

# Tuberous Sclerosis Complex Travel and Lodging Patient Assistance Programs

## What is the purpose of these programs?

**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 at an approved TSC Center of Excellence.

## About the Programs

NORD provides assistance through two Tuberous Sclerosis Complex (TSC) Assistance Programs:

The NORD TSC Clinical Trial Travel & Lodging Assistance Program and the NORD TSC Centers of Excellence Travel & Lodging Assistance Program.

Both provide financial support and concierge travel arrangements for patients diagnosed with tuberous sclerosis complex, (or under consideration for diagnosis).

The **NORD TSC Clinical Trial Travel & Lodging Assistance Program** assists provides financial assistance for travel & lodging related to participation in a tuberous sclerosis complex clinical trial within the United States.

The **NORD TSC Centers of Excellence Travel & Lodging Assistance Program** provides financial assistance for travel & lodging in furtherance of treatment for TSC at a TSC Center of Excellence.

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

## Tuberous Sclerosis Complex Travel & Lodging Patient Assistance Program



## 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](http://www.rarediseases.org)



Alone we are rare. Together we are strong.®

# Travel and Lodging Patient Assistance Details

## What kinds of assistance are offered in these programs?

- Travel and financial assistance for participation in United States based clinical trials

or

- Travel and financial assistance in furtherance of care and treatment for tuberous sclerosis complex to an approved TSC Center of Excellence  
<https://www.tsalliance.org/individuals-families/tsc-clinics/>
- 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 program 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 study screening and Center of Excellence visit, and one parent/guardian at subsequent study visits or subsequent COE 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 COE visit and are based on established Program guidelines. (See Award Limits)
- 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.

## Application Process

- Patients/families may self-refer to the Tuberous Sclerosis Complex Travel and Lodging Programs, or may be referred by the Tuberous Sclerosis Alliance or by a TSC study site or Center of Excellence.
- 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.

## Award Limits

- NORD seeks to provide assistance both to those travelling for participation in clinical trials and those travelling for TSC COE care and treatment.
- For those traveling, who are NOT participating in a clinical trial, awards are limited to \$5,000 in a calendar year regardless of the number of study visits.
- Reimbursement for meals is limited to up to \$100/day for up to two (2) people the award is granted.
- Reimbursement for ground transportation is limited to transportation to/from study/treatment site and parking and is limited to \$100/day.

## TSC Travel & Lodging Patient Assistance Program

Questions? Call NORD:  
203.616.4320

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