



Tuberous Sclerosis Alliance

# Adults with TSC

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Because rare diseases  
really aren't that rare.

#IAMTSC



## ‘Part of a community, part of a purpose’

Mackenzie Moore knows all too well the struggles of **Tuberous Sclerosis**. “My life changed forever,” she says of learning she had the condition at 19 years of age. For years prior, Mackenzie suffered from severe headaches and migraines. No one could pinpoint why she was having such difficulty, and medicines were failing her. In March 2009, she had her first grand mal seizure. She was able to secure an appointment with doctors at UCLA, and was diagnosed with **TS**. By the following March, doctors would discover where her seizures were occurring and by mid-year, she would undergo two brain surgeries.

Still, Mackenzie battles with headaches, as well as anxiety, a new seizure type, gastrointestinal problems and hearing loss. But she continues to search for solutions and to better understand **TS**. “I know my body,” Mackenzie says, “and I have had to go through quite a lot in my life.”

Maneuvering through life and dealing with **TS** can be hard, and she is the first to say it. But what she has found extremely beneficial is the annual TS Alliance Step Forward **for A Cure** walk, held annually throughout the country **by various Alliance chapters**.

“It’s the only opportunity to be part of a community, part of a purpose, with people you belong with, who get the struggle,” she says. Meeting many people and being able to connect with others helps better inspire her, and “to remind me to be thankful.”

## The 2018 World TSC Conference is here!

Dallas, Texas is the host city. July 26-29. The latest and most comprehensive TSC diagnosis, treatment and research information will be unveiled. Next month’s newsletter will feature several highlights related to issues faced by adults living with TSC. The sessions focus on management of TSC as an adult; current clinical studies and updates on new treatment options; reproductive issues; lung involvement; seizure management and mental health issues. Stay tuned.

### Adult Resources



#### **CBD CLINICAL TRIAL CURRENTLY**

**RECRUITING:** Cannabidiol Clinical Study for TSC and Epilepsy (ages 1-65 years old)

A double-blind, randomized, placebo-controlled study to investigate the efficacy and safety of cannabidiol as add-on therapy in patients with Tuberous Sclerosis Complex who experience inadequately-controlled seizures.

For more information about this study being conducted in the United States, please go to <https://www.tsalliance.org/wp-content/uploads/2016/11/GW-Pharma-CBD-epilepsy-trial-ad-revised-6.25.2018.docx>

#### **READ THIS BLOG**

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