



What is Noonan Syndrome?

Noonan syndrome is a genetic condition that occurs in males and females of all racial and ethnic backgrounds. It can cause certain facial features, heart defects, bleeding problems, short stature, and developmental delays, especially with speech and language. Noonan syndrome occurs in about 1 in 1,000 to 2,500 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

Noonan Syndrome Support Group

Toll-free: 1-888-686-2224
www.noonansyndrome.org

Family Village

www.familyvillage.wisc.edu

GeneReviews

www.geneclinics.org/profiles/noonan

Genetics Home Reference

www.ghr.nlm.nih.gov/ghr/disease/noonansyndrome

Human Growth Foundation

Toll-free: 1-800-451-6434
www.hgfound.org

The MAGIC Foundation

Phone: 708-383-0808
www.magicfoundation.org

How may Noonan syndrome affect my child?

Learning: Most children with Noonan syndrome have normal learning. Some may have developmental delays and lifelong learning disabilities. Problems with speech and language are common.

Physical: Facial features may include widely spaced eyes, droopy eyelids (ptosis), and low set ears. These features may be very mild in adults. A broad or webbed neck may be noted. The chest may be an unusual shape with nipples that appear low-set. Many children with

Noonan syndrome are shorter than average.

Medical: Problems with feeding and slow weight gain are common in babies. Between 50% and 80% of children with Noonan syndrome are born with a heart defect. Abnormal bleeding or bruising is common. Mild hearing loss and vision problems can also occur. It is common for males with Noonan syndrome to have undescended testicles (cryptorchidism).

How does Noonan syndrome occur?

Noonan syndrome is caused by a change in a gene (mutation). A child with Noonan syndrome may be the first and only family member affected, or the genetic trait may be passed down from an affected parent. Parents of a newly diagnosed child should be checked carefully to look for signs of the condition. There is a 1 in 2 chance that each child will have Noonan syndrome when a parent carries the gene. Genetic counseling is recommended for parents to learn about the genetic cause of Noonan syndrome in their family, and possible health risks for other children.

How is Noonan syndrome treated?

Noonan syndrome cannot be cured, but many symptoms can be treated. Infants and toddlers (birth to 3 years) should be connected with *Early On*[®] Michigan if there are concerns about learning, speech, or behavior; while children over 3 years of age should be referred for special education services if concerns arise. Heart defects may be treated with medication or surgery. It is important to check hearing and vision on a regular basis. Lab tests should be done to check blood clotting. Growth should be monitored and use of growth hormone may be considered to increase final adult height. Other treatments may be needed for health problems as they arise. Children with Noonan syndrome 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

Supported in part by project # 6 H91MC00215-04-01 as a Special Project of Regional and National Significance (SPRANS), Title V (as amended), Social Security Act, administered by the Maternal and Child Health Bureau, Health Resources and Services Administration, United States Department of Health and Human Services.