome
Dyslexia
Angelman Syndrome
Emotional Disturbance
Epilepsy
Lowe Syndrome
Cerebral Palsy
Oppositional Defiant Disorder
& many more

The **Cerebral Palsy Family Reimbursement Association** is actively recruiting board members. Our mission is to assist families (such as those who are currently on a waiting list for state assistance) with the purchase of special equipment that is not covered by insurance. This can include bathing and toileting equipment, therapy equipment, and adaptations to the home and vehicle.

We are a non-profit organization and will be seeking various fund-raising opportunities. If you are a parent of a child with Cerebral Palsy and are interested, please call Laura McClement at (253) 549-0048.