

Visit 2: Eating for Your Brain

Objective: At this visit you have the opportunity to review how to keep a food record, calculate the phenylalanine in food, and complete an activity, “Learning the ‘Real’ Phe Content of Food.”

In This Section:

- How to Record Your Food Intake – Accurately
- Rate Your Own Food Record
- Learning the “Real” Phe Content of Food
- Eating Out with PKU
- Sample Menus
- Reading Labels

At This Visit:

- Nutrition assessment- bring your 3 day food record to clinic
- Physical assessment- a brief visit with PKU doctor
- Review how to keep a food record accurately, calculate phenylalanine
- Rate your food record
- Learning the “Real” Phe Content of Food
- Review label reading
- Discuss eating out with PKU
- Confirm next visit

Who is involved:

- **You**
- Your support team:
 - Your parents
 - PKU clinic physician
 - PKU clinic nutritionist



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How To Record Your Food Intake—Accurately



It is important to keep a record of the food you eat and the formula you drink. It is also important to keep these records carefully and accurately. Why??

- Carefully kept records help your nutritionist monitor how your blood phe levels change with different amounts of phe from food. The information from food records is used to make formula changes and change your phe from food prescription.
- The information from food records helps your nutritionist to make sure you are getting the best, most nutritious foods possible.
- Finally, food records are an important way for you to learn about the phe in foods and how phe affects your body and blood phe level.

So, what information is important, anyway?

DATE

List the date of your food record. Clearly separate each day.

AMOUNT

Write down the amount of food that you ate...in grams, cups, ounces, tablespoons, teaspoons... Include the size (for example, a large banana or 2 small oranges).

TYPE

Write down *exactly* what type of food you ate—Campbell's tomato soup, frozen green beans, low protein bread from Bread Machine Mix. Was the carrot canned or fresh? Was the candy a lollipop or a cinnamon disk? List the brand name when available.

FORMULA

Include how your formula is made. List the amount of powder, the amount of water, and everything else (2% milk, evaporated milk) that goes into your formula. If you didn't finish all of your formula, write down how much you had.

FREE FOODS

Be sure to record all free foods and the amount of these foods eaten. These protein-free foods still contain energy (calories)—your nutritionist keeps track of your total daily energy intake too.



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Name _____

Date _____

RATE YOUR OWN FOOD RECORD

Give yourself one point for each of the following:

- I have **three** days of food records _____
- My food records are clearly written or printed _____
- I have clearly marked each day _____
- My food records are dated _____
- I have recorded how my Phenyl-free is made _____

For each day of your food record, give yourself one point if you have completed this information.

	Day 1	Day 2	Day 3
I recorded how much Phenyl-free I drank	_____	_____	_____
I described the foods I ate. (That is, whenever I needed to I listed brand names and how my food was prepared)	_____	_____	_____
I listed the gram weights of my foods. (That is, whenever it was the BEST MEASURE I used my gram scale to weigh foods)	_____	_____	_____
I listed measurements of my foods. (That is, whenever I needed to I listed diameters and sizes of my foods)	_____	_____	_____
I listed phe values of my foods.	_____	_____	_____
I recorded the free foods that I ate.	_____	_____	_____

I feel that these records are a true recording of what I actually eat. YES = 1 NO = 0 _____

Total Points _____



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Learning the “REAL” Phe Content of Foods

OBJECTIVES:

- Participants will be able to describe methods to estimate the phe content of foods
- Participants will be able to describe why it is important to accurately measure portion sizes
- Participants will be able to identify types of foods for which it is especially important to accurately measure portion sizes

METHOD:

- For each of the foods, participants will:
 - Estimate the portion size and amount of phe
 - Weigh and measure the food, then calculate the actual amount of phe
 - Compare the estimate to the actual value
- Then, discuss questions on page 3 of the worksheet.
- If time permits, discuss other situations in which it is important to identify a strategy for estimating portion sizes. What type of planning can be done ahead of time (e.g., measuring)? What are some strategies for “surprise situations” (e.g., eating at a friend’s house or a new restaurant)?

