Rett’s Syndrome
Information Handout

By: Kim Casimbon
What is Rett syndrome?
The National Institute of Neurological Disorders and Stroke (2015) identified Rett syndrome as a neurodevelopmental disorder, which affects mostly girls. It is “characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability”.

Symptoms include:
- Loss of speech and motor control
- Functional hand use replaced by compulsive hand movements
- Difficulty breathing
- Severe digestive problems
- Orthopedic abnormalities including scoliosis and fragile bones
- Disrupted sleep patterns
- Extreme anxiety
- Seizures
- Impaired cardiac and circulatory function
- Parkinsonian tremor

Causes of the Disorder:
- A genetic disorder where mutation occurs randomly in their MECP2 gene
- MECP2 is critical for normal brain function and involved in maintaining the connections between neurons
- Sometimes, those who are affected may have other female family members who have a mutation but no clinical symptoms may display; these females are called “asymptomatic female carriers”


Gillette Children’s Specialty Healthcare is a non-profit hospital in St. Paul, Minnesota that focuses on pediatric medical treatment and research. Their website provides specific information on services that are offered for children. Their assistive technology webpage provides further information on what types of patients they serve and what their services include.


Rettsyndrome.org has a specific webpage called “School & Day Program” for those working with students with Rett’s Syndrome. The page emphasizes educating others about the syndrome through sharing information (via PowerPoint, letters to peers and parents) and selecting the right program for the child to meet her special needs and personality.


Teach More/Love More gives a general overview about Rett’s Syndrome, common signs, and prevalence. It also provides information about the impact of the syndrome onto the child’s intelligence and learning and what professionals parents should seek. The website also mentioned how parents can help their child and what other resources that they can take advantage of, such as, books and websites to visit.


Girl Power 2 Cure is an organization that helps spread awareness about Rett’s Syndrome and provides the support that families need. They raise money to fund their partner, Rett Syndrome Research Trust, to help find treatments and a cure for the syndrome through research.
ASSISTIVE TECHNOLOGIES (CONT.)

This is a PDF file that lists different assistive technologies available that children can use to communicate. It lists the names, size of the technology, cost, and features.

This website provides information about the Student, Environments, Tasks, and Tools (SETT) framework that promote collaboration when making decisions through assistive technology. It contains handouts that teachers can use for their classroom.

REFERENCES/USEFUL WEB SOURCES

⇒ University of Nebraska-Lincon. Augmentative and alternative communication. Retrieved from http://cehs.unl.edu/aac/

RETT’S SYNDROME (CONT.)

Stages of the disorder:

Stage I (Early Onset): 6-18 months; a decrease in eye contact, interest in toys, hand-wringing may begin; delays in gross motor skills.

Stage II (Rapid Destructive Stage): 1-4 years old; loses purposeful hand skills and spoken language; breathing irregularities; unsteady walking and difficulty in initiation of motor movements; slowed head growth.

Stage III (Plateau or Pseudo-Stationary State): 2-10 years old; apraxia (the inability to perform motor functions); seizures; improvement in behavior (less irritability and crying; more interest in surrounding; more alert and improved attention span and communication).

Stage IV (Later Motor Deterioration Stage): reduced mobility, curved spine, muscle weakness, increase muscle tone with abnormal posture of arm, leg, or upper body; those who previously walked may stop walking.

Prevalence

• The occurrence of Rett’s Syndrome is estimated at 1 in 10,000 females.
• Approximately 16,000 children and women who are affected by it in the United States
• Since it affects less than 200,000 individuals, it is considered as a rare disease, it qualifies for orphan drug status with favorable tax deductions and marketing exclusivity on a drug.

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RETT’S SYNDROME ORGANIZATIONS

National Organizations
Rett Syndrome Organizations
http://www.rts.org

Rett Syndrome Organizations in Maryland
National Institute of Child Health and Human Development (NICHD)
National Institutes of Health, DHHS
31 Center Drive, Rm. 2A32 MSC 2425
Bethesda, MD 20892-2425
http://www.nichd.nih.gov
Tel: 301-496-5133
Fax: 301-496-7101

State & Local Organizations
Easter Seals
233 South Wacker Drive
Suite 2400
Chicago, IL 60606
info@easterseals.com
http://www.easterseals.com
Tel: 312-726-6200 800-221-6827
Fax: 312-726-1494

Rett Syndrome Research Trust
67 Under Cliff Road
Trumbull, CT 06611
monica@rsrt.org
http://www.rsrt.org
Tel: 203-445-0041

ASSISTIVE TECHNOLOGIES

Assistive Technologies (Web links)
This is a website that consists of stories of children with disabilities and how Tobii C12 technology significantly helped them when trying to communicate with others through this device.

This is a website that provides hands-on resources that teachers, parents, and other professional working with students with disabilities can use. More of their resources are designed as visual communication devices such as a picture card where children are taught to use a certain sequence when making a request; they are taught to point to a picture and eventually should be able to use verbal language to make the request.

This website provides general information about Rett Syndrome and how an enriched environment can help. It also provides several helpful links for those who want to find out about Augmentative and Alternative Communication (AAC) and other assistive technologies to help those with Rett Syndrome.

RETT’S SYNDROME ORGANIZATIONS

Rett Syndrome Organizations
4600 International Rett Syndrome Foundation
4600 Devitt Drive
Cincinnati, OH 45246
admin@rettsyndrome.org
http://www.rettsyndrome.org
Tel: 513-874-1298 800-818-7388

Easter Seals
233 South Wacker Drive
Suite 2400
Chicago, IL 60606
info@easterseals.com
http://www.easterseals.com
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