



Forms and Questionnaires

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 - a. How do you feel about yourself?
 - b. Knowledge of mPKU
 - c. Social Support
 - d. Home Organization Scale
 - e. Attitudes about Treatment
 - f. Life Stress Questionnaire
 - g. Opinion Questionnaire

Case Information

Resource Mother Name:

Name of Woman with mPKU:

Address of Woman with mPKU:

Home Phone:

Work Phone:

BACKGROUND INFORMATION:

CURRENT SITUATION/REASON for REFFERRAL TO RESOURCE MOTHER:

INFORMAITON ON DIET/PRESCRIPTION from CLINICAL NUTRITIONIST:

Communication Form: Resource Mothers Program

Resource Daughter ID#

Date of Contact:

Resource Mother:

Home Visit:___ Phone:___

Who initiated the contact? ___ Resource Mother ___ Resource Daughter

Were you well received? ___ Yes ___ No

Was the appointment kept? ___ Yes ___ No

Who else was present at this visit?

BRIEFLY, what transpired during this contact with your Resource Daughter?

___ Cooked

___ Shopped (Groceries, etc.)

___ PKU Clinic Visit

___ Brought food

___ Provided Emotional Support

___ Hospital/Other Clinical Visit

___ Went out for activity

___ Visited Daughter/Baby

___ Helped Obtain Services

Comments:

Are there any concerns, questions, issues that need to be addressed by the Resource Mother's Program Staff? If yes, what are they?

Are there any concerns, questions, issues that need to be addressed by the staff at the clinic which follows your Resource Daughter? If yes, what are they?

Please rate this contact in terms of the following scales:

Intervention for the Resource Daughter?

1 2 3 4 5
Not Productive.....Productive

How was the contact for the Resource Mother?

1 2 3 4 5
Frustrating/Depressing.....Pleasant/Fulfilling

Please retain a third copy for your notes. Send the original and second copy to the Resource Mother's Staff. The second copy will be sent to the Resource Daughter's Clinic. Questions/comments will be forwarded to the appropriate person for follow-up.



Resource Mothers Program
REQUEST FOR PAYMENT & REIMBURSEMENTS

Name: _____

Social Security #: _____

Mailing Address where check will be sent:

Phone: _____

Date of Request: _____

Please check one or more:

___ **Training Stipend** (\$300)

___ **Initial Payment** after first visit (\$250)

___ **Final Payment** at completion of pregnancy (\$550)

___ **Mileage Expense**

Roundtrip miles to Resource Daughter's home _____

Number of trips to Resource Daughter's home _____

Roundtrip miles to PKU clinic _____

Number of trips to the PKU clinic _____

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

___ **Postage** (Please attach all applicable receipts, keeping a copy for your records).

Total Amount Requested: _____

Mail this form to:

Maternal PKU Program
Children's Hospital, Boston
300 Longwood Ave
IC Smith 106
Boston, MA 02115
Attn: Melissa Gennaccaro

Or FAX to:

(617) 734-2652
Attn: Melissa Gennaccaro

For office use only

Date submitted to accounting _____

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.

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

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.	_____	_____

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

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."

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7
strongly _____ strongly
disagree _____ agree

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."

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7
strongly _____ strongly
disagree _____ agree

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."

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7
strongly _____ strongly
disagree _____ agree

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		

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 |

- | | | |
|--|-----|----|
| 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 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 |