Visit 4: Genetics and Reproduction

Objective: At this visit you have the opportunity to review how PKU affects your decisions about reproduction. Decision-making about "high risk" behaviors will also be discussed.

In this section:

- High Risk Behaviors
- PKU and Adult Cognitive Function
- Phenylketonuria and Pregnancy
- *Essentials of PKU*

At this visit:

- Nutrition assessment- bring your 3 day food record to clinic
- Physical assessment- a brief visit with PKU doctor
- Discussion with genetic counselor about PKU, genetics, and reproduction
- Discussion of high-risk behaviors and PKU
    - Smoking, alcohol, drugs, high blood levels
    - Effects on decision making (e.g., while driving)
- Confirm next visit

Who is involved:

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

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High Risk Behaviors

Whether you have PKU or not, there are issues that every individual faces and needs to make choices about. You are in your teens now, but it's important to know that adults of all ages face these choices too.

Smoking
Drinking
Taking drugs
Having sex

Do your friends smoke? Is there drinking at the get-togethers you go to? Does anyone you hang around with smoke pot? Take other drugs?

You may have already faced situations in which you needed to decide whether or not you would accept a drink, cigarette, joint. What did you decide? How do you feel about your decision when you look back on the situation?

It's important to know that there are risks associated with each of these behaviors. As your health-care team, it is our job to provide you with reliable information affecting your health and to be clear about our values. We advise you not to smoke, drink or take drugs. We want you to make informed decisions, and act responsibly. We believe that your health and well-being should be a priority and that true friends will respect and support your choices.

As an adolescent, it is your job to take more steps toward independence, to become competent and responsible for your own needs, feelings, and behaviors. You will gradually emerge as a separate, independent person with your own identity and values. The decisions you make on a daily basis result in real consequences that shape your future.

We trust that you will ask for the support you need as you make your own decisions.

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Smoking Facts

Cigarettes carry a high risk of cancer.
Cigarette smoke smells bad.
Cigarettes are expensive.
Smoking will decrease your lung capacity.
Smoking will interfere with your ability to play sports…and your ability to just go for a walk, or run up a flight of stairs.
Smoking will make your skin age faster.
Smoking will eventually give you little wrinkle lines all around your mouth.
Tobacco will eventually stain your fingers and teeth yellow.

Drinking Facts

Alcohol, in any amount, affects your body in some form.
Alcohol changes the way your brain processes information.
Alcohol affects your ability to make decisions.
Drinking alcohol during pregnancy will damage a developing baby.
Alcohol interferes with your judgment.
Alcohol can damage your liver.

Drinking and Having PKU

High blood phe levels change the way your brain processes information.
High blood phe levels interfere with your judgment.
Alcohol changes your brain processing and interferes with your judgment.

High blood phe levels + alcohol dramatically increases these effects. “It doesn’t take much”. Even one drink together with high blood phe levels can significantly impair your thinking.

Beer and wine contain phenylalanine.
Liqueurs that contain cream (e.g. Bailey’s Irish Cream) contain phenylalanine.
Hard alcohol does not contain phenylalanine.

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Taking Drugs

Drugs of any kind will change the way your brain processes information.
Drugs of any kind, in any amount + high blood phe levels will significantly impair your thinking.
Drugs that you smoke carry the same risks as smoking cigarettes PLUS the risks of the drugs themselves.
You can unwittingly take drugs by leaving your drink (non-alcoholic or otherwise) unattended at a party or club. NEVER leave your drink unattended. If you walk away from your drink, get a new one.

Sexual Relationships

Are you in a relationship and thinking about having sex? Are you thinking about having casual sex? This is a topic with several issues, both PKU and non-PKU related issues. Most of the issues are the same for guys and girls. Included in this section is information from Planned Parenthood. The issues about having sex apply both to your first time ever, and also your first time in a new relationship. Sex changes a relationship.

