

### **Fact #3: Newborn screening is more than a test**

Testing of the newborn screening sample by the State Public Health Laboratory is just one part of the newborn screening process. Every state newborn screening program consists of the following parts:

**Screening** – collection of newborn blood samples and testing to identify infants with potential markers of congenital conditions

**Follow-up** – rapid location and referral of screen-positive infants

**Diagnosis** – medical evaluation and additional testing of screen-positive infants to make a definitive diagnosis or to rule out a disorder

**Management** – rapid planning and implementation of long-term therapy for infants diagnosed with a newborn screening disorder

**Evaluation** – assessment of the previous four activities to identify opportunities for quality improvement and gauge benefits to the patient, family and society

**Education** – education of parents, primary care providers, legislators, newborn screening personnel (laboratory and follow-up staff) and stakeholders

## **Parent stories...**

“On February 27, 2007 our daughter was born. She was a healthy, beautiful, baby girl and we couldn't be happier that she was finally here. We took her home from the hospital and introduced her to our family and friends. Our family had a healthy new member with no complications and we couldn't be happier.

Ten days after bringing our daughter home from the hospital things finally started getting back to normal in our household. Then we received a phone call on that day that the newborn screening test showed a positive result for phenylketonuria (PKU).

We are very thankful for the newborn screening test given to our child when she was born. Without the test we wouldn't have known anything was wrong with her until much later in her life when it would have been too late to help her. Because of the newborn screening test our daughter is reaching all her milestones and is a very intelligent little girl with nothing stopping her from reaching her full potential in life. It's all because of the newborn screening test. I'm sure we can speak for a lot of other families when we say that it was our daughter's savior to a higher quality of life.”

**Parents of a daughter diagnosed with PKU**

