

# An Introduction to the National Organization for Rare Disorders (NORD)



## What is NORD?

The National Organization for Rare Disorders (NORD) is an independent charity dedicated to the identification, treatment, and cure of rare "orphan" diseases, such as phenylketonuria (PKU) through education, advocacy, research, and patient service programs. NORD helps eligible patients – those with medical and financial needs – afford the medication and treatment their healthcare professionals have prescribed.<sup>1</sup> Funding for NORD comes from corporate donations, foundation grants, public contributions, and membership dues.

## NORD Programs for PKU

NORD offers two programs for individuals seeking assistance with the costs associated with their PKU treatment. Financial assistance is provided on a case-by-case basis for individuals seeking acceptance into one, or both, of the available PKU programs.

Medical Assistance Program	Premium and Co-pay Assistance Program
<p>Covers reasonable expenses required for the diagnosis, treatment, and care for an individual with PKU that are not covered by an individual's insurance plan.</p> <p>Examples of costs and assistance that may be covered as a part of this program include: travel costs to diagnostic centers, laboratory tests and evaluations not covered by insurance.</p> <p>To qualify for this program an individual must have a diagnosis of PKU, certificate of medical need, proof of no coverage and complete application and waiver forms.</p>	<p>Offers financial support for publicly and privately-insured patients needing assistance with high premium and out-of-pocket co-payment/co-insurance costs for the prescribed therapies for PKU.</p> <p>Examples of costs that may be covered as a part of this program include: insurance premiums and deductibles and co-payments for prescription medication.</p> <p>To qualify for this program an individual must have a diagnosis of PKU, be a US citizen or legal resident, complete application and waiver forms, have a prescription for an FDA-approved drug for PKU, and provide documentation to verify financial need.</p>

<sup>1</sup> NORD is required to comply with the standards set forth by the Office of the Inspector General (OIG) and a financial means test is required to qualify individuals for premium and co-pay assistance programs.



## How do individuals apply for a NORD PKU Assistance Program?

Your BioMarin RareConnections™ Case Manager is available to assist individuals in a referral to NORD. By applying for assistance through BioMarin RareConnections™ our team can then assist you with any paperwork, questions, or status inquiries.

Individuals and/or clinics can self-refer to NORD for assistance. However, it is important to note that by doing this BioMarin RareConnections™ will not be able to assist with paperwork, questions, or status inquiries.

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**Hours of Operation**  
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