MATERIALS:

Worksheet

Scale

Ruler

Calculator

Low Protein Food List

Selected foods: banana, orange, Russet potato, red potato, diced potatoes (frozen), French fries, potato chips, cereal



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Learning the “REAL” Phe Content of Foods

Objective

To improve your knowledge of portion sizes and phe values by comparing sizes and weights of selected foods

Items needed

gram scale, ruler, selected foods, small paper plates, pencil or pen, calculator, Low Protein Food List

Directions

For each of the foods on this worksheet:

- Estimate the portion size and amount of phe
- Weigh and measure the food, then calculate the actual amount of phe
- Compare your estimate to the actual values

Then answer the questions on page 3.

FOOD #1: Banana

	<u>Your Estimation</u>	<u>Actual</u>	<u>Difference</u>
Portion size	x-small small medium large x-large	x-small small medium large x-large	
Weight	_____ grams	_____ grams	_____ grams
Phe	_____ milligrams	_____ milligrams	_____ milligrams

FOOD #2: Orange

	<u>Your Estimation</u>	<u>Actual</u>	<u>Difference</u>
Portion size	small medium large	small medium large	
Weight	_____ grams	_____ grams	_____ grams
Phe	_____ milligrams	_____ milligrams	_____ milligrams

FOOD #3: Potato A

	<u>Your Estimation</u>	<u>Actual</u>	<u>Difference</u>
Portion size	small medium large	small medium large	
Weight	_____ grams	_____ grams	_____ grams
Phe	_____ milligrams	_____ milligrams	_____ milligrams

FOOD #4: Potato B

<u>Your Estimation</u>	<u>Actual</u>	<u>Difference</u>
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Portion size	small	medium	large	small	medium	large	
Weight	_____	_____	_____	_____	_____	_____	_____ grams
Phe	_____	_____	_____	_____	_____	_____	_____ milligrams

FOOD #5: Diced Potatoes

	<u>Your Estimation</u>			<u>Actual</u>			<u>Difference</u>
Portion size	½ cup	1 cup	1½ cup	½ cup	1 cup	1½ cup	
Weight	_____	_____	_____	_____	_____	_____	_____ grams
Phe	_____	_____	_____	_____	_____	_____	_____ milligrams

FOOD #6: French Fries

	<u>Your Estimation</u>			<u>Actual</u>			<u>Difference</u>
Portion size*	½ cup	1 cup	1½ cup	½ cup	1 cup	1½ cup	
	small	medium	large	small	medium	large	
Weight	_____	_____	_____	_____	_____	_____	_____ grams
Phe	_____	_____	_____	_____	_____	_____	_____ milligrams

*Use 2 ways of estimating portion sizes. (Small, medium and large correspond to McDonald's French fries serving sizes; pick the size that you think is closest to what is on the plate.)

FOOD #7: Chips

	<u>Your Estimation</u>			<u>Actual</u>			<u>Difference</u>
Portion size*	½ cup	1 cup	1½ cup	½ cup	1 cup	1½ cup	
	lunch pack	1 oz	big grab	lunch pack	1 oz	big grab	
Weight	_____	_____	_____	_____	_____	_____	_____ grams
Phe	_____	_____	_____	_____	_____	_____	_____ milligrams

*Use 2 ways of estimating portion sizes

FOOD #8: Cereal

	<u>Your Estimation</u>			<u>Actual</u>			<u>Difference</u>
Portion size	1 cup	1½ cup	2 cups	1 cup	1½ cup	2 cups	
Weight	_____	_____	_____	_____	_____	_____	_____ grams
Phe	_____	_____	_____	_____	_____	_____	_____ milligrams



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For which of the foods was your estimation MOST accurate? _____

For which of the foods was your estimation LEAST accurate? _____

What was the difference between your estimation and the actual amount of phe? _____

Did you over-estimate or under-estimate? _____

For which foods do you think it is most important to be accurate in estimating portion sizes? _____

Why? _____

What would you do if...

