

Tuberous Sclerosis Complex Travel and Lodging Patient Assistance Program

What is the purpose of this program?

NORD's Tuberous Sclerosis Complex Travel & Lodging Patient Assistance Program provides patients diagnosed with Tuberous Sclerosis Complex (or under consideration for diagnosis) with financial assistance for travel and lodging related to participation in a clinical trial and or furtherance of treatment.



About the Program

NORD will administer a Patient Assistance Travel and Lodging Program that will provide financial support and concierge travel arrangements for patients diagnosed with Tuberous Sclerosis Complex, (or under consideration for diagnosis). The Program provides financial assistance for travel & lodging related to participation in a Tuberous Sclerosis clinical trial or furtherance of treatment for TSC.

Our goal is to ensure patients are supported and their burden is lessened with regards to the cost and arrangement of travel to and from their study or treatment visits.

For additional information or, if you are in need of such assistance, please contact NORD at:

Phone: 203.616.4320

Fax: 203.349.3199

Email: TSCTravel@rarediseases.org

NORD

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is an independent charity dedicated to the identification, treatment and cure of rare "orphan" diseases such as Tuberous Sclerosis Complex through education, advocacy, research and patient service programs.

NORD was founded by families struggling to obtain access to treatments and whose advocacy for change led to the passage of the Orphan Drug Act in 1983.

Funding for NORD comes from a variety of sources including corporate donations, foundation grants, public contributions, and membership dues

Learn more about NORD by visiting:
www.rarediseases.org

Tuberous Sclerosis Complex Travel & Lodging Patient Assistance Program



Alone we are rare. Together we are strong.®

Travel and Lodging Patient Assistance Details

What kinds of assistance are offered in this program?

- Assistance for participation in clinical trials or in furtherance of treatment for TSC.
- Travel must be to an approved TSC clinic for TSC treatment or clinical trial.
- For participants under the age of 21 (and for patients 21 & older as medically necessary) assistance will also be provided for 1 family member (or guardian) for each study or medical visit.
- NORD will cover in advance, the cost of lodging and airfare for study participants in accordance with Program established guidelines. All other approved expenses will be managed on a reimbursement basis.
- A NORD representative will find suitable lodging, and provide lodging costs for a qualified patient, up to two parents/guardians at screening and first clinic visit, and one parent/guardian at subsequent study visits. The program allows for subsidy assistance with a cap of \$200 per night.
- A maximum reimbursement rate for transportation, lodging, meals and ground transportation will be applied and is based on length of stay required for trial or treatment visit and are based on established Program guidelines.
- Entertainment expenses will not be reimbursed (E.g., movie rental, theater, alcohol, cigarettes etc.)
- Mileage: Google Map round-trip mileage indicating home address of subject and address of the study site will be used to calculate mileage. Mileage will be reimbursed at the current Internal Revenue Service business reimbursement rate of \$0.545.

Application Process

- Patients/families may self-refer to the Tuberous Sclerosis Complex Travel and Lodging Program, or may be referred by Bcureful, or by a TSC study site or treatment center.
- NORD will work with or contact the patient/support person to make all travel arrangement e.g. hotel, plane, car, etc.
- NORD will pre-pay as possible all pre-arranged travel and lodging expenses; when not possible, eligible expenses will be reimbursed upon appointment verification of patient visit and a patient completed NORD reimbursement form provided to the patient/support person.



Receipts

- Reimbursement for all travel and lodging related expenses must be accompanied by receipts.

TSC Travel & Lodging Patient Assistance Program

Questions? Call NORD: 203.616.4320

NORD Offices: 55 Kenosia Avenue, Danbury, CT 06810 • 1900 Crown Colony Drive, Quincy, MA 02169 • 1779 Massachusetts Avenue, Washington, DC 20036

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