



Data Collection

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DATA COLLECTION SCHEDULE

Data Requested	When/Frequency of Obtaining Data
1. Registration and Background Form	Enrollment: fill out as much of the form as possible initially. Some information (such as IQ) can be added later.
2. Blood Levels Record	Weekly, or as often as blood specimens are obtained, even if the woman is not yet pregnant. Record only the PHE and the TYR results on this form. If blood TYR is not routinely done, record PHE only for that date. Full amino acid profile results are requested at enrollment, 6, 23, 20, and 32 weeks gestation. Enter the PHE and TYR results from the full profile, and send a hard copy of the amino acid profile to the coordinating center for data entry.
3. Nutrition Assessments	Monthly, beginning at diet initiation, and every 6 months if the woman is not pregnant. There is no need to enter more assessments, even if they have been done. Once each trimester during pregnancy, send a copy of the actual food record to the coordinating center. The granting agency requires that a second analysis of the food record be done three times during the pregnancy for quality control purposes. The nutritionist at the coordinating center will contact you regarding any discrepancies in the analysis.
4. Weight Record	Monthly, beginning at diet initiation
5. Appointment Record	Diet initiation or entry into study (baseline data), then at 6, 12, 20, and 32 weeks gestation. The database will calculate when these appointments are due based on the LMP. Enter the data from the date closest to the target date.
6. Course and Outcome of Pregnancy	Completion of Pregnancy. Send OB record.
7. Pediatric	Birth
8. Psychosocial Questionnaires (These are not on the computer database. Please send the hard copy to the coordinating center.)	6 and 32 weeks gestation. If the woman enters the study after 6 weeks gestation, questionnaires should be given within 2 weeks, and then again at 32 weeks. If the woman has a RM, she will help the woman to fill out the questionnaires. Otherwise, it is the coordinator's responsibility. Send the completed forms to the coordinating center as soon as the forms are completed.
9. Resource Mother's Visit Log	Keep ongoing record throughout the intervention. Send to coordinating center at the completion of pregnancy.
10. One Year Follow Up	Age one year.
11. Medical and Support Services Needed	Age one year.



Resource Mothers Program

REQUEST FOR PAYMENT-PSYCHOLOGICAL TESTING

Name:

Social Security #

Mailing Address where check will be sent:

Phone: _____

Date of Request: _____

Please check all that apply:

_____ (WAIS-R) III Testing -mother (\$250)

_____ Bayley and HOME Inventory - infant (\$250)

_____ Mileage Expense

Total Miles _____ x \$0.345 cents/mile = _____

Total Amount Requested: _____

Mail this form to:

Maternal PKU Program, Children's Hospital, Boston, 300 Longwood Ave, IC Smith 107,
Boston, MA 02115, Attn: Melissa Gennaccaro

Or FAX to:

(617) 734-2652
Attn: Melissa Gennaccaro

SAMPLE LETTER TO MOTHER

Date

Dear Mrs. _____:

Thank you very much for your continued participation in the Maternal PKU Resource Mothers Study. You are helping us find out what kinds of supports are most helpful to women with PKU. By allowing us to evaluate you and your baby, you are also helping us find out whether supports make a difference in the long-run.

You were administered the Wechsler Adult Intelligence Scale - Third Edition. This is a standard test that identifies a person's strengths and weaknesses in areas such as vocabulary, arithmetic, reasoning, memory and visual-motor speed. In all areas, you performed well within the average range. You had strengths in the areas of vocabulary and memory. You had relative difficulties on the arithmetic subtest, particularly when word problems became more complex or when calculations involved fractions.

Your son was evaluated when he was 12 months old. He appeared to be an alert, sociable and curious little boy. During this evaluation, he was cooperative, engaged and cheerful. He appeared to enjoy the variety of test materials and focused his attention very well for a child his age.

He clapped when he thought he had done well and simply dumped the toys or blocks when he thought the task was uninteresting or too difficult. Both responses are entirely normal for babies his age.

His spontaneous verbalizations were limited, but his ability to gesture to make his wishes known was well-developed.

On the Bayley Scales of Infant Development, your son passed items up to the 12-month level on the Mental Scale. He turned pages in a book, imitated sounds, built a tower of

two blocks, and put a peg in a pegboard. He did not yet point to pictures or place blocks in a cup when asked to do so. However, he seemed very interested in the materials and tried very hard to figure out what we were asking him to do.

