



# Adults with TSC



Tuberous Sclerosis Alliance

January 2019

Volume 35



## Strides & Pride

Our new #Step4TSC walk site featuring our new logo is now LIVE. Check it out and see if there is a walk near you: <http://www.stepforwardtocure.tsc.org>

## ‘My Journey with TSC’ series ... *With Kimberly Brenton*

“You can’t get caught up in the ‘what ifs,” says Kimberly Brenton, a 46-year old resident of Maine. She was the guest speaker in this month’s Adult Informational Call.

Brenton has TSC; she is the mother of a teenage daughter with TSC; and she has a mother with TSC. All three might be considered mild cases, all with varying manifestations of the condition, but for Brenton, “this could happen, that could happen, and I find that anything can happen with TSC.” But she cautions: if it is not happening now, then shelve it. Don’t ignore the issues related with TSC, she says, but don’t dwell either.

Brenton is a strong proponent of taking care of yourself and keeping up with the monitoring of the condition – both for herself and her daughter. (Brenton’s mother suffered seizures as a child but has not had one since Brenton was 12.) She had to learn that with herself and her daughter, who has been seizure free for a few years now, advocating is key to find the right support, be it from doctors or support groups and schools.

Even more important is living life. “I don’t wake up and think, am I going to have a seizure today?” Or for her daughter, who loves roller coasters and rides them. Brenton doesn’t stop her.

And while she admits she was overwhelmed at first, and has to deal with her anxiety or depression, Brenton really does take it one day at a time and finds solace in taking part in research studies and TSC groups. “I want to help people on the crazy journey and let them know they are not alone.”

Visit <https://www.tsalliance.org/individuals-families/adults/> to find more information on the free monthly calls.

## Adult Resources

...

### JOIN US IN TORONTO

The 2019 research conference is being held June 20-22 in Canada at the Chelsea Hotel Toronto. It is organized in partnership with Tuberous Sclerosis Canada Scélrose Tubéreuse and the TS Alliance of Mexico. For more information, visit: <https://www.tsalliance.org/sa-ve-these-dates-for-our-toronto-research-conference/>



### 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, including TSC Connect, the Government Action Team and the Junior Leader Program.

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

You may also contact Dena Hook at: [dhook@tsalliance.org](mailto:dhook@tsalliance.org) or 1-800-225-6872, ext. 215.

## SAVE THE DATE

COMEDY FOR A CURE WILL BE SUNDAY, APRIL 7, AT ACADEMY NIGHTCLUB IN HOLLYWOOD, CALIF. LEARN MORE AT [HTTPS://TSALLIANCE.SCHOOLAUCTION.NET/COMEDY2019](https://tsalliance.schoolauction.net/comedy2019)