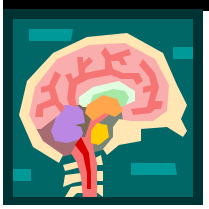

Disability Awareness Begins With You

Sotos Syndrome

Sotos Syndrome is a rare genetic disorder characterized by excessive physical growth during the first 2 to 3 years of life. The disorder may be accompanied by mild mental retardation, delayed motor, cognitive, and social development, hypotonia (low muscle tone), and speech impairments.

Children with Sotos Syndrome tend to be large at birth and are often taller, heavier, and have larger heads (macrocrania) than is normal for their age. Symptoms of the disorder, which vary among individuals, include a disportionately large and long head with a slightly protrusive forehead, large hands and feet, hypertelorism (an abnormally increased distance between the eyes), and downslanting eyes.

Clumsiness, an awkward gait, and unusual aggressiveness or irritability may also occur. Although most cases of Sotos Syndrome occur sporadically, familial cases have also been reported.

Typical Characteristics of Sotos Syndrome:

Growth: Rapid growth is common during the first five years of life. Thereafter growth continues to parallel the 97th percentile or above. Head circumference has been documented well above the 98th percentile.

Birth: The presence of a high arched palate (roof of the mouth is narrow and arched upward), poor suck, and low muscle tone often produces feeding problems. Jaundice occurs frequently.

Craniofacial: Facial features include a large head with a tall, narrow skull, wide set downslanting eyes, flat-bridged nose, early eruption of teeth (as early as 3 months of age), thin hair pointed chin, prominent forehead, and "receding hairline".

Skeleton: An advanced bone age (the bones grow and mature faster than expected for the child's chronological age) is common. The hands and feet may be large in comparison with the rest of the body. Flat or pronated (collapsed inward) feet are common, and scoliosis may develop.

Development: Motor delays are common due to hypotonia. Prolonged drooling and mouth breathing may be present due to poor tone of facial muscles. Delays in gross and fine motor movement are marked in early childhood and improve in the school years. Coordination problems may persist into adulthood. Receptive language (understanding others) tends to be more advanced than expressive language (formation of words), setting the stage for frustration. The child may whine or scream to demonstrate desires or emotions. Older children seem to develop competence and normal speech patterns. Borderline to average intelligence is expected, with learning deficits noted in language, math, and socialization. Intellectual, social, and emotional maturity may evolve on widely different timetables.

Other Features:

Any of these may or may not be present:

- Behavioral patterns including phobias, aggression, obsessions, adherence to routine, autistic-like behavior, attention deficit disorder, above-average memorization skills.
- Enlarged ventricles of the brain, hydrocephalus (rare), abnormal EEG's and seizures (with at least 1/3 of seizures being fever-related).
- Frequent ear infections and upper respitory infections, asthma, and allergies.
- Constipation, megacolon.
- Delayed toilet training, urogenital anomalies.
- Congenital heart anomalies.
- Nystagmus, strabismus.
- Increased sweating.
- Hyperthyroidism, hypothyroidism.
- Possible increased risk of tumors.

Information from: http://www.ninds.nih.gov/health_and_medical/disorders/sotos.htm & http://www.well.com/user/sssa/whatisit.htm

SAVE THE DATE!

May 22, 2003
7-8:30 p.m.

Presented by Pro Stars, a project of (PC)2:

"How Caregivers are Organizing to Gain Respect, a Living Wage, and Benefits," presented by Suzanne Wall, Secretary/ Treasurer & a Local Representative of the Homecare Workers Union, SEIU Local 775, at TACID, 6315 So. 19th St.