



...out of the darkness
into the light...®

National Organization for Rare Disorders, Inc®

NORD Medical Foods Assistance Program For Patients with Phenylketonuria (PKU)

55 Kenosia Avenue ● PO BOX 1968 ● Danbury, CT 06813-1968
Tel: 866-924-0100 ● Fax (203) 798-2964

Dear Friend,

Enclosed is an application form to apply for assistance with the out-of-pocket costs associated with purchasing medical formula/foods as indicated for Phenylketonuria (PKU).

The NORD Medical Foods Assistance Program is a program of last resort designed to provide financial relief to PKU patients who do not qualify for or already exhausted state, county assistance, or a manufacturer-sponsored patient assistance program, and are having difficulties paying for the medically necessary formula/food as directed by a physician or dietician.

If you meet the guidelines below, please complete and return enclosed application.

❖ Eligibility Criteria -

- Patient must have a diagnosis of Phenylketonuria (PKU).
- Patient must be a legal resident of the US and reside in the US or its territories.
- Income considered up to 500% of the Federal Poverty Level (based on household size)
 - \$52,000 or less for a single person
 - \$70,000 or less for a couple
 - \$106,000 or less for a family of 4.
- Proof that patient does not qualify for or has exhausted eligibility in any other state, county or Patient Assistance Program.
- Proof of denial of coverage from insurance plan (can submit copy of page from Plan's Certificate of Benefits).

Product coverage is limited to prescription medical foods/formulas (includes amino acid-modified products that contain a synthetic source of protein and exclude phenylalanine).

If approved, you will be notified in writing. Please contact the program at the toll-free number above if you have a questions.

Sincerely,

NORD Medical Foods Assistance Program

NORD® PKU MEDICAL FOODS/FORMULA ASSISTANCE PROGRAM APPLICATION

PATIENT INFORMATION

PLEASE PRINT

Applicant

Name: _____
(If patient is a minor, parent/guardian's name required here.)

Address: _____

Daytime Phone: _() _____

Evening Phone: _() _____

Name of person requiring medical foods/formula:

Date of Birth: (mm/dd/yyyy) ____/____/____

Relationship to person applying: _____

Email (optional) _____

Preferred form of contact: Phone _____
Email _____
Letter _____

FINANCIAL INFORMATION

Yearly Gross Household Income \$ _____

Number of dependents _____ (include person applying))

Please submit proof of income (copy of 2008 IRS Tax return or current paycheck stub)

Monthly cost for medical foods/formula \$ _____

Have you applied for State Medical Food Assistance?

____ Yes ____ No ____ None available

If Yes, what is the yearly amount that State Assistance will cover? \$ _____

Have you applied to any manufacturer's assistance program?

____ Yes ____ No

If Yes, name of manufacturer: _____

INSURANCE INFORMATION

Primary Health Insurance: _____

Policy # _____

Is there coverage for Medical Foods/Formula under this policy?

____ Yes ____ No

If Yes, indicate amount: _____

HEALTHCARE PROVIDER

(check one)

Physician

Dietician

Name: _____

Address: _____
(Clinic) _____

Telephone: _____

FAX: _____

Office Contact: _____
(or email address)

DEA# _____ (If physician)

State License # _____ (If physician)

Patient Diagnosis: _____

Healthcare Provider signature:

Note: Product coverage is currently limited to prescription medical foods/formulas (includes amino acid-modified products that contain a synthetic source of protein and exclude phenylalanine).

Medical Food/Formula Prescription

Date: / /

Sig: _____

Dispense as written: _____

MEDICAL/ INSURANCE /FINANCIAL RELEASE OF INFORMATION

I hereby authorize the following release to the National Organization for Rare Disorders, Inc. (NORD) PKU Medical Foods Assistance Program Medical/Insurance/Financial information about myself or dependent that they may request. This record will be kept confidential. Any materials released to NORD will not be transmitted to any third-party not associated with the program without written consent or other authorization by the patient or parent/guardian where applicable.

Acknowledgements:

I acknowledge that NORD is a charity with limited resources, and that the Assistance Program is a program of last resort after all federal and state assistance programs have been utilized. I also acknowledge that this Program can be terminated at any time if resources are exhausted.

Agreements:

I agree to notify NORD of any changes that may affect my eligibility in the Program. Such changes would include: insurance, formula, marital status, employment and/or wages, approval from other sources of funding (e.g., Medicare, Medicaid, other state or county programs, other assistance programs.)

I agree to notify NORD as soon as possible if at any time I receive refunds from my insurance carrier, healthcare provider, pharmacy provider for payments that have been paid by NORD during my eligibility through the Program.

Signature of Applicant: _____

Return application to: NORD

P.O. Box 1968

Danbury, CT 06813-1968

Phone: 1-866-924-0100 or FAX: 203-798-2964

FREQUENTLY ASKED QUESTIONS

Q What does NORD stand for?

NORD is the National Organization for Rare Disorders, an independent non-profit charity dedicated to the identification, treatment, and cure of rare disorders. Detailed information is available at www.rarediseases.org.

Q Who is eligible to apply for assistance?

United States residents with a confirmed diagnosis for PKU with a demonstrated lack of benefit coverage for medical food are eligible to apply for assistance. Applicants must also meet certain financial eligibility criteria.

Q What is meant by demonstrated lack of benefit coverage for medical foods?

Applicants must supply documentation that they have exhausted available state assistance and/or denial of insurance coverage by their health plan.

Q What are the specific financial criteria?

Income levels up to 500% of Federal Poverty Level (based on family size) are eligible for assistance.

Q Are there any age limitations?

No. The NORD PKU Medical Foods program is open to PKU patients of any age.

Q Are patients with metabolic disorders other than PKU eligible for this program?

Not at this time. The NORD PKU Medical Foods program is the first of its kind. Pending its success, NORD is interested in expanding the program for other metabolic disorders.

Q What is the application process?

First, the patient or guardian calls the NORD MF Program at 1-866-924-0100 to request an application packet. Once the application form is completed and returned to NORD, it is reviewed and a decision is rendered within five business days.

Q Will the application be available on NORD's website?

Individuals will have access to the application on NORD's website after May 1, 2008 www.rarediseases.org/programs/medications that can be downloaded for completion and mailed or faxed to NORD.

Q What is the role of the medical professional during the application process?

A medical professional certifies the patient diagnosis and provides a prescription for medical food.

Q How do the patient and medical professional become aware of the status of the patient's application?

NORD communicates the status of the application with the applicant.

Q How long does it take to get approval?

Once the applicant supplies all required supporting information in the application process, NORD makes its decision within 10 to 12 business days.

Q Is there an appeal process for denied applications?

NORD allows the applicant to appeal the decision if there is sufficient proof that there has been a change in financial status. Patients have 30 days from the denial notification to submit a re-appeal letter along with supporting documentation.

Q What assistance do approved patients receive?

NORD reduces the patient's costs for medical foods by becoming a third party payer by working with the manufacturer of the products used by the patient to arrange for payment.

Q Are patients able to apply for financial assistance to obtain low protein modified foods?

At the present time, NORD is offering assistance for medical foods with amino acid modifications that contain a synthetic source of protein and exclude phenylalanine.

Q How long is the assistance provided?

Approved patients receive up to 12 months of assistance. Patients must re-qualify annually.