The Young Woman's Guide to Sexuality (www.plannedparenthood.org/womenshealth/ywg.html)

The Young Man's Guide to Sexuality (www.plannedparenthood.org/health/mangd1.html)

Facts About Birth Control (www.plannedparenthood.org/bc/bcfacts2.html)

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Sexual Relationships and Issues Specific to People With PKU

There many ways to have a family, whether you are gay or straight. In any kind of relationship where there is to be a pregnancy the information below applies.
Having a baby is a huge responsibility for anyone. Even in the ideal scenario where,

1. Both parents are in a committed long-term relationship,
2. The pregnancy is planned and wanted,
3. There is a good household income and health insurance,
4. Neither parent has significant health issues to manage,
5. The baby does not have any special health issues to manage,
6. The new parents have good support systems with friends/family,

…raising a child is HARD, and expensive.

Additionally, if one or both parents have their own health issues that requires planning ahead and organization skills, and/or the child has special needs, the picture gets more complicated and much HARDER.

All couples have a risk of having a child with any significant medical issue at birth. A significant medical issue could be a heart defect, or a kidney problem, or a cleft lip…. The risk for all couples in the general population is about 3-5%. This is your background risk and is separate from your risk of having a child with PKU. Below is a discussion of the genetics of PKU.

Where does PKU come from?

All of our genetic information is stored in the form of genes. Genes are like recipes, which provide instructions to do everything from giving us our hair and eye color, to making the enzymes that break down the food we eat. All of this genetic information is passed down from our parents. We have two copies of every gene: one copy comes from our mother (in the egg) and one copy comes from our father (in the sperm). Individuals with PKU have received two non-functioning copies of the gene for PKU. That is, they have a mutation on each copy. This means that the PKU enzyme (called phenylalanine hydroxylase) made by this gene is not able to function properly and the phenylalanine cannot be broken down. Individuals who receive just one non-functioning copy of the PKU gene are called carriers. Since carriers have one normal copy of the PKU gene, they are able to make enough enzyme that they do not have symptoms of PKU and never need a low-phenylalanine diet. Couples in which both parents are carriers (like your parents) have a ¼ or 25% chance of having a child with PKU with each pregnancy.

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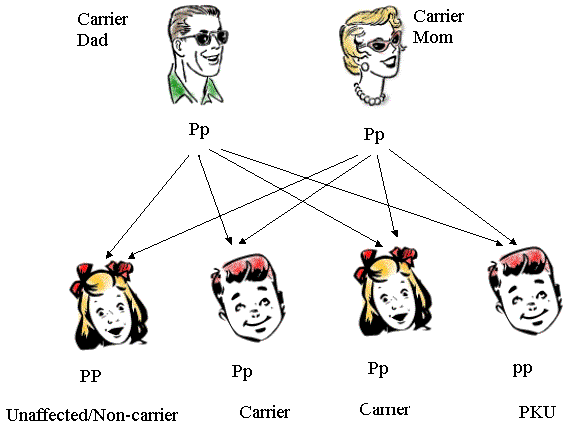
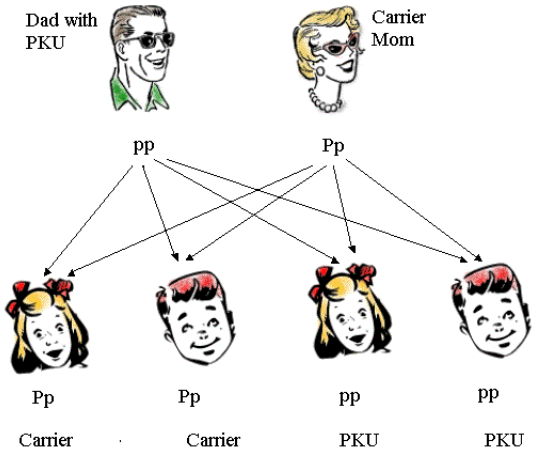


I have PKU, can my children have it too?

When individuals with PKU have children, there are two possibilities, depending on whether or not their partner is a carrier for PKU. The person with PKU can only pass on one of his/her mutated genes. If his/her partner is a carrier, he/she has a chance of also passing on his/her mutated gene and the couple will have a child with PKU. There is also a 50% chance of having a child who inherits one mutated gene from the parent with PKU, and the normal gene from the other parent. This child would be a carrier. To simplify things, all of your children will be carriers for PKU. If your partner is a carrier, you have a 50% chance of having a child with PKU.



