

Janet Napolitano, Governor
State of Arizona



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A Teacher's Guide To PKU



Hi, my name is



I have PKU and I want you to learn more about it so you can help me. This booklet will tell you about PKU. Except for my special diet, I am just like the other children in your classroom.

IMPORTANT PHONE

NUMBERS

Contact Person(s): _____

Relationship: _____

Phone Number(s): _____
(work) (home)

Resources for Activities

Children's PKU Network

Via De La Valle, Ste 120

Del Mar, CA 92014

Phone (800) 377-6677 (toll free)

Fax (619) 233-0838

E-Mail: PKUNETWORK@aol.com

National PKU News

6869 Woodlawn Avenue N.E. #116

Seattle, WA 98115-5469

Phone (206) 525-8140

E-mail: schuett@pknews.org

Website: www.pkunews.org

New England Connection for PKU & Allied Disorders

Attn: Marybeth Ferullo

PO Box 3235

Woburn, MA 01888-2135

Contact the president of NECPAD, Donna McGrath at (978)658-6975 or

E-mail: NECPAD@gmail.com

www.necpad.org

THINGS TO DO WITH FOOD!

Many nutrition activities can be adapted to use allowable PKU foods so all children can participate in the same way. Remember to review the allowable foods and amounts with the parents of the child with PKU.

Use the Same Fruit or Vegetable

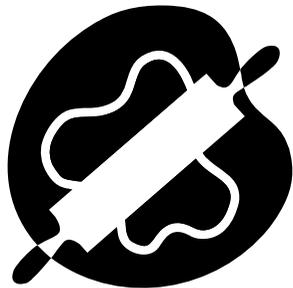
- Slice, chop, make juice
- Prepare in different ways: raw, boiled, fried, or broiled (corn can be on the cob, cut off, popped, ground into flour)
- Trace where a food comes from or go on field trips (e.g., Oranges are grown on a tree; squeezed or canned or bottled; sold in a store; taken home or to school to eat or drink.)



Use Different Fruits or Vegetables

- Compare colors, shapes, textures, tastes
- Show where grown (in ground, on a tree, bush, etc.)

Classroom baking projects can be adapted to include the child with PKU. Special recipes have been developed which reduce the protein in baked foods by using special low protein baking mixes. Ask the PKU child's family if they have any special recipes that they would share with you and ask them how to order any special low-protein products you need.



PKU Basics



These are the facts...

Phenylketonuria (or PKU) is an inherited disorder of protein breakdown. Children with PKU do not have a functioning enzyme to break down an amino acid called phenylalanine (PHE for short), which is found in all food proteins.

Protein in foods is important for building and repairing the body's tissues. Amino acids are often called the "building blocks" of protein. Twenty amino acids can be joined together in various combinations to form all the different kinds of proteins in foods.

Enzymes are special substances in the body that work to separate the amino acids in the food proteins and recombine them to form different proteins that the body needs.

All children need PHE for normal growth and tissue repair. In most people, any extra PHE is broken down and used by the body in different ways. PHE usually breaks down to another amino acid tyrosine. Because the child with PKU lacks the enzyme which breaks down dietary PHE to tyrosine, the PHE builds up in the body tissues, including the blood. This extra PHE can prevent normal brain development and result in mental retardation.

The good part is...

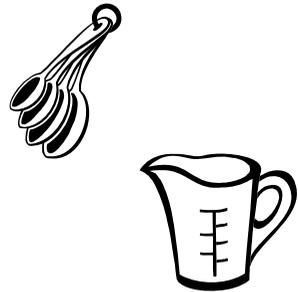


All states have a newborn screening program, which checks baby's blood during the first week of life to see if the infant has PKU or other metabolic disorders. The infant with PKU can then be treated with carefully controlled diet, which allows just enough Phenylalanine for growth, but prevents the elevation of blood PHE that interferes with normal brain development. Blood monitoring of Phenylalanine along with dietary adjustments are done on a regular basis. Early diagnosis and continued dietary treatment are essential for a normal growth and development in a child with PKU.

And now the diet...

Since PHE is found in all foods with protein, children with PKU must limit the amount of protein they eat from food. Foods that contain high amounts of protein are also high in PHE and should not be eaten. Foods with small amounts of protein and PHE can be eaten in controlled amounts. Some foods are "free" foods because they contain no protein and are free of Phenylalanine. These foods are eaten to help boost the child's intake of calories needed for energy.

