

ICARE Member Reports

- ***Tuberous Sclerosis Alliance***
- Mission: To find a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected.
 - The TS Alliance meets its mission by:
 - Stimulating and supporting research on TSC;
 - Providing education, information and support to individuals with TSC and their families;
 - Educating health care providers and the public about TSC;
 - Supporting advocacy efforts on behalf of individuals with TSC and research programs at the National Institutes of Health and through the Department of Defense

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- ***Major topics of interest in epilepsy research***
 - Role of the TSC_{1/2} genes and the mTOR pathway in epilepsy and in TSC
 - Basic mechanisms of infantile spasms
 - Underlying mechanisms of refractory epilepsy
 - Animal models of TSC with epilepsy and behavioral phenotypes
 - Drug screening programs for epilepsy in TSC
 - Clinical trials for epilepsy in individuals with TSC
- ***Types of research support or other activities***
 - TS Alliance Research Grant Awards
 - Drug Screening Program Awards
 - TSC Natural History Database (with >900 study participants)
 - Research Conferences and Workshops
 - TSC_{1/2} Variation Database

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- *Resources available for shared use or other opportunities for collaboration*
 - TSC Tissue Donation Program (through the NICHD Brain and Tissue Bank for Developmental Disorders at the University of Maryland)
 - TSC_{1/2} Variation Database
 - TSC Natural History Database (>900 study participants enrolled)
 - TSC Clinic Network
 - New TSC Drug Screening Program

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- *Priorities for future activities*
 - Public awareness campaign to identify more individuals with TSC
 - TSC Drug Screening Program
 - Increase research grant support for Postdoctoral Fellowships and Junior Investigators
 - Clinical Trial Network
 - Increase enrollment and use of TSC Natural History Database
 - Release White Paper on the Future of TSC Research