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.
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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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- 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](http://www.tsalliance.org)
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• 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