



Tuberous Sclerosis Alliance

# Adults with TSC

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Because rare diseases really aren't that rare.

#IAMTSC



## A Work in Progress

### *Seizure management and impact on quality of life*

**Dr. Peter B. Crino**, chair of the department of neurology at the University of Maryland's School of Medicine, led an informative session at the 2018 World TSC Conference on the management of seizures, the maintaining of quality of life, and the strides being made in epilepsy treatment. The nuances of TSC are many, from those who are mildly affected to those more severe. For Dr. Crino, while the goal of therapy is "no seizure," the conversation should be more directed toward what is acceptable quality of life and the controlling of seizures to the best level for the individual.

"In TSC, frank conversations are necessary," he said. His job in meeting an adult for the first time is to set the stage to recalibrate what the future holds. "We haven't necessarily failed," he said, it's just finding the right treatment – from which medicine or medicines will work, to what are the side effects, to what can the patient live with to maintain a proper being.

The session started with learning the basics of TSC. One thing is certain - Epilepsy is a chronic disease within TSC and 70 percent to 90 percent of individuals with TSC experience seizures, an electrical disturbance of brain function. What a patient does during such an event can affect quality of life. A drop seizure and the frequency of those events will greatly affect daily life activities, while an absence seizure may not be as detrimental. And because the nature of seizures is erratic and ever-changing - for example, you may have had seizures as a child and they went away for years only to return in your 20s, or puberty and menopause enter into the equation - the treatment must change.

Tubers in the brain, he said, are generally believed to the cause of seizures. The conception that tubers in the brain compare to Rocky Road ice cream is false. Study of brain resections have shown that there are smaller areas in the brain matter that are abnormal and contribute to the misfiring.

Once clinical diagnoses are made and routine testing achieved, talk between a neurologist and a patient focuses on what kind of treatment is best. And there are many: Afinitor, CBD, epilepsy surgery, vague nerve stimulator, special diets. The message remains: Clear conversations, realistic goals for quality of life, and control of seizures. It can be done!

The conclusion of the session introduced guests to Jennifer Waldron, a TSC warrior and Chair of The TS Alliance of Connecticut. She has been seizure free for 6 years. The changes in her quality of life as an adult have included: limiting her time outside in the heat; limiting alcohol and caffeine; getting enough rest; and taking her medicine on time every day. Perhaps her biggest advice is to listen to the professionals but also to be an advocate for yourself.

Please visit: <https://www.tsalliance.org/2018-world-tsc-conference-videos/> for Dr. Crino's session and many more.

#### Epilepsy in TSC

- Epilepsy is a chronic disease within TSC
- High incidence 70-90% of TSC individuals
- Most common genetic cause of infantile spasms
- Can you develop seizures as an adult with TSC?
- -YES, you can develop seizures at any age in TSC
- Can seizures go away then return?
- -YES, seizures do what they want.....
- Can you have multiple seizure types?
- -YES, and these can change
- Are all seizures in TSC medically refractory?
- -NO, many individuals are successfully treated with medications

***NEXT MONTH: Genetics, Reproductive Issues and the Impact on Relationships.***

### Adult Resources



#### YOUR VOICE NEEDED

Adults between 18 and 45 are being asked to take part in a survey conducted by Diane Biederman, a genetic counseling student at the University of South Carolina. The goal of the anonymous survey is to understand how TSC affects daily lives, including decisions on family planning. The survey takes about 10 minutes to complete and participants have the opportunity to enter a drawing for a \$25 Amazon e-gift card.

To participate in this survey, please go to:

[https://www.surveymonkey.com/r/Adults\\_with\\_TSC](https://www.surveymonkey.com/r/Adults_with_TSC)



**2018 - 19 Junior Leader Program**  
Application:  
Deadline: October 5, 2018

#### Program Description

Launched in 2016, the Junior Leader Program was designed with post-high school education in mind-whether it's attending a trade school, obtaining certification or earning an associate's or bachelor's degree. The TS Alliance offers this opportunity for young adults with TSC, or their siblings, to get involved with local Community Alliances to offer support while raising awareness for TSC. Throughout the school year, program participants will complete a series of awareness and support activities, concluding with an exit interview with their TS Alliance staff mentor. 2018 marks the third year of this program and our five previous Junior Leaders created opportunities in their communities for young adults with TSC and their siblings to interact with one another, attended our March on Capitol Hill and provided critical perspective on the unique challenges faced by individuals with TSC as they transition into adulthood.

#### How to Apply

Seven applicants will be accepted into the program during the 2018-2019 school year. Application Deadline is October 5, 2018.

Please visit [www.tsalliance.org/juniorleader2018](http://www.tsalliance.org/juniorleader2018) to apply.

If you have any questions please email April Cooper, Director, Community Programs, at [acooper@tsalliance.org](mailto:acooper@tsalliance.org) or call 240.258.7295.