

# Adults with TSC

Because rare diseases really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

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## Upcoming 2018 TSC World Conference

The 2018 World TSC Conference in Dallas Texas is quickly approaching July 26<sup>th</sup>-29<sup>th</sup>. It is going to be an incredible few days where specialist from around the world will gather to share exciting research, the latest treatments and explain the wide range of manifestations. There are different tracks available with **Track C focusing on adults**. These sessions will touch 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.

Besides the incredible sessions led by the best specialists from around the world, the World TSC Conference allows individuals an opportunity to connect on a personal level. The first night of the conference there will be a meet and greet for adults with TSC and their spouses. Then each night, after a day of sessions, there will be adult gatherings where individuals can discuss the topics of the day, share their journeys or simply enjoy downtime with lots of fun and laughter.

I had the opportunity to attend the last World Conference 4 years ago and it was life changing. I knew going in that I was going to come away with an incredible amount of information, but had no idea how much I needed the personal connections. For the first time in my life I was surrounded by others that really understood my journey and lifelong friendships were made. For more information including a complete agenda go to:

<http://www.tsalliance.org/2018-world-tsc-conference/> or register at: <http://www.cvent.com/events/2018-world-tsc-conference/event-summary-44f4bd32dfd0409792e43183948ac79d.aspx>

- Shannon Hanks-Grandia, ARC



## Adult Resources



### -- Upcoming Adult Topic Calls

- 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/>

### - Upcoming TSC Walks:

Chicago, IL on June 2<sup>nd</sup>

Long Beach, CA on June 9<sup>th</sup>

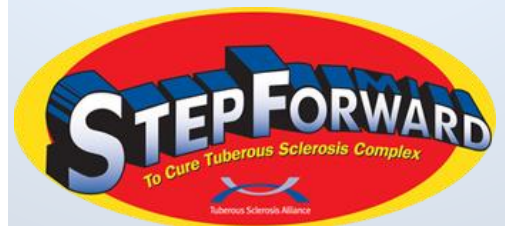
Lansing, MI on June 9<sup>th</sup>

Evendale, OH on June 10<sup>th</sup>

Mint Hill, NC on September 8<sup>th</sup>

To register for an upcoming walk go to:

<http://giving.tsalliance.org/site/PageServer?pagename=Step17> Register



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