

Resource Mother Protocol

Assignment of Resource Mother (RM)

1. The woman with PKU signs a release of information and agrees to working with a RM.
2. The RM who lives the closest to the woman is assigned within two weeks if the woman is planning a pregnancy and within one week if she is already pregnant
3. Background information on the woman with PKU is shared with RM including:
 - Medical history
 - Nutritional history
 - Psychosocial history
 - Current blood phenylalanine
 - Treatment protocol

4. Number of visits planned:

The RM should plan to visit the woman with PKU 20 times. The following schedule is provided as a guideline for planning purposes; some women will need more or less frequent intervention depending on individual circumstances. However, a total of 20 visits is expected regardless of the timing of visits.

A. Planned pregnancy

Before pregnancy: one visit per month. Since it is unknown how long it will take for the woman to become pregnant, the number of visits will vary; however, in most cases the woman will be pregnant within 6 months. If she is not, a referral to infertility expert should be made.

Number and timing of Resource Mother visits for planned pregnancies

Visits before pregnancy	+	Visits in first half of pregnancy	+	Visits in second half of pregnancy	= 20 visits
1		11		8	
2		11		7	
3		10		7	
4		9		7	
5		9		6	
6		8		6	
7		8		5	
8		7		5	
9		7		4	
10		6		4	
11		5		4	
12		5		3	

B. When woman is already pregnant

Number and timing of Resource Mothers visits in unplanned pregnancies

Diet initiation (Wks gestation)	Visits first trimester	+	Visits second trimester	+	Visits third trimester	= 20 visits
2-3	8		6		6	
4-5	7		7		6	
6-7	6		8		6	
8-9	4		8		8	
10-11	2		10		8	
11-13	1		10		9	
>13	-		10		10	

Initial visit

The purpose of the initial visit is to become acquainted with the woman and determine in which areas she is likely to need help with adherence to the treatment protocol.

The following psychosocial questionnaires are required by the study and should be administered at approximately 6 and 32 weeks gestation. Generally, they should not be done during the first visit so that you can establish rapport with the woman.

- Knowledge of maternal PKU
- Social support questionnaire

Self esteem questionnaire
Locus of control measure
Home organization -diet checklist
Attitudes about treatment
Life stresses questionnaire

In addition, there are several questionnaires which many RM find useful in determining the Resource Daugther's likes, dislikes and needs. These are optional and are for use by the RM only

Follow up visit checklist

The RM spends her time in areas she deems necessary for the woman to adhere to medical recommendations. This checklist can be used to identify problem areas:

Diet

The woman with PKU:

- Has phenylalanine levels in control
- Consumes all medical food daily
- Keeps food record
- Demonstrates understanding of system for counting phenylalanine
- Takes blood levels weekly
- Keeps appointments at
 - metabolic clinic
 - obstetrician
 - WIC (if applicable)
- Eats low protein foods
- Cooks low protein foods

Psychosocial

The woman with PKU:

- Uses social supports
- Has positive attitudes about diet and pregnancy
- Has supplies on hand needed for diet implementation
 - medical food (formula)
 - low protein foods
 - appropriate groceries
- Is connected to community resources
- Appears to cope with the stress of the diet (is not anxious or depressed)