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## SCHOOL LUNCH STRATEGY FOR PARENTS

Following is a copy of a “school lunch strategy” developed by the parents of a child with PKU.

- A detailed letter sent to the child’s teacher that explains (briefly) PKU. The letter discusses this family’s management strategies—“rules” for formula drinking and guidelines for food.
- A list of approved and non-approved snack foods. Portion sizes are listed and *lots* of examples (brand names, etc.) are provided.
- A letter to be distributed to parents of other children in the class. This letter briefly describes PKU and asks parents to let the family know when treats will be provided to the class.

## PKU INFORMATION SHEET

*We have written down the following information to help you better understand our child's PKU condition. We have also provided you with some additional information through publications and a video. We encourage you to offer us advice on anything we can do to make the handling of her diet as easy for you as possible. We would also like to encourage you to ask us about anything that you would like to better understand.*

1. \_\_\_\_ requires a special diet because she has a medical condition called PKU (Phenylketonuria).
2. I have provided a pamphlet called "Education of Students with Phenylketonuria." This provides information about how to work with our child and how to help her in her struggle to stay healthy yet "not be different" from the other kids.
3. \_\_\_\_ is required to drink a special liquid food to obtain the majority of the protein that she needs to grow. This medical food is specifically modified to exclude the one amino acid (phenylalanine) in protein that causes problems for children with PKU. This year, she has chosen NOT to bring her "milk" to school. Instead, she will drink it immediately before she comes to school and after she's home. Note though, that this might change if we determine that she is abnormally hungry, gets lethargic, or if the phe level in her blood is affected.
4. \_\_\_\_ is currently allowed 280 mg of phenylalanine (phe) per day in addition to her "milk." For comparison, one gram of protein usually has 50 mg of phe in it.
5. \_\_\_\_'s health is monitored closely by the U of W PKU Clinic. She is seen each month for weighing, measurements, blood draw, and nutritional assessment. She also takes a nutrition class with other kids with PKU, learning the habits she'll need to grow up healthy. The third Wednesday afternoon of each month is her appointment and she will be out of school during that time. Although we realize it is detrimental for her to miss school, it is a necessary part of her health maintenance. She will make up any schoolwork that she misses during that time.
6. A "Yes" and "No" snack list has been included to help you determine appropriate snacks.
7. We need notification of special parties so we can provide an appropriate food for her. Whenever possible, we will provide a similar food to that being served so she doesn't feel left out. We have found that being open with the other kids and parents works best, so we have provided you with a letter to be sent home to all parents in the class. This letter briefly explains what she has and requests that parents contact us two or three days in advance of any parties. This allows us to prepare something for \_\_\_\_.
8. It is very important that \_\_\_\_ not be given "No" foods. This means no sharing of food items with other kids. Unlike an allergy, if \_\_\_\_ is given a "No" food, she will not become acutely

ill. It is long term exposure to these foods that causes problems. Therefore, if after your best efforts she eats a “No” food, please let us know immediately. This allows us to adjust her diet for the next few days to plan for a lower phe diet.

9. \_\_\_\_ is going through a difficult stage with her diet. Although she is very good about not eating things she shouldn't, she is acutely aware that she “is different.” We feel that it is important for all children in the class to know that she cannot eat all foods, but it must be tempered a bit so \_\_\_\_ is not embarrassed. It would be best if special occasions did not revolve around food whenever possible.
10. \_\_\_\_ appreciates having the ability to buy hot lunch occasionally like the other kids. For this reason, it is important that the lunch supervisor be aware of her dietary restrictions. Previously, we have provided low protein substitutes for some of the hot lunch meals, such as low protein pizza and burritos. \_\_\_\_'s dad drops the food off on her way to work and then \_\_\_\_ buys it back at lunch. It sounds a bit odd, but has been a great thing for her! If this would work, please let us know. She can have the canned fruit, salad (no dressing), or veggie sticks that are often served.

*Thank you very much for your cooperation. Please feel free to contact either of us at ANY time if you have any questions or concerns. We want to make this work without an incredible amount of planning, so would appreciate any suggestions you might have!*

Sincerely,

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| <p style="text-align: center;"><b>PKU INFORMATION SHEET:<br/>APPROVED SNACK LIST</b></p> |
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## **“YES” FOODS**

*The following is a list of “Yes” foods that may be given to \_\_\_\_ in unlimited amounts. They are free of phenylalanine (phe) and do not have to be approved by me before given to her. Please bear in mind that when a specific brand name is listed, please use only that brand. Others may differ considerably in phe content.*

**Frozen Snacks** – Popsicles – any type of frozen Kool-Aid type liquid, frozen fruit bars (non-dairy), Otter pops, fruit sorbets (no chocolate), Mama Tish’s Italian Ices (no chocolate). All must be non-Nutrasweet (no aspartame) varieties.

**Puddings and Gelatin-type Snacks** – Del Monte Snack cups (gelatin type), Hunt’s Juicy Gels, Hunt’s Lemon Snack Pack pudding, other brands contain gelatin which is very high in phe.

