## How will I get the results of the newborn screen?

- Parents will be notified by your baby's primary care provider ***or*** a Newborn Screening Follow-Up team member if results show a possible problem.
- You will be advised on what needs to be done to help your baby. Some babies need additional testing immediately and some testing can wait a few days.
- You should also check with the primary care provider to make sure they have results of your baby's screen.

## Why do babies need to be re-screened?

- In Maryland, all babies are screened two times: in the hospital (24-48 hours after birth) and again in their pediatrician's office (around 10-14 days of age)
- Babies who were screened too early (before eating well for at least 24 hours) must get the first screen again as soon as possible.
- Some babies need to be screened again if the previous screen shows a potential problem.
- Some babies need to be screened again because the previous screen had too much or too little blood.

***If your baby needs more screening, please get it done right away!***

## Will my baby have other screening tests in the hospital?

Your baby will also be screened for:

- hearing loss
- birth defects
- critical congenital heart disease

## Questions?

- Ask your doctor or nurse if you have questions or concerns.
- Call the Newborn Screening Follow-Up Program at **443-681-3916**
- Visit our website: ***phpa.health.maryland.gov/genetics***

MARYLAND
Department of Health

Larry Hogan, Governor

Boyd Rutherford, Lieutenant Governor

Robert R. Neall , Secretary

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Maryland Department of Health

Office for Genetics and People with

Special Health Care Needs

# Newborn Metabolic Screening — Your Baby's First Test.....

**.....it is not just a "PKU" anymore!**

## What do I need to know about Newborn Metabolic Screening?

- Some babies have rare problems that require treatment to stay healthy.
- Babies who are born with these diseases usually seem healthy at birth.
- Most babies do not have a family history of these diseases.
- We screen **all** babies to find the ones who may need treatment.
- If we find problems early, we can help prevent serious problems like an intellectual disability or even death.
- Babies born in Maryland have had newborn metabolic screening since 1965.
- The first screen was for PKU (Phenylketonuria), which is why it is sometimes called the "PKU test".

## What is included in Newborn Metabolic Screening?

Newborn Metabolic Screening includes over 50 possible conditions, including:

- The inability to break down certain proteins or the sugar in breast milk and most formulas
- The inability to use certain fats for energy
- Abnormal hemoglobin or sickle cell disease
- Problems with the thyroid or adrenal glands
- The presence of cystic fibrosis
- The inability to fight infections

***There are a few conditions that are not currently included on the Maryland Newborn Screening Panel. These conditions are rare, but they can cause severe neurological problems or even death. If you want your baby screened for these conditions, your baby's primary care provider can order the additional screening through another laboratory. More information is available at:***

***phpa.health.maryland.gov/genetics***

***Newborn Metabolic Screening saves lives.....***

***one heel at a time!***

## How will my baby be screened?

- Before your baby is screened, a nurse or doctor at the hospital will answer any questions you may have about newborn metabolic screening.
- You have the right to refuse screening. Please think it over carefully. Your baby is depending on you!
- Before you leave the hospital, a few drops of blood will be taken from your baby's heel and put on a special filter paper.
- The filter paper is sent to the Maryland State Newborn Screening Laboratory where the blood is screened for over 50 possible conditions.
- If your baby is not born in a hospital, talk to your baby's primary care provider about newborn metabolic screening.