

## Tuberous Sclerosis Information Sheet

Tuberous sclerosis, also called tuberous sclerosis complex, is a rare, multi-system genetic disease that causes benign tumors to grow in the brain and on other vital organs. Those vital organs include the kidneys, heart, eyes, lungs and skin. It usually affects the central nervous system and results in a combination of symptoms including seizures, developmental delay, skin abnormalities and kidney disease.

Three types of brain tumors are associated with TSC: cortical tubers, which generally form on the surface of the brain, subependymal nodules, which form in the walls of the ventricles and giant-cell astrocytomas, a type of tumor that can block the flow of fluids within the brain.

The disorder affects as many as 40,000 individuals in the United States and about one to two million individuals worldwide, with an estimated prevalence of one in 6,000 newborns.

Many people with TSC show evidence of the disorder in the first year of life. However, clinical features can be subtle initially, and many signs and symptoms take years to develop. As a result, TSC can be unrecognized or misdiagnosed for years.

### Symptoms and Signs

- Seizures.
- Patches of light-colored skin, areas of thickened skin and growths under or around the nails.
- Benign tumors.

### Treatment

Tuberous sclerosis is a lifelong condition that requires careful monitoring and follow-up. Surgery may remove tumors before they negatively affect organs. Skin lesions may be removed or faded using dermabrasion and laser treatments.

### Educational Implications

Not all students with tuberous sclerosis will have educational issues. However, some will have developmental delays, learning difficulties, behavior issues, sleep disorders, communications issues and difficulties with social interaction.

### Educational Options

Those students whose tuberous sclerosis adversely affects their educational performance may benefit from special education under the Individuals with Disabilities Education Act (IDEA). To qualify under IDEA, a student must meet eligibility criteria in one of thirteen specific disability

categories. IDEA entitles a student with a disability to a free appropriate public education (FAPE) and an individualized education program, including individual goals, objectives, related services, accommodations and modifications.

Students that do not qualify for services under IDEA may qualify under Section 504 of the Rehabilitation Act. To qualify under Section 504, a student must have a physical or mental impairment that substantially limits one or more major life activities (for example learning, breathing, thinking, concentrating, walking, bodily functions). Under Section 504, a student is entitled to equal opportunity, and may qualify for a Section 504 plan that provides regular or special education and related aids and services.

A student with a health condition who does not require special instruction and related services can receive, as appropriate, a wide range of supports in the general education classroom, including accommodations, individualized health plans (IHP), emergency care plans (ECP) and local education agency supports.