



Adults with TSC

Because rare diseases
really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

February 2018

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Adult Initiative

Over the years the TS Alliance has acknowledged the need to support adults living with TSC and in 2002 the Adult Initiative was developed. The purpose of the initiative is to reinforce the TS Alliance Mission statement, "Find a cure for TSC while improving the lives of those affected."

The goals of the Adult Initiative are:

- Ensuring that every individual with TSC receives the best care and support possible throughout their life.
- Improving the quality of life for adults with TSC and empowering each individual to have the best and most productive life possible.
- Advancing our knowledge of TSC as it affects adults with the disease: and
- Become active in helping to search for ways to improve treatments and change the course of the disease.

There are 5 steps to the Action Plan that was developed:

- 1) Develop a support network for adults with TSC.
- 2) Access to the best clinical at the TSC Clinics nationwide and/or through consultations with TSC clinic physicians and TSC experts.
- 3) Natural history studies to identify the impact of TSC throughout the lifespan and registry to identify individuals eligible for clinical studies and clinical trials.
- 4) Advancing our knowledge of TSC as it affects adults with the disease.
- 5) Searching for ways to improve treatments and change the course of the disease.

The adult task force, which led to the Adult Regional Coordinators are a product of this initiative along with the Adult Topic Calls. In addition, this upcoming year, Community Alliance Chairs and Walk coordinators are being encouraged to work with the Adult Regional coordinators to ensure adults are aware of upcoming events and supported.

One more exciting step towards the initiative is the upcoming World Conference in Dallas, Texas on July 26-28. There is a track dedicated to adults (**Track C: Adults** —These sessions 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.)

Moving forward there is still a lot of work to do. Every individual and caretaker with TSC can make a difference by attending community events, local walks, volunteering, participating in studies, completing surveys by the TS Alliance when they appear via email or social media and sharing their stories.

To access the Adult Initiative in its entirety go to: <http://online.fliphtml5.com/tosk/qjax/#p=2>

- Shannon Grandia ARC

Adult Resources



-- Upcoming Adult Topic Calls

- Thursday, March 29, 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)

- Recording of February's Adult Topic Call: Dealing with Personal Tragedy
<http://www.tapeacall.com/7kac748buq>

- World Conference in Dallas Texas, July 26-29, 2018. For more information go to:
<http://www.tsalliance.org/2018-world-tsc-conference/>



- 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/>

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