

TUBEROUS SCLEROSIS

SYMPTOMS OR BEHAVIORS

- Benign tumors
- Skin abnormalities
- White patches on skin
- Seizures (all types)
- Epilepsy
- Kidney disease
- Vision problems
- Developmental delay
- Learning disabilities
- Sleep disorders
- Behavior problems
- Sudden Rage
- Attention Deficit Hyperactivity Disorder
- Acting out
- Obsessive compulsive
- Repetitive behaviors
- Destructive
- Self-harming behavior
- Autism Spectrum Disorder

ABOUT THE DISORDER

Tuberous sclerosis, also called tuberous sclerosis complex (TSC1 or TSC2), is a genetic condition that produces benign tumors or lesions on the skin, in the central nervous system, and on other vital organ such as the eyes, heart, kidneys, and lungs. The disease affects people differently, some severely and others mildly, some are so mild that they remain undiagnosed for many years or are never diagnosed. The brain and spinal cord are the most commonly affected organs causing a combination of symptoms or behaviors including seizures, developmental delay, autism, and behavior problems. Most people with mild tuberous sclerosis complex live a normal life, but there can be complications that result in severe symptoms. People with tuberous sclerosis complex need to be monitored by their physician.

Tuberous sclerosis complex affects approximately 25,000 to 50,000 people in the United States and nearly one million worldwide. It affects all races and ethnic groups and both genders. Tuberous sclerosis complex is caused by defects, or mutations in two genes (TSC1, located on chromosome 9 and TSC2 located on chromosome 16). Only one needs to be affected to cause disease. Both genes are believed to suppress tumor growth in the body.

When one of these genes is defective, tumors are not suppressed and tuberous sclerosis complex results. In addition, the TSC1 and TSC2 genes play a role in early fetal development of the brain and skin. Tuberous sclerosis complex is transmitted either through genetic inheritance or in most cases as a spontaneous genetic mutation.

The first noticeable signs of tuberous sclerosis complex are seizures, white patches on the skin and delayed development. Tuberous sclerosis complex is diagnosed by a combination of medical tests: brain MRI, renal ultrasound, echocardiogram of the heart, EKG, eye exam, and Wood's Lamp evaluation of the skin.

There is no cure for tuberous sclerosis complex, but there are treatments to assist with the control of the symptoms. Tumors may be removed before they become too large and negatively affect organs. Skin lesions may be removed or faded using dermabrasion and laser treatments.

Seizures may be controlled with the use of seizure medication. ADHD, OCD or other behaviors may also be controlled using prescribed pharmaceuticals. In addition, specialized instruction and intervention benefit individuals who have developmental issues.



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EDUCATIONAL IMPLICATIONS

Students with tuberous sclerosis complex will have various symptoms and those symptoms may change daily, monthly and yearly. It is important to realize that not all students with Tuberous Sclerosis will have educational issues. However, one-half to two-thirds of students who are diagnosed with tuberous sclerosis will have developmental delays, learning difficulties, hyperactivity, obsessive compulsive disorder (OCD), behavior problems or sleep disorders. These are in addition to other physical symptoms that impact the student's academic performance. Learning difficulties and behaviors at school need to be addressed continuously to prevent further negative impact on the student's development.

INSTRUCTIONAL STRATEGIES AND CLASSROOM ACCOMMODATIONS

Instructional strategies and classroom accommodations will vary depending on the student's symptoms and behaviors. Staff need to monitor the student's health and cognitive deficits.

- If seizures are present, the school nurse in cooperation with school staff should develop plans/accommodations that meet the student's specific needs (an IHP/EP). This may include an individual and/or emergency health plan.
- If vision problems are present, accommodations specific to those needs must be addressed such as preferential seating, enlargements and specialized equipment.
- If physical problems are present (organ function, gross or fine motor skills) specific accommodations must be addressed that assist with physical comfort and the completion of motor task.
- If behavior problems are present, research based teaching practices and appropriate accommodations for the specific behaviors must be implemented.
- Accommodations need to be made based on specific areas of learning or developmental difficulties that are present.
- Support family in continuing medical contact and consult with the medical providers.
- If absences occur because of surgical removal of tumors, plans must be made to help the student keep current with school work.

RESOURCES

Epilepsy Foundation

4351 Garden City Dr. Suite 500
Landover, MD 20785-7225
1-800-332-1000 (free of charge)
www.epilepsyfoundation.org

National Organization for Rare Disorders (NORD)

P.O. Box 1968
Danbury, CT 06813-1968
203-744-0100
www.rarediseases.org

Tuberous Sclerosis Alliance

801 Roeder Road, Suite 750
Sliver Springs, MD 20910-4467
800-225-6872 (free of charge)
<http://tsalliance.org>
email: info@tsalliance.org

Epilepsy Foundation of Minnesota

1600 University Ave W Ste 205
St. Paul, MN 55104
651-287-2300
<http://www.efmn.org/>

Publications:

Tuberous Sclerosis Complex.
J. R. Sampson and V. Holets
Wittemore (Editors). Oxford
University Press, Jan. 1999.
ISBN: 0195122100

Tuberous Sclerosis Complex:
From Basic Science to Clinical
Phenotypes.
Paolo Curatolo (Editor).
MacKeith Press, August 2003.
ISBN:1898683395