



NORD®
National Organization
for Rare Disorders

TUBEROUS SCLEROSIS COMPLEX BCUREFUL TSC CLINIC TRAVEL ASSISTANCE PROGRAM

What is the purpose of this program?

Having a rare diagnosis is difficult. Adding in the cost of numerous consults and the complex care required to treat and manage it, makes a rare disease even harder.

This Program seeks to lessen the financial burden for the TSC patient community.

TRAVEL & LODGING ASSISTANCE



About the Program:

The Tuberous Sclerosis Complex -Bcureful TSC Clinic Travel & Lodging Assistance Program provides financial assistance for travel and lodging expenses associated with care and treatment at a TSC Alliance Center of Excellence or recognized TSC clinic.



Who is eligible for this program?

You must meet all of the following criteria to be eligible:

- Have a confirmed diagnosis of tuberous sclerosis complex (TSC) or under consideration for the diagnosis of TSC.
- Be a United States citizen or permanent resident.
- Have a confirmed appointment at a TSC Alliance Center of Excellence or recognized TSC clinic. The appointment must be scheduled for no more than 90-days from application date.

Alone we are rare. Together we are strong.®

What kinds of assistance are available?

NORD will coordinate directly with eligible patients, families and caregivers related to travel arrangements for TSC Alliance Center of Excellence or TSC clinic appointments (financial support within program established limits).

- Airfare for TSC patient and one (1) caregiver/support person is available for those traveling a 3-hour or greater driving distance from appointment site. Airfare arrangements are scheduled and prepaid by NORD.
- Hotel is available for participants with a 3-hour or greater driving distance from appointment site. Hotel stay will be booked and prepaid by NORD (not to exceed \$200 plus tax/night).
- Ground transportation between the airport and hotel and/or appointment site will also be a covered expense up to \$50/trip. (Receipts required for all ground trans not pre-booked & prepaid by NORD).
- Hospital/clinic parking up to \$50/trip will be reimbursed with the submission of receipt.
- Mileage reimbursement at the current IRS rate will be reimbursed for those participants who are traveling by car and not utilizing airfare assistance.

Is there a limit to the financial award available in this program?

- For participants traveling 1-7 nights for a single clinical visit, assistance cannot exceed \$2,500 in a calendar year and is dependent on funding availability.
- For participants traveling greater than 7 nights for single clinical visit, assistance cannot exceed \$3,000 in a calendar year and is dependent on funding availability.
- It is imperative, that should you wish to receive financial assistance, that you contact NORD in advance of your travel so that we may ascertain if there is sufficient funding to provide the support you are seeking. Travel and/or expenses incurred that are not prior approved by NORD may not be honored.

How do I get more information and apply?

Contact NORD T&L Assistance Program

Monday-Friday 8:30 am – 6:00 pm ET



203.616.4320



203.349.3199



TSCTravel@rarediseases.org



US MAIL to: NORD
Attention: TSC-Bcureful Travel Program
7 Kenosia Avenue
Danbury, CT 06810

NORD is Here for You

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

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. NORD assists eligible patients (those with medical and financial needs) in affording the treatments and medical services their healthcare professionals have prescribed.



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