



Tuberous Sclerosis Alliance

Adults with TSC Newsletter



March 2019

Volume 37

My Journey with TSC

With Damon Toroian

"Whatever comes up, we will deal with it," says Damon Toroian, 41, of California. "It changes for the better, it always does."

He was diagnosed at 3 years of age after having seizures. Thankfully, the neurologist was able to quickly diagnose TSC from Damon's seizures, his white skin patches, and the cysts on his face and nail beds. An MRI also discovered the tubers in his brain. Medicines controlled his seizures for a bit and when they would reappear, a change in dosage or a new medicine would allow for seizure freedom throughout his childhood.

Damon says his biggest hurdle in childhood and throughout high school was the social aspect. He says it was hard for him to talk with people and feel comfortable. Anxiety and depression would also be part of his TSC fabric. Academically, however, he thrived. He studied bioscience and went onto college, eventually receiving his PhD. In college, he was able to assimilate more socially and

was able to make good friends.

While in the PhD program at the University of California, his seizures started again but they were different. As a child, his seizures were short staring spells and he would rebound quickly with a medicine change. Now older, his seizures were becoming clusters with the individual seizures lasting longer. He also discovered issues with his kidney. His seizure clusters were affecting his quality of life – living alone was now an issue; he couldn't drive; and he lost his job. He would have a VNS implanted and brain surgery, and arthritis is entering the picture. But he's learning a lot as he tries to find seizure control and he's branching out: trying photography, playing guitar, exercising, and going to therapy. "It's worthwhile," he says of his therapy.

Next up for Damon is trying diet to help him control his seizures. The Modified Atkins Diet and the Ketogenic Diet are being discussed. He plans on starting one soon. He is not "letting anything stop me."

Adult Resources

Upcoming Adult Topic Call

Thursday, April 18, 2019

"Anxiety Issues in TSC," presented by Tanjala Gipson, MD, Director, TAND Clinic at LeBonheur Children's Hospital, at 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 or (800) 225-6872.

To find your Adult Regional Coordinator [click here](#).

Questions? Contact Dena Hook, Vice President, Support Services, at dhook@tsalliance.org.

Upcoming TS Alliance Events



The 18th Annual Comedy for a Cure will take place Sunday, April 7 at Academy LA in Los Angeles, California. To learn more and get tickets [click here](#).



The first Regional TSC & LAM Conference will be held Saturday, April 13 in Boston, Massachusetts. To learn more about the Regional TSC & LAM Conference Series and to register [click here](#).



Upcoming Step Forward Walks:
[Saturday, April 6 - Scottsdale, AZ](#)
[Saturday, April 27 - Houston, TX](#)
[Sunday, April 28 - Seattle, WA](#)

To find a walk near you [click here](#).