



# Adults with TSC

Because rare diseases  
really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

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**HAPPY HOLIDAYS...  
AND MANY CONTINUED  
BLESSINGS IN THE NEW YEAR**



## Going Deeper To Unlock a Cure

The Tuberous Sclerosis Alliance is leading the way with its Biosample Repository, a research initiative that seeks to collect tissue and blood samples from individuals affected with TSC.

It was one of the topics discussed at the annual meeting of the American Epilepsy Society, held in New Orleans this month. The TSC Biosample Repository is governed and wholly funded by the TS Alliance thanks to generous support from Bill and Kristina Watts, the Cowlin Family Fund, the Engles Collaborative Research Fund, Jim and Andrea Maginn, and many additional donors through the Unlock the Cure campaign.

Dr. Peter Crino, director of the TS Clinic at the University of Maryland, is one of the researchers associated with this endeavor.

“The idea is that we do know the genes that cause tuberous sclerosis complex,” he said. “But there is much more than the genetic mutation.” Dr. Crino said that research is showing many other changes to the cells in affected individuals that can be evaluated. “The next level involves investigation into other systems in the body,” such as blood samples and tissue samples.

The goal is to collect more than 2,000 samples.

The TSC Biosample Repository houses human biological materials such as blood, DNA, and tissues linked to detailed clinical data in the [TSC Natural History Database](#). High-quality biosamples and their associated clinical data will enable researchers to discover biomarkers, establish human cell lines or tissue arrays for drug testing, and search for clues to understand why TSC is so different from person to person.

**If you would like more information about the Biosample Repository, please visit:** <https://www.tsalliance.org/individuals-families/biosample-repository/>.

### Adult Resources



#### CONSIDER VOLUNTEERING

The TS Alliance seeks volunteers to facilitate local connections for those affected by TSC, raise revenue and increase awareness. There are several ways to participate: TSC Connect; The Step Forward to Cure TSC Walks; Community Alliances; the Government Action Team; the Junior Leader Program.

Find out more at <https://www.tsalliance.org/volunteer>

You can also contact Dena Hook at:

[dhook@tsalliance.org](mailto:dhook@tsalliance.org) or  
1-800-225-6872, ext. 215.

#### READ THIS BLOG

Rylee Grandia is a young adult living with TSC. She is a TS Alliance Junior Leader speaking up about her experiences living with TSC and she is using her diagnosis to help others. Visit <https://thelifeofrytsc.blogspot.com>