# Fast Facts for Families and Partners about Newborn Metabolic Screening



## What is newborn metabolic screening?

All states screen (test) newborns for serious diseases that can harm newborn babies.

### What is the purpose of newborn metabolic screening?

- Even though a newborn baby may appear to be healthy, a disorder can be present at birth that cannot be seen (has no symptoms).
- *All* newborn babies are screened, so that the babies with these conditions can be found and treated as early as possible.
- If these diseases are not found and treated in the first days of life, they can cause life-threatening illness, *permanent* brain damage, and in some cases, death.
- If newborns with these conditions receive early diagnosis and treatment, they can grow and develop normally, or treatment can prevent or lessen many of their medical problems.

# How is the screening done?

- All babies are screened before they leave the birth hospital, but never later than 72 hours (3 days) old. A few drops of blood are taken from the baby's heel, put on a special form, and sent to the state health department laboratory for testing.
- All babies get a second newborn screening test at 8-14 days of age usually at the first "well-baby check" at the doctor's office. The screen is done a second time because some conditions could be missed if the first specimen was collected too early.
- The screening results are reported to the birth hospital or primary care physician.

# What does a "positive" screen mean?

- The Colorado Department of Public Health and Environment's newborn screening lab performs first and second screens on the 70,000 babies born in Colorado every year.
- Of those 70,000 newborn babies, about 2,000 babies will have a "positive" (abnormal) screen. Of those 2,000 babies, about 100 babies will be diagnosed with a disease.
- These numbers dramatically show that a positive screen *does not mean* that a child has one of these disorders. A "screen" is not a diagnostic test. A "screen" identifies a smaller group of babies that need further testing, to find out if any of the babies in the group have a disease.
- The baby's doctor will be told the results of the positive test and will be responsible to make arrangements with the family for the baby to have additional testing. When you take your baby to the doctor, ask your doctor for the results of the baby's newborn screen.

#### How much does the metabolic screening cost?

- The newborn screening fee is paid by the hospital.
- A one-time fee covers both the first and second screens.
- Hospitals get reimbursed for the fee by private insurance and Medicaid.
- No infant is denied newborn screening because of a family's inability to pay. If a family has no health insurance, the hospital pays for the screening.

## Where can I get more information about metabolic screening?

- The baby's doctor can answer questions about newborn metabolic screening.
- For more information about Colorado's newborn metabolic screening program:
  - o www.nbscolorado.org
  - o the state laboratory web page at <a href="http://www.cdphe.state.co.us/lr/NBS/index.htm">http://www.cdphe.state.co.us/lr/NBS/index.htm</a>.
  - o Laura Taylor, Newborn Metabolic Screening Program, Follow-Up Coordinator (at the telephone numbers provided at the bottom of this page)
- More information about newborn screening in general can be found online at
  - o the March of Dimes http://www.marchofdimes.com/pnhec/pnhec.asp
  - o www.newbornscreening.info

Health Care Program for Children with Special Needs (HCP)
Prevention Services Division ~ Colorado Department of Public Health and Environment