

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.

Founded in 1974, the TSC Alliance will celebrate 50 years of progress and promise throughout 2024 by highlighting milestones and accomplishments from the past while also looking forward in our quest to create a future where everyone with TSC has what they need to live their fullest lives.

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
4,278

peer-to-peer connections in 2023, 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.

Raised
\$29
million

from more than 1,000 engaged donors and community members since launching the Unlock the Cure research funding campaign in 2011, thereby advancing TSC research.

812
million

media impressions in 2023 dramatically increasing the visibility of TSC.



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

\$113 million

toward TSC research since 2002.

Grew our volunteer base from
95 to more than **2,500**
volunteers, highlighting our
community-building expertise.

