National PKU Alliance
Maternal PKU Emergency Assistance Program

PROGRAM DETAILS AND APPLICATION INSTRUCTIONS

Thank you for referring your patient to the Maternal PKU Emergency Assistance Program (MPKUEAP) established by the PKU Adult Program of the National PKU Alliance. The goal of the Maternal PKU Emergency Program is to assist women with PKU who are currently pregnant and have no access to foods modified to be low in protein due to financial barriers. To be eligible for the emergency assistance program the patient must be under the care of a qualified health care professional practicing at a metabolic clinic in the USA and currently reside in the USA.

The MPKUEAP is not meant to supply a woman through her entire pregnancy but to serve as a bridge to assist pregnant women through the highly critical early weeks of pregnancy and to assist with lowering of PHE levels to clinical recommendations as quickly as possible. The food is meant to supplement foods naturally low in protein so that they can last for a reasonable period of time. Any woman who doesn't experience an increase in PHE tolerance and is in need of additional assistance after the emergency assistance packaged is used and is in need of additional assistance can apply again for an additional assistance package.

The emergency assistance package consists of staple foods that are generally easy to incorporate into a/the diet, and require minimum preparation. The package will consist of:

15 boxes of low protein pasta
1 container of Mix Quick
3 loaves of home-style bread

Each request for assistance will be handled on an individual basis. Additional information impacting the pregnancy that may be relevant to this application may also be submitted in addition to this application form. If the patient is approved, the emergency assistance package will be sent directly to the patient's home. An email will also be sent to the practitioner notifying them of approval. If the patient is denied, an email will be sent to the practitioner who then will notify the applicant.

In order to evaluate the effectiveness of the program, the National PKU Alliance will contact the metabolic RD who submitted this application six weeks after the post partum date listed on the application form to report the potential impact of the assistance has had on the outcome of the pregnancy contextually related to the history of the pregnancy. The release signed by the recipient on the application form will enable the dietitian to report those results.

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For questions regarding this program or application, please call Christine Brown at 715-713-0138 or email at christine.brown@npkua.org.

National PKU Alliance
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NPKUA Maternal PKU Emergency Assistance Program Application

Section One – Metabolic Practitioner Information (Please Print Clearly)

Note: Application **MUST** be submitted by a licensed qualified healthcare professional affiliated with an institution specializing in PKU

First Name	Last Name	Credentials

Clinic Name and Address

Clinic City	Clinic State	Clinic Zip Code

Clinic Phone	Email Address

Practitioner's Certification Statement

I request an emergency assistance package be provided for the herein patient who has demonstrated a medical need and is unable to afford foods modified to be low in protein. I verify that the information provided on this application is complete and accurate. I understand that the patient must be part of the population for which this program is indicated and I certify these foods modified to be low in protein are medically indicated for this patient. I understand that the patient must qualify and meet the program criteria to be eligible for assistance.

The emergency assistance package provided to the above patient is considered a donation to the patient from the National PKU Alliance Maternal PKU Emergency Assistance Program. I understand that I will not receive any reimbursement from the National PKU Alliance whether for administration fees or otherwise.

I understand the National PKU Alliance will contact me six weeks following the post partum date indicated in this form to follow-up regarding the outcome of the pregnancy as it relates to birth weight and length, head size, heart condition and other markers of health typical of concern for a baby born to a mother with PKU. This may include post partum blood phenylalanine levels as indicated to monitor the effectiveness of provision of this assistance. The data will be collected solely for the purposes of evaluating the effectiveness of the Maternal PKU Emergency Assistance Program.

I represent and warrant that this facility has obtained all applicable authorizations, consents, and notices necessary to comply with all federal and state laws and regulations relating in any way to medical and/or health privacy including but not limited to the HIPAA Privacy Rule, codified at 45 C.F.R. Parts 160, 162 and 164, as amended from time to time. I verify that to the best of my knowledge the information set forth in this application is complete and accurate.

Practitioner's Signature	**Date**

Section Two - Patient Contact Information (Please Print Clearly)

Note: If approved, Emergency Assistance Package will be delivered to patient address

First Name	Last Name	Date of birth

Shipping Address (no P.O. Box)

City	State	Zip Code

Phone	Email Address

Section Three – Clinical Information (Please Print Clearly)	
Current Gestational Age	Estimated Due Date
Did patient present to metabolic clinic prior to conception? Yes ☐ No ☐ If no, at approximately how many weeks of gestational age did patient present? ___________	Current PHE Tolerance _______ mg PHE tolerance not pregnant (if known) ________ mg
Please list last three PHE levels and date Level _________ (mg/dl) Date ____________ Level _________ (mg/dl) Date ____________ Level _________ (mg/dl) Date ____________ Average pregnancy PHE level _____________	Are there any known complications currently with the developing fetus? Yes ☐ No ☐ If yes, please briefly describe:
Is this the patient's first pregnancy? Yes ☐ No ☐	If no, please briefly describe the outcome of all previous pregnancies.

Section Four - Patient Coverage Information	
Does the patient have private medical insurance? Yes ☐ No ☐	If yes, does the insurance cover low protein foods? Yes ☐ No ☐
Is the patient enrolled in a state or federal program which provides health care coverage? Yes ☐ No ☐	If yes, does the state / federal program provide foods modified to be low in protein? Yes ☐ No ☐
Has the patient received donations of foods modified to be low in protein from any third party? Yes ☐ No ☐	If yes, please briefly describe the donation(s) and if it was a one-time donation or a reoccurring donation. (Please note previous receipt of donations does not necessarily disqualify an applicant.)

Note: If there is any other information pertinent to this application which may be useful to evaluate the applicant's qualifications please provide details on a separate sheet of paper and submit with the application. Thank you.

Patient's Certification and Authorization Statement	
By signing below I verify that the information provided in this application is complete and accurate and that without enrollment in the Maternal PKU Emergency Assistance Program I would not be able to afford these foods modified to be low in protein. I also understand that completing this application does not ensure that I will qualify for this program. I consent to the release of my medical information by my health care providers pertaining to pregnancy and other information as necessary to the Maternal PKU Emergency Assistance Program to complete the application process to be used for program authorization purposes and provide services through this program. The clinical and coverage information provided is for the sole use of the National PKU Alliance for the purposes of determining program eligibility and will not be released to any third parties. I understand that the National PKU Alliance will supply my name, address, and phone number to companies for the purposes of product dispensement and to learn about other medical foods (formula and foods modified to be low in protein and treatments that may be helpful to me in managing my PKU. I understand that the National PKU Alliance reserves the right at any time for any reason to contact me directly to request additional information and confirm receipt of the emergency assistance package. I, myself, administrators, heirs, assignees and anyone entitled to act on my behalf, do hereby waive and release any and all actions, claims, injuries, demands, liabilities, losses, damages, or expenses of whatever kind and nature including, but not limited to, attorney fees which may be incurred at any time by reason of participating in this assistance program. I, myself, and anyone entitled to act on my behalf also do hereby waive and release any and all actions, claims, injuries, demands, liabilities, losses, damages or expenses of whatever kind and nature against the NPKUA.	
Patient's Original Signature	**Date**

FAX OR EMAIL COMPLETED FORM TO

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