



# Adults with TSC

Because rare diseases really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

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## Support, Strength Solidarity, Success

The 2018 World TSC Conference was held at the end of July in Dallas, Texas. More than 800 people (mostly individuals with TSC and their parents) attended what was a most informative event. Twenty-seven countries and 41 states were represented. Discussions were held on: the global status of TSC, including diagnosis, surveillance and treatment; the path to new drugs for TSC; preventative trials and cannabidiol (CBD) treatments; the potential for personalized medicine; and TSC-Associated Neuropsychiatric Disorders (TAND). In coming newsletters, we will expand upon issues pertinent to you!

Recordings of the general sessions are available on The TS Alliance web site:

<https://www.tsalliance.org/2018-world-tsc-conference-general-session-livestreams/>

*Adult Regional Coordinators gather after a session on TSC-Associated Neuropsychiatric Disorders (TAND) moderated by Dr. Petrus de Vries. From left: Shannon Grandia, Brooke Simsa, Rob Grandia, Kathy Henkel, Dr. Petrus de Vries, Jake Irby (back), Scott Moskowitz and Seth Fritts. For more information on TAND and to download the TAND checklist and read the behaviors associated with TSC, go to [www.tsalliance.org/tand](http://www.tsalliance.org/tand)*



It was my honor to attend the TSCWC. Even after volunteering for 38 years, I still tear up. Thank you so very much to each and every person and their hard work and time for making it such a success! To see so many there and, more importantly, to see so many emotions and hear stories - from new parents to an adult diagnosed in her 50s. Reuniting with people from 20 years ago, to meeting those for the first time. Seeing the adult initiative a reality now. I was proud to speak with my ARCs with Dr. Petrus de Vries on a panel to honor the memory of Keith Hall. The joy I had from my husband, daughter and SIL there was my highlight. Please take advantage of the recordings.

- **Kathy Henkel ARC for Region 8 (Delaware, Virginia, West Virginia, Maryland, North Carolina, South Carolina, Washington, DC)**

My highlight was bringing my wife into "my world" to meet my family of ARCs and my extended family of the hundreds at the conference. Along with and better than that is that she found out what I was going through as someone with TSC from all angles by the sessions we attended.

- **Scott Moskowitz, ARC for Region 7 (Connecticut, Vermont, Maine, Rhode Island, New Hampshire, New York, New Jersey, Massachusetts)**

## Adult Resources



### MARK YOUR CALENDARS

#### Free Adult Informational Call

On Thursday, Sept. 13: My TSC Journey by Mary Ann Scroggins. 8 pm (Eastern), 7 pm (Central), 6 pm (Mountain), 5 pm (Pacific).

To join, use the toll-free call-in number, 1-866-613-5223, enter access code 4334003#. Each call lasts 1 hour. Please note time zones and start times.

#### Step Forward To Cure TSC Walks

Mint Hill, North Carolina: Sept. 8

Long Island, New York: Sept 22

Pittsburgh, Pa.: Sept. 29

Clark, New Jersey: Sept. 30

Las Vegas, Nevada: Oct. 13

Visit [stepforwardtocurets.org](http://stepforwardtocurets.org) to find a walk near you!

#### TS Alliance Benefit

Friday, Sept. 14 at 7 pm at Barnaby's in Aston, Pa. Team Lyons Pride is hosting event. Open bar, live music, food, prizes - \$35 per person. All proceeds go to The TS Alliance. Visit <http://giving.tsalliance.org/goto/lyonsroar>