

Clinical Trial Travel and Lodging Support

For patients participating in Catalyst Pharmaceuticals THE MuSK Trial – Cleveland Clinic

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.



Those coping with illness should not also have to worry about how to pay for it.

About the Program

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 THE Musk Trial study. 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: 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

THE MuSK Trial – MSK-002



Alone we are rare. Together we are strong.®

Clinical Trial Travel and Lodging Support Details

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Reimbursement Policy

- Available to all study participants that travel a distance > 100 miles round trip to the Cleveland Clinic Main Campus.
- 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.
- 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 \$0.545.

Receipts

- Reimbursement for all travel and lodging related expenses must be accompanied by receipts.



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.

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Questions? Call NORD toll-free: 1-855-864-4026.

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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