



## What is Tuberous Sclerosis?

Tuberous sclerosis (TS) is a genetic condition that occurs in males and females of all racial and ethnic backgrounds. It often affects the central nervous system, causing seizures. It can also lead to non-cancerous tumors in various organs such as the skin, brain, kidneys, heart and eyes. TS occurs in about 1 in 6,000 people.

### Michigan Resources & Support

#### Tuberous Sclerosis Alliance of Michigan

[www.tsalliance.org](http://www.tsalliance.org), click on Local Resources

#### Children's Special Health Care Services

Family Phone Line  
Toll-free: 1-800-359-3722  
[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

#### Tuberous Sclerosis Alliance

Toll-free: 1-800-225-6872  
[www.tsalliance.org](http://www.tsalliance.org)

#### Epilepsy Foundation of America

Toll-free: 1-800-332-1000  
[www.efa.org](http://www.efa.org)

#### Family Village

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

#### GeneReviews

[www.geneclinics.org/profiles/tuberous-sclerosis](http://www.geneclinics.org/profiles/tuberous-sclerosis)

#### 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/ghr/disease/tuberoussclerosis](http://www.ghr.nlm.nih.gov/ghr/disease/tuberoussclerosis)

### How may tuberous sclerosis affect my child?

**Learning:** Many people with TS have normal intelligence. Others may have lifelong learning problems that range from mild impairment to severe mental retardation.

**Behavior:** Hyperactivity, attention deficit disorder, or aggressive behavior may occur. Children with TS may also be diagnosed with an autism spectrum disorder.

**Physical:** Skin changes are common in people with TS. They usually do not lead to serious medical problems, but can cause cosmetic concerns. Skin signs can include white or pale areas, tough and dimpled patches,

facial tumors and fibrous growths around the nails.

**Medical:** Children with TS often have seizures (epilepsy). The seizures are caused by “tubers”, small areas of the brain’s outer layer that did not develop normally. Other brain tumors may also occur. Tumors may also form in other organs including the heart, lungs, kidneys and eyes. Some tumors may get smaller and disappear with age while others may grow and cause problems later in life. Most of the tumors are benign (non-cancer) but may have a risk for becoming cancerous.

### How does tuberous sclerosis occur?

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

### How is tuberous sclerosis treated?

TS cannot be cured, but some symptoms can be treated. Seizures may be treated by medication. Tumors may be treated by surgery. Imaging studies by ultrasound, CT or MRI should be done to screen for tumors. The frequency and types of studies will depend on symptoms and screening results. 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. Other therapies or treatments may be needed for health problems as they occur. Children with TS 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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