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Girls and PKU

Phenylalanine will damage your developing baby. The harmful effects vary, but generally, the higher the levels the more damage that happens. Your baby can be harmed by your high phenylalanine levels BEFORE you even know that you're pregnant.

The baby's health problems that result from high blood phenylalanine levels in the mother are called Maternal PKU Syndrome. Maternal PKU syndrome can include: heart defects, small head (microcephaly), mental retardation, growth retardation, intestinal defects, and miscarriage (ie. the damage is severe enough that the pregnancy cannot go to term). A common misconception is that Maternal PKU syndrome can only happen if the baby also has PKU. The effects of high maternal blood phenylalanine are completely independent of whether or not your child has PKU.

It's really important to use reliable birth control, and use it religiously so that you don't get pregnant before you're ready. Every pregnancy should be a planned pregnancy.

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PKU and Adult Cognitive Function

Why do adults with PKU need to manage their blood phe levels and keep them low?
Over time elevated blood phe levels cause changes in the brain that:

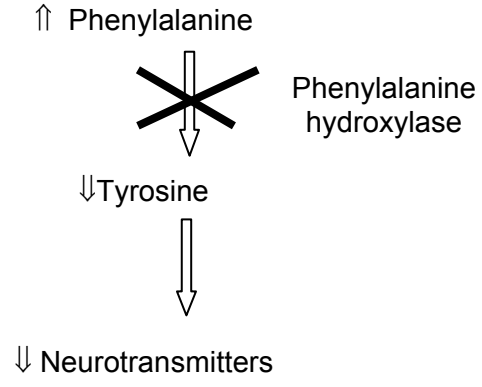
- Lead to **decreased cognitive function** (IQ).
- Lead to a decrease in some aspects of learning such as **executive function**
- Affect aspects of neuropsychological function such as **emotions**.

What causes these changes in the brain?
These changes in the ability of the brain to function properly are caused by lowered levels of chemicals in the brain called **neurotransmitters**.

What are neurotransmitters?
Neurotransmitters are " brain wave messengers".

- The level and activity of neurotransmitters affect a person's emotional response to a situation
- Neurotransmitters affect **executive function** tasks.
  These tasks include planning purposeful action, decision making, flexible problem solving, and learning from feedback. Deficits in these areas may cause problems in school or in keeping a job.

How are my phe levels and my neurotransmitter levels related?
Elevated blood phe levels interfere with the production of neurotransmitters in the brain. Low blood phe levels mean that the expected amount of neurotransmitters can be produced.



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What does this mean for people who have high blood phe levels?
Adults with PKU who have elevated blood phe levels and the resulting low neurotransmitter levels for a long time may be at increased risk for eventually developing some of these neurological symptoms.

- Headaches
- Decreased short term memory
- Increased irritability (crankiness)
- Inability to cope with life, i.e., anxious, weepy
- Greater occurrence of thought disorders and mood disturbances
  - Increased risk of problems with depression
  - Increased risk of problems with impulse control
  - Increased risk of fear of leaving the house

For more information on this see: The National PKU News website: www.pkunews.org. Click on the link "Adults with PKU."

What exactly is executive functioning?

In general, it is believed that successful social performance involves higher-order cognitive skills and processing. This higher level of functioning is called *executive functioning.*

Executive functions are defined as the decision-making and planning processes that our brains use when we start a task or when we face a new challenge to our thinking. In other words, executive functioning is our ability to use new information or how we use information that we already know.

Higher order executive functions influence one's behavior in several ways. For example, by helping us:

- Inhibit inappropriate social actions
- Delay or restrain inappropriate responses
- Figure out what to pay attention to in our immediate environment
- Set goals for our activities
- Plan a strategy for our activities
- Shift between activities

Social communication or using appropriate language in interpersonal settings is also a major executive functioning task. For example, these social communication skills have been defined as:

- Recognizing and appropriately responding to the social and informational requirements of a situation
- Recognizing underlying codes and meanings in language
- Organizing and expressing ideas through several methods at the same time, e.g., words, gestures, and body language
- *Recognizing changes in the social situation and the ability to make verbal and thought changes fairly rapidly*

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Does 'good' or 'poor' executive functioning affect your daily life?
For example, Suzy discovered that high blood phe levels affect her executive functioning. During the fall quarter, her levels were high. She spent a lot of time trying to decide which final exam to study for, and she ended up not doing well on any of her exams. During the winter quarter, her blood phe levels were less than 6. She found it easier to make good decisions, and was able to organize her studying. Her grades during winter quarter were much higher than in the fall.

