

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
 - Therapeutic targets in TSC that may be applicable to other epilepsies
 - Neurocognitive and neurodevelopmental deficits in TSC and epilepsy
 - Prevention of infantile spasms and their cognitive/behavioral sequelae
 - Infantile spasms and TSC
 - Intractable epilepsy and TSC
- Types of research support or other activities
 - Postdoctoral fellowships, research grants, Courage Awards
 - The Tuberous Sclerosis Complex Natural History Database Project
 - Tuberous Sclerosis Complex Research Program in the CDMRP
 - TSC Clinical Research Consortium
 - TSC research updates at regional meetings around the country
 - TS Alliance research teleconferences
 - TS Alliance TSC Alert newsletter

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Tuberous Sclerosis Alliance

- Resources available for shared use or other opportunities for collaboration
 - TSC Natural History Database Project
 - TSC Clinical Research Consortium
 - [TS Alliance Research Teleconference audio files](#)
 - Update on the Neurocognitive Clinical Trial and How Seizure Tracker Plays an Important Role
 - High Throughput Drug Screening to Find New Treatments for TSC
 - [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**
 - Enable successful initiation of clinical studies by the TSC Clinical Research Consortium
 - Enable translational research to advance key hits from the TSC Drug Screening Program into clinical studies as rapidly as possible
 - Expand the TSC Natural History Database to include quality-of-life measurements while simplifying data entry and report generation