? You are at McDonald's with some friends and know that you have 100 mg phe from food left. What do you order? _____

? You are going to go out to eat with your family. You've saved up 150 mg—enough to order French fries, and you're excited because the restaurant serves big steak fries. You only know how much phe is in a serving of small French fries. How will you know how many fries to eat? _____

? You are visiting your Auntie Annie's apple farm, and she offers you a GIGANTIC apple. It looks delicious, but you aren't sure how much phe to record on your food record. What do you do? _____

? Last month at clinic, the nutritionist asked you how much cereal you ate for breakfast. Your reply was, "a bowl, but I don't know how many cups or grams it was." You want to have an answer for her this month. How do you find out how much cereal you've eaten? _____



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Brand	Food	Measure	Weight (gm)	Phe (mg)	No. of Exch.	Mg Phe/ Gm Food	Pro. (gm)	Energy (kcal)
	Apples, fresh, sliced	1 cup	128	7	0.5	0.05	0.2	74
	Apples, fresh, whole, medium	1 apple	180	9	0.6	0.05	0.4	106
	Banana, fresh, peeled, medium	1 banana	114	43	2.9	0.38	1.2	105
	Orange, fresh, medium peeled	1 orange	180	38	2.5	0.21	1.5	70
	Orange, fresh, sections or pieces	½ cup	120	25	1.7	0.21	1.1	57
	Potatoes, all colors, baked or boiled, diced	¼ cup	41	36	2.4	0.88	0.8	33
	Potatoes, all colors, raw, chopped	½ cup	82	75	5.0	0.91	1.8	65
Ore-Ida	Potatoes, Country Fries	18 pieces	84	75	5.0	0.89	1.7	120
Ore-Ida	Potatoes, Golden Fries	16 pieces	84	75	5.0	0.89	1.8	120
Ore-Ida	Potatoes, O'Brien	¾ cup	84	75	5.0	0.89	1.8	60
Ore-Ida	Potatoes, Steak Fries	7 pieces	84	79	5.3	0.94	1.8	110
	Potato Chips, Plain or Barbeque	3 chips	5	13	0.9	2.60	0.4	27
	Potato Chips, slightly crushed	¼ cup	10	26	1.7	2.60	0.7	54
Frito-Lay	Tostitos, Restaurant Style	3 chips	14	50	3.3	3.57	1.2	65
General Mills	Corn Chex Cereal	½ cup	15	54	3.6	3.60	1.1	57
General Mills	Rice Chex Cereal	½ cup	12	28	1.9	2.26	0.7	49
LoProfin	Low Protein Breakfast Cereal Loops	1 cup	28	2	0.1	0.07	0.1	110
McDonald's	French Fries, large order	1 order	176	229	15.3	1.30	8.0	540
McDonald's	French Fries, medium order	1 order	147	191	12.7	1.30	6.0	450
McDonald's	French Fries, small order	1 order	68	88	5.9	1.29	3.0	210
McDonald's	French Fries, super size order	1 order	198	257	17.1	1.30	9.0	610

Food	Portion Size	Weight
Apple, raw, with skin	small (2 ½ inch diameter)	106 g
Apple, raw, with skin	medium (2 ¾ inch diameter)	138 g
Apple, raw, with skin	large (3 ¼ inch diameter)	212 g
Banana, raw	extra-small (less than 6 inches long)	81 g
Banana, raw	small (6 to 6 7/8 inches long)	101 g
Banana, raw	Medium (7 to 7 7/8 inches long)	118 g
Banana, raw	Large (8 to 8 7/8 inches long)	136 g
Banana, raw	Extra-large (longer than 9 inches)	152 g
Oranges, raw	Small (2 3/8 inch diameter)	96 g
Oranges, raw	Medium (2 5/8 inch diameter)	131 g
Oranges, raw	Large (3 1/16 inch diameter)	184 g
Potatoes	Small (1¾ to 2¼ inch diameter)	170 g
Potatoes	Medium (2¼ to 3¼ inch diameter)	213 g
Potatoes	Large (3 to 4¼ inch diameter)	369 g

Data from USDA National Nutrient Database for Standard Reference; http://www.nal.usda.gov/fnic/cgi-bin/nut_search.pl



Eating Out with PKU...Tips for Finding a Low Phe Meal

- Call ahead to ask what is on the menu

What low phe choices are available?

Will the restaurant prepare low protein foods you bring?

- Formula, formula, formula

Bring some formula to drink at dinner.

Drink formula ahead of time

- Bring favorite low protein food items

- Talk about choices ahead of time

What low phe foods are found on most menus?

- Eat a low-phe snack before leaving the house

Toast, salad, soup, etc.