A child with PKU has a special drink, called a medical food or metabolic formula. This drink has most of the protein (with little or no PHE), calories, vitamins and minerals that a child needs for growth. The special drink has little or no PHE and provides almost all the nutrients that other children receive from their food. It may have a test and smell that may seem unpleasant to someone not used to it. However, children with PKU acquire a taste for the drink at an early age and have grown up with it.



The amount of drink and food the child consumes in a day is carefully calculated by the child's nutritionist and doctor. All foods must be carefully measured to control the amount of PHE the child eats. This amount is adjusted to the child's changing needs as he or she grows. A child with PKU learns at an early age that his or her diet is restricted and to ask a parent if a new food is allowed. By school age, children with PKU generally know what he or she can eat.

MEAL REGULATIONS AT SCHOOL....

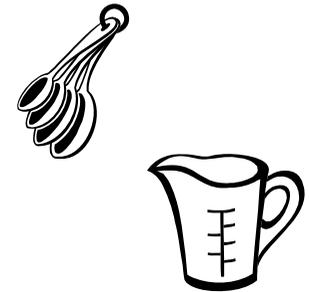
The USDA nondiscrimination regulations (7 CFR 15b), as well as the regulations governing the National School Lunch Program and School Breakfast Program, make it clear that substitutions to the regular meal **MUST** be made for children who are unable to eat school meals because of their disabilities, when that need is certified by a physician.

SKILL SHARPENERS!

Here are several activities which could strengthen developmental and academic skills needed by all children, but especially important for the development of a PKU child's self-sufficiency. The following activities are appropriate for several ages:

Measuring and Pouring Skills

Use cups and spoons to measure liquid and dry ingredients.



Fine Motor Skills

When age appropriate, use a knife to cut, chop and spread foods or playdough.

Academic Skills

- Follow a recipe.
- Keep food records (have child count mgs of Phenylalanine or grams of protein)
- Read and collect food labels.
- Learn to budget money, calories, grams of protein, or time.
- Color favorite foods, by using a coloring book.



DIFFERENCES ARE FUN!

A child with PKU has a special diet. The teacher can use this situation to teach all the children that there are differences among people and it is these very differences that make the world more interesting.



"PEOPLE ARE UNIQUE"

- Make body tracings.
- Collect photographs of each child and the whole class.
- Measure each child's height and weight.
- Describe each other (verbally for the younger child, written for the older child).
- Have each child take a turn at showing the class how he/she is special.
- Cut out pictures of different people from magazines.

"PEOPLE EAT DIFFERENT FOODS"

FOOD CUSTOMS:

- Geography (seacoast, ranch lands, farms, etc.)
- International (Mexican, Chinese, Italian, etc.)
- Religious (Jewish, no pork; Hindu, no beef)
- Seasonal (summer and winter fruits & vegetables)
- Vegetarians (no foods from animal sources)

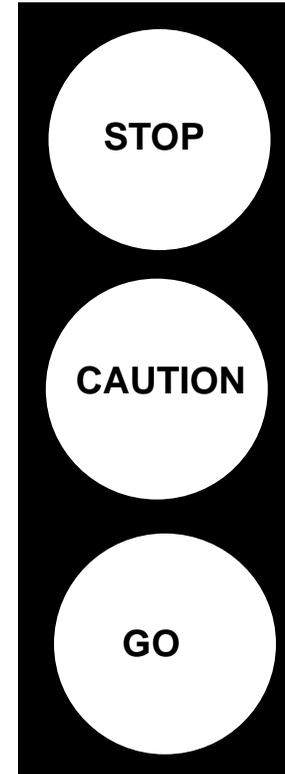
HEALTH:

- Overweight (low calories & low fat)
- Diabetes (controlled sugar)
- PKU (special drink & low protein foods)
- Heart disease (low fat & low salt)
- High blood pressure (no salt)



Parents have...

complete, detailed list of foods to use and avoid in feeding their child with PKU. If needed, they can provide a detailed list of foods with specific amounts that they could be eating. Some examples include:



NOT ALLOWED....

meat, fish, chicken, turkey, milk, cheese, ice cream, yogurt, eggs, beans, nuts, peanut butter, soy foods (like tofu and "vegetarian meat alternatives")
NutraSweet * (aspartame).

