

A place of hope...



The TSC Alliance is here to help!



How do I keep up to date?

Simply join our mailing list at tscalliance.org/join to get the latest information, obtain research updates, learn about upcoming special events and educational opportunities, subscribe to our magazine and much more.



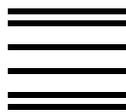
Hope no matter how complex™

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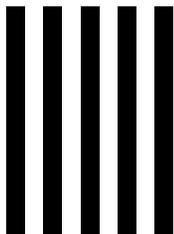
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About the TSC Alliance

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 are a source of hope and connection for all affected by TSC. We drive research, increase care quality, improve 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 that 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](https://tscalliance.org) or [contact us at info@tscalliance.org](mailto:info@tscalliance.org).

What is tuberous sclerosis complex?

Tuberous sclerosis complex (TSC) is a rare genetic disease that affects people at all stages of life. Every individual's experience with TSC is different—many live independently while others require complex care. The TSC Alliance is working toward a future where every person and family affected by TSC has what they need to live their fullest lives. TSC causes tumors to grow in different organs and can impair their function, primarily the brain, heart, kidneys, skin and lungs.

Changes in the brain caused by TSC have the biggest impact on quality of life, from seizures and developmental delays to intellectual disabilities, behavioral challenges and autism. TSC is the leading genetic cause of epilepsy, including infantile spasms. A strong correlation also exists between TSC and autism—an estimated 40-50% of individuals with TSC have autism spectrum disorder.

TSC is a complicated disease. Some people live with few symptoms while others need continual support. Most people with TSC live normal lifespans. Too often, TSC goes undiagnosed. But we know at least two babies born each day in the United States will have it. Nearly one million people worldwide are estimated to be living with TSC, with approximately 50,000 in the United States. The TSC Alliance connects them.

Where do I learn more?

The **TSC Navigator** at tscalliance.org/tscnavigator is an easy-to-use online tool to help guide individuals and families through the complexities of TSC across the lifespan, proactively manage their care and live their fullest lives.

In addition, our website at tscalliance.org is the world's leading resource for information and support for individuals with TSC and their families, as well as healthcare providers and researchers. The site is packed with information including the

latest clinical research and treatments, a wide variety of downloadable publications, several educational videos and much more.

What if I have questions about TSC?

For those newly diagnosed with tuberous sclerosis complex or who have a general medical question, feel free to contact Ashley Pounders, MSN, FNP-BC, Director of Medical Affairs, at 800-225-6872 (toll-free), 301-562-9890 or apounders@tscalliance.org.

For after hours assistance (Mon-Fri 6-9 pm ET or Sat-Sun 9 am-9 pm ET), please call 240-463-7250.

What if I'm an adult with TSC?

The TSC Alliance offers several resources for adults with TSC, including an Adult Regional Coordinator program comprised of adult volunteers who are available to provide peer support and answer questions you may have. In addition, tscalliance.org/adults offers additional information, publications and other tools such as how to find a doctor.

How can I connect with others with TSC?

Peer support is extremely helpful for anyone living with TSC. Therefore, the TSC Alliance offers several ways for you to find others impacted by the disease, including:

- **TSC Connect** is an organized partnership of individuals whose lives have been affected by TSC. These volunteers are committed to offering support and sharing their experiences with others who are faced with the challenges of TSC. Volunteers come to the network with a wealth of knowledge, awareness and experiences. TSC Connect is designed to connect individuals either by specific geographical area, manifestations, or age of TSC individual or by specific needs such as help with the school system or transition resources. If you want to reach a TSC Connect volunteer, simply call 800-225-6872.
- **Social Media:** TSC Alliance social networks—such as Facebook, Instagram, Twitter, LinkedIn, YouTube and Inspire—easily and quickly help you connect with others online. Find them at tscalliance.org/getsocial.
- **Community Alliances** provide support and local resources for the TSC Alliance. Currently more than 36 Community Alliances are spread across the United States, led by empowered and caring volunteers who work closely with the national organization to facilitate local connections for those affected by TSC, raise revenue and increase awareness. Learn more at tscalliance.org/local.

Please send me a free information packet and add me to your mail list, which includes a free subscription to the TSC Alliance's magazine, *Perspective*. (US residents only.)

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ E-mail address: _____

Connection to TSC:

Parent/caregiver. My child with TSC was born in _____ (year).

Adult with TSC. I was born in _____ (year).

Grandparent Sibling Relative

Healthcare professional Educator

Other: _____



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