Sample Menus

Common items available that are moderate in phenylalanine

Thai

- **Thai Salad:** Fresh lettuce, onion, tomato, cucumber, and bean sprouts served with peanut sauce (ask them to leave off the peanut sauce)
- **Gang Dang:** Red curry with coconut milk, mushrooms, bamboo shoots, basil and hot pepper (coconut milk slightly high in phe – ¼ cup has approximately 56 mg phe, so watch your portion size)
- **Tum Yum:** Spicy hot and sour soup with chili paste, lemon grass, mushroom, galanga, lime leaf and lime juice. Choice of chicken or prawns. (Ask them to leave out the chicken/prawns)
- **Kee Mao Noodle:** Stir fried fresh side rice noodles and choice of meat with onion, zucchini, green and red peppers, hot pepper sauce and fresh basil (Ask them to make this dish without any meat)
- **Kao:** Steamed rice (be aware of how much phe is in a portion of rice)

Mexican

- **Chips and salsa:** Watch your portion size on the chips (suggestion: count out the number you want to have before you eat them)
- **Veggie Fajitas:** A delicious combination of fresh vegetables served piping hot. Includes broccoli, carrots, mushrooms, green peppers, onions (eat with ½ - 1 tortilla)
- **Burrito Verde:** Chunks of pork in a light tomatillo sauce, green peppers, onions and spices. All rolled in a flour tortilla (Ask them to leave out the pork. Also ask them what is in the tomatillo sauce. Eat ½ of tortilla)
- **Ask the server what other dishes can be prepared with vegetables!**

Italian

- **Mixed Greens (piccola or grande):** Cherry tomatoes, English cucumbers, parmesan and croutons, tossed with house vinaigrette (Ask them to leave off the parmesan and croutons and to add other vegetables that you might like)
- **Grilled Asparagus:** Add to any meal
- **Broccoli:** Add to any meal
- **Spinach saltate:** Fresh spinach sautéed with toasted garlic
- **Capellini Puttanesca:** Prawns, artichoke, olives, capers, peppers and herbs in a spicy tomato sauce (Ask them to leave off the prawns, watch the amount of pasta you eat)

Chinese

- **Chinese broccoli:** With oyster sauce and garlic (Calculate how much phe is in oyster sauce)
- **Sauteed spinach with garlic sauce**
- **Ye mein with Chinese mushrooms:** Vegetarian (ask what is in it)
- **Stir fried rice/noodles:** Ask what options are available for vegetables and then watch the amount of rice and noodles you eat.

Reading Labels

Some people think it's fun . . . Some people think it's boring . . . What is it? Label Reading! Label reading is a valuable skill to learn, because **it is the only way you can be sure of exactly what you are eating.** Take this short "quiz." The answers are on the next few pages.

1. If the label says the product contains "0" grams protein, is it actually a free food?
 YES NO

2. On average, 1 gram of protein contains how many milligrams of phe?
 5 mg 25 mg 50 mg 100 mg

3. The serving size listed on the label is always an entire package of food.
 TRUE FALSE

4. Check the ingredients which contain phe:

- | | | |
|--|--|---|
| <input type="checkbox"/> Agar | <input type="checkbox"/> Autolyzed yeast | <input type="checkbox"/> BHA and BHT |
| <input type="checkbox"/> Calcium caseinate | <input type="checkbox"/> Calcium carbonate | <input type="checkbox"/> Carob |
| <input type="checkbox"/> Citric acid | <input type="checkbox"/> Cracker meal | <input type="checkbox"/> Dry whey |
| <input type="checkbox"/> Gelatin | <input type="checkbox"/> Glycerine | <input type="checkbox"/> Malt |
| <input type="checkbox"/> Mannitol | <input type="checkbox"/> Methylcellulose | <input type="checkbox"/> Monosodium glutamate |
| <input type="checkbox"/> Nonfat dry milk | <input type="checkbox"/> Sodium caseinate | <input type="checkbox"/> Soy protein isolate |
| <input type="checkbox"/> Turmeric | <input type="checkbox"/> Whey solids | <input type="checkbox"/> Xanthan gum |

5. Look at the food label and ingredient list below. Circle the ingredients that have phe. How many milligrams of phe does this food have? _____
 What do you think this label is describing? _____