On the Bayley Motor Scale, he again passed items through the 12-month level. He walked, threw a ball, and squatted down. He seemed to have good balance and excellent coordination. He seems eager to "get up and go" on his own.

Overall, his performance was well within the average range. He may soon enjoy looking at pictures in picture books, learning simple songs with hand motions, and playing simple games, such as finding hidden objects. He is ready to work on simple puzzles and shape sorters. Even though he is too young to repeat after you, he is ready to listen to stories, poems, songs, counting games, and the alphabet. The more language he hears, the better. In the motor area, he will enjoy exploring on his own and learning to independently use play equipment, such as the swing and slide. Jumbo crayons and a paint brush may be fun, too, although you will need to watch that he isn't too messy!

In general, he is developing very nicely. You seem to be doing a good job providing him with stimulation and structure.

Once again, thanks for your participation. If you have any questions or would like to discuss the results of his evaluation any further, please do not hesitate to contact me or the Coordinator of the Resource Mothers Study. Best wishes for a pleasant summer.

Sincerely,

DATE

Dear Psychologist:

Thank you for your interest in helping out with the Resource Mothers Study for Maternal PKU. Briefly, this is a study to determine whether a home visitation program to provide support for women who must follow a very restrictive diet during pregnancy improves outcome. Outcome data included in the study are the mother's intelligence, and a rating of the home environment and the infant's developmental scores when the baby is a year of age.

Specifically, the testing required at this time is indicated below:

1. Wechsler Adult Intelligence Scale –III [We provide the protocol, but you need access to the test kit.]
2. Bayley Scales of Infant Development 2nd Edition (Please be sure to include both the Bayley Mental Scale Developmental Index and the Performance (Motor) Scale Developmental Index.) [Again, we can provide the protocol, but you need access to the test kit.]
3. HOME Inventory: Caldwell BM, Bradley RH. Home Observation for Measurement of the Environment, 1984 [We will send you copies of this instrument, with instructions for administration.]

We request that you send a brief letter to the mother, summarizing the results of her own testing (if she would like) and the results of her child's developmental assessment. These summaries should not include scores, but should give the mother a list of her strengths and weaknesses, in a gentle and helpful manner. With regards to the child, the child's range of functioning should be indicated. Often, we add a few suggestions for ways to stimulate the child. We do make recommendations for early intervention, if appropriate. We've included a sample letter that you might find helpful.

The original test protocols and a copy of the letter to the mother should be sent to the Coordinator of the Maternal PKU Resource Mothers Study.

We pay \$250.00 for the WAIS-III and an additional \$250.00 for the Bayley and HOME Inventory. Travel costs to the woman's home or other place for testing will be reimbursed at \$.32/mile.

Please submit an invoice to me and include the following so that we may process it as efficiently as possible: Name, address to which the check should be sent, social security number, and a phone number. You can expect to receive a check in 4-6 weeks.

Please call me at 978-352-7865 if you have any questions about the administrative aspects. If you have any questions related to the psychology protocol or the report,

please contact Susan Waisbren, PhD, who is a psychologist and principal investigator of the study. Her phone number is: 617-355-4686 and her email is susan.waisbren@tch.harvard.edu. We look forward to working with you.

Sincerely yours,

Fran Rohr, MS RD
Coordinator, Resource Mothers Study

FILLING OUT DATA FORMS ONLINE

The data forms for the Resource Mother's Randomized Clinical Trial may be filled out over the internet. This is intended to simplify data collection and keep data entry up-to-date. You have the option of filling out the data forms online, or if you prefer, filling out the hard copy of the forms and sending to Children's Hospital, Boston either by fax or mail.

To access the database over the internet, you will need a computer with internet access and a browser (such as Internet Explorer, Netscape, or AOL). Most computers have browsers installed, so this should not be a problem.

