Utah Department of Health & Human Services

# Utah Newborn Screening

Detect and minimize or prevent common disorders

## About
### Newborn Screening

Newborn Screening identifies conditions that can affect a child's long-term health, development or survival. Early detection, diagnosis, and intervention can prevent death or disability and enable children to reach their full potential.

Every state in the U.S. has a newborn screening program that screens newborns for many treatable congenital conditions. Since the symptoms of these serious conditions do not always appear at birth, early detection is lifesaving.

Utah Newborn Screening screens for more than 40 disorders, as well as screens for hearing loss and critical congenital heart disease (CCHD).

## Types of
### Newborn Screening

#### Bloodspot (Heel stick)

Infants born in Utah have blood collