



# Tuberous Sclerosis Complex (TSC) Natural History Database and Biosample Repository



## Natural History Database (NHD)

Implemented in 2006, the NHD captures clinical data to document the impact of TSC on a person's health over his or her lifetime. More than 2,500 people with TSC are enrolled in the project across 21 U.S.-based clinical sites. The TSC Alliance makes data available to investigators to answer specific research questions and identify potential participants for clinical trials and other studies.

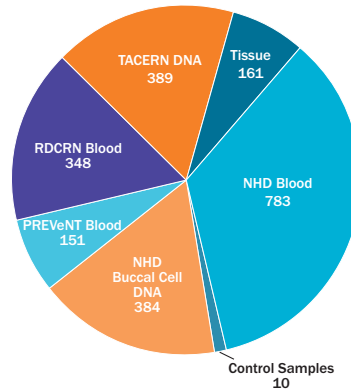


Data include information about TSC including symptoms, treatments, and genetic results. Variables include sections on clinical trial participation, genetics, perinatal conditions, cardiovascular, dental, dermatological, liver, neurological, ophthalmology, pulmonary, renal, comorbidities, COVID-19, and other rare conditions. These data are connected to biosamples in the TSC Biosample Repository.



## Biosample Repository (BSR)

The TSC Biosample Repository stores samples of blood, DNA, and tissues that scientists can use in their research. The samples we collect are all linked to clinical data in our TSC Natural History Database. We welcome biosample donation from any individual affected by TSC.



Since collection initiated in 2016, we have collected 2,226 samples and continue to obtain additional samples. The pie chart shows the types of samples we have obtained including samples from studies such as Preventing Epilepsy using Vigabatrin in Infants with TSC (PREVeNT), TSC Autism Center of Excellence Research Network (TACERN), and those of the Rare Disease Clinical Research Network Developmental Synaptopathies Consortium.

## Sample Inventory

Scan the QR code to see our current inventory.



**Interested in utilizing NHD data or biosamples? The process is simple!**

**Researcher submits requested biosamples**



**Application reviewed by the NHD-BSR Steering Committee**



**Request reviewed and approved**



**Sample processing and shipping by VAI**



Since inception, the TSC Alliance has distributed portions of more than 1,800 samples to 40 distinct researchers.

## Partnering Opportunities

The TSC Alliance is eager to partner with sponsors of clinical trials or clinical research studies to collect biosamples centrally at the TSC Biosample Repository. Such biosamples will remain under the control of the study's biosample use committee until the conclusion of the project, at which time the samples will become part of the openly available TSC Biosample Repository. This provides a win-win opportunity to ensure the long-term availability of valuable samples.

Additionally, if an individual with TSC is having surgery to remove any part of tissue – such as epilepsy surgery, brain tumor removal, or kidney or lung surgery – please contact the TSC Alliance with as much advance notice as possible at [biosample@tscalliance.org](mailto:biosample@tscalliance.org). The TSC Alliance is also able to collect cord blood and placental tissue.

**For additional information, email: [biosample@tscalliance.org](mailto:biosample@tscalliance.org).**



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