

ICARE Member Report

- **Tuberous Sclerosis Alliance (TS Alliance)**
- **The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected.**

ICARE Member Report:

Tuberous Sclerosis Alliance

- **Major topics of interest in epilepsy research**
 - Infantile spasms and TSC
 - Intractable epilepsy and TSC
 - Therapeutic targets in TSC
 - Neurocognitive and neurodevelopmental deficits in TSC and epilepsy
- **Types of research support or other activities**
 - TS Alliance grants support three TSC epilepsy research studies
 - The Tuberous Sclerosis Complex Natural History Database Project
 - TS Alliance Research Teleconferences
 - TS Alliance TSC Alert Newsletter
 - Tuberous Sclerosis Complex Research Program in the CDMRP
 - TSC research updates at Town Hall Meetings around the country

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Tuberous Sclerosis Alliance

- Resources available for shared use or other opportunities for collaboration
 - TSC Natural History Database Project
 - [TS Alliance Research Teleconference audio files](#)
 - Seizure Tracker: Empowering Both Patients and Researchers
 - TSC and Special Diets
 - TSC Epilepsy Surgery
 - [Other research resources](#)
 - TSC1 and TSC2 Variation Database
 - The NICHD Brain and Tissue Bank for Developmental Disorders
 - TSC1/2 knock-out mice

TS Alliance website at www.tsalliance.org



ICARE Member Report: Tuberous Sclerosis Alliance

- **Priorities and/or plans for future activities**
 - TSC Drug Screening Program
 - Establish a clinical trials network through the TSC Clinics
 - Utilize the TSC Natural History Database Project to answer research questions developed by the Epilepsy Working Group and it's leader, Elizabeth A. Thiele, MD, PhD