

Tuberous Sclerosis Complex and Lymphangioleiomyomatosis Pregnancy Registry (TSC-LAM Registry)

Status: RECRUITING

Eligibility Criteria

Sex: FEMALE

Age:

Healthy Volunteers: This study is NOT accepting healthy volunteers

Inclusion Criteria:

- A pregnant woman with a clinical or genetic diagnosis of TSC as determined by the 2021 Consensus Guidelines (1)
- A pregnant woman with a diagnosis of LAM
- A pregnant woman with a variant of uncertain significance in TSC 1 or TSC 2
- A pregnant woman who is pregnant and the fetus has a 50% chance of TSC as deemed by the PI or Sub-Is
- A pregnant woman whose fetus is found to have concern for TSC secondary to rhabdomyomas, tubers, or congenital subependymal giant cell astrocytoma.
- An infant born to an enrolled individual.

Exclusion Criteria:

- A pregnant woman without TSC who has used preimplantation genetic testing for TSC unless qualifies under inclusion criteria #4.
- Infants diagnosed with TSC whose birth mother was not enrolled.

Conditions & Interventions

Conditions:

Tuberous Sclerosis Complex, Lymphangioleiomyomatosis

Keywords:

Tuberous Sclerosis Complex, TSC, Lymphangioleiomyomatosis, LAM

More Information

Description:

This study is an observational registry designed to gather information about Tuberous Sclerosis Complex (TSC) and Lymphangioleiomyomatosis (LAM) in pregnant women and their child.

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Phase:

IRB Number:

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