SEGA Tumors

About subependymal giant cell astrocytoma (SEGA) tumors and tuberous sclerosis complex (TSC)

Affecting approximately 1 million people worldwide, tuberous sclerosis complex (TSC) is a rare genetic disease that can affect many vital organs, and causes symptoms and resulting disorders such as noncancerous tumors, epilepsy, autism, cognitive impairment, and psychiatric disorders. Subependymal giant cell astrocytoma (SEGA) is a non-cancerous brain tumor affecting approximately 20% of those with TSC. Although SEGA tumors are non-cancerous, if they start to grow or if they block fluid movement in the brain, they can lead to serious problems such as headaches, vision problems and brain swelling known as hydrocephalus.

TSC symptoms and manifestations vary from person to person and may change over time. As TSC is a rare and complicated disease, many people may not have heard of TSC and as such, the disease may go undetected. It is important to ensure that patients monitor symptoms closely with a healthcare professional experienced with the disorder to keep track of current manifestations and check for new ones.

How tuberous sclerosis complex (TSC) works in the body

The treatment you may receive for SEGA associated with TSC may include medical and/or surgical approaches. In normal cells, the TSC1 and TSC2 genes form proteins that help control an important regulator of cell growth called mammalian target of rapamycin (mTOR). In people with defects of the TSC1 or TSC2 genes, these proteins are not made, so mTOR is not regulated correctly. As a result, the extra mTOR makes cells grow too much, which causes tumors to form throughout the body.

Questions to ask your doctor

- How is TSC inherited?
- What multidisciplinary team of specialists should I be seeing to address the manifestations of TSC?
- What are the different manifestations of TSC I need to monitor for? When do I need to monitor for them?
- Where is the nearest TSC specialty center?
- Are there new treatments or clinical trials that I should consider?
- What resources are available to support patients with TSC and their loved ones?
Additional resources

Videos

Approaching TSC Young Adulthood

[Video of Approaching TSC Young Adulthood]

Approaching TSC Young Adulthood [1]

TSC Common Threads: TSC Affects Each Person Differently [2]

TSC Common Threads: The Moss Family [3]


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TSC Patient Journey Infographic [9]

Embarking on Young Adulthood with TSC: Monitoring for Manifestations Over Time [10]

For more information and resources about TSC check out www.facingtsc.com [11]

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