

Being Involved

Shannon Grandia, Adult Regional Coordinator, Regions 1 & 2

A recent Adults with TSC topic call was an open forum that took an interesting focus. With a successful TSC Day of Advocacy and Awareness Day in Maryland, March on Capitol Hill just wrapping up, and the Step Forward for a Cure TSC® walks coming soon, Jocelyn and Frank Cenna joined the call and shared their experiences. Frank is a 65-year-old adult with TSC, and his sister Jocelyn is his caretaker. Despite many medical obstacles and busy schedules Jocelyn and Frank have made being involved with the TS Alliance a priority.

During Maryland's second TSC Day of Advocacy and Awareness, advocates ranging in age from 6 weeks old to 65 years old visited



Jocelyn and Frank Cenna at the National Walk on the Mall

30 offices and were recognized on the House and Senate floor of the Statehouse in Annapolis, MD. On the call Jocelyn shared how amazing the
Continued on Page 2

Adult Resources

Upcoming Adult Topic Call

Thursday, May 2, 2019
"Nutrition and TSC," presented by Ashely Pounders, MSN, APN, FNP, 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.

For more adult resources including recordings of past topic calls, 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.



The Third Annual Sound Bites, An Evening of Food, Wine, and Music, will return to The Metropolitan in Golden Valley, Minnesota on Friday, May 10, 2019. To find out more and get tickets, [click here](#).

Upcoming TS Alliance Events

2019 PLAN NOW TO JOIN US FOR THE
**REGIONAL TSC & LAM
CONFERENCE SERIES**
For Individuals and Families with TSC and LAM

The second Regional TSC & LAM Conference will be held Saturday, June 15 in St. Louis, Missouri. To learn more about the Regional TSC & LAM Conference Series and to register [click here](#).



Upcoming Step Forward Walks:
Saturday, May 4 - Connecticut
Sunday, May 5 - Washington, DC
Saturday, May 11 - Dallas, TX

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

Continued from Page 1

day was and the impact of seeing Frank with the representatives, “It is important for these representatives to see adults with TSC. It shows them TSC is a lifelong disease.”

And although health issues keep Frank and Jocelyn from walking the halls of congress themselves, they make sure to write about their journey so those who were able to visit their representatives’ offices could share their story. Jocelyn also played a vital role by assisting with scheduling the meetings with the representatives. Maryland had both Senators and four out of eight House members sign onto the Dear Colleague letter for continued

Federal funding of the Tuberous Sclerosis Complex Research Program.

Next on Jocelyn and Frank’s agenda is the Step Forward for a Cure National Walk on the Mall in DC on May 5, where they play a significant role in fundraising and walking for their own team, as well as recruiting others to join the event. When asked why it is so important to be a part of the walk, Jocelyn stated they want to help the future of the many children who live with TSC. She continued, “The DC walk builds community and enables us to make new friends. The day is filled with fun activities, a fabulous walk around the monuments, good

food and music.”

Jocelyn and Frank have been an important figure in the Silver Spring and Annapolis, MD TSC community for more than 20 years and joined the DC-area walks in 2012. They know the benefits of being involved and doing what they can. This TSC journey goes through many phases and there are times when Jocelyn and Frank can be more involved and times when health issues simply don’t allow. But what is important is doing what you can when you can. “Networking with caregivers and other TSC adults enables them to not feel all alone and share their stories,” said Jocelyn.



Advocates from Maryland pose with Governor Larry Hogan as part of Maryland TSC Day of Advocacy and Awareness 2019

Photo Credit: Executive Office of the Governor



**ARE YOU A YOUNG
ADULT (Age 16-24)
WITH TSC?**

Join our new young adult facebook page to connect with other young adults with TSC.

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, and other professionals about their experiences managing TSC, the challenges they’ve faced and where they find hope.

[Listen to the latest episode now](#)



TSC Global Awareness Day is May 15. To learn more and see how you can get involved in raising awareness of TSC, [click here](#).