Hunter Syndrome (MPS II) Patient Assistance Programs

NORD® National Organization for Rare Disorders

FAQ

What is the purpose of this program?

NORD's Hunter Syndrome Patient Assistance Programs offer eligible individuals diagnosed with Hunter syndrome (MPS II) financial support when faced with limited resources to pay for:

- Out of pocket health care costs such as: health insurance premiums, deductibles, copayments & coinsurance costs for the care and treatment of Hunter syndrome including:
  - diagnostic testing costs
  - medical appointments & consults
  - physician prescribed FDA approved medications and therapies

Who is eligible to apply for NORD's Hunter Syndrome Assistance grants?

These programs are designed to help patients who:

- Are a United States citizen or U.S. resident of six (6) months or greater with evidence of residency such as a utility bill showing the patient's name and address
- Have a diagnosis of Hunter syndrome or under evaluation for diagnosis of Hunter syndrome
- Fall within the Program's financial guidelines and adhere to application requirements that are set in advance by NORD

What kinds of assistance can I request from NORD?

NORD programs can assist eligible individuals/families with expenses in a number of categories:

- The Hunter Syndrome Premium Copay Program assists eligible individuals who have health insurance with funding to cover health insurance premiums, deductibles, copayments & coinsurance costs associated with the care of Hunter syndrome.
  - Some examples of these expenses may be:
    - medical expenses paid toward health insurance premiums and/or deductible
    - copayment for a medical office visit
    - out-of-pocket cost for medications prescribed by your physician to treat Hunter syndrome
    - a coinsurance payment for a physician prescribed laboratory or diagnostic test

- The Hunter Syndrome Medical Assistance Program assists eligible individuals who are uninsured, or for whom coverage has been denied with out-of-pocket costs for medical expenses such as medical visits, laboratory & diagnostic testing, physician prescribed therapies and other specific medical expenses for the treatment of Hunter syndrome. Additionally, mileage for travel to & from a Hunter syndrome medical related appointment may be reimbursed in this program.

- The Hunter Syndrome Diagnostic Testing Assistance Program offers to public and privately insured patients, and uninsured and underinsured who meet established eligibility requirements, financial support with out-of-pocket costs associated with diagnostic testing

What is NORD?

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is an independent charity dedicated to the identification, treatment and cure of rare "orphan" diseases through education, advocacy, research and patient service programs.

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.

Funding for NORD comes from a variety of sources including corporate donations, foundation grants, public contributions, and membership dues.

At NORD. we know what it is like to live with or care for someone with a rare disease, and we continuously endeavor to support those dealing with these challenges.

How do I get more information and apply?

Contact NORD's Hunter Syndrome Programs
Monday-Thursday 8:30 am – 7:00 pm EST
Friday 8:30 am – 6:00 pm EST

Phone: 855.864.4021
Fax: 203.349.3190
Email:
huntersyndrome@rarediseases.org

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What is the application process?

Awards are granted on a first come, first served basis to eligible individuals. Patients may be referred to the program by their health care provider, their case managers, or they may self-refer. The RareCare® Patient Services Representative will guide the applicant through the application process, verify eligibility for inclusion in the Hunter Syndrome Program(s), determine financial eligibility using our Electronic Income Verification System (EIV) and award assistance.

How does NORD demonstrate compliance with regulations required of charities?

NORD independently designs its patient assistance programs based on the needs of specific patient communities.

No pharmaceutical company or donor controls or influences our programs.

Our patient assistance decisions are based on consistently applied financial eligibility criteria and diagnosis only.

Patients have their choice of health care provider, treatment and treatment location, and can make changes at any time.

Patients' privacy and well-being are priorities at NORD. We do not share or provide patient names or data with donors, nor do we disclose or identify donors to patients.

Patients are able to make the choices that are best for them because NORD's assistance covers all FDA-approved products available for a diagnosis. Our programs also help with more than medication: patients can use their funds to pay for other physician prescribed services related to their diagnosis such as, laboratory and diagnostic testing, physical and occupational therapy, durable medical and adaptive equipment, and travel to medical appointments.

At NORD, we are honored to be a partner on your rare disease journey.
We look forward to assisting you.

Once a patient is accepted into the assistance program(s) how long are they eligible?

Premium, Copay and Medical Assist awards are issued for a calendar year.

Patients are encouraged to reapply annually if continued assistance is needed.

How does the payment or reimbursement process work?

Premium, Copay and Medical Assist awards may be prepaid by NORD with appropriate documentation or reimbursed to the patient in accordance with appropriate receipts and documentation.

All claims submitted for reimbursement must be provided within 30 days of date of service and include receipts or other evidence of payment, such as a credit card statement.

Reimbursements will be made within ten (10) business days of receipt by NORD.

How do I apply for assistance from NORD's Hunter Syndrome Patient Assistance Program?

Phone: 855.864.4021
Fax: 203.349.3190
Email: huntersyndrome@rarediseases.org

US MAIL to: NORD

Attention: Hunter Program
55 Kenosia Avenue, Danbury, CT
06810

NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians. Donations to NORD for this and other programs may be made by contacting NORD at **rarediseases.org**.