To help you better understand executive functions, perhaps you can think of personal examples of how you have successfully used your executive functions to adapt to a new situation, or perhaps, you can think of situations in which you were 'flat-footed' because you were not able adapt quickly enough.

High blood phenylalanine levels interrupt effective executive functioning. Without executive functioning a person loses his/her judgment, ability to make appropriate decisions, and the ability for self-reflection and self-correction.

Adapted from: http://depts.washington.edu/soccomm/processing.html , 8/8/03

10 signs that your blood levels are over 10

1) You are cranky
2) You are jittery
3) You have a tremor in your fingers when you fully extend your arm in front of your body
4) You feel extra tired for no apparent reason
5) Your reflexes are 'jerky', that is, your response is not a smooth one
6) You develop a rash on your arms and neck that lotion does not help
7) You have headaches that are not relieved by the usual over the counter medications
8) Your friends tell you that you are not thinking as clearly as usual
9) You are not able to clearly remember something that you have just read or been told
10) Your hair or your skin smells a bit 'musty' because of the high levels of phenylactetone you produce when your blood phe levels are high

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Assessment of PKU Adolescent Transition Curriculum

Session 4.

Objective: At the end of this visit you will have the opportunity to review how PKU affects your decisions about reproduction. You will have an opportunity to apply the problem-solving model to socially 'high-risk' behaviors.

Post Session Objective: Each participant will be able to explain how PKU affects his/her decisions about reproduction. Each participant will have had an opportunity to apply the problem-solving model to decisions about 'high-risk' behaviors.

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

1)
_____

2)
_____

3)
_____

II. How will you incorporate this problem-solving model into your decisions about 'high-risk' activities?

_____

_____

III. In your view, what is the 'important' decision a person with PKU needs to make about having a family or bearing children?

_____

_____

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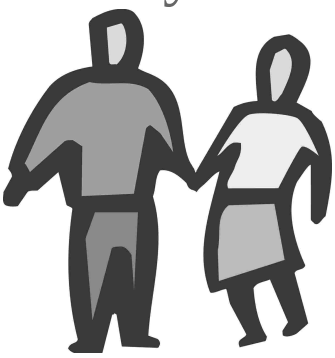
Phenylketonuria and Pregnancy



Part I: General Information

Published 1999, Reviewed 2002
PacNoRGG Genetics Update
A Fact Sheet for Practitioners

What Is Phenylketonuria (PKU)?

Phenylketonuria (PKU) is an inborn error in the metabolism of the amino acid phenylalanine (phe). It results from an absence or decreased activity of the enzyme phenylalanine hydroxylase. Untreated PKU causes mental retardation. However, routine newborn screening and immediate initiation of rigorous treatment with a low phenylalanine diet can prevent disabilities associated with PKU, including mental retardation, ADHD, and seizures.

Dietary treatment requires the use of a semi-synthetic medical food (formula) as the primary source of protein. The formula limits phe intake, but still provides enough phe for growth and development. The goal of treatment is to maintain serum phe levels of 2-6 mg/dl in order to support normal cognitive development and functioning. Treatment is required for the lifetime of the individual with PKU.

What is Maternal PKU?

An elevated maternal level of phenylalanine that causes damage to a developing fetus is termed "maternal PKU." The term refers to the cause of the damage, rather than to the features of the damage.

There is a 1:1.5 gradient of phe across the placenta. Thus, the fetus is exposed to a higher concentration of phe than that which exists in maternal blood. Because of this gradient, serum phe levels that are safe for adults are harmful to the fetus. The higher the serum phe concentration, the greater the degree of damage to the fetus.

What are the effects of untreated or poorly treated Maternal PKU on reproductive outcomes?

