



NORD®

TUBEROUS SCLEROSIS COMPLEX (TSC) - BCUREFUL RESEARCH STUDY PARTICIPATION TRAVEL ASSISTANCE PROGRAM

What is the purpose of this program?

Deciding to participate in a clinical trial is an important decision for patients and families. When entering a research study or clinical trial, the expense required to travel to and from a study site may be considered a barrier to participation. This program eliminates that barrier.

Thanks to funding from a TSC Alliance Bcureful grant, this program lessens the burden on families impacted by TSC.

TRAVEL & LODGING ASSISTANCE



About the Program

The TSC Bcureful Research Study Participation Travel Assistance Program provides individuals diagnosed with TSC with financial assistance for travel and lodging related to participation in a TSC Alliance recognized investigator-driven TSC research study .



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).
- Be enrolled in a TSC Alliance recognized investigator-driven TSC Research Study.
- Be referred to NORD by Research Study site coordinator.
- Meet the program's financial eligibility criteria.
- Be a United States citizen or permanent resident.

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 research study participation (financial support within program established limits).
- Airfare for research study participant and one (1) caregiver/support person is available for those traveling a 3-hour or greater driving distance from study site. Airfare arrangements are scheduled and prepaid by NORD.
- Hotel expense for participants with a 3-hour or greater driving distance from study site. Hotel stay will be booked and prepaid by NORD unless pre-approved by NORD for reimbursement.
- Ground transportation between the airport and hotel and/or study site will also be a covered expense up to \$85/trip. (Receipts required for all ground trans not pre-booked & prepaid by NORD).
- Parking at the research study site only up to \$50 total for each clinical research study trip (submission of receipt required).
- 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 awards available in these program?

- Assistance to participant cannot exceed \$2,500 in a calendar year.
- 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.



rarediseases.org