



# Phenylketonuria Facts for Kids



- Phenylketonuria, also known as PKU, is a genetic disorder that affects a person's ability to process an important part of protein called phenylalanine or Phe. Genetic disorders are related to genes, which determine how we look and how our bodies work.
- We get Phe from the food we eat, and it helps our bodies grow, learn, and feel healthy.
- Soon after birth, babies born in the United States are checked for PKU and other medical conditions. This is called newborn screening.
- If children and adults with PKU eat too much Phe, it will actually hurt them.
- Children and adults with PKU have to eat such small amounts of Phe that they cannot eat meats, 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!
- 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!
- We all need protein to grow and stay healthy, so children and adults with PKU also drink something called medical food that does not contain Phe, but has all the other parts of protein and many other important nutrients.
- Other than their special diet, a child with PKU is just like you!
- Kids with PKU need help from their friends and family to be sure they feel good about what they eat.
- Think about how you eat during the day. What if you had to keep track of everything you ate, every day?
- Having PKU is sometimes really hard, especially when you can't have a food that all your friends are eating.
- PKU can be great too! Lollipops and many other sugar-based candies do not contain Phe and are okay for children and adults with PKU!
- The PKU diet is just one of many special diets. Can you name any others?
- Only 1 in about 15,000 babies are born with PKU, which means PKU is very rare.
- On September 19, 2012 two U.S. Senators (Johnny Isakson from Georgia and John Kerry from Massachusetts) introduced a Congressional Resolution to establish the first National PKU Awareness Day. The resolution passed by unanimous consent, which means all Senators (Republicans and Democrats) agreed it was the right thing to do!
- The National PKU Awareness Day resolution explains what PKU is, the history of PKU, and the importance of sharing information about PKU with others.
- You are helping children and adults with PKU by celebrating PKU Awareness Day!

