

# So You're Thinking About Getting Pregnant.....

Your Own Guide to Maternal PKU

Planning your first pregnancy is so exciting!! As a woman with PKU planning a pregnancy you probably would like to know what to expect before, during and after your pregnancy. This information sheet will hopefully answer some of your questions.



## **Before Pregnancy**

1. Have a pre-pregnancy check up with your Family doctor (GP). This check-up should include a look at your :
  - Rubella (German measles) titre--how much immunity you have to it
  - Chicken pox titre--how much immunity you have to it
  - Hepatitis B status
  - Toxoplasmosis screen (a parasitic infection from cat litter, dirt, handling meat)
  - STD
2. Adjust your diet to get your phe level between 2 - 6 mg% for 6 months before you start trying to conceive. You should stay on birth control at this time.
3. To get your phe level in the target range, you will need to do weekly food records and blood dots. Your Adult Metabolic Clinic dietitian will work closely with you during this time.
4. In order to be well nourished prior to pregnancy, taking all of your prescribed metabolic formula is essential. It needs to be spread out over the day in 3-4 separate drinks. Food records and menu planning will be very helpful.
5. Avoid alcohol
6. Stop smoking
7. Get enough folic acid. Your metabolic dietitian will let you know how much folic acid you are getting from your formula. You will be taking a folic acid supplement daily; most pills have between 0.4 - 1 mg/tablet.
8. Look at your home and workplace habits and exposure. Hot tubs, saunas, more than 2 cups (400 mg) caffeine, photocopiers and microwaves may affect your pregnancy. The type of exercise you do may change during your pregnancy. Your family doctor can help you with these decisions.
9. Focus on the positive things you CAN do and include your partner in planning meals and solving challenges.

10. Consider a Resource Mom. Your Metabolic Clinic has 2 trained Resource Moms who may help you with various aspects of your PKU management.

## **During Pregnancy**

It is difficult to predict how any particular pregnancy will progress. Below are some examples of things you may expect, although you may not experience them all. There are some great pregnancy guides out there such as:

What to Expect When you're Expecting  
My Girlfriends Guide to Pregnancy

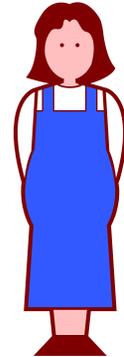
### ***First Trimester (0 to < 14 weeks):***

1. A range of feeling and moods such as:
  - intense hunger or nausea
  - food cravings or disliking foods you used to enjoy
  - intense fatigue
  - apprehension and excitement
2. Fairly restrictive phe diet at first--about 200-300 mg/d. Your dietitian at the Adult Metabolic Diseases Clinic will work closely with you. Keeping daily food records using a gram scale, sending them to the clinic weekly and doing a blood dot for phe and tyrosine 2 times a week is essential for making good decisions about your diet.
3. A weekly weight is important. Depending on your pre-pregnancy weight, this trimester we look for a weight gain of about 2-5 pounds. It's a good idea to have a bathroom scale at home. Healthy weight gain contributes to a healthy baby and keeps phe levels in the optimal range.
4. Visits to your GP for blood pressure, weight, urine tests for sugar/protein and consultation about general pregnancy issues.
5. Blood Tests will be done at your local lab at week 12, 20 and 32 to make sure you and your baby are getting proper nutrition. These blood tests are:
  - Plasma amino acids
  - Albumin
  - Cholesterol
  - Ferritin
  - Selenium
  - CBCAt 12 weeks B12 and folate will be done in addition to those tests above.



6. An ultra sound will be planned for weeks 10-12, 18-22 and 32-34. The ultrasound between week 10-12 is for dating and placental placement.
7. Your dietitian may or may not ask you to add tyrosine powder or a vegetable oil (canola or soybean) to your formula.

