

## Checking Your Child's Progress

### Blood Tests

Because babies grow so rapidly during the first year of life, blood is tested often for Phe content. Your baby's doctor will tell you how often it needs to be done. It could range from twice a week to every two weeks, depending on how well controlled Phe levels are.

You will be taught how to obtain a blood sample to check the Phe levels for your baby. The procedure will become quick and simple the more you do it. You will prick your baby's foot with a small lancet using what is called the heel-stick method to obtain drops of blood that are then allowed to soak into a special filter paper. When your child is older, his finger will be used, in place of the foot.

For three days before taking a blood sample, you will need to accurately record your child's total food and beverage intake. The clinic will provide instructions and a form on which to record the name of the food, the exact amount eaten either in household measures (cups, tablespoons, etc.) or in grams, the amount of Phe in the food, and the calorie content. These amounts can be found on the serving lists provided.

### Blood Phe Levels

The amount of Phe in the blood is a way to indirectly measure how much Phe is present in body tissues. The brain, of course, is of most concern because too much Phe is harmful to brain development. Because blood transports nutrients to the brain, the concentration of Phe in the blood will give the doctor an idea of how much might be in the brain.

Recommended blood Phe levels vary, but Utah metabolic specialists say between 2 and 6 milligrams per deciliter (mg/dL) or 120-360 micromoles per liter ( $\mu\text{mol/L}$ ). All scientific values are given using the metric system. This is a very tiny amount when measured, so it is done with sensitive laboratory equipment.



### Clinic Visits

Continue to go to regular appointments with your baby's pediatrician or family doctor to provide ongoing well-child care. You will learn the importance of a Medical Home in providing consistent care for your child. Immunizations still need to be given at the appropriate times. Your baby will probably get all the usual childhood illnesses; if your child is sick, be sure to consult your doctor.

Because PKU is a lifelong condition that could harm growth and development, your child will need to be seen often in the metabolic clinic in addition to regular appointments with his medical home. If growth and development are normal and the Phe levels are within therapeutic range, the frequency of clinic visits may decrease with time.

At clinic visits, your child may be given developmental, physical and neurological tests. Family relations may also be evaluated since how your baby interacts with family members is an important part of his development. Diet changes will be made, if necessary, and any questions you have will be answered.