To enter data online, please follow these steps:

1. Go to: <http://134.174.23.80/pkurm>
2. You should now be at the welcome and login page. To login, type your username and password that the study coordinator will assign to you. Press "OK."
3. You should now be looking at a list of patients in your clinic. You have access to view, enter, and edit patients from your clinic only.
4. If you wish to enter a new patient, select "Add new patient." TO respect confidentiality, no patient names are included in the database. One you enter a new patient, she will be assigned a study number. You will need to make note of this number for future reference.
5. If you wish to add or edit data for an existing patient, click on the patient's study number, and you will have access to all forms for that patients.
6. Data entry is fairly self-explanatory. If you have any questions, however, please contact Fran Rohr.

HARD COPIES OF FORMS

If you would prefer not to enter data online, you may fill out these forms and either mail or fax them to Fran Rohr. Mailing labels and a fax cover sheet are included in the “communication” section for your convenience.

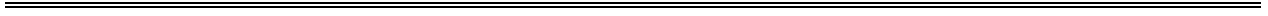
Forms include:

1. Registration and Background
2. Blood PHE Log
3. Nutrition Assessment
4. Weight Record
5. Course of Pregnancy
6. Adherence to Plan (Appointments)
7. Newborn Pediatric Evaluation
8. Offspring One Year Evaluation
9. Offspring Medical and Support Services

Registration and Background Form

Patient ID:	Today's date:
Treating Clinic:	Patient Age when diet started:
Treatment Group: <input type="checkbox"/> Resource <input type="checkbox"/> Control	
Patient's Date of Birth:	
Patient Ethnicity: <input type="checkbox"/> Caucasian <input type="checkbox"/> African American <input type="checkbox"/> Asian <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Native American <input type="checkbox"/> Other	
Language Spoken: <input type="checkbox"/> English <input type="checkbox"/> Other	
Travel time to clinic: _____ hours	
Timing of diet initiation: <input type="checkbox"/> Post <input type="checkbox"/> Prior (when was treatment started?)	
Date diet started: _____ (entry should look like: 3/28/2001)	
Date LMP: _____ leave blank if patient is not pregnant (same date format)	
Marital Status: <input type="checkbox"/> Married <input type="checkbox"/> Single <input type="checkbox"/> Unknown	
Patient's years of education:	Husband's years of education:
Patient Employed? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Husband Employed? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Patient's type of work:	Husband's type of work:
Pre-Pregnancy natural blood phenylalanine level (highest or most recent off-diet level): _____ mg/dl	
Pre-Pregnancy height: _____ cm	
Pre-Pregnancy weight: _____ kg - - Weight Status: <input type="checkbox"/> Normal <input type="checkbox"/> Over <input type="checkbox"/> Under	
Patient's Full Scale IQ: (from WAIS -Revised)	
Enter the number of each type of outcome of any previous pregnancies.	
Previous live birth:	
Previous spontaneous abort:	
Previous stillbirth:	
Previous terminated birth:	
To be completed by Children's Hospital, Boston: Hollingshead/redlich Score:	

Blood Level Log



Nutrition Assessment

Weight Log

Patient ID:		Today's date:	
Date of Weight:			
Weight:	kg		
Location where weight was taken:	___ PKU Clinic ___ Doctor's Office ___ Home/Other		

		Today's date:	
Date of Weight:			
Weight:	kg		
Location where weight was taken:	___ PKU Clinic ___ Doctor's Office ___ Home/Other		

Patient ID:		Today's date:	
Date of Weight:			
Weight:	kg		
Location where weight was taken:	___ PKU Clinic ___ Doctor's Office ___ Home/Other		

Patient ID:		Today's date:	
Date of Weight:			
Weight:	kg		
Location where weight was taken:	___ PKU Clinic ___ Doctor's Office ___ Home/Other		

Patient ID:		Today's date:	
Date of Weight:			
Weight:	kg		
Location where weight was taken:	___ PKU Clinic ___ Doctor's Office ___ Home/Other		

Appointment Log

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Patient ID:	Today's date:
Appt Date:	
Appointment type: <input type="checkbox"/> Metabolic <input type="checkbox"/> Obstetric <input type="checkbox"/> Lab Tests <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other	

