



What is Smith-Magenis Syndrome?

Smith-Magenis syndrome (SMS) is a genetic condition that occurs in males and females of all ethnic and racial backgrounds. It causes certain facial features, behavior difficulties and mental impairment. SMS occurs in about 1 in 15,000 to 25,000 people.

Michigan Resources & Support

Children's Special Health Care Services

Family Phone Line
Toll-free: 1-800-359-3722
www.michigan.gov/cshcs

Early On® Michigan

Toll-free: 1-800-EARLY ON
www.1800earlyon.org

Michigan Birth Defects Program

Nurse Follow-up Coordinator
Toll-free: 1-866-852-1247
E-mail: BDRfollowup@michigan.gov

Michigan Genetics Connection

www.migeneticsconnection.org

National Resources & Support

Parents and Researchers Interested in Smith-Magenis Syndrome

Phone: 972-231-0035
www.prisms.org

Family Village

www.familyvillage.wisc.edu

GeneReviews

www.geneclinics.org/profiles/sms

Genetic and Rare Diseases Information Center

Toll-free: 1-888-205-2311
E-mail: GARDinfo@nih.gov

Genetics Home Reference

www.ghr.nlm.nih.gov/condition=smit-hmagenissyndrome

How may SMS affect my child?

Learning: Children with SMS usually have developmental delays. Most have mild to moderate mental impairment. Parents report their children with SMS have a remarkable memory for names, places and events.

Behavior: Children with SMS often have an appealing personality and great sense of humor. Some common behaviors present a challenge. These include sleep disturbances, mouthing objects or hands, sudden mood changes and self-injury. Children may also have unusual behaviors that are specific to SMS, such as hand licking and page flipping.

Physical: Children with SMS may

have certain facial features, such as flat cheekbones and eyebrows that meet in the middle. They are often short for their age. A hoarse, deep voice is a common feature. A square-shaped face and prominent jaw become more noticeable as a child with SMS grows up.

Medical: Babies with SMS often have low muscle tone and feeding problems. Constipation is common. There may be hearing loss and eye problems. Some children with SMS have birth defects such as cleft lip, heart defects, and kidney defects. A person with SMS may have an unusual gait, and is prone to curvature of the spine (scoliosis).

How does SMS occur?

SMS is caused by a problem in the #17 chromosome. In most cases, a very small piece of the chromosome is missing (deleted), including some of the genes within it. The child with SMS is usually the first and only family member affected, but sometimes the deleted chromosome is passed down from a parent. Genetic counseling is recommended for parents to learn about the genetic cause of SMS in their family, and possible risks for other children.

How is SMS treated?

SMS cannot be cured, but some symptoms can be treated. Infants and toddlers (birth to 3 years) should be connected with *Early On*® Michigan as soon as possible. When there are concerns about learning, speech, or behavior in a child over 3 years of age, a referral for special education services should be made. Speech, occupational and physical therapy may help. Medication may help sleep disturbances, and there may be ways to improve behavior. Additional therapies and treatments may be needed as other problems arise. A child with SMS should be checked for any problem with the kidneys, heart, spine, or eyes. Children with SMS and their families benefit from having a primary care physician who helps to coordinate their care with medical specialists and other community-based services.

For more information, call Michigan's Genetics & Birth Defects Program toll-free at 1-866-852-1247 or e-mail Genetics@michigan.gov

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