

Resource Mother's Randomized Clinical Trial Training Guide for Resource Mothers



SECTION 1: ORGANIZATION AND CONTACT INFORMATION

1. Description of the Resource Mother's Program
2. Organizational Chart
3. List of Resource Mothers
4. Communication with Coordinating Center



SECTION 2: BACKGROUND READING

1. Psychosocial Factors in Maternal PKU: Prevention of Unplanned Pregnancies
2. Psychosocial Factors in Maternal PKU: Adherence to Medical Recommendations
3. PKU In Adolescents: Rationale and Psychosocial Factors In Diet Continuation
4. Maternal Phenylketonuria: A Metabolic Teratogen
5. The International Study of Pregnancy Outcome in Women with Maternal PKU: Report of a 12-year Study
6. Outcome at Age 4 Years in Offspring of Women with Maternal Phenylketonuria
7. PKU Adults and Their Return to Diet: Predicting Diet Continuation and Maintenance



SECTION 3: MPKU TREATMENT PROTOCOL

1. Summary of Schedule of Assessments for the Maternal PKU Treatment Plan
2. The Maternal PKU Treatment Plan
3. Resource Mothers Protocol
4. Assessment Forms for the Resource Mother



SECTION 4: DIET OVERVIEW



SECTION 5: SKILLS OF THE RESOURCE MOTHER

1. Communication/Listening
2. Confidentiality
3. Home Visitation
4. Informed Consent/Release of Information



SECTION 6: FORMS AND QUESTIONNAIRES



SIDE POCKETS

1. PKU Primer
2. NIH Consensus Statement on Phenylketonuria: Screening and Management