Other Syndromes and Disorders

Individuals who have some of the characteristics of Sotos syndrome, but not enough to be classified as "typical" Sotos, are often said to be "Sotos-like." When arriving at a diagnosis of Sotos or Sotos-like, other syndromes with shared features should be considered. These may include:

- Fragile X Syndrome
- Weaver Syndrome
- Gorlin Syndrome
- Beckwith-Wiedemann Syndrome
- Bannayan/Ruvalcaba/Riley-Smith Syndrome
- Simpson-Rosen-Golabi-Behmel Syndrome
- Storage Disorders
- Marshall-Smith Syndrome
- IODM (infant of diabetic mother)
- Cerebral Palsy
- Ehlers Danlos Syndromes
- Pituitary Gigantism
- Pineal Tumor

Organized in 1988, the Sotos Syndrome Support Association (SSSA) is made up of families, physicians, genetic counselors and health care agencies throughout the U.S. and the world. The SSSA is a nonprofit 501(c)(3) organization.

The purpose of the Sotos Syndrome Support Association is to provide:

- A social support environment for professionals and families of individuals with a diagnosis of Sotos and similar syndromes.
- An understanding of the condition through education.
- An e-newsletter for members to share ideas, articles and inspirations.
- An annual conference for professionals and families to network and gain insight from experts on such topics as genetics, neurology, psychology and education.
- An opportunity for professionals involved with Sotos syndrome to meet colleagues and collect data for research.

For Information and Membership, contact:

SOTOS SYNDROME SUPPORT ASSOCIATION

P.O. Box 4626 Wheaton, IL 60189

888.246.7772

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e-mail: sssa@sotossyndrome.org

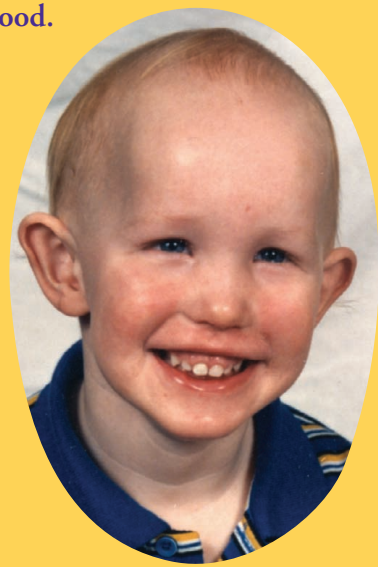
SOTOS SYNDROME SUPPORT ASSOCIATION

Awareness *and* Understanding *through* Education *and* Support

A reference guide for parents, physicians, and other health professionals

Sotos syndrome, previously known as cerebral gigantism, is a genetic condition that causes rapid growth and developmental delays in early childhood.

The diagnosis is made by physical examination, developmental history and laboratory tests. Most people with classic Sotos syndrome have changes in a gene called NSD-1.



Characteristic Features

Birth

Jaundice is common. A high arched palate, (roof of the mouth is narrow and arched upward), poor suck, and low muscle tone often produce feeding problems.

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), pointed chin, prominent forehead, thin hair and a "receding hairline."

Growth

Rapid growth is common during the first five years of life. Thereafter, growth continues to parallel the 97th percentile or above. Final adult height is not seriously increased. Head circumference has been documented well above the 98th percentile.

Skeleton

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 low muscle tone. 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 ability (understanding others) tends to be more advanced than expressive language (formation of words), setting the stage for frustration. The child may throw a tantrum to express desires or emotions. Older children tend to develop better speech and behavior patterns.

There is a wide range of intellectual outcomes from significant deficits well into the normal range. Learning deficits in language, math, and socialization are common. 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; extra fluid surrounding the brain and within the brain (true hydrocephalus is rare); abnormal EEG's and seizures (with at least 1/3 of seizures being fever-related); frequent ear infections and upper respiratory infections; asthma and allergies; constipation, megacolon, delayed toilet learning, urogenital abnormalities; congenital heart anomalies; nystagmus, strabismus; increased sweating and thirst; hyper- or hypothyroidism; low increased risk for rare tumors.

Intervention Strategies

There are no specific interventions unique to the Sotos diagnosis. Rather, interventions for each child should be based on that child's assessed needs. Programs such as infant stimulation, occupational therapy, physical therapy, speech therapy, and adaptive physical education may play a significant role in the nurturing of a child with Sotos syndrome. In a structured environment, the child is able to practice necessary skills without excessive distractions.

Alternative strategies for effective movement and communication can give a child additional mobility and the language to encourage self-help skills. As with any child, self-esteem in a child with Sotos syndrome is bolstered by successful completion of tasks and mastery of developmental skills.