**Candy** – Sweet Tarts, Lifesavers, Skittles, Starburst, Sprees, Red Hots, Mike & Ike’s, clear lollipops, blowpops, Jolly Ranchers, Runts, Nerds, butterscotch (hard candies), candy canes, lemon drops, bubble gum (no sugarless), cinnamon disks, pastel type party mints, Gobstoppers, jaw breakers, root beer barrels, sour candy straws, cotton candy

**Beverages** – Gatorade, Powerade, All Sport, Kool-Aid (not sugarless), Kool-Aid Bursts, Squeezits, Hi-C, Hawaiian Punch, Capri Sun, soda pop (not diet), apple juice, grape juice, cranberry and cranberry blend juices, lemonade (not diet), limeade, Tang, Slurpies, Slush Puppies, Frozen Cokes, Sunny Delight

*The following is a list of things that may appear on the school lunch menu or snack menu. Please give only up to the amount listed and record on the food log I have provided. Send the food log home at the end of the day so it can be accounted for on her daily diet record.*

**Fresh Fruit** – apples 1; applesauce ½-1 cup; apple chips; banana ½-1 medium-sized; raisins 1 tiny box or 1 snack box; cantaloupe ½ -1 cup; grapefruit ½ medium-sized; honeydew ½-1 cup; orange ½ medium-sized; fresh cherries 10-15; grapes red or green seedless up to 30; fresh peach ½-1 medium, nectarine ½-1 medium; pear 1 medium; tangerine ½-1 medium; strawberries up to 15; blueberries ½ cup; kiwi 1 medium; plums 1-2 small; star fruit ½-1 medium; watermelon ½-1 cup; pineapple (fresh or canned) ½-1 cup

**Canned Fruit** – Dole tropical fruit salad ½ cup; snack pack canned peaches, pears, pineapple, or fruit cocktail 1 can

**Dried Fruit** – Banana chips ½ cup; apricots ½ cup; prunes 2-3 medium

**Dried Fruit Snacks** – Betty Crocker brand fruit snacks (any shape!), Fruit by the Foot, Fruit Roll Ups, String Things, Sunkist Fruit Rolls, Fun Fruits – all 1 package each

**Vegetables** – Carrot sticks raw up to 2 whole or 15 baby or ¼- ½ cup cooked; celery sticks 1 stick raw or ½ cup cooked; cauliflower florets ½ cup raw or cooked; mushrooms up to 2 whole raw or ¼ cup canned; pickles sweet or dill up to 10 slices or 1 large pickle or up to 5 mini dills; olives (black or green) up to 10 whole; asparagus 2-4” long cooked spears or ¼ cup diced or sliced cooked; green beans ½ cup cooked; broccoli ½ cup raw or cooked; Brussels sprouts 2 cooked; cabbage ½ cup cooked; corn kernels ¼ cup cooked; cucumber raw ½ medium or ½ cup sliced; lettuce ½ - 1 cup; bell peppers 2-3 rings ¼ inch thick; zucchini ½ cup cooked; cherry tomatoes up to 6 or up to 1 small tomato sliced; water chestnuts canned sliced ¼ cup

**Potatoes** – baked or boiled ½ small potato; French fried 6-12 2-inch long ¼ inch diameter; Ore-Ida golden crinkles ~16; shoestrings ~38; Tater Tots ~10-14; Fast Fries 14-18

*The following list contains snacks the school or other children may bring in as treats. Although serving sizes are listed, it is very important that I know how much she actually consumed.*

**Sweet Snacks** – Graham cracker with 4 scored sections 1 whole; Nabisco “Biscoes” (not chocolate) 4 cookies; Chico-San mini rice cakes all flavors except cheese 4; Quaker mini rice cakes (flavors: apple cinnamon, butter popped corn, caramel corn, or cinnamon crunch) 4; Quaker regular sized rice cakes (banana crunch, cinnamon, or plain) 1; Kellogg’s Rice Krispie Treat (individually packaged, regular flavor only) 1

**Salty Snacks** – Saltines 2; Pepperidge Farms goldfish (plain) up to 15; Bugles plain flavored up to 12; Pringles Country, Original, BBQ, or rippled 10; potato chips (regular or BBQ) 10; popcorn 1 cup (not buttered, but “butter flavor” okay).

## **“NO” FOODS**

*The last list is a list of foods that are **NEVER** to be given to \_\_\_\_ under any circumstances. Even small tastes of these are not permitted. (We call them “No” foods).*

Meat, fish, eggs, poultry, dairy products, hot dogs, soy products, cheese, nuts, peanut butter, granola bars, breakfast bars (NutraGrain, Pop Tarts, etc.), regular breads or buns, cookies, chocolate, Nutrasweet (aspartame), ice cream, Hydrox or Oreo cookies, wheat crackers, Triscuits, Teddy Grahams, Creamsicles, regular Jello, gummy bears, regular cake, cupcakes, muffins

Dear Parents,

We are the parents of a child in your son or daughter's third grade class at ABC Elementary. We are new to the school and are writing each of you in regard to our daughter \_\_\_\_\_.

\_\_\_\_\_ has an inherited metabolic disorder called PKU (Phenylketonuria). Children with PKU are on very special diets because their livers cannot metabolize an amino acid called phenylalanine. This amino acid is found in all forms of protein, so their protein intake is very limited. Basically, foods she cannot have include meat, fish, eggs, poultry, dairy products, grains (cookies, cakes, crackers) and legumes. Most of the food she eats is either a vegetable or a fruit, with some specially prepared low protein foods for a main course. Kids with PKU also drink a medical formula that gives them the protein they need to grow and develop, but not the amino acid they cannot metabolize.

We are asking for your help during this school year. It seems to work best when everyone (parents, kids, teachers, etc) is aware of \_\_\_\_\_'s PKU. Although we don't want people to go to additional work, we would like to know a few days in advance of any parties being planned for special occasions or when you are bringing a treat into the classroom. This allows us time to prepare and send a low protein version for \_\_\_\_\_. If you could call us, either at home or at work, and let us know when the occasion is and what you are serving, we would be greatly appreciative. Our home number is \_\_\_\_\_ and our work numbers are \_\_\_\_\_ and \_\_\_\_\_.

Thank you very much! If your children ask questions or comment on why \_\_\_\_\_ is on a "special diet," please let them know that lots of people can't eat everything and she is required to do this to stay healthy. Usually the kids are very understanding and only want to help! If you have any questions, please do not hesitate to call us!

Sincerely,