



# Adults with TSC

Because rare diseases really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

April 2018

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## Social Media Adult Regional Coordinator

My name is Danielle Clark and much to my surprise, I was diagnosed with Epilepsy at 26 years old. I had my first complex partial seizure when I was on a walk with my boyfriend who is now my husband. He said I was making noises, had a blank stare and when I 'came back', I didn't remember any of it. At the time, I was working in a small hospital outside of San Antonio, and my co-workers told me that I was doing the same thing in the office multiple times a day. I was at a loss, confused, and not sure where this was coming from. The only thing different in my life, at that time, was that I had started taking birth control pills. The logical thought was maybe this was a response to the medication. Someone, suggested I see a Neurologist in my small town and when I showed him a calendar I kept with all the "blank stares" I was having, he immediately said they were seizures. I was in SHOCK! Where had they come from? Was it "the pill"? He said no and wanted to do a sleep study. What is that? I had SO many questions, and no resources. The sleep study was inconclusive so he referred me to a Neurologist in San Antonio. This Neurologist was affiliated with the medical school here and he had a lot of interns with him when he saw me. He saw "white spots" on my body which I have always had, but my pediatricians could never tell my parents what they were. Seeing the spots combined with the records from my small town Neuro, he said, "You have Tuberous Sclerosis".... WHAT IS THAT????? He also did all the radiology testing to confirm, EMU, MRI, etc. and I was grilled by the Med students... it was exhausting.

I WISH I'd had someone to turn to and ask questions. I went from a healthy childhood, with chickenpox, and a broken wrist in college to Epilepsy and a disease I couldn't spell or pronounce? Needless to say, it has taken me many years to come to terms with my diagnosis. My current Neurologist is wonderful! She requests radiology orders from my Internal Medicine MD to check on my kidneys, lungs, etc., since my Internal Med is not familiar with TSC. At the time of my diagnosis, I wish I knew about the Alliance or had gone to Epilepsy support groups, to ask questions, to know more and know I wasn't alone. Later I did find out that "the pill" can trigger seizures in a brain with Tubers. So, my Neuro was wrong. I was SO firm in that, the pill was the ONLY thing that was different in my life and was certain it was the medication, despite what they said. This is another reason, I'm a big advocate for Patients' rights. We need to self-advocate, always!

I'm volunteering and sharing my story because we are all different, but the same in many ways. We are a community of questions and answers. Finding answers and supporting each other.... That is why I'm here. My new position as a Social Media Adult Regional Coordinator is to support the Adult Regional Coordinators and adults within the TSC community.



- Danielle Clark Social Media ARC

## Adult Resources

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### -- Upcoming Adult Topic Calls

- Thursday, April 19, 2018  
"My TSC Journey"  
Katie Maciulewicz-Gass
- Thursday, May 17, 2018  
"My TSC Journey"  
Makenzie Moore
- Thursday, June 7, 2018  
"Open Forum"

Adult Regional Coordinators

Call-in number: 866-613-5223

Access Code: 4334003#

Time: 8:00 P.M. (Eastern), 7:00 P.M. (Central), 6:00 P.M. (mountain), 5:00 P.M. (Pacific)

- Fall issue of the TS Alliance *Perspective* is here:

<http://online.fliphtml5.com/tosk/tkan/>

- A blog written by Rylee Grandia, the Junior Leader focusing on the perspective of a young adult:

<https://thelifeofrytsc.blogspot.com/>

- Link to locate your Adult Regional Coordinators:

<http://www.tsalliance.org/individuals-families/adults/adult-regional-coordinators/>

- **World Conference** in Dallas Texas, July 26-29, 2018. For more information go to:

<http://www.tsalliance.org/2018-world-tsc-conference/>

- **Comedy for a Cure in LA** earlier this month raised \$256, 705. To see pictures from the incredible night click on the link:

[https://www.facebook.com/pg/TSCComedyForACure/photos/?tab=album&album\\_id=1600774913324177](https://www.facebook.com/pg/TSCComedyForACure/photos/?tab=album&album_id=1600774913324177)

- If you have any questions please contact Dena Hook, Vice President of Support Services, at: [dhook@tsalliance.org](mailto:dhook@tsalliance.org)

