



Phenylketonuria

Facts for School Faculty & Staff



- Phenylketonuria, also known as PKU, is an inherited brain threatening genetic disorder that affects a person's ability to process an important part of protein called phenylalanine or Phe. Phe is in almost all foods and is important for growth and development.
- How is PKU diagnosed? Babies are screened for PKU with a simple test shortly after birth. Positive screens are then confirmed by a more detailed diagnostic test. Only 1 in about 15,000 babies are born with PKU. Newborn screening will celebrate its 50th anniversary in 2013!
- Children and adults with PKU must limit Phe intake. A high level of Phe in the body is toxic and can cause severe brain damage.
- Since we all need protein to grow and stay healthy, individuals with PKU drink a special medical formula to meet their protein requirements which is free of Phe.
- The standard treatment for PKU is a strict diet very low in Phe for life. Children and adults with PKU have to eat such small amounts of Phe that they cannot eat meat, poultry, fish, dairy, eggs, beans or nuts. Someone with PKU cannot eat pizza, birthday cake, regular bread, yogurt, cheese, ice cream, chocolate, hot dogs, hamburgers, or turkey on Thanksgiving! The sweetener aspartame, present in many sugar-free foods and diet soft drinks, must also be avoided, as aspartame contains a high amount of Phe.
- Children and adults with PKU eat fruits, vegetables, and special foods very low in protein. Some cereals and crackers are okay in small amounts. Phe must be calculated using a gram scale, measuring cups or by counting how many pieces, all day, every day. Using math is an important part of managing PKU!
- Having PKU is sometimes very hard, especially when a child or teenager can't have a food that all their friends are eating.
- Kids with PKU need help from their family, friends, teachers, and other community members to be sure they feel good about what they can eat.
- The PKU diet is just one of many special diets. You can talk to your students about how the PKU diet lowers blood Phe levels just as insulin regulates blood sugar for someone with diabetes.
- Children and adults with PKU have to test their blood Phe content regularly (weekly to monthly) using at home tests cards that are analyzed by a laboratory or by having blood drawn at a doctor's office or hospital.
- It is important to remember that as long as a child with PKU maintains their strict diet, they will have normal growth and development.
- Unfortunately, many teenagers and adults with PKU discontinue treatment due to the difficulty of following a strict diet and the high cost of medical food. In addition to brain damage, untreated PKU can cause other neurological complications, such as depression, anxiety, and memory loss.
- The first National PKU Awareness Day, December 3, 2012, was established by a Congressional Resolution introduced by two U.S. Senators (Johnny Isakson from Georgia and John Kerry from Massachusetts). The resolution explains what PKU is, the history of PKU, and the importance of sharing information about PKU with others.
- May is PKU Awareness Month and December 3rd is PKU Awareness Day. Thank you for helping to raise awareness!

