Guide to PKU

Babysitters

What is PKU?

PKU is short for Phenylketonuria (fen-el-key-ton-uria). It is a genetic 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.

What happens?

When a person with PKU eats protein his/her body cannot break it down all the way. Eating too much protein will cause an unhealthy buildup of something called PHE (fee), which is short for phenylalanine (fen-el-al-a-neen). To stay healthy, those with PKU must follow a diet low in whole protein and drink PKU formula every day.

What is a low protein diet?

A low protein diet is mostly fruits and vegetables plus special low protein foods. People with PKU cannot have foods high in whole protein like meat, poultry, fish, eggs, nuts, seeds, peanut butter, milk, yogurt, cheese and other dairy products. Regular bread, pasta, rice and cereal also contain protein and are usually not permitted.

Be a Super Sitter!

- Make sure the child drinks PKU formula at the scheduled times. Ask the parent for tips to help the child drink the formula.
- Always encourage diet adherence. “Just a taste” can set a bad example that not following the diet is an acceptable behavior.
- When the child is drinking the formula be positive. Any negative comments about the taste or smell may discourage the child from drinking the formula.

PKU formula is the main source of protein in the PKU diet. People with PKU must drink formula every day.

What can they have?*

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 sugar-free gums, diet drinks and some 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

Today's Menu

Formula_____

Time_____

Meals_____

_____

_____

_____

_____

Snacks_____

_____

_____

LOW PRO

Parent Contact Info

We will be at:_____

_____

We will be home at:_____

Cell:_____

Email:_____

Notes:_____

_____

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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.

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