Outcome of Pregnancy

Patient ID:	Today's date:
Treating Clinic:	Patient Age when diet started:
What was the outcome of the study pregnancy? <input type="checkbox"/> Live Birth <input type="checkbox"/> Stillbirth <input type="checkbox"/> Spontaneous Abortion <input type="checkbox"/> Termination Date of Outcome:	
Did the patient experience any of the following?	
Nausea:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Hyperemesis Gravida:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Gestational Diabetes:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Hypertension:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other Symptoms:	<input type="checkbox"/> Yes <input type="checkbox"/> No
To be completed by Children's Hospital, Boston. When did the patient's Phe level remain under control for the remainder of the pregnancy? 6 mg/dl or lower: _____ weeks after LMP 10 mg/dl or lower: _____ weeks after LMP	

Newborn Pediatric Evaluation

Patient ID:	Today's date:
Treating Clinic:	Patient Age when diet started:
Infant gender: ___ Boy ___ Girl	
Infant Date of Birth:	
Infant gestation age: weeks	
Measurements	
Procedure: Take each measurement twice. If the difference between the two measurements is more than 100 grams or 0.2 cm, then take a third measurement. Enter the confirmed measurements below.	
Infant weight:	grams
Infant length:	cms
Infant head circumference:	cms
Examination	
Heart appears to be normal: ___ Yes ___ No	
Infant cardiac exam comments:	
Other anomalies noted:	

Offspring One Year Evaluation

Patient ID:	Today's date:	
Treating Clinic:		
What was the test date for the offspring?		
Bayley Scales of Infant Development-Second Edition Mental scale Developmental Index: _____ Performance (Motor) Scale Developmental Index: _____	Home Inventory (for infants and Toddlers)	
	Scales	Raw Scores
	Responsivity	
	Acceptance	
	Organization	
	Play Materials	
	Involvement	
	Variety	
<u>Total Score</u>		
Mother living in household:	___ Yes ___ No	
Father living in household:	___ Yes ___ No	
Grandparents living in household:	___ Yes ___ No	
Other relatives living in household:	___ Yes ___ No	
Foster Parents living in household:	___ Yes ___ No	
Other adults living in household:	___ Yes ___ No	
At this time, the head of household (parent or guardian) of the offspring has years of education: _____, is employed ___Yes ___ No, and works as a: _____.		
Enter any comments here, such as important changes in the patient's family environment:		
To be completed by Children's Hospital, Boston: Hollingshead/redlich Score: <input style="width: 50px; height: 15px;" type="text"/>		

Offspring Medical Services During the First Year of Life

Patient ID:	Treating Clinic:	Today's date:
Number of Pediatric Visits during the child's first year of life:		
Number of Visits to the Metabolic Center for child follow-up:		
Number of days of in-patient hospitalization:	If in-patient services were used, enter the Name of Hospital: City of Hospital:	
Other medical services obtained: (include surgeries, diagnostic work-ups, etc.)		
Other developmental or outside health services. Enter the number of times each service was used during the infant's first year of life. If additional services were used, fill-in up to three services' names and the number of times each service was used.		
Service	# times	
Visiting Nurse		
Early Intervention		
Home Health Aide		
Other (A)		
Other (B)		
Other (C)		

Resource Mother Contact Log

Today's date:		
Date contact was made:	Contact type: ___ Phone ___ Other Location ___ Home	Time spent: ___ minutes (not including travel)
Comment:		
Today's date:		
Date contact was made:	Contact type: ___ Phone ___ Other Location ___ Home	Time spent: ___ minutes (not including travel)
Comment:		
Today's date:		
Date contact was made:	Contact type: ___ Phone ___ Other Location ___ Home	Time spent: ___ minutes (not including travel)
Comment:		

Psychosocial Questionnaires

(These are Required by the Resource Mother's Study)

The following set of questionnaires should be administered at 6 and 32 weeks gestation by the Resource Mother. If the woman enrolls after 6 weeks gestation, forms should be administered as soon as possible after the first visit.

If the woman with PKU has a Resource Mother, the Resource Mother will administer the forms. If not, the clinic coordinator should do so.

These questions are not online. Please fill them out and return them to the study coordinator in Boston.