Elevated maternal serum phe levels may cause spontaneous abortion, microcephaly, congenital cardiac anomalies, poor intrauterine growth, an d mental retardation. Serum phe levels at the time of conception and in early pregnancy are the most critical to the organ development of the fetus.

What is the intellectual development of children of women with PKU?

The intellectual development of children whose mothers have PKU appears to be directly related to maternal serum phe levels. The Maternal PKU Collaborative Study provides some data about intellectual development:

- Almost 100% of the children whose mothers had serum phe levels of $\geq$ 20 mg/dl were mentally retarded.
- More than 20% of the children of women who had serum levels between 3-10 mg/dl were mentally retarded. (This is higher than the expected frequency of mental retardation of 3% in the general population.)

There is little data on the intellectual development of children whose mothers had serum phe levels of 1-4 mg/dl throughout pregnancy because few women were able to achieve and maintain these low levels.

Who is at increased risk for having a baby damaged because of elevated maternal phe levels?

Any woman who has serum phe levels greater than 6 mg/dl—even if she does not herself carry the diagnosis of PKU—is at risk. (This includes women with "hyperphenylalaninemia.")

Can a woman with PKU be treated to improve reproductive outcomes?

Yes. If maternal serum phe levels are <4 mg/dl prior to conception and during pregnancy, the risk to the fetus is decreased. However, the risk of damage to the fetus cannot be entirely eliminated by treatment during pregnancy.

What is the treatment during pregnancy for women with PKU?

Nutritional management is the key to pregnancy treatment

for women with PKU. "Safe" maternal serum phe levels cannot be achieved without the use of medical food (formula), and formula is essential to healthy maternal weight gain. Formula should provide 80-90% of protein and energy intake during pregnancy.

Optimum management of PKU for a pregnant woman requires huge emotional, physical and financial commitments by the woman and is extremely labor-intensive for her health care providers. Optimum management begins months before conception. It is important for any woman with PKU who is contemplating pregnancy to understand that optimum management will lower the chance that her baby will be born with damage because of her phe levels, but will not ensure that her baby will be healthy.

What is a Reasonable Management Algorithm for Women with PKU?

If not pregnant and prefers not to become pregnant:

- discuss risks of pregnancy
- provide birth control options
- discuss options for family planning...surrogate mother, adoption

If not pregnant and wishes to become pregnant:

- counsel about reproductive risk
- describe treatment protocol and goals
- discuss costs of medical care
- describe risks to the fetus even with excellent control of serum phe levels

If pregnant, immediate action is required:

If a woman with PKU is pregnant and the pregnancy is not planned, this is a ***medical crisis*** because each day of high maternal serum phe levels can cause further damage to the developing fetus.

- refer to metabolic genetics clinic for counseling regarding risks and outcome
- refer to high risk pregnancy clinic or perinatologist for coordination of services between metabolic nutritionist and obstetrician/perinatologist for high risk obstetrical care
- discuss cost of formula, maternal medical care, and infant medical care

If pregnancies are not planned and rigorous treatment is not followed, the number of infants born with mental retardation will erase the public health benefit of newborn screening.

Regional PKU Clinic Contacts

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Judy Peterson, MS, RD
PKU Program Coordinator
Idaho Department of Health and Welfare
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Oregon
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Resources

National PKU News Webpage
http://www.pkunews.org

University of Washington PKU Program
http://depts.washington.edu/pku/

This brochure was written by
Cristine Trahms, MS, RD, FADA; Beth Ogata, MS, RD, and Robin Bennett, MS, CGC as a project of the PacNoRGG Education Committee.

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http://mchneighborhood.ichp.edu/pacnorgg

Phenylketonuria and Pregnancy

Part II: Pregnancy Management

Published 1999, Reviewed 2002
PacNoRGG Genetics Update
A Fact Sheet for Practitioners

What is Maternal PKU?

An elevated maternal level of phenylalanine that causes damage to a developing fetus is termed "maternal PKU." The term refers to the cause of the damage (high phe levels in the mother), rather than to the resulting damage to the baby. Most often, the baby of a woman with PKU does not actually have PKU.

