

A Constituent Services Overview 2024

The TSC Alliance supports the TSC community through community-based outreach and support services, improving medical access, and providing educational resources.

Community-Based Outreach and Support Services

Community Support Network was reimagined in 2023. The TSC Alliance launched a new community support model that puts the TSC Community center – focusing on local resources, support services, and access to medical care – in conjunction with energizing the current and future volunteer leaders to propel the TSC Alliance to the next level.

In 2023, the TSC Alliance will host 15 Community Regions with more than 150 active leaders trained to support and provide resources to the TSC community. Our volunteers will serve in over 12 leadership roles made up of dedicated and passionate parents, relatives, adults with TSC, friends and supporters.

To get connected with community volunteers, please email our Community Leadership at communityleadership@tscalliance.org.

Support Navigator is an online tool to help individuals and families navigate the complexities of TSC across the lifespan, manage their care proactively, and live their fullest lives. Our Support Navigators can assist you along your unique journey. They can help answer questions, process, and understand your diagnosis, contact TSC recognized specialists, and explore treatment options.

To contact our Support Navigators, please email support@tscalliance.org or call 240-463-7250 between 9 a.m. and 9 p.m. Eastern Time Zone.

Educational Support. The TSC Alliance is here to support and empower individuals to be an informed advocate for your child. Whether you are looking for local resources, need support during the Individualized Education Program (IEP) process, have questions about a 504 plan or are looking for information and resources for teachers and school administrators, our trained staff and volunteers can provide guidance on education issues and training for local school districts on how learning is unique for people with tuberous sclerosis complex (TSC).

Educator Mentor Program (EMP) was developed to support school systems in understanding the learning needs of children with TSC. The EMP includes administrators, therapists, physiologists, and teachers from pre-kindergarten to college level having experience with TSC. They provide one-on-one support to any professional in the school system needing education and support in understanding the educational complexities of TSC.

Adult Support. In 2012, the TSC Alliance launched our Adult Initiative to prioritize the needs of adults with TSC, invest in research to understand how TSC changes in adulthood, and develop a support network and resources for both young adults and adults. You can find many of

these resources in the [Navigating the transition years of TSC](#) and [Navigating the adult years of TSC](#) guides.

Other ways the TSC Alliance supports and helps to empower our Adults with TSC includes:

- [Adult Support and Resource Leads](#)
- [Community Resource Lead](#)
- [Future Leaders Program](#)
- [Adult Topic Calls](#)
- [Transition Workshops](#)
- [TSC Alliance Adult Community Facebook Page](#)

For more information contact Shelly Meitzler and Elizabeth Skufca at support@tscalliance.org or (800) 225-6872.

Spanish Support Network are members that are committed to offering support and sharing their experiences with other who are faced with the challenges of TSC. The Spanish Support Network provides the latest medical information, education and support to those individuals who are seeking understanding about the genetic disorder and offering them words of encouragement and empowerment.

For more information contact Katie Smith at ksmith@tscalliance.org or 800-225-6872.