Questionnaires included:

- a. How Do You Feel About Yourself
- b. Knowledge of Maternal PKU
- c. Social Support Questionnaire
- d. Attitudes About Treatment Questionnaire
- e. Home Organization Scale
- f. Life Stress Questionnaire
- g. Opinion Questionnaire

Subject Number:

Date:

Social Support Questionnaire

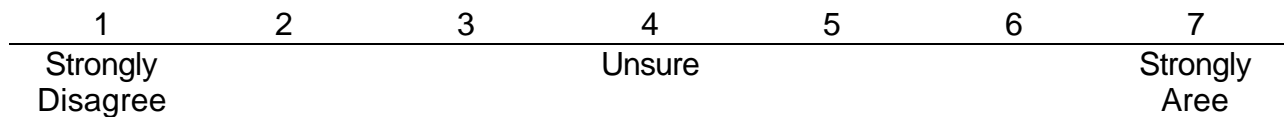
Note: Words in *italics* are meant as instructions and should not be read aloud.

Please take a minute to think of three friends or relatives who are close to you. *If the woman is married, say:* Please include your husband as one of these three people. *If the woman is not married, say:* If you have a boyfriend, please include him as one of the three people. *For all women, say:* Now I am going to ask you how strongly each person feels about your being on diet.

1. What is your relationship to the first person you thought of (ie mother, friends, etc.)?

Please point to the place on the line that best described how much you agree or disagree with this statement:

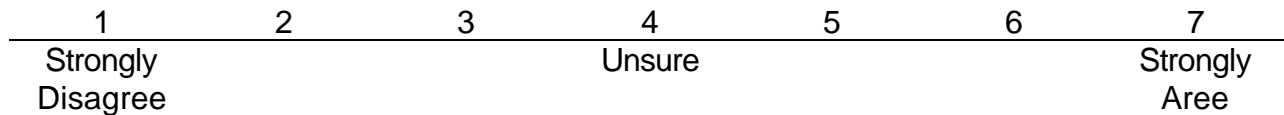
"My _____ wants me to keep strictly on the PKU diet."



2. What is your relationship to the second person you thought of (ie mother, friends, etc.)?

Please point to the place on the line that best described how much you agree or disagree with this statement:

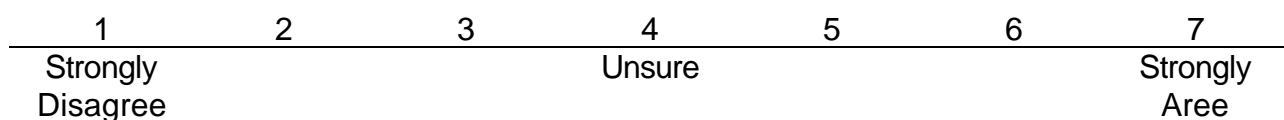
"My _____ wants me to keep strictly on the PKU diet."



3. What is your relationship to the third person you thought of (ie mother, friends, etc.)?

Please point to the place on the line that best described how much you agree or disagree with this statement:

"My _____ wants me to keep strictly on the PKU diet."



Knowledge of Maternal PKU

Date:

Subject Number:

Circle the best answer.

1. PKU is _____.

- A. a blood disease
- B. an enzyme deficiency
- C. a kidney disorder
- D. a protein deficiency
- E. an iron deficiency

2. Mental retardation in babies born to mothers with PKU is likely caused by _____?

- A. an enzyme deficiency in the baby
- B. PKU in the baby
- C. high blood phenylalanine
- D. the father carrying the gene for PKU
- E. too little protein in the mother's diet during pregnancy

3. The best known treatment for maternal PKU to prevent damage to the baby is _____?

- A. following a well-balanced diet
- B. following a vegetarian diet
- C. following a high protein diet during pregnancy
- D. following a low phenylalanine diet after a positive pregnancy test
- E. following a low phenylalanine diet before conception and throughout pregnancy

4. In addition to mental retardation, other problems that have been seen in babies born to mothers with PKU include _____.
- A. low birth weight
 - B. heart problems
 - C. small head size
 - D. all of the above
 - E. none of the above
5. Twenty mg/dl is considered a high blood phenylalanine level. On a low phenylalanine diet during pregnancy, blood phenylalanine levels should be controlled to what level?
- A. Less than 1 mg/dl
 - B. 2-6 mg/dl
 - C. 6-8 mg/dl
 - D. 10-15 mg/dl
 - E. 16-20 mg/dl
6. Which of the following snacks has the least amount of phenylalanine?
- A. Chocolate chip cookies
 - B. An apple
 - C. A hamburger
 - D. Potato chips
 - E. A bagel with jelly
7. Children born to mothers with PKU _____.
- A. never have PKU
 - B. have a 1 in 1000 chance of having PKU
 - C. have a 1 in 100 chance of having PKU if the father carries the gene for PKU
 - D. have a 50-50 chance of having PKU if the father carries the gene for PKU
 - E. will always have PKU

