

# PKU NUTRITIONAL MILESTONES

## School Years

It is important to include your child in treating PKU from an early age. Use this guide to build PKU knowledge and skills.

### Preschool (4- 6 years of age)

- ▶ PKU formula awareness:
  - ▶ Can name his/her formula
  - ▶ Knows number of times per day to drink formula
  - ▶ If drinking powdered formula, watches and helps mix formula
- ▶ PKU food knowledge:
  - ▶ Knows he/she eats limited phenylalanine (phe) or protein
  - ▶ Is aware of the difference in eating habits from family and friends
  - ▶ Able to state "YES, NO" or "red, yellow, or green light" foods
  - ▶ Can assist in making meals and snacks through counting, weighing or measuring
- ▶ PKU management skills:
  - ▶ Can give a simple description of PKU to friends or family
  - ▶ Understands basic reasons for PKU clinic visits and why blood draws are important
- ▶ Help your child understand PKU through books such as *The Adventures of Ruby Pricklebottom*



#### Resources:

- ▶ My PKU Binder from National PKU Alliance: <https://www.npkua.org/What-is-PKU/My-PKU-Binder>
- ▶ How Much Phe? The Essentials: <https://shop.pkunews.org/products/how-much-phe-the-essentials>

### School Age (7-12 years)

- ▶ PKU formula awareness:
  - ▶ Prepares and takes formula with supervision
  - ▶ Knows daily formula goal
- ▶ PKU food knowledge:
  - ▶ Knows phe or protein goal for the day
  - ▶ Keeps track of foods eaten and starts to count phe or protein
  - ▶ Helps with grocery shopping, meal planning, measuring and preparing meals and snacks
  - ▶ Makes appropriate food choices at school and in social situations
- ▶ PKU management skills:
  - ▶ Knows how often blood draws are required
  - ▶ Recognizes the target range for blood phe levels
  - ▶ Recognizes what influences high blood phe levels (taking formula, staying within phe or protein prescription, illness)
  - ▶ Can explain PKU to school staff and friends
- ▶ Help your child understand PKU through books such as *Everybody Has Something*



#### Resources:

- ▶ PKU and the Brain: New Research and Therapies: <https://www.npkua.org/What-is-PKU/PKU-and-the-Brain>

# Eating At Day Care or School

Providing formula and a low protein diet throughout the school day is essential for your child's success. Teachers and caregivers must also understand PKU and how it is treated. Discuss a plan with your dietitian on how to monitor and provide appropriate meals and snacks.

This could include:

- ▶ A letter from your genetics/metabolic team reviewing PKU and diet needs
- ▶ Schedule a parent meeting with all daycare or school staff to navigate meals
  - ▶ Who will prepare and supply formula?
  - ▶ What foods are accessible at daycare or school? Is there a need to order low protein foods?
  - ▶ Who will supervise food and formula intake during meals and snack time?
  - ▶ Communication between parents and school for tracking foods and formula
  - ▶ When available, access to refrigerators or microwaves for meal and formula needs
- ▶ Use these additional resources to help create the best plan for school

## Resources:

- ▶ Lettuce Eat... Something Other Than Salad at School & Daycare: <https://pkunews.org/pku-in-the-cafeteria/>
- ▶ PKU Friendly Meal Substitutions for School: <https://pkunews.org/wp-content/uploads/2019/08/201908-PKU-Friendly-Meal-Subs.pdf>
- ▶ Low Protein School Lunch Program: Food Services Guide Summary: <https://www.cambrooke.com/support/documents-resources>

# Managing PKU in the Classroom

Reviewing PKU and its potential affects on learning is another important step for making sure your child is successful in the classroom. A meeting with all educators will help determine if any additional support is needed. This may include an educational plan to improve your child's learning. Make sure to set up a meeting before the school year. Contact your PKU clinic for letters explaining PKU and treatment if needed.

## Educators should know the following:

- ▶ Blood phenylalanine (phe) levels go up and down depending on many things. This includes taking a special PKU formula, eating foods low in protein and avoiding foods high in protein like meats and dairy.
- ▶ High blood phe levels can cause executive function issues including: attention span, processing information, working memory, planning, and organizing. This may affect learning in the following ways: ADHD-like symptoms, difficulties following more than one direction at a time, and struggling to finish tests within a given time period.
- ▶ It is important for both parents and educators to communicate on a regular basis if there are any changes in behavior. PKU diet changes may need to be made.

Reference An Educator's Guide to PKU: <https://newenglandconsortium.org/brochures/educators-guide-to-pku.pdf>

## Resources:

- ▶ <https://canadianpkuandallieddisorders.wildapricot.org/resources/Documents/Educational%20-%20English/CanPKU-Elementary-School-Guide.pdf>
- ▶ <https://www.gemssforschools.org/conditions/pku/default>
- ▶ <https://www.npkua.org/What-is-PKU/School-Information>