

Adults with TSC

Because rare diseases really aren't that rare.

#IAMTSC



Tuberous Sclerosis Alliance

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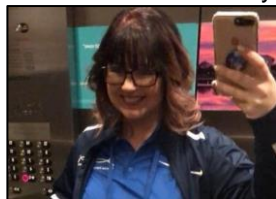
March on the Hill

This past week individuals from across the country came together in Washington D.C. to meet with representatives in Congress and Senate to advocate for the Tuberous Sclerosis Complex Research Program funded by the Department of Defense – Congressionally Directed Medical Research Programs. Many of you shared your stories with either your Adult Regional Coordinator or local Community Alliance Chair. The adult community was well represented as adults with TSC marched the halls along with caretakers of TSC to make sure all walks of the TSC journey were represented and your voices were heard. Those letters went to each of your representatives explaining why the continued funding is so vital. To learn more about the Tuberous Sclerosis Complex Research Program and the research it has funded go to: <http://cdmrp.army.mil/tscrp/default>

Here are some photos of a few that advocated for you.



Jennifer Waldron, CT
Senator Gardner, CO
Dana Holinka, CO
Seth Fritts, CO (ARC Region 3)



Brooke Simsa, OH (ARC Region 5)



Laura Marks, NY
Scott, NY (ARC Region 7)
Congressman King, NY
Lori Distefano, NY
Carol White, NY



Rylee Grandia, CA (Junior Leader)
Congressman Takano, CA



Analisa Zimmerman, NV
Kathleen Kingston, NV
Senator Cortez-Masto, NV
Tara and Billy Zimmerman, NV
Lysana Davis, NV



Congressman Sessions, TX
Leslie Boudreaux Russell, TX
Adolfo Orive, TX

Keith Hall Distinguished Leadership Award

In addition, a volunteer dinner was held where the first Keith Hall Distinguished Award was handed out to Kathy Henkel, longtime advocate and ARC for Region 8. It was a memorable moment in which Andrea Hall (Keith's Widow) discussed how much volunteering and the Adult Initiative meant to Keith and how proud he would be to know others are continuing the important work. Kathy Henkel gave an empowering and emotional speech explaining why supporting our adult community is so important and why it has been her mission to make sure all of those living with TSC felt supported. Kathy has been volunteering for the past 38 years and has made an incredible impact for all those affected by TSC.



- Shannon Grandia ARC

Adult Resources



-- Upcoming Adult Topic Calls

- Thursday, April 19, 2018
"My TSC Journey"
Katie Maciulewicz-Gass
- Thursday, May 17, 2018
"My TSC Journey"
Makenzie Moore
- Thursday, June 7, 2018
"Open Forum"

Adult Regional Coordinators

Call-in number: 866-613-5223

Access Code: 4334003#

Time: 8:00 P.M. (Eastern), 7:00 P.M. (Central),
6:00 P.M. (mountain), 5:00 P.M. (Pacific)

- Recording of February's Adult Topic Call: Dealing with Personal Tragedy
<http://www.tapeacall.com/7kac748buq>

- Fall issue of the TS Alliance *Perspective* is here:

<http://online.fliphtml5.com/tosk/tkan/>

- A blog written by Rylee Grandia, the Junior Leader focusing on the perspective of a young adult:

<https://thelifeofrytsc.blogspot.com/>

- Link to locate your Adult Regional Coordinators:

<http://www.tsalliance.org/individuals-families/adults/adult-regional-coordinators/>

- World Conference in Dallas Texas, July 26-29, 2018. For more information go to:

<http://www.tsalliance.org/2018-world-tsc-conference/>

- If you have any questions please contact Dena Hook, Vice President of Support Services, at: dhook@tsalliance.org

