

# Need Financial Assistance for PKU Treatment and Management?

*Learn more about the National Organization  
for Rare Disorders (NORD), Inc<sup>®</sup>*



National Organization  
for Rare Disorders

# NORD Is Here to Help

## Overview

The National Organization for Rare Disorders (NORD), Inc<sup>®</sup> is a not-for-profit health agency dedicated to the identification, treatment, and cure of rare “orphan diseases” such as PKU through education, advocacy, research, and patient services programs. NORD helps eligible patients—those with medical and financial needs—afford the medications and treatment their healthcare professionals have prescribed.

NORD funds come from corporate donations, grants from concerned companies such as BioMarin Pharmaceutical Inc., foundation grants, public contributions, and membership dues.

**NORD  
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patients afford their  
medications and  
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## PKU programs

NORD provides two programs for patients who require PKU treatment. Financial help is provided on a case-by-case basis to patients accepted into one or both of these NORD programs.

### PKU Premium/Co-payment Assistance Program:



- NORD may work directly with your insurance company and specialty pharmacy to arrange for payment of your health insurance premiums, deductibles, and/or co-payments to pay for medication to treat PKU.
- NORD may provide direct reimbursement to you for lab tests associated with starting or staying on medication to treat PKU.

### Medical Foods Assistance Program:



- NORD may provide direct reimbursement to you for prescription medical foods and formula, which includes amino acid–modified products that contain a synthetic source of protein and do not contain phenylalanine (Phe).
- NORD may provide you with coupons or manufacturers' discounts for medical foods or formula or establish an account with the manufacturer on your behalf.



# Financial Help With PKU Medications and Lab Costs



## The PKU Premium/Co-payment Assistance Program

NORD may help you pay for insurance premiums, deductibles, and co-payments associated with medical treatment for PKU if you are eligible.

### Eligible expenses

If you meet eligibility requirements and are accepted into the program, NORD may:

- Directly reimburse your specialty pharmacy for the insurance co-payments for your PKU medication.
- Reimburse you for previous co-payments for medication to treat PKU when you submit a receipt.
- Reimburse you for certain lab tests associated with starting or staying on medication to treat PKU when you submit a receipt.

## How to apply

Applications are accepted and reviewed on an ongoing first-come, first-served basis. NORD will notify you by mail within 10–12 business days of acceptance into the program. Eligibility for NORD assistance is guaranteed for up to 12 months as long as you remain compliant with treatment. You must reapply each year.

### To apply, you must:

- Complete an application provided by NORD.
- Meet other general eligibility requirements.
- Provide documentation so NORD can examine your household income and available assets and compare them to your household and medical expenses.

If your application is denied, you can appeal the decision if there is sufficient proof that there has been a change in your financial status. You will have 30 days from the denial notification to submit an appeal letter along with any new documentation. You may reapply whenever a change in your financial status occurs.

## Contacting the PKU Premium/ Co-payment Assistance Program

NORD patient representatives can be reached by calling **1-800-999-6673 (option 1, ext. 239)**. Telephone lines are staffed Monday through Friday from 9 AM to 5 PM Eastern Time (ET). NORD patient representatives are available to answer your questions and to assist you in completing the application.



# Financial Help With PKU Medical Foods



## The Medical Foods Assistance Program

NORD may help you with the expenses associated with medical foods for PKU. Note that the amount of funding donated to NORD each year determines the number of participants accepted into the program, the level of assistance available per family, and the duration of the program.

## Eligible expenses

If you meet eligibility requirements and are accepted into the program, NORD may:

- Reimburse you for out-of-pocket co-payments for medical foods or formula when you submit a receipt.
  - Note that product coverage is limited to prescription medical foods and formula that contain a synthetic source of protein and do not contain Phe.
- Provide you with coupons or manufacturers' discounts for products that you use.
- Directly reimburse the companies from which you purchase your medical foods or formula.

## How to apply

Applications are accepted and reviewed on an ongoing first-come, first-served basis. NORD will notify you by mail within 10–12 business days of acceptance into the program. Eligibility for NORD assistance is guaranteed for up to 12 months. You must reapply each year.

### To apply, you must:

- Complete an application provided by NORD.
- Meet other general eligibility requirements.
- Provide documentation that:
  - State assistance is not available, and/or
  - Insurance coverage for medical foods has been denied.

If your application is denied, you can appeal the decision if there is sufficient proof that there has been a change in your financial status. You will have 30 days from the denial notification to submit an appeal letter along with any new documentation. You may reapply whenever a change in your financial status occurs.

## Contacting the Medical Foods Assistance Program

NORD patient representatives can be reached by calling **1-866-924-0100**. Telephone lines are staffed Monday through Friday from 9 AM to 5 PM (ET). NORD patient representatives are available to answer questions and to assist you in completing the application.



*For more information, contact:*

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## The National Organization for Rare Disorders, Inc.<sup>®</sup>

NORD, Inc.<sup>®</sup>

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Danbury, CT 06813-1968

**PKU Premium/Co-payment Assistance:**

1-800-999-6673 (option 1, ext. 239)

**Medical Foods Assistance:** 1-866-924-0100

**Fax:** 1-203-798-2964

**E-mail:** [patientassistance@rarediseases.org](mailto:patientassistance@rarediseases.org)

**Web site:** [www.rarediseases.org](http://www.rarediseases.org)



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