

What Teachers Should Know About PKU

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As a teacher, you have the chance to make a real difference in a child's life. In order to do that for a child with PKU, you should know a few things about the disorder before you begin to teach them.

First, let me give you some background information about PKU. PKU is short for Phenylketonuria (Fee-nill-kee-toe-nur-ee-ah), which is an autosomal recessive metabolic disorder. This means that it is inherited from both parents; both parents must be carriers in order for their child to have PKU. It is classified as a metabolic disorder because their bodies do not produce the enzyme that breaks down the protein-related amino acid, phenylalanine (Phe) (Marshall). When Phe is not metabolized correctly, it builds up in the blood, and it can cause brain damage (Understanding PKU). Most infants are tested for PKU during their first few hours of life because the phe can begin doing damage to the brain that early. The treatment for PKU is a special low-phe diet, and if an infant is found to have PKU and is put on this diet right away, brain damage can be avoided (Newborn).

As a teacher, it is important that you remember that every child is unique, not just the ones with PKU. Each child with PKU has a specific phe tolerance because each child's body produces a different amount of the enzyme that breaks down phe, so they have differing amounts of phe that their bodies will metabolize. Every child needs some phe for brain development, whether they have PKU or not, but a child with PKU needs less than a child without PKU (About PKU).

The low-phe diet can be summarized with rules to maintain a low blood phe levels that are called "The Three Rs." The first "R" is restrict. A child with PKU needs to have a restricted amount of phe foods in their diet. This restriction needs to be adjusted according to each child's phe tolerance; each child will have a limit on how many grams of phe he or she can have in a

day. The second “R” is replace; because the high phe foods are also high in protein, the child needs to replace the protein that they are not getting with protein supplements, such as formulas. They also need to make sure that they are still getting enough calories during their day according to their activity and age. The third “R” is record. A child with PKU must keep track of what and how much they eat each day, so that they know how much phe they have had (About PKU). They also need to keep track of their blood phe levels (much like a diabetic would) to make sure that their diet is working properly (PKU What You Should Know).

You may be wondering what a child with PKU can eat. Since they can not eat foods that are high in phe, they can not eat things that are high in protein such as meat, nuts, dairy, eggs, baked goods that are high in flour, or foods containing aspartame (a sugar substitute). Though they cannot eat the same dairy products or eggs that we would, there are dairy products and other substitutes available to buy especially for children with PKU. Also, some no-phe things that they can eat are their phe-free formulas, any kind of oil, or pure sugar foods like popsicles, smarties, or dum dum suckers. Some low-phe foods that are also available for children with PKU are some fruits and vegetables and starch (such as potatoes and some cereals or grains) (About PKU). There is also a new medicine called Kuvan that helps the body to break down more Phe. It is only given to children who cannot keep their blood phe levels low even when on the diet. It helps to reduce their blood levels in combination with the diet (Projectkuvan).

In a classroom, you would not be able to pick out the child with PKU. They have the same intelligence and characteristics as any other student in the class; they are just on a diet. As far as academic modifications are concerned, all you have to be prepared for with your student with PKU is success. Lauren is a high school aged girl who has PKU, and is very active in academics and extracurricular activities. She does everything that a normal teenaged girl does:

she loves to cook, and play sports. She makes her own meals that go along with what her family is having, and her mother says that Lauren's PKU has been a blessing because it taught her to be responsible. Lauren also says "It is possible to have PKU and live a normal life, and I guess I'm proof of that" (Projectkuvan). Another person with PKU is a boy named Kyle. He is in Kindergarten this year, and is doing very well in school. He can do everything that a child without PKU can do. His family can make reservations at the places they want to eat, and the cooks will prepare food that he can eat. He goes out to eat with his brother Tommy and the rest of his family, they just have to be careful what they order. Baked potatoes and fries are some foods he can eat that are available at most restaurants. At home, Kyle's mom makes special food for him that matches what the family is having each night (Martin).

As a teacher, the most important thing you can do is make sure that they feel like they are a part of the class. Some other suggestions would be to make sure that they child with PKU only eats foods that are from his parents and remember that they know what is best for their child because they are the ones who are keeping track of his phe levels each day. Also, make sure that you notify the parents before you have class parties that involve food and ask if they are able to make something to send in so that their child is not left out of the party. Making a classroom rule that no students can trade food is also a good idea because the child with PKU cannot trade foods and if no one else can either, it makes them feel more included (About PKU). As a teacher, you should also make sure that the child with PKU takes home all of their uneaten foods from lunch because the parents need to know how much they ate in order to calculate their phe for the day. Having a box of special foods for the child is also a good idea if another student brings in birthday treats or something, but you have to make sure to ask the parents if the food is okay because even if you see the child eating fruit snacks, for example, that does not mean that

they can have all kinds of fruit snacks. The brands matter; General Mills and Kellogg's are good examples because a child with PKU can have General Mills fruit snacks, but not Kellogg's fruit snacks (Martin). Sometimes you will have to keep track of what the child eats at school too. For example, if you have a snack box for them and they have something out of it, the parents need to know so they can add that into the child's phe for the day. A chart for keeping track of foods can be found online, and I would encourage you as the teacher to try filling it out for a day so that they better understand what the student goes through every day. Like I said earlier, make sure that you are careful not to make them feel excluded because they already feel different because of their diets; it is your job to make them feel like they fit in.

I would also suggest that you try to make some food for the child with PKU even if you do not give it to them because it helps you to better understand what the child's situation is. I made rice crispie bars for a child with PKU, and it is a lot of work. You have to weight each of the ingredients so that you can find out how much phe is in the bars. For example, each gram of marshmallows contains .38 grams of phe, and each gram of butter has .39 grams, and each gram of rice crispies is 3.21 grams of phe (Martin). Next, you have to weight the bar before you give it to the child so that you know how much phe is in that specific bar. This experience helped me to understand more fully what it is like to have PKU, and so I think it would be helpful for a teacher to do the same thing in order to more fully understand their students, because the better you understand, the better chance you have to make a real difference in a child's life.

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