ALLOWED BUT CONTROLLED....

fruits, fruit juices, vegetables, vegetable juices, breads, cereals, crackers, potato chips, popcorn, special low-protein foods. **

FREE FOODS*....

soda, Kool-Aid, lemonade, popsicles, jelly, gum drops, suckers, hard candy.

* Foods, beverages, candy or gum containing NutraSweet, Equal or aspartame should be avoided by persons with PKU, because these sweeteners are made of more than 50 percent PHE.

** Some food manufacturers use special ingredients to make very low protein foods (such as pastas and baked goods) for the PKU diet. Some of these items may be sent to school as part of the child's meal or snack. These foods are an important addition to a child's diet with PKU because of the added variety they allow without providing much protein or Phenylalanine.



How you can help...

Treat the child with PKU as a strong, healthy member of the class. Remember, he/she is no different from anyone else in terms of social, emotional, physical and academic growth and development.



Keep an open line...

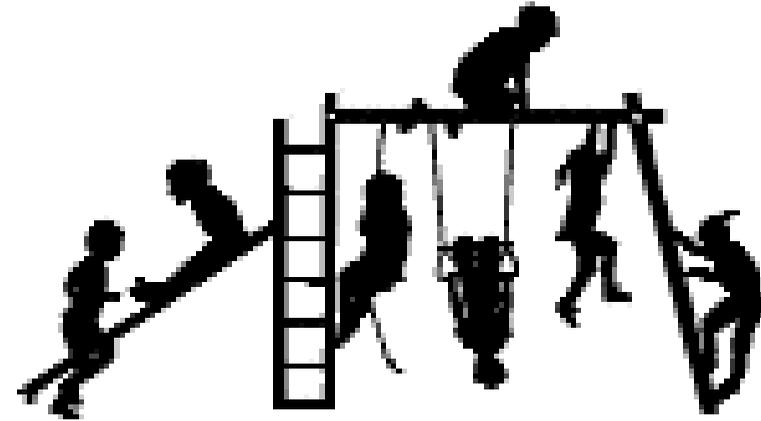
of communication with the child's parents or significant family members to reinforce parent teaching and monitoring of food eaten away from home. The child's parents are your closest experts on PKU.



- **If the child has eaten any food not allowed.**
- **If the child does not eat foods that are sent from home.**
- **If the child trades food with classmates.**
- **If the child's health, behavior, or balance seems markedly different.**
- **If special occasions such as birthday or holiday parties are planned, to make sure there is a low-protein food for the child. Parents may want to send a supply of low-protein treats that store well and can be available for special or unexpected occasions.**

PLEASE DO NOT feed the child with PKU *any* foods that are not allowed on the previous list or lists provided by parents. Even "little tastes" add up and result in an elevation of Phenylalanine in their blood. While the PKU child's curiosity may be aroused by these foods, he/she is accustomed to doing without them.

ACTIVITIES



This section has suggestions for classroom activities for all the children in your class. Remember, because the PKU child was identified early and has been on a PKU diet, he/she is like all the other children in your classroom.

Be sure to check with the parents of a PKU child in planning any food-related activities. The parents can tell you how much of each food the child is allowed. You might even get some extra help in the classroom that day.

The following pages present some ideas for activities which you can develop to meet the needs and abilities of your students.

Questions & Answers



If a child with PKU eats a high protein food, will he or she feel sick?



If a PKU child does eat a high protein (PHE) food, he/she will probably not feel sick or different in any way. It is the elevated blood PHE level over time from the continued eating too much PHE that interferes with mental development. These mental changes may not be seen for several months or longer. It is these slow and subtle change that sometimes make it difficult for a child with PKU to understand that high protein foods are harmful.



What is the connection between NutraSweet and PKU?



NutraSweet is a brand name for the sweetener, aspartame, which is used in many presweetened foods and beverages (diet soda), medications and in Equal, a table top sugar substitute. When aspartame is metabolized or broken down in the body, over half of it is PHE. Products containing aspartame should be avoided by the child with PKU. This is why there is the warning required on all food products and medications sweetened with aspartame, typically found in small print near the ingredient list:

PHENYLKETONURICS: contains Phenylalanine.



When can the diet be discontinued?



