# What will my baby be screened for?

#### **AMINO ACIDEMIAS**

- Argininosuccinic aciduria (ASA)\*
- Citrullinemia, type I (CIT)\*
- Homocystinuria (HCY)\*
- Maple syrup urine disease (MSUD)\*
- Classic phenylketonuria (PKU)\*
- Tyrosineemia, 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 deficiency (3-MCC)\*
- Methylmalonic acidemia cobalamin disorders (Cbl-A,B) & methylmalonyl-CoA
- βeta-Ketothiolase deficiency (βKT)\*
   Propionic acidemia (PROP)\*
- Holocarboxylase synthetase deficiency (MCD) \*

#### **ENDOCRINE**

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

More information continued on next side

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

#### What is the screen looking for?

The dried blood spot screening looks for a variety of genetic and congenital 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 testing.

#### 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 by the newborn screening laboratory to ensure quality testing and to improve newborn screening results.

Left-over blood spot specimens are only released to researchers or other health care providers if the parent or guardian has signed a consent directing the newborn screening program to release their baby's specimen.

If you do not want your baby's left over blood spots stored after the screening is done, please contact the lowa Department of Health and Human Services at the phone number or address below for assistance.

Iowa Newborn Screening Programs
Iowa Department of Health and Human Services
321 East 12th Street
Des Moines, IA 50319
Phone 1-833-496-8040

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

Dried Blood Spot	Passed	Not Passed
Follow-up appointment://:::		
Notes:		
Hearing Screen	Passed	Not Passed
Follow-up appointment:/		
Notes:		
Pulse Oximetry	Passed	Not Passed
Follow-up appointment://		::
Notes:		

#### **Contact**

Iowa Department of Health and Human Services Newborn Screening Programs 1-833-496-8040

Iowa Newborn Bloodspot Screening Follow Up Program 1-866-890-5965 or 319-384-5097



Scan our QR code for more information or visit us at hhs.iowa.gov/newborn-screening

To order more brochures, call Iowa HHS at 1-833-496-8040



# **Screening Program**

STATE OF IOWA DEPARTMENT OF Health and Human SERVICES

**Dried Blood Spot Screening** 

### **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
- Congenital Cytomegalovirus (cCMV)
- 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, unless the parent or guardian refuses. 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.

#### How will I find out the results?

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?

1-888-425-4371

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.

For assistance in locating the nearest provider, please contact lowa HHS 1-833-496-8040 lowa Family Support Network

#### **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.

#### How will I find out the results?

Your baby's doctor or a nurse will tell you the results of the pulse oximetry newborn screen.

#### 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.

Iowa HHS 1-833-496-8040

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

## FATTY ACID OXIDATION DISORDERS

- Carnitine uptake defect & Carnitine transport defect (CUD & CTD) \*
- Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency (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)\*

### LYSOMOMAL STORAGE DISORDERS

- Glycogen storage disease type II (Pompe)
- Mucopolysaccharidosis type II (MPS I)

#### OTHER

- Biotinidase deficiency (BIOT)\*
- Cystic fibrosis (CF)\*
- Classic galactosemia (GALT)\*
- Severe combined immunodeficiencies (SCID)\*
- Spinal Muscular Atrophy (SMA)\*
- X-Linked adrenoleukodystrophy (XALD)\*

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<sup>\*</sup> Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC)
Recommended Uniform Screening Panel - Core PanelFor more disorder specific information visit http://
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psalises.est.xmp. |