Guide to PKU

Grandparents

What is PKU?

PKU is short for Phenylketonuria (fen-el-key-ton-uria). It is a serious metabolic disorder that some people are born with. People with PKU are not sick, but need a special PKU formula and a diet that is low in whole protein and phenylalanine to stay healthy.

What is phenylalanine?

Amino acids are the building blocks of proteins. Phenylalanine (PHE) is an amino acid. A person with PKU lacks the enzyme needed to break down PHE, which is needed for the body.

What happens?

PKU is not a food allergy with an immediate reaction when the wrong foods are eaten. Eating too much protein causes an unhealthy buildup of PHE. These high levels are harmful to the brain and can lead to learning problems and other medical conditions if not well managed.

High PHE levels may cause:

- Lack of attention or focus
- Learning disabilities
- An overall tiredness or lack of energy
- Behavior problems
- Anxious feelings
- And more…

PKU formula and a low protein diet will help keep your grandchild healthy. All you have to do is provide foods low in protein in proper portions, and make sure all formula is consumed when scheduled.

What is a low protein diet?

In order to limit the amount of PHE that your grandchild eats, he/she must follow a diet low in whole protein. The PKU diet mostly consists of fruits, vegetables and special low protein foods. Your grandchild must avoid high protein foods such as meat, poultry, fish, eggs, nuts, seeds, peanut butter, milk, yogurt, cheese and other dairy products. Regular bread, pasta, rice and cereal also contain whole protein and are usually not permitted.

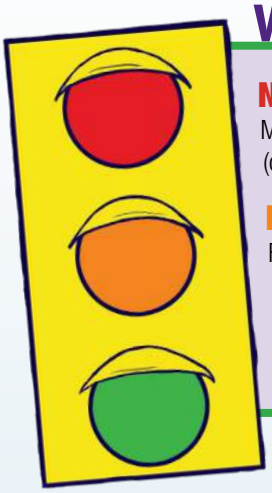
PKU formula provides the special protein your grandchild needs to grow and stay healthy.

The PKU diet must be started and followed strictly from birth and continued for life.

Individuals with PKU must drink a special ***formula*** *to supply the body with the necessary protein requirements for growth and maintenance. There is also a wide range of commercially available low protein food products for today's PKU population.*

Available at **MedicalFood.com**

What can I feed my grandchild?*



NOT PERMITTED

Meat, poultry, fish, eggs, nuts, peanut butter, seeds, regular bread, pasta, rice, grains, beans, milk, yogurt, cheese (other dairy), and foods containing aspartame such as some sugarless gums, diet drinks and medications.

PERMITTED IN LIMITED AND MEASURED AMOUNTS

Fruit juice, rice milk, butter, starchy vegetables such as peas, corn and potatoes.

PERMITTED LOW PROTEIN FOODS

Special foods made to be low in protein, such as low protein breads, pastas and baking mixes. Many fruits and vegetables, dairy-free margarine, cooking oils and many sugar-based sweets (such as lollipops and jelly beans).

*This is not a complete list. Permitted foods and quantities will vary. Always consult the metabolic clinic prior to making any changes to the PKU diet plan.
To find out the PHE content of food, visit HowMuchPHE.org or MetabolicDietApp.org

Bake low protein with your grandchild!

What can I do?

Support your grandchild's parents in teaching the child that following the PKU diet is important.

Respect the wishes of the parents and only provide food permitted on the low protein diet.

Learn to cook low protein. There are many great cookbooks available. Your grandchild will love when there is always something good to eat at your house.

Avoid Aspartame

Food, chewing gum, medications and diet drinks that contain the artificial sweetener aspartame are completely off limits. Other artificial sweeteners are allowed, but aspartame contains phenylalanine and is harmful to those with PKU.

Be sure to read labels carefully to avoid aspartame.

Things to remember:

- Always encourage diet adherence. "Just a taste" can set a bad example that not following the diet is an acceptable behavior.
- Your grandchild is not sick or different from any other child. The only difference with PKU is the need for a special formula and the foods allowed.
- You are not to blame. PKU is a genetic disorder and is no one's fault. Each time two people who carry the PKU gene have a child, there is a 1 in 4 (25%) chance the baby will have PKU.

The information contained in this educational material is for information purposes only and is not intended to replace medical advice from a metabolic professional. Health-related decisions should be made in partnership with a qualified healthcare provider. This material is not intended to be a substitute for professional medical advice, diagnosis or treatment.

All featured products are medical foods for the dietary management of proven Phenylketonuria (PKU) and must be used under medical supervision.

NUTRICIA 1-800-365-7354 | MedicalFood.com

© 2020 Nutricia North America. 3/20 ZPKUESG

This PKU educational handout is brought to you by Nutricia Metabolics, maker of Periflex®, PhenylAde® & Lophlex® brand of PKU Formulas. For more information visit MedicalFood.com