



# Adults with TSC

Because rare diseases really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

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## Giving...

**T** The **Tuberous Sclerosis Alliance** is dedicated to being a resource for all affected with the condition. Take advantage of the site and its offerings at [www.tsalliance.org](http://www.tsalliance.org)

**H** Never forget to have **hope** and seek **help**. A new medicine, a new treatment, a new support group may be around the corner. Keep looking and stay fresh in your thoughts.

**A** For **adults**, the network is strong. Join our free informational calls to discuss issues pertinent to you. To participate in the calls, use the toll-free call-in number: 1-866-613-5223 then enter access code: 4334003#. Or you can connect with another adult by contacting an Adult Regional Coordinator in your area. <https://www.tsalliance.org/individuals-families/adults/adult-regional-coordinators/>

**N** One manifestation of TSC is **neuropsychiatric** disorders. TSC-Associated Neuropsychiatric Disorders (TAND) includes a wide range of cognitive, behavioral and psychiatric manifestations. TAND describes the interrelated functional and clinical issues of brain dysfunction in TSC. It was a very popular session at the 2018 World TSC Conference earlier this year. You can find videos on TAND and access the TAND checklist at <https://www.tsalliance.org/tand>

**K** Check your **kidneys**, one of the organs affected because of TSC. Regular checkups are the most important thing you can do regarding all your affected organs.

**S** For young adults, **school** issues can be a primary concern. Go to <https://tsalliance.org/schoolissues> to help you navigate in the educational system, from elementary school to college level.



## Adult Resources



### YOUR VOICE NEEDED BY NOV. 30

Adults between 18 and 45 are being asked to take part in a survey conducted by Diane Biederman, a genetic counseling student at the University of South Carolina. The goal is to understand how TSC affects daily lives, including decisions on family planning. The survey takes about 10 minutes to complete and participants have the opportunity to enter a drawing for a \$25 Amazon e-gift card.

To participate in this survey, please go to:

[https://www.surveymonkey.com/r/Adults\\_with\\_TSC](https://www.surveymonkey.com/r/Adults_with_TSC)

### CONSIDER VOLUNTEERING

The TS Alliance seeks volunteers to facilitate local connections for those affected by TSC, raise revenue and increase awareness. There are several ways to participate: TSC Connect; The Step Forward to Cure TSC Walks; Community Alliances; the Government Action Team; the Junior Leader Program.

### READ THIS BLOG

Rylee Grandia is a young adult living with TSC. She is a TS Alliance Junior Leader who is speaking up about her experiences living with TSC and she is using her diagnosis to help others. You can access her blog at <https://thelifeofrytsc.blogspot.com>

## My Journey with TSC.... Mary Brand

Last month's adult call featured Mary Brand of Texas. Her journey with TSC started with a misdiagnosis. Her seizures started at 11/2 years of age and doctors were stumped. Her family moved around a lot as her father was in the military, they even spent time overseas. She found her love of writing as a child. A turning point came at age 7 when she suffered a 3-hour grand mal seizure. Learning difficulties became part of the norm, and speech and physical problems started. But she persevered and while she had trouble with math and science, writing was her passion as were singing and performing in Community Theater. That is where she found her creative outlet and people with whom she could relate. She met her husband as well. Her TSC problems continued with brain surgery at age 40 to remove a giant cell astrocytoma and she regrouped. She takes multiple medicines daily but her next goal: To write a romance novel. All the best, Mary!