



Guide to PKU

For Educators and School Health Providers

What is PKU?

PKU is short for Phenylketonuria (fen-ul-key-toe-NU-ree-uh). PKU is a rare genetic condition in which a person's body can't break down an amino acid called phenylalanine (PHE).

Amino acids are the building blocks of proteins, and PHE is found in most foods. People with PKU cannot effectively breakdown PHE, leading to a buildup in the body. Without treatment, over time too much PHE can cause brain damage, including developmental delays and neurological symptoms.



Students with PKU may experience:

- Trouble focusing in class
- Mood swings
- Fatigue or low-energy, especially in the afternoon
- Social struggles as a result of significant differences in diet

What can they eat?

***NOT TYPICALLY PERMITTED:**

Meat, fish, eggs, nuts, peanut butter, regular baked goods, regular pasta, beans, soy, cow's milk, dairy yogurt, dairy cheese and foods containing aspartame.

***SOMETIMES PERMITTED IN LIMITED AMOUNTS:**

Rice milk, rice, butter, heavy cream, starchy vegetables like peas, corn and potatoes.

***PERMITTED, LOW PROTEIN FOODS**

Many fruits and vegetables, cooking oils, many sugar-based candies, special foods made to be low in protein (such as low protein bread and pasta).



**This list is far from exhaustive, and nutrition restrictions and needs vary across individuals. Always work closely with your student's caregivers for guidance on appropriate foods.*

Supporting a Student with PKU

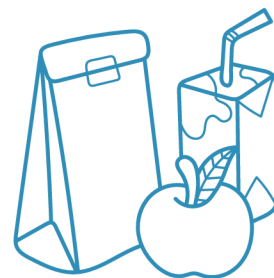
- Teach your student with PKU as you would any other student; remember that PHE levels can fluctuate and not all individuals with PKU experience the impacts listed.
- Help empower your student to take care of their health by accommodating their nutrition needs throughout the day, including allowing them to drink their medical formula when needed and making sure they are included in food-based activities.
- Maintain a policy that prohibits food sharing to help reduce social isolation, limit peer pressure and encourage diet adherence.

Helpful Tips to Remember:

- ✓ **PKU is not an illness, and your student will not experience a medical emergency in your classroom because of their PKU.**
- ✓ **Avoid surprise food-based activities or parties involving food without checking with caregivers first.**
- ✓ **Maintain open communication with your student's caregivers and ask questions when needed!**

School Lunch Requirement

PKU is a recognized medical condition under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA). As such, all federally funded school lunch programs are required to provide low-protein meal options for students with PKU.



To learn more about PKU please scan the QR code or visit npkua.org