Nutrition Facts	
Serving Size 1 bar (34g)	
Servings Per Container 6	
Amount Per Serving	
Calories 130	Calories from Fat 20
	% Daily Value *
Total Fat 2.5g	4%
Saturated Fat 1g	5%
Cholesterol 0mg	0%
Sodium 70mg	3%
Total Carbohydrate 27g	9%
Dietary Fiber 3g	12%
Sugars 13g	
Protein 1g	
Vitamin A 0%	Vitamin C 0%
Calcium 2%	Iron 8%

INGREDIENTS:

RICE FLOUR, HIGH FRUCTOSE CORN SYRUP, ROLLED OATS, ROLLED BARLEY, RICE BRAN, SUGAR, MALT, CORN SYRUP, SUGAR, PARTIALLY HYDROGENATED VEGETABLE OIL, APPLES, FIGS, DATES, PLUMS, CORN BRAN, NATURAL FLAVORS, ACACIA GUM, BARLEY, WHEY, BEET JUICE COLOR, DRIED STRAWBERRIES, GUAR GUM, FRUIT PECTIN, NONFAT MILK, NONFAT YOGURT (WHEY, NON-FAT MILK CULTURES), CITRIC ACID, LETHICIN, GLYCERINE, COLOR, DRIED RASPBERRIES, DRIED CRANBERRIES.

READING LABELS: ANSWERS

Question 1: If the label says the product contains 0 grams protein, is it actually a free food? YES NO

The fact is, 0 may be a rounded-off figure, and the item may contain *nearly 0.5 to 0.9 grams* of protein per serving, a significant source of phe. By carefully reading the food label and knowing which ingredients contain phe, you can learn to identify foods that are truly “free.” Remember, while the food label will include information about the protein content of food, it will not include specific information regarding phenylalanine.

Question 2: On average, 1 gram of protein contains how many milligrams of phe?
 5 mg 25 mg 50 mg 100 mg

On average, **1 gram of protein contains 50 mg phe.** This means that a food label that reads 0 grams of protein could actually contain 25-50 mg phe per serving!

⇒ If a food label said the food contained 1 gram of protein per serving, how much phe would you estimate? _____

Question 3: The serving size listed on the label is always an entire package of food.
 TRUE FALSE

Don't forget to think about serving sizes! The amount you eat is not always the same as what the food label will call a “serving size.” For example, 1 serving of soda is 8 ounces, but most people drink an entire can of soda, which is 12 ounces.

⇒ How many 8 ounce servings would be in a 24 ounce soda? _____

Question 4: Check the ingredients, which contain phe:

- | | | |
|---|--|---|
| <input type="checkbox"/> Agar | <input checked="" type="checkbox"/> Autolyzed yeast | <input type="checkbox"/> BHA and BHT |
| <input checked="" type="checkbox"/> Calcium caseinate | <input type="checkbox"/> Calcium carbonate | <input checked="" type="checkbox"/> Carob |
| <input type="checkbox"/> Citric acid | <input checked="" type="checkbox"/> Cracker meal | <input checked="" type="checkbox"/> Dry whey |
| <input checked="" type="checkbox"/> Gelatin | <input type="checkbox"/> Glycerine | <input checked="" type="checkbox"/> Malt |
| <input type="checkbox"/> Mannitol | <input type="checkbox"/> Methylcellulose | <input type="checkbox"/> Monosodium glutamate |
| <input checked="" type="checkbox"/> Nonfat dry milk | <input checked="" type="checkbox"/> Sodium caseinate | <input checked="" type="checkbox"/> Soy protein isolate |
| <input type="checkbox"/> Tumeric | <input checked="" type="checkbox"/> Whey solids | <input type="checkbox"/> Xanthan gum |

There are many ingredients added to prepared foods, including vitamins and chemicals that act as thickeners, emulsifiers, stabilizers, and color maintainers. Use the next page as a reference to check unfamiliar ingredients. Add to it when you come across a new ingredient. (Be sure to check with your nutritionist first!)