8. The problems that are seen in babies from untreated pregnancies in mothers with PKU _____.
- A. are entirely reversible
 - B. can be corrected by surgery
 - C. can be corrected by treating the baby with a low phenylalanine diet
 - D. generally result in the child having mental retardation, learning difficulties, birth defects, and the need for special services
 - E. go away as the child grows older
9. After a child is born to a mother with PKU, it is important _____.
- A. to place the child on a high protein diet
 - B. to perform newborn screening for PKU with special care and consideration so that if the child has PKU, he or she can begin dietary treatment
 - C. to hold off on newborn screening for PKU for a month since the baby has had enough stress
 - D. for the mother to be on a high protein diet
 - E. to immediately place the child on a low protein diet.
10. The best advice to give a young woman with PKU who thinks she might be pregnant is to _____.
- A. wait and see if it is true
 - B. wait, but stop eating meat in the meantime
 - C. wait, but start using birth control
 - D. immediately contact the PKU Clinic for guidance
 - E. contact her friends for guidance

Answers: 1b, 2c, 3e, 4d, 5b, 6b, 7d, 8d, 9b, 10d

How Do You Feel About Yourself?

Date:

Subject Number:

Please read the following statements and then check the column to tell if it is "like you" or "unlike you."

	Like Me	Unlike Me
1. I often wish I were someone else.	_____	_____
2. I find it very hard to talk in front of a group.	_____	_____
3. There are a lot of things about myself I wish I could change.	_____	_____
4. I can make up my mind without too much trouble.	_____	_____
5. I'm a lot of fun to be with.	_____	_____
6. I get upset easily at home.	_____	_____
7. It takes me a long time to get used to anything new.	_____	_____
8. I'm popular with people my own age.	_____	_____
9. My family expects too much of me.	_____	_____
10. My family usually considers my feelings.	_____	_____
11. I give in very easily.	_____	_____
12. It's pretty tough to be me.	_____	_____
13. Things are all mixed up in my life.	_____	_____
14. Other people usually follow my ideas.	_____	_____
15. I have a low opinion of myself.	_____	_____
16. There are many times when I'd like to leave home.	_____	_____
17. I often feel upset about the work that I do.	_____	_____
18. I'm not as nice-looking as most people.	_____	_____
19. If I have something to say, I usually say it.	_____	_____
20. My family understands me.	_____	_____
21. Most people are better liked than I.	_____	_____
22. I usually feel as if my family is pushing me.	_____	_____
23. I often get discouraged at what I am doing.	_____	_____
24. Things usually don't bother me.	_____	_____
25. I can't be depended on.	_____	_____

Date:

Subject ID:

Opinion Questionnaire

These are a series of attitude statements. We want you to answer the following questions about the way you feel. There are no right or wrong answers. Don't take too much time answering any one question, but do try to answer them all. Please circle "YES" or "NO" for each question.

- | | | | |
|-----|--|-----|----|
| 1. | Do you believe that most problems will solve themselves if you just don't fool with them? | Yes | No |
| 2. | Do you believe you can stop yourself from catching a cold? | Yes | No |
| 3. | Are some people just born lucky? | Yes | No |
| 4. | Most of the time, did you feel that getting good grades meant a great deal to you? | Yes | No |
| 5. | Are you often blamed for things that just aren't your fault? | Yes | No |
| 6. | Do you believe that if somebody studies hard enough, he or she can pass any subject? | Yes | No |
| 7. | Do you feel that most of the time it doesn't pay to try hard because things never turn out right anyway? | Yes | No |
| 8. | DO you feel that if things start out well in the morning that it is going to be a good day, no matter what you do? | Yes | No |
| 9. | Do you feel that most of the time, parents listen to what their children have to say? | Yes | No |
| 10. | Do you believe that wishing can make good things happen? | Yes | No |
| 11. | When you get punished, does it usually seem it's for no good reason at all? | Yes | No |
| 12. | Most of the time, do you find it hard to change a friend's mind or opinion? | Yes | No |
| 13. | Do you think that cheering more than luck helps a team to win? | Yes | No |
| 14. | Did you feel that it was nearly impossible to change your parent's mind about anything? | Yes | No |

