

# Guide to PKU

# Teachers & School Nurses

## What is PKU?

PKU is short for Phenylketonuria (fen-el-key-ton-uria), which is an inherited metabolic condition. People with PKU cannot break down the amino acid phenylalanine (fen-el-al-a-noon) in their bodies. Phenylalanine (PHE) is found in all food that contains protein. PKU is a serious medical condition that is managed with a special PKU formula and a diet low in whole protein and PHE.

## What happens?

Since people with PKU cannot break down PHE, too much whole protein in their diet will cause an unhealthy and dangerous build up of PHE in their bodies. High PHE 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
- Behavior problems
- Learning disabilities
- Anxious feelings
- An overall tiredness or lack of energy
- And more...

To help prevent this, individuals with PKU must follow a special diet low in whole protein and drink their PKU formula throughout the day.

## What should I do?

**Teach** your student as you would anyone else. PHE levels can fluctuate. Your student with PKU may sometimes need additional time or attention to keep pace with the classroom.

**Help** to make sure your student drinks his/her PKU formula. Peer pressure may cause children to secretly spill out or hide formula. It is important your student has a safe place to consume and store the formula.

**Communicate** openly with parents and ask questions. Since you spend a good portion of the day with your student, you may be the first to notice PKU-related learning or behavior problems. Bringing this to the parents' attention quickly is very important for successful PKU management.



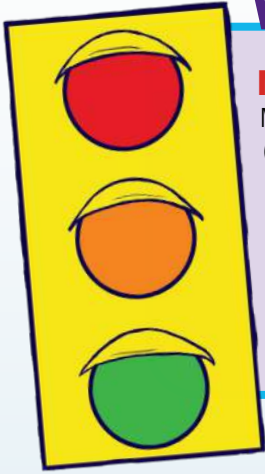
*PKU formula is a critical part of the diet. Since someone with PKU cannot have many foods that contain whole protein they rely on PKU formula to supply special protein. PKU formula is typically consumed several times per day.*



## Helpful Tips

- ✓ Always encourage diet adherence. "Just a taste" can set a bad example that not following the diet at school is acceptable behavior.
- ✓ Treat this child the same as other students. PKU is not an illness and your student is not sick. As long as they follow the special diet and drink PKU formula, your student can be just as successful as the rest of the class.
- ✓ Do not let PKU identify your student. Helping to establish a sense of self outside of PKU is a lesson your student will remember for life.

# 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 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](http://HowMuchPHE.org) or [MetabolicDietApp.org](http://MetabolicDietApp.org)



## PKU DIET PLAN

My child \_\_\_\_\_  
drinks \_\_\_\_\_ fl oz of PKU formula at school.

### Parent Contact Information

The best way to reach me is by (circle one):

Phone

Email

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Notes: \_\_\_\_\_

## FACT

*PKU is a medical diagnosis included in the Rehabilitation Act (section 504) and the Americans with Disabilities Act. All federally funded school lunch programs are required to provide a low protein option for children with PKU.*

\*For US only

## Classroom Birthdays

Although your student with PKU cannot have regular cake, cookies or cupcakes, there are low protein versions of these fun treats. Be sure to let parents and cafeteria staff know about an upcoming celebration so they can provide an alternative snack.



## Resources

### To learn more about PKU and the diet, visit:

**National PKU Alliance – [www.npkua.org](http://www.npkua.org)**

The National PKU Alliance is the national non-profit organization focused on making a difference in the lives of those with PKU.

**Canadian PKU and Allied Disorders – [www.CanPKU.org](http://www.CanPKU.org)**

The CanPKU is the non-profit organization focused on making a difference in the lives of those with PKU living in Canada.

**Nutricia – [www.MedicalFood.com](http://www.MedicalFood.com)**

Learn more about PKU and other metabolic disorders in our dedicated education section and link to our informative blog [LowProLiving.com](http://LowProLiving.com)

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.



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