

Clinical Trial Travel and Lodging Support

For patients participating in Catalyst Approved MuSK-002 Clinical Study

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, Catalyst Pharmaceuticals has contracted directly with NORD to provide patient/family assistance services.

NORD is administering a Patient Assistance Travel and Lodging Program that provides financial support and concierge travel arrangements to patients who participate in the **MuSK-002 Clinical Study** with Amifampridine Phosphate. Our goal is to ensure patients are assisted and their burden is alleviated regarding both the making of travel arrangements to and from their study visits and the subsequent costs incurred.

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

Phone: 1-855-864-4026

Fax: 1-203-349-3278

Email: MUSK-MG@rarediseases.org

NORD

The National Organization for Rare Disorders is an 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
- Airfare will be reimbursed at the actual rate for economy seats.
- 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, up to two parents/guardians at screening and first clinic visit, and one parent/guardian at subsequent study visits. Where this is not possible, the lowest cost option suitable hotel will be used, with a cap of \$200 per night. The maximum reimbursable expense will be for two hotel nights, depending upon the scheduling of tests at each visit and flight schedules unless extenuating circumstances occur.
- Meal costs will be reimbursed up to \$75 per person per day. For partial days, the suggested distribution is \$15/breakfast, \$25/lunch and \$35/dinner.
- Patient and support person(s) daily reimbursement will be \$25-\$50 will be provided while at the study site to cover incidentals (e.g., parking, taxi from hotel to study site, etc.). 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.
- 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 \$.34.

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: 1-855-864-4026.