Opinion Questionnaire 2

- | | | |
|--|-----|----|
| 15. Do you believe that parents should allow children to make most of their own decisions? | Yes | No |
| 16. DO you feel that when you do something wrong, there is very little you can do to make it right? | Yes | No |
| 17. Do you believe that most people are just born good at sports? | Yes | No |
| 18. Are most of the other people your age stronger than you are? | Yes | No |
| 19. Do you feel that one of the best ways to handle most problems is just not to think about them? | Yes | No |
| 20. Do you feel that you have a lot of choice in deciding who your friends are? | Yes | No |
| 21. If you find a four leaf clover, do you believe that it might bring you good luck? | Yes | No |
| 22. Did you often feel that whether or not you did your homework had much to do with what kind of grades you got? | Yes | No |
| 23. Do you feel that when a person your age is very angry with you, there's little you can do to stop him or her? | Yes | No |
| 24. Have you ever had a good luck charm? | Yes | No |
| 25. Do you believe that whether or not people like you depends on how you act? | Yes | No |
| 26. Did your parents usually help you if you asked them to? | Yes | No |
| 27. Have you felt that when people where angry with you it was usually for no reason at all? | Yes | No |
| 28. Most of the time, do you feel that you can change what might happen tomorrow by what you do today? | Yes | No |
| 29. Do you believe that when bad things are going to happen, they are just going to happen no matter what you try and do to stop them? | Yes | No |
| 30. Do you think that people can get their own way of they just keep trying? | Yes | No |
| 31. Most of the time, do you find it useless to try and get your own way at home? | Yes | No |

Opinion Questionnaire 3

- | | | |
|--|-----|----|
| 32. Do you feel that when good things happen, they happen because of hard work? | Yes | No |
| 33. Do you feel that when someone your age want to be your enemy that there is little you can do to change matters? | Yes | No |
| 34. Do you feel that it is easy to get friends to do what you want them to do? | Yes | No |
| 35. Do you usually feel that you have little say about what you get to eat at home? | Yes | No |
| 36. Do you feel that when someone doesn't like you, there's little you can do about it? | Yes | No |
| 37. Did you feel that is was usually almost pointless to try in school because the other kids were just a lot smarter than you were? | Yes | No |
| 38. Are you the kind of person who believes that planning ahead makes things turn out better? | Yes | No |
| 39. Most of the time, do you feel that you have little to say about what your family decides to do? | Yes | No |
| 40. Do you think it's better to be smart than to be lucky? | Yes | No |

Date:

Subject ID:

Home Organization Scale

Determine if there are items for managing the PKU diet. Notice what facilities are available for cooking and storing foods. Ask if the items are not in view. This information will help determine which recipes can be made and how much can be made at a time.

ITEM	YES	NO
Formula (at least two weeks supply)		
Blender or other means for mixing the formula		
Container for storing the formula		
Special low protein products		
Written diet guidelines		
Low protein cookbook		
Measuring cups or scale		
Measuring spoons		
Notebook or other type of food record		
Supplies for blood testing		
Calendar		
Cooking pot		
Refrigerator		
Stove		
Oven or Toaster oven		
Microwave		
Freezer (in refrigerator or separate)		
Sandwich maker		
Bread machine		
Total Number of items marked "YES"		

Date:

Subject Id:

Life Stress Questionnaire

These questions refer to events that you feel have been stressful. Please explain each item checked and give an approximate date or your age for each item checked.

Event	✓	Date or Your Age
1. You yourself suffered a serious injury, illness, or assault.		
2. A serious injury, illness, or assault happened to a close relative.		
3. Your parent, child, or spouse died.		
4. A close family friend or another relative (aunt, cousin, grandparent, etc.) died		
5. You had a separation caused by marital difficulties.		
6. You broke off a steady relationship.		
7. You had a serious problem with a close friend, neighbor, or relative.		
8. You became unemployed or you have sought work unsuccessfully for a month.		
9. You were fired from your job.		
10. You had a major financial crisis.		
11. You had problems with the police and appeared in court.		
12. Something you valued was lost or stolen in the last 6 months.		
Total number checked		

