

Adults with TSC F **Newsletter**







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Why I Volunteer

Daniel Price, Auxiliary Adult Regional Coordinator West

I was adopted from mainland China at three years old and diagnosed with TSC at six years old. My parents did not know about my condition until they had me evaluated by a dermatologist for the bumps on my face. I am now a young adult working part time in the travel/airline industry. I am also a young man who is gay and a supporter to the LGBTQ community who is just taking one day at a time.

I have been involved with the TSC community for about almost three years now. I have participated and volunteered a lot of my time Daniel Price at the 2018 World TSC Conference in Dallas. to the TSC community locally

and globally, spreading awareness and raising money to help find a cure. I started with the TS Alliance back in 2017 just trying to get answers about my health condition.



I then connected with the Cincinnati TSC Clinic and also with the TS Alliance of the Pacific Northwest and the TS Alliance in Maryland. One

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Adult Resources

Adult Topic Calls will return in September! Stay tuned for more information on the date and topic of the next call. You can listen to recordings of the previous topic calls here.

For more adult resources including previous issues of the Adults with TSC Newsletter, 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.

Upcoming TS Alliance Events



Get your tickets now for our 45th Anniversary Gala on Thursday, October 3, 2019 at the Edison Ballroom in New York City! **Learn More**



The third Regional TSC & LAM Conference will be held Saturday, September 7 in Chicago, Illinois. To learn more about the Regional TSC & LAM Conference Series and to register click here.



Upcoming Step Forward Walks: June 22 - Chicago, IL Walk September 7 - Charlotte, NC Walk September 14- Tulsa, OK Virtual

To find a walk near you click here.

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of the first events I ever attended was the TSC community picnic outside Seattle, Washington. There I meet Gloria Triebenbach and Debbie Rothweiler. the Chair and Co-Chair of the TS Alliance of the Pacific Northwest. At the event I connected and met other young adults and families



Daniel Price in his super hero garb at a Step Forward to Cure TSC Walk.

living with TSC. That is where I was inspired to engage with the TSC community even more.

When I reached out to the TS Alliance. I wanted to volunteer my time at the 13th annual Comedy for a Cure in Los Angeles, California. There I got to meet April Cooper, TS Alliance Director of Community Programs, as well as President and CEO Kari Luther Rosbeck, I also met Rob and Shannon Grandia, Adult Regional Coordinators. While volunteering for this charity event, I was able to meet other TSC families and join with them in raising awareness and donations for the work of the TS Alliance. Next year will mark three years volunteering at this event. Other volunteer opportunities have been Step Forward to Cure TSC walks in Seattle as well as Northern and Southern California; Sound Bites in Minnesota; Regional Conferences in Houston, San Diego, Saint Louis and Los Angeles; and the 2018 TSC World Conference in Dallas. Recently I attended the TS Alliance Board Meeting in Chicago and the 2019 March on Capitol Hill in Washington, DC. In October, I plan to volunteer at the 45th Anniversary Gala in New York City.

While attending the 2018 TSC World Conference. I met Clare Stuart of **Tuberous Sclerosis** Australia. Through that meeting, I had the opportunity to help them with their first Comedy for a Cure in Melbourne. Australia, expanding my volunteer work from the United States to the global TSC community. Many of you wonder

how I have the time or money to travel and go to all of these events and places. I am currently working as a Customer Service Agent for Southwest Airlines in Seattle, Washington. My travel benefits with Southwest allow me to fly at minimal cost, and my job provides the scheduling flexibility to attend

Participating in so many events the TS Alliance holds each year empowers and inspires me to improve and to always be a better person today than I was yesterday. It gives me the feeling that when I am at any low points I am not alone and that there are people out there to help guide me through the waves of TSC all of us experience at times.

Many people ask me why give my time? I say to them, because the TS Alliance is not just a group of people trying to raise money for a cure, even though that is the goal. But it's much more than that: It is a community of people, families, and friends who share compassion, love, and understanding for one another about each person's journey with TSC. Knowing my TSC family will be there when I need them is the most important thing in my life.

"Success isn't about how much money you make, it's about the difference you make in people's lives." - Michelle Obama, 2012 Democratic National Convention



TSC Now is the TS Alliance's podcast series!

Check out the last episode!

Additional Resources

TSC Talks, a podcast hosted by Jill Woodworth, explores tuberous sclerosis complex and other related issues. Each week Jill talks to parents/ caregivers, adults affected by TSC, experiences managing TSC, the challenges they've faced and where they find hope.

Listen to the latest episode now



TSC Matters is a bimonthly e-newsletter from the TS Alliance!

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