



# What is Prader-Willi Syndrome?

Prader-Willi syndrome (PWS) is a genetic condition that affects males and females of all racial and ethnic backgrounds. It causes problems with a child's health, behavior and learning. PWS occurs in about 1 in 10,000 to 20,000 people.

## Michigan Resources & Support

### Prader-Willi Syndrome Association of Michigan

[www.pwsausa.org/mi](http://www.pwsausa.org/mi)

### Children's Special Health Care Services

Family Phone Line

Toll-free: 1-800-359-3722

E-mail: [ppp@michigan.gov](mailto:ppp@michigan.gov)

[www.michigan.gov/cshcs](http://www.michigan.gov/cshcs)

### Early On® Michigan

Toll-free: 1-800-EARLY ON

[www.1800earlyon.org](http://www.1800earlyon.org)

### Michigan Birth Defects Program

Nurse Follow-up Coordinator

Toll-free: 1-866-852-1247

E-mail: [BDRfollowup@michigan.gov](mailto:BDRfollowup@michigan.gov)

### Michigan Genetics Connection

[www.migeneticsconnection.org](http://www.migeneticsconnection.org)

## National Resources & Support

### Prader-Willi Syndrome Association (USA)

Toll-free: 1-800-926-4797

[www.pwsausa.org](http://www.pwsausa.org)

### Family Village

[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

### GeneReviews

[www.geneclinics.org/profiles/pws](http://www.geneclinics.org/profiles/pws)

### Genetic and Rare Diseases Information Center

Toll-free: 1-888-205-2311

E-mail [GARDinfo@nih.gov](mailto:GARDinfo@nih.gov)

### Genetics Home Reference

[www.ghr.nlm.nih.gov/condition=praderwillisyndrome](http://www.ghr.nlm.nih.gov/condition=praderwillisyndrome)

## How may Prader-Willi syndrome affect my child?

**Learning:** Every child with PWS is unique, but most have developmental and speech delays or learning problems to some degree. The mental impairment is usually mild or moderate. Rarely, a child may have severe mental retardation.

**Behavior:** Behavioral problems may include sleep disturbance, obsessive-compulsive behavior, temper tantrums and skin picking.

**Physical:** Children with PWS may have lighter skin, hair and eyes than other family members. They may be short for their age and have smaller hands and feet than average. Small

external genitalia are common. The amount of saliva in the mouth may be less than usual.

**Medical:** Low muscle tone and trouble with feeding are typical in infancy. Curvature of the spine (scoliosis) and eye muscle problems may be present. Overeating, leading to rapid weight gain, begins in early childhood. Without strict control, obesity, diabetes and other weight-related problems are likely to develop. Low sex hormone levels (hypogonadism) are common, leading to lack of normal physical development and infertility.

## How does Prader-Willi syndrome occur?

PWS is caused by changes in genes located on the #15 chromosome. The genetic cause can often be found with special tests. The child is usually the first and only family member affected. Sometimes, the condition can recur in sisters or brothers. Genetic counseling is recommended for parents to learn about the genetic cause of PWS in their family, and possible risks for other children.

## How is Prader-Willi syndrome treated?

PWS cannot be cured, but some symptoms can be treated. Special feeding techniques may be needed for a baby with PWS. After the first year or two, food intake will need to be strictly controlled. Behavior therapy may help control the urge to eat. Infants and toddlers (birth to 3 years) should be connected with *Early On*® Michigan as soon as possible. If 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. Other therapies or treatments may be needed for developmental or health problems as they arise. Children with PWS 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](mailto:Genetics@michigan.gov).

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