



# Adults with TSC Newsletter



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Issue 46

## COVID-19 Updates

The Tuberous Sclerosis Alliance is here for you during the COVID-19 pandemic. For ongoing updates about COVID-19 and other TS Alliance resources, please visit [www.tsalliance.org/COVID-19](http://www.tsalliance.org/COVID-19).

## Adult Resources

### Upcoming Adult Topic Calls:

#### Thursday, June 25, 2020:

“Open Forum” presented by Adult Regional Coordinators

All Adult Topic calls start at 8 pm Eastern, 7 pm Central, 6 pm Mountain, 5 pm Pacific.

You can join the call using your computer or dialing in on the phone. **You need to register in advance to participate in the call.**

**You can register by clicking here.**

After you register you will be sent a confirmation email with details on how to join the call. Also, remember to add the call to your calendar after you register. Each call's length is one hour.

If you have questions or would like to receive handouts (if available) before each call, contact Dena Hook at [dhook@tsalliance.org](mailto:dhook@tsalliance.org) or (800) 225-6872.

## Coping with Anxiety as an Adult with TSC

By Rita Mason

Anxiety. A seven-letter word that carries with it such power. Power that can debilitate anyone, at any given time, on any given day.

In the TSC community, it is one of the largest components of the condition.

Karen Agricola led the discussion on anxiety in this month's Adult Information Call. Agricola has been one of the advanced practice registered nurses or nurse practitioner for Cincinnati

Children's TSC Clinic since 2007. She works closely with all its specialists in crafting and modifying treatment plans for people with TSC.

She stated during the call that being monitored for the physical manifestations of TSC is required. But recently, more exposure is also being given to the neurological manifestations, such as epilepsy, ADHD, intellectual disabilities and autism. And now TSC providers are being

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TSC Now is the TS Alliance's podcast series!

[Check out the last episode!](#)

## Additional Resources

TSC Talks, a podcast hosted by Jill Woodworth, explores tuberous sclerosis complex and other related issues. Each week Jill talks to parents/caregivers, adults affected by TSC, and other professionals about their experiences managing TSC, the challenges they've faced and where they find hope.

[Listen to the latest episode now](#)



TSCMatters

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given a new tool in the name of TAND.

What is TAND? It stands for TSC-Associated Neuropsychiatric Disorders. It was developed to help providers and their patients navigate behavioral and mental-health issues. It is now recommended that upon diagnosis, an individual be screened for TAND and again at least annually.

Sound advice seeing as anxiety affects 90 percent of individuals with TSC. Along with anxiety, other top-rated neuropsychiatric issues include depression, ADHD and aggressive disruptive behavior.

The TAND checklist, which can be found on the TS Alliance website, is “vital in helping individuals and providers to begin a conversation” and move forward with the correct treatment, Agricola said.

Anxiety can be problematic when excessive and uncontrollable. Edginess, restlessness, fatigue, impaired concentration, irritability, increased muscle soreness and trouble sleeping are other avenues. Panic disorders, phobias and obsessive-compulsive disorder may also occur.

Treatment, and hopefully treatment early on, for anxiety can begin with a primary care doctor or your TSC specialist, but must be part of a whole-body approach. For example, anxiety is found to be extremely common in TSC individuals who have epilepsy. Seizure medications that have a mood stabilizer aspect can help treat epilepsy and anxiety.

Another common pharmaceutical drug used in the treatment of TSC, Wellbutrin, also helps with depression.

Agricola stresses the whole-body approach. Tests such as MRIs can reveal something physical that might be leading to fatigue. Follow the steps: an MRI shows a bleed in the brain, which causes blood loss, which can lead to anemia which then causes fatigue. Toxic drug levels or an issue with thyroids lead to anxiety for edginess.

Once the medical route is established, then it is incumbent upon the individual to find other avenues for treatment.

Therapy can be very helpful. Support groups can be helpful in giving social benefits for someone dealing with depression. Exercise is key: walking outside is a huge mood boost and changes your body metabolically. Solid sleep patterns and finding a routine are also important.

The current COVID-19 crisis was also mentioned as a source of anxiety, and Agricola said to be sure to follow the safety guidelines, know your limits and take deep breaths to stymie the fears.

You can find additional information and the TAND checklist at [www.tsalliance.org/tand](http://www.tsalliance.org/tand).

**For more adult resources including previous issues of the Adults with TSC Newsletter, information on reproductive health and contact information for your Adult Regional Coordinator, check out the Adult page on the TS Alliance website [here](#).**