In the past, children with PKU were frequently taken off the diet around school age, however today doctors are recommending "diet for life." Women with PKU who were not on the PKU diet before and during pregnancy have delivered babies with severe birth defects (heart defects, facial defects, growth retardation, and mental retardation). It is especially important for women with PKU to have their diets in good metabolic control before and during pregnancy to avoid having babies with severe birth defects. Remember a child with PKU will never be able to break down Phenylalanine in the normal way. Failure to adequately follow the PKU diet at any age can cause mental and nervous system damage.



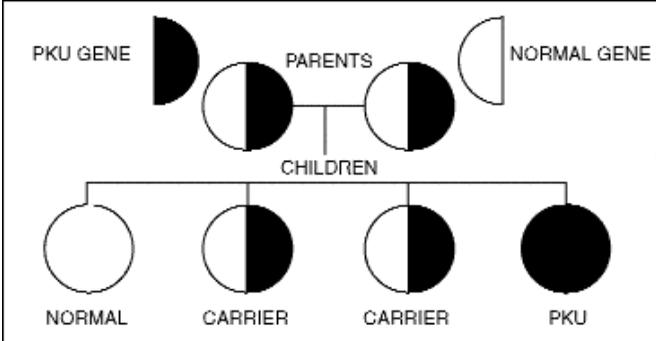
How often are children with PKU born?



Approximately one child in every 15,000 births has PKU. This amounts to 200 to 300 new cases each year in the United States. With effective newborn screening programs in most states, most infants with PKU begin treatment within the first few weeks of life. When the diet therapy is well controlled, it is so effective that the children grow and develop normally and attend regular schools.



Since PKU is inherited, do all the children in that family have PKU?



For a child to have PKU, each of the parents must be a "carrier" of the PKU gene. A carrier has one normal gene and one PKU gene, but can break down Phenylalanine normally. A child with PKU inherited a PKU gene from each parent. When these parents have offspring, there is a 25% chance that the child will be free of the PKU gene, a 50% chance that the child will be a carrier and a 25% chance that the child will have PKU. With each pregnancy, there is the same 25% chance that the newborn will have PKU. There may be only one child with PKU in the family, while in other families there may be multiple children affected.



How do the parents know what to give the PKU child to eat and drink each day?



The child's diet depends on the individual child's diet prescription and preferences from the low-protein foods list. The diet prescription tells how much "special drink" (medical food) the child should have and how many milligrams of phenylalanine the child would get from table foods each day.

Here is a typical diet for a 6-year-old boy with PKU. His diet calls for a "special drink" made especially for PKU and 300 milligrams of PHE from table foods.

Food

mg, PHE

BREAKFAST

- Kix, 6 Tbsp30
- Banana, 1/2 medium30
- Orange juice, 6 ounces15
- PKU Special Drink, 6 ounces0

LUNCH

- Tomato soup, 1/2 cup52
- Saltine crackers, 230
- Lettuce salad, 1/2 cup15
- French dressing, 2 Tbsp.0
- Fruit cocktail, 3/4 cup15
- PKU Special Drink, 6 ounces0

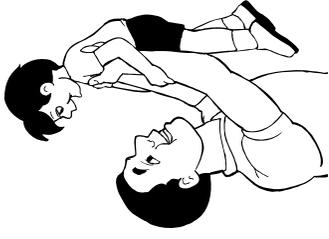
SNACKS

- Popsicle, 10
- Apple, 1 medium8
- Kool-Aid, 8 fluid ounces0
- PKU Special Drink, 6 ounces0

DINNER

- Rice, cooked, 4 Tbsp.60
- Green beans, cooked, 3 Tbsp. 1/4 cup.15
- Jello Gelatin, 6 Tbsp.30
- Special drink, 6 fluid oz.0

TOTAL**300 mg. PHE**
7



How can a child grow with so little food?



The PKU child's special drink contains amino acids (to make protein), vitamins, minerals and calories needed for growth. It really is a special drink! The food that the child eats provides the rest of the necessary nutrients. "Free" foods and drinks provide additional calories and variety.



Does the child with PKU look or act differently from other children?



No, the child with PKU is just like the other children in your classroom except that he/she has a special diet.



How can I explain the PKU diet to other children in the class?



Young children can understand that since cars with different engines use different fuel (gas, diesel, etc.), some children have bodies that work in different ways and need different food. Older children can understand the similar concept of a "food allergy". It is important that classmates do not trade food items or Lunches with the PKU child.



Don't hide the fact that the PKU child's dietary needs are different. Speak with the child's family for suggestions on how to answer this question.