There is a 1.5:1 gradient of phe across the placenta. Thus, the fetus is exposed to a higher concentration of phe than that which exists in maternal blood. Because of this gradient, serum phe levels that are safe for adults are harmful to the fetus. The higher the serum phe concentration, the greater the degree of damage to the fetus.

Who is at increased risk for having a baby damaged because of elevated maternal phe levels?

Any woman who has serum phe levels greater than 6 mg/dl—even if she does not carry the diagnosis of PKU—is at risk.

Can Maternal PKU be treated to improve reproductive outcomes?

Yes. If maternal serum phe levels are <4 mg/dl prior to conception and during pregnancy, the risk to the fetus is decreased. The risk of damage to the fetus cannot be entirely eliminated by treatment during pregnancy.

Optimum management of PKU for a pregnant woman requires huge emotional, physical and financial commitments by the woman and is extremely labor-intensive for her health care providers. Optimum management begins months before conception. It is important for any woman with PKU who is contemplating pregnancy to understand that optimum management will lower the chance that her baby will be born with damage because of her phe levels, but will not assure that her baby will be healthy.

Abbreviations: phe - phenylalanine, PKU - phenylketonuria

What Is A Reasonable Pregnancy Management Protocol for Women with PKU?

All pregnancies should be carefully planned. Women with PKU who are considering pregnancy should be referred to a regional genetics center. Pregnancy management should be a joint effort of the woman and her support system, health care providers, health agencies, and the metabolic team.

Nutritional management is the key to pregnancy treatment for women with PKU. "Safe" maternal serum phe levels cannot be achieved without the use of medical food (formula), and formula is essential to healthy maternal weight gain. The formula limits phe intake, but still provides enough phe for fetal growth and development. Formula should provide 80-90% of protein and energy intake.

Step 1: Pre-Pregnancy Counseling

The woman with PKU and her partner should participate in pre-pregnancy counseling with an experienced genetic counselor. They should understand the risks involved with the pregnancy, and the treatment. Even with the best dietary control, normal pregnancy outcome cannot be guaranteed. Elevated maternal serum phe levels may cause spontaneous abortion, microcephaly, congenita cardiac anomalies, poor intrauterine growth, and mental retardation. Serum phe levels at conception are critical to the organ development of the fetus. Effective treatment requires extraordinary commitment from the woman with PKU and a strong relationship with a team of professionals who are familiar with the treatment of high risk, PKU pregnancies. The team should include an experienced obstetrician and nutritionist.

Issues to be discussed:

- risks of pregnancy
- commitment required for treatment
- financing of treatment and formula

Step 2: Plasma Phe Levels to <6 mg/dl

If the woman is planning to become pregnant, she should bring her plasma phe levels to <6 mg/dl; this may take several weeks. She must maintain blood levels in this range for several weeks to understand the effort required and to establish new

patterns of formula intake, meals and cooking.

Issues to be discussed:

- effort required to lower blood phe levels
- effects of treatment on other family members

Step 3: Plasma Phe Levels to 1-4 mg/dl

If the couple is still considering pregnancy, plasma phe levels must be lowered to 1-4 mg/dl. Levels should be maintained in this range for 2-3 months to establish new patterns of food choices and meals, and increased formula intake.

Issue to be discussed:

- effort required to lower and maintain appropriate blood phe levels

Step 4: More Pre-Pregnancy Counseling

The couple should meet again with the genetic counselor. At this point they need to be sure that they understand the risks of maternal PKU and pregnancy and are prepared for the rigors of management of a high-risk pregnancy. They also need to be sure that the financial arrangements are made for formula, and medical and nutritional monitoring. The couple should be counseled that as for any other couple, conception may take months or even years.

Issues to be discussed:

- pregnancy risks, efforts required to maintain blood phe levels
- financial arrangements
- fertility issues

Step 5: Continuous Monitoring During Pregnancy

Monitoring a high-risk pregnancy requires weekly plasma phe levels and nutrition consultations, monthly amino acid profiles, careful record keeping of food and formula intake, monitoring of weight gain and overall nourishment. Ultrasound assessments of fetal growth and measurement of other standard biochemical parameters of pregnancy are also required. The physiologic changes of pregnancy may pose difficulties for effective dietary management, especially nausea and vomiting associated with early pregnancy.

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