

Clinical Trial Travel and Lodging Support

For patients participating in the Everolimus clinical trial

Deciding to participate in a clinical trial is an important decision for patients and their families. When entering a clinical trial, the time required to arrange travel to and from the study site may be considered a barrier to participation.

The National Organization for Rare Disorders (NORD) is the answer if these issues of cost and time are a patient or family member concern.



Every person who participates in a research study is creating the possibility of a potential treatment.

About the Program

For this clinical trial, Boston Children's Hospital (BCH), has contracted directly with NORD to provide patient/family assistance services.

NORD will administer a Patient Assistance Travel and Lodging Program that will provide financial support and concierge travel arrangements to patients who participate in the **Everolimus** clinical trial. Our goal is to ensure patients are supported and their burden is alleviated with regards to the cost and arrangement of travel to and from their study visits.

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

Phone:
Fax:
Email:

NORD

The National Organization for Rare Disorders is an 501(c)(3) independent charity dedicated to the identification, treatment, and cure of rare diseases through education, advocacy, research, and patient/family assistance services.

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



Alone we are rare. Together we are strong.®

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Reimbursement Policy

- Available to all study participants
- NORD will attempt to find suitable lodging through the National Association of Hospital Hospitality Houses as well as other resources, and provide lodging costs for a qualified patient and one parent/guardian for all extended visits. Where this is not possible, the lowest cost option suitable hotel will be used, with a cap of \$210 per night including taxes and fees. The maximum reimbursable expense will be for one hotel night, depending upon the scheduling of tests at each visit and flight schedules unless extenuating circumstances occur.
- Meals for the patient and 1 caregiver will be reimbursed at \$50 per person/per day and \$25 per person/day for half day visits.
- Incidental travel expenses such as parking and tolls will be reimbursed up to \$35 per visit. NORD will not provide a daily stipend for the incidentals mentioned above, but rather will reimburse for these types of expenses as receipts are presented. Tolls do not require receipts since costs can be verified by route review.
- 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 per mile.
 - *Access to ADA accessible vehicle transportation will be accommodated on request.*
- Entertainment expenses will not be reimbursed (E.g., movie rental, theater, alcohol, cigarettes etc.)

Receipts

- Reimbursement for all travel and lodging related expenses must be accompanied by receipts.
- Meal reimbursement requires itemized receipts.
- If the receipts include the cost of meals for other people not covered by the reimbursement policy, then the costs associated with the applicable participants must be noted as such.



Reimbursement Process

- If eligible for the study, the study site's Research Coordinator will send NORD a referral form with patient/support person information.
- NORD will then 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 study site verification of patient visit and a patient completed NORD reimbursement form provided to the patient/support person.

Questions?

Call NORD toll-free: 1-844-876-0774

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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