5. Look at the food label and ingredient list below. Circle or underline the ingredients that have phe.

How many milligrams of phe does this food have? 50 mg x 1 gram = about 50 mg

What do you think this label is describing? Fibar Low-Fat Snack Bars

Nutrition Facts	
Serving Size 1 bar (34g)	
Servings Per Container 6	
Amount Per Serving	
Calories 130	Calories from Fat 20
	% Daily Value *
Total Fat 2.5g	4%
Saturated Fat 1g	5%
Cholesterol 0mg	0%
Sodium 70mg	3%
Total Carbohydrate 27g	9%
Dietary Fiber 3g	12%
Sugars 13g	
Protein 1g	
Vitamin A 0%	Vitamin C 0%
Calcium 2%	Iron 8%

INGREDIENTS:

RICE FLOUR, HIGH FRUCTOSE
 CORN SYRUP, ROLLED OATS,
ROLLED BARLEY, RICE BRAN,
 SUGAR, MALT, CORN SYRUP,
 SUGAR, PARTIALLY HYDROGEN-
 ATED VEGETABLE OIL, APPLES,
FIGS, DATES, PLUMS, CORN BRAN,
 NATURAL FLAVORS, ACACIA GUM,
BARLEY, WHEY, BEET JUICE
 COLOR, DRIED STRAWBERRIES,
 GUAR GUM, FRUIT PECTIN, NONFAT
MILK, NONFAT YOGURT (WHEY,
NON- FAT MILK CULTURES), CITRIC
 ACID, LETHICIN, GLYCERINE, COLOR,
DRIED RASPBERRIES, DRIED
CRANBERRIES.

Phenylalanine-Containing Ingredients

(Foods with these ingredients are not “free.”)

autolyzed yeast	chicken extract	nonfat dry milk
barley, malt, or rice flour	cracker meal	sodium caseinate
beef extract	cracked wheat	soy protein isolate
beef fat	dried whey	vegetable protein
carob	dry yeast	wheat gluten or bran
casein	gelatin	whey or whey solids
calcium caseinate	hydrolyzed vegetable	yeast extract

Phenylalanine-Free Ingredients

(Foods with these ingredients are “free,”
if the other ingredients on the food label are “free.”)

acetylated monoglycerides	glycerol monostearate	resinous glaze
adipic acid	guar bean gum	riboflavin hydrochloride
agar	hydrogenated oils (ex. cottonseed, soy)	sodium acid pyrophosphate
algin or alginate	invert sugar	sodium alginate
alpha-tocopherol	lactic acid	sodium aluminum phosphate
artificial color or flavor	lactose	sodium ascorbate
ascorbate or ascorbic acid	lecithin	sodium benzoate
BHA and BHT	locust bean gum	sodium bisulfite
calcium carbonate	malic acid	sodium carbonate
calcium propionate	maltodextrins	sodium citrate
calcium steryl-2-lactylate	mannitol	sodium metaphosphate
caramel color	methylcellulose	sodium phosphate
carotene	modified food starch	sodium propionate
carrageenan	mono and diglycerides	sodium silico aluminate
cellulose gum or gel	mono calcium phosphate	sodium triphosphate
citric acid	monostearate	sorbitol or sorbitan
cyteine hydrochloride	natural flavors	THBQ
dextrose	niacin/niacin hydrochloride	thiamine mononitrate
disodium guanlyate	partially hydrogenated	titanium dioxide
disodium inosinate	vegetable shortening	tocopherol
disodium phosphate	pectin	tricalcium phosphate
EDTA	polysorbate 60	tumeric
ferric orthophosphate	potassium citrate/carbonate	vegetable fat, gum or colors
ferrous sulfate	propylene glycol	vitamin A palmitate
folic acid	pyridoxine hydrochloride	vitamin B6 hydrochloride
fumaric acid	reduced iron	xanthan gum
glycerine		xylitol

Assessment of PKU Adolescent Transition Curriculum

Session 2.

Objective: At this visit you will have the opportunity to review how to keep a food record, calculate phenylalanine in food, and complete and activity 'Learning the 'Real' Phe Content of Food.

Post Session Objective: Each participant will be able to explain how to keep a food record to a parent or friend, have completed the calculate phenylalanine in food and 'Learning the 'Real' Phe Content of Food activities.

I. Please tell us three things that you have learned during this visit

1)

2)

3)

II. What is the most important part of keeping and accurate food record?

III. In your view, what is the most problematic part of eating away from home?
