



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



natural history
DATABASE

Natural History Database (NHD)

Implemented in 2006, the Natural History Database (NHD) captures clinical data to document the impact of TSC on a person's health over their lifetime. More than 2,800 people with TSC are enrolled in the project across 22 U.S.-based clinical sites. The TSC Alliance makes data available for investigators to address research questions and identify potential participants for clinical trials.



Data includes information about TSC variables: Symptoms, treatments, genetic results, clinical trial participation, cardiovascular, dental, dermatological, liver, neurological, ophthalmology, perinatal health, pulmonary, renal, comorbidities and other rare conditions.

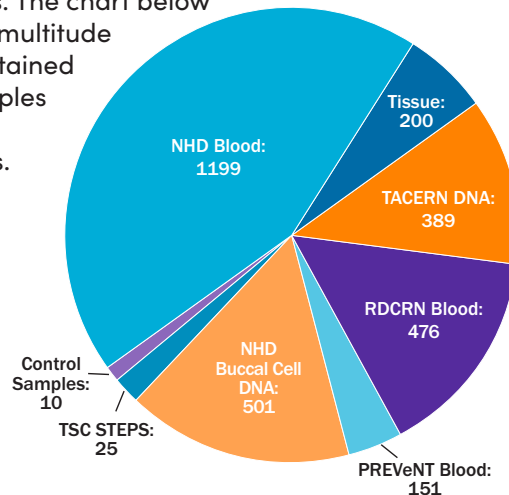
These data are connected to biosamples in the TSC Biosample Repository (BSR).



biosample
REPOSITORY

Biosample Repository (BSR)

The BSR stores samples of blood, DNA, and tissues that are linked to clinical data in the NHD. We welcome biosample donations from any individual affected by TSC. Since collection initiated in 2016, we have collected over 2,500 samples. The chart below illustrates the multitude of samples obtained including samples from partner clinical studies.



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 3,521 samples to 53 distinct researchers for 59 distinct projects.

Partnering Opportunities

The TSC Alliance is eager to partner with sponsors of clinical trials or research studies to collect biosamples centrally at the BSR. These biosamples remain monitored by the study's biosample use committee until the conclusion of the project. Biosamples will then become part of the openly available BSR. This provides opportunity to ensure the long-term availability of valuable samples.

Specialized Tissue Collection

Additionally, if an individual with TSC is having surgery on TSC affected tissue please contact the TSC Alliance as early as possible to receive a collection kit. The TSC Alliance is also able to collect cord blood and placental tissue.

For more information,
email biosample@tscalliance.org.

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