About tuberous sclerosis complex

TSC causes tumors to grow in different organs and can impair their function, primarily the brain, heart, kidneys, skin and lungs.

TSC is the leading genetic cause of epilepsy.

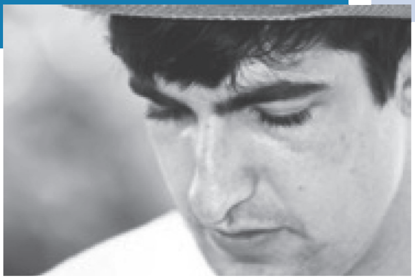
UP TO 1 MILLION PEOPLE WORLDWIDE HAVE TSC.

85%

OF PEOPLE WITH TSC EXPERIENCE SEIZURES, OF WHICH 40% HAVE MEDICINE RESISTANT EPILEPSY.

TSC occurs in all races and ethnic groups and in both males and females.

About 1/3 of people with TSC inherit the disease, while the other 2/3 result from a spontaneous mutation.



Approximately 50,000 in the United States have TSC.

TSC affects an estimated 1 in 6,000 live births.

Autism occurs in about 50% of people with TSC.

TSC impacts no two people in the same way – even identical twins.

Since 1984, the TSC Alliance has funded more than **$37 million** to further basic, translational and clinical research. But much more research is needed to identify new treatments and, one day, a cure.

Currently, there is no cure for TSC.

About the TSC Alliance

The TSC Alliance® is an internationally recognized nonprofit that does everything it takes to improve the lives of people with tuberous sclerosis complex (TSC). We improve quality of life for everyone affected by TSC by catalyzing new treatments, driving research toward a cure and expanding access to lifelong support.

TSC is a rare genetic disease that causes tumors to grow in different organs, from the brain and heart to the lungs and kidneys to the skin and eyes. Nearly one million people worldwide have TSC. Some live independently with few symptoms while others require complex care.

We are a source of hope and connection for all affected by TSC. We drive research, increase care quality and access and advocate with and for people affected by the disease. Through our collaboration and partnerships, we've advanced FDA-approved treatments and created support systems around the world so no one has to navigate TSC alone.

The TSC community is our strongest ally. With the power of families and the support of donors, volunteers, researchers, educators, industry partners and more, we can create a future where everyone with TSC can realize their full potential—no matter how complex their journeys are to get there. **Join us at tscalliance.org or contact us at info@tscalliance.org.**

What differentiates the TSC Alliance

The TSC Alliance is a model nonprofit in the rare disease research and support sector. Here are some ways we have demonstrated our unique ability to reach our constituents and impact their quality of life.

Facilitated
3,473
peer-to-peer connections in 2024, helping to reduce the stress and anxiety of a TSC diagnosis and provide ongoing support.

Established and built the first TSC Natural History Database, as well as a TSC Biosample Repository, and brought together a consortium of researchers who completed the first preventative clinical trial in both TSC and epilepsy.

1.1
billion
media impressions in 2024 dramatically increasing the visibility of TSC.

Raised
$19.2
million
from 1,800 engaged donors and community members since 2019 to accelerate research with the goal to change the course of TSC.

Galvanized the TSC community, and through their advocacy efforts, the Department of Defense Congressionally Directed Medical Research Program has appropriated

$121 million

toward TSC research since 2002.

Within our 14 Community Regions, **140** active leaders helped cultivate and mobilize more than **2,500** participants at volunteer-led, TSC community events.

Worked to support the FDA approval of **3 drugs** to treat TSC symptoms.

GREATNONPROFITS 2024 TOP-RATED NONPROFIT

Platinum Transparency 2024 Candid.

BBB ACCREDITED CHARITY

Charity Navigator FOUR-STAR