**Second Trimester ( 14 to <27 weeks):**



1. A range of feelings and moods including (or not including):
  - Heartburn, indigestion, hearty appetite
  - Gas and bloating
  - Dizziness/faintness
  - Hunger
  - Backache
  - Leg cramps, swelling, varicose veins
  - Irritability and mood swings, boredom
2. Possible increase in the amount of phe from food (to possibly 300-600 mg/day). Your food choices and formula amounts will change (increase) to keep up with the baby's growth. Sometimes tyrosine powder and oil amounts are increased. It all depends on your weight gain and phe levels. So....
3. Weekly weights continue this trimester; a slow, steady weight gain of about 1/2 pound a week (1/4 kg), depending on your pre-pregnancy weight.
4. blood dots done 2x a week are essential
5. daily food records sent to clinic weekly are extremely useful
6. Visits to your GP for weight, blood pressure, urine sugar/protein, fetal heart beat, fundus height (belly size) and a chance to discuss general pregnancy questions. A 4-hour glucose tolerance test may be scheduled.
7. Blood Tests will be done at your local lab at week 20 for:

Plasma amino acids	Ferritin
Albumin	Selenium
Cholesterol	CBC

You may need an iron supplement depending on the lab results.
8. An ultrasound may be scheduled between weeks 18 -22. This detailed ultrasound looks at the baby's measurements, bones, heart, face, amniotic fluid levels and umbilical cord for blood flow.
9. You may (or may not) meet the maternal fetal medicine experts at BC Women's Hospital. They are the doctors that look at your baby's ultrasound and overall progress.

10. This would be a good time to make some extra low protein meals and freeze them. They'll be very welcome after the baby is born and you and your spouse are quite tired. Try low protein pizzas, pizza burgers, chicken nuggets, quiche, perogies or other favourites.

***Third Trimester (27 - 41 weeks):***

1. a range of feelings and symptoms such as:
  - Braxton Hicks contractions, strong baby activity
  - itchy abdomen
  - leg cramps, swelling, varicose veins
  - achiness in lower abdomen
  - heartburn, gas, constipation, faintness, dizziness
  - apprehension about labour and delivery
  - absentmindedness
  - boredom, weariness, anxiousness
2. Possibly further increases in daily phe allowance depending on blood phe results. Further adjustments (increases) to your formula, tyrosine powder and canola/soybean oil amounts.
3. weekly weights looking for a steady rate of weight gain
4. blood tests 2x a week
5. food records done daily and sent to clinic from which you and your dietitian can decide which foods or liquids can most easily be adjusted by you.
6. more frequent visits (weekly) to the GP toward the end of this trimester for blood pressure, urine sugar/protein, fundal height, size and position of the baby, fetal heart beat, symptom and answering questions about general pregnancy, labour, delivery.
7. If you live outside the Vancouver area, a decision will be made with you as to the best place to deliver your baby (ie at BC Women's or at your local hospital). If you live in-town or out-of-town, the decision about who will deliver your baby depends on how involved the "high risk pregnancy" perinatologists have been in your pregnancy so far and whether or not your family doctor delivers. If your family doctor does not deliver babies, then an obstetrician from BC Women's will deliver your baby.
8. Ultrasound between 32-34 weeks. Some women are not asked to have this ultrasound. It depends on how the pregnancy is progressing.
9. Blood Tests will be done at your local lab at week 32 for:
  - Plasma amino acids



Albumin  
Cholesterol  
Ferritin  
Selenium  
CBC

### **After Delivery**

1. After your baby is born it is recommended (and hoped) that you will continue with an eating plan that will keep your phe levels between 2-6 mg%. Your dietitian can work with you on this goal.
2. Your phe tolerance will drop again to almost what your tolerance was before pregnancy. This will seem like quite a change from the type and amount of food you were eating near the end of your pregnancy. Trying to plan for this change in tolerance will help you with your plan to keep your blood levels low (see point #1)
3. If you are planning to breast-feed your baby you will need more calories, protein and fluids than before your pregnancy. Your dietitian will work closely with you to make sure your formula and food amounts are just right.
4. You will likely stop the additional tyrosine and vegetable oil but it depends on the results of your blood tyrosine levels and how your breastfeeding is going.
5. Breast-feeding is physically demanding and you will likely lose weight gradually without trying. This would not be a good time to "diet" or restrict calories too much as it can affect your milk supply and quality.
6. You will be pretty tired the first 2-6 weeks after the baby is born. It's a good idea to use some of those frozen, lower protein meals that you prepared in your second trimester. It will reduce your temptations for higher phe foods and help you with point #1 again!

