### What will my baby be screened for?

#### **AMINO ACIDEMIAS**

- Argininosuccinic aciduria (ASA)\*
- Citrullinemia, type 1 (CIT)\*
- Homocystinuria (HCY)\*
- Maple syrup urine disease (MSUD)\*
- Classic phenylketonuria (PKU)\*
- Tyrosinemia, type I (TYR-1) \*

#### ORGANIC ACIDEMIAS

- Glutaric acidemia type I (GA-1)\*
- 3-Hydroxy 3-methylglutaric aciduria (HMG)\*
- Isovaleric acidemia (IVA)\*
- 3-Methylcrotonyl-CoA carboxylase (3-MCC)\*
- Methylmalonic acidemia cobalamin disorders (Cbl-A,B) & methylmalonyl-CoA mutase deficiency (MUT) \*
- βeta-Ketothiolase (βKT)\*
- Propionic acidemia (PROP)\*
- Holocarboxylase synthetase deficiency (MCD) \*

### **ENDOCRINE**

- Congenital adrenal hyperplasia (CAH)\*
- Primary congenital hypothyroidism (CH)\*

\* Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Recommended Uniform Screening Panel - Core Panel

More information continued on next side...

# Dried Blood Spot Screening

looking for?

What is the screen The dried blood spot screening looks for a variety of genetic and inherited disorders. A list can be seen on the insert.

How is the screen done?

A few drops of blood are taken from your baby's heel and put on a special paper. The state public health laboratory then does the

How will I find out the results?

The Newborn Screening Program will notify your baby's health care provider. If there is an abnormal result, you will get a call letting you know the next steps. Ask about your baby's dried blood spot results at your first well child check.

What if my baby does not pass?

Don't panic! If you get a call from your baby's health care provider, it does not always mean your baby has one of these medical conditions. It is important to take your baby for repeat testing as soon as possible.

What happens to the blood after screening?

Left-over blood specimens may be available for additional testing if your baby should need it. It may also be used to ensure quality testing and to improve newborn screening results.

With consent from a parent or legal quardian, the blood specimen may also be used for research purposes. If you do not want your baby's left over blood spots stored after the screening is done, please contact the lowa Department of Public Health at the phone number or address below for assistance.

Contact

Iowa Newborn Screening Programs Bureau of Family Health

Iowa Department of Public Health

321 East 12th Street Des Moines, IA50319 Phone 1-800-383-3826

#### Need help remembering the results?

Use the space below to record your baby's newborn screening results.

<b>Dried Blood Spot</b>	Passed	Not Passed
Follow-up appointment://:::		
Notes:		
Haaring Oansan	Danasid	Not Decemb
Hearing Screen	Passed	Not Passed
Follow-up appointment://:::		
Notes:		
Pulse Oximetry	Passed	Not Passed
Follow-up appointment://:::		
Notes:		

To learn more about newborn screening, visit http://idph.iowa.gov/genetics/public/newborn-screening

Iowa Department of Public Health **Newborn Screening Programs** 1-800-383-3826

Iowa Newborn Bloodspot Screening Follow up Program 1-866-890-5965





Iowa Newborn Screening Program

To order more brochures, call the Healthy Families Line at 1-800-369-2229.

# Iowa Newborn Screening

Newborn screening is a way to identify babies who may have serious medical conditions. These conditions are often treatable, but may not be visible at birth. Early treatment of these conditions can prevent against more serious illness, disability or death. Newborn screening tests include:

- Dried Blood Spot Screening (Genetic or Congenital Disorders)
- Hearing Screening
- Pulse Oximetry Screening (Critical Congenital Heart Disease)

Due to the importance of catching these conditions early, state law requires that newborns receive the screens listed above. If you have questions, please refer to the appropriate contact information.

If your baby does not pass a newborn screen, it is crucial that you follow-up as recommended. Early detection and intervention will result in the best possible outcome for your baby.



# Hearing Screening

What is the screen looking for?

The hearing screen is a quick and effective way to determine if your baby can hear sounds needed to learn language.

How is the screen done?

Hearing screening is safe and will not hurt. It can be done in about 10 minutes. There are two types of screens done for hearing loss depending on the equipment available to the hospital or local audiologist, AABR and OAE. Neither test will make your baby uncomfortable, and they are often done while your baby is asleep.

the results?

How will I find out A health care provider/audiologist will talk with you about the results of your baby's screening. Please make sure you tell your provider the name of your baby's primary care provider so they can send them the results. If your baby passed the hearing screen, you should continue to look for signs of late onset hearing loss.

What if my baby does not pass?

If your baby does not pass or is missed at the birth screen, make sure he or she is screened as soon as possible. Please take your baby back to the birth hospital or audiologist for a hearing screen within two weeks. It is important to find hearing loss quickly, because babies whose hearing loss is not found early may have a hard time learning language. Simply watching your baby startling or responding to sound is not a substitute for a formal hearing screen.

**Contact for** assistance locating providers

Iowa Family Support Network 1-888-425-4371

Iowa Department of Public Health 1-800-383-3826

## Pulse Oximetry Screening

What is the screen looking for?

The pulse oximetry screen looks for low levels of oxygen in the blood that may indicate a problem with the heart or lungs. Critical congenital heart disease occurs when a baby's heart does not develop normally.

How is the screen done?

Pulse oximetry is fast, simple and accurate. It can be used on babies soon after they are born. Hospital nursery staff will do the screening when the baby is at least 24 hours old. A small sensor is placed on the baby's right hand and left foot allowing a connected device to measure the baby's oxygen level.

Your baby's doctor or a nurse will tell you

How will I find out the results?

the results of the pulse oximetry newborn

What if my baby does not pass?

Your baby will not pass if:

-Your baby has a low level of oxygen.

-There is a 3 percent difference between the reading in your baby's hand and foot.

At this point, a complete physical examination will be completed to determine why your baby did not pass the screen. There may be several reasons, including respiratory problems or infections.

Contact

Iowa Department of Public Health 1-800-383-3826

## What will my baby be screened for? (cont.)

#### **FATTY ACID OXIDATION DISORDERS**

- Carnitine uptake defect & Carnitine transport defect (CUD) \*
- Long-chain L-3 hydroxyacyl-CoA dehydrogenase (LCHAD)\*
- Medium chain acyl-CoA dehydrogenase deficiency (MCAD) \*
- Trifunctional protein deficiency (TFP)\*
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD) \*

### **HEMOGLOBINOPATHIES**

- Sickle cell anemia (Hb SS)\*
- Hemoglobin SC disease (Hb SC)\*
- Sickle beta-thalassemia (Hb Sβ)\*

### **OTHER**

- Biotinidase deficiency (BIOT)\*
- Cystic fibrosis (CF)\*
- Classic galactosemia (GALT)\*
- Severe combined immunodeficiencies (SCID)\*

\* Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Recommended Uniform Screening Panel - Core Panel

For more disorder specific information go to:

http://www.shl.uiowa.edu/screening/newborn/disorderslist.xml