



# Adults with TSC Newsletter



May 2019

Issue 39

## Caring for the Whole Patient

Rita Mason

It has a name: TSC-Associated Neuropsychiatric Disorders (TAND).

It has a face behind the name: Dr. Tanjala Gipson, a pediatric neurologist and neurodevelopmental specialist at LeBonheur Children's Hospital at the University of Tennessee.

And it has beneficiaries: Us. Those of us in the TSC community, whether we are an individual with TSC, a parent or relative of someone of TSC, or a person working with those who have TSC.

What is TAND and why is it so beneficial? It is an "umbrella term" for behavior, both neurodevelopmental and neuropsychiatric, says Dr. Gipson, who helped spearhead the development of the checklist. She spoke in April on a free informational call geared to adults as part of the TS Alliance's community outreach.

Somewhat new in the world of TSC, TAND describes the interrelated functional and clinical manifestations of brain dysfunction in TSC, including aggressive behaviors and autism, as well as school and occupational difficulties.

"It is different to treat these conditions," says Dr. Gipson. "For example, anxiety in someone with TSC is not the same as anxiety in someone without TSC." In some cases, there might be language impairment, where the

person has trouble understanding social cues. Or, there might be an escalation of anxiety after seizures have resolved; anxiety might present as aggression if the individual is nonverbal. Also, managing medicine is especially important because certain medications might not help a person with TSC as it does in the general population.

But as Dr. Gipson said on the phone, "You guys teach me so much, you are the experts." She says what she has learned while participating in TSC conferences and meeting TSC families and individuals has been invaluable. It is what cemented her staying in the TSC world to combine her love of neurology and neurodevelopment.

Some of her recommendations in trying to combat an issue like anxiety: managing medications carefully with a TSC doctor; exercise; engaging with family and friends for support; planning out the week or the month to better prepare for situations that might cause stress; and protecting yourself and helping yourself self-advocate at work or in school.

For more help, the TAND checklist is a framework and vital in the care of TSC. You can find it and additional resources at [www.tsalliance.org/TAND](http://www.tsalliance.org/TAND).

## Adult Resources

### Upcoming Adult Topic Call

Thursday, June 6, 2019

"Open Forum," presented by Adult Regional Coordinators, 8 pm Eastern, 7 pm Central, 6 pm Mountain, 5 pm Pacific

To participate simply use the toll-free call-in number: 1-866-613-5223 then enter access code: 4334003#. 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.

**For more adult resources including recordings of past topic calls, information on reproductive health and contact information for your Adult Regional Coordinator, check out the Adult page on the TS Alliance website [here](#).**

**Questions?** Contact Dena Hook, Vice President, Support Services, at [dhook@tsalliance.org](mailto:dhook@tsalliance.org).



TS Canada ST will be hosting an [Educational Meeting](#) on Saturday, June 22 in conjunction with the [2019 International TSC Research Conference](#) in Toronto, Canada. [Learn More](#)

## Upcoming TS Alliance Events



The second Regional TSC & LAM Conference will be held Saturday, June 15 in St. Louis, Missouri. To learn more about the Regional TSC & LAM Conference Series and to register [click here](#).



**Upcoming Step Forward Walks:**  
[Saturday, June 1 - West Chester, PA](#)  
[Saturday, June 8 - Lansing, MI](#)  
[Saturday, June 8 - Northglenn, CO](#)  
[Saturday, June 8 - Long Beach, CA](#)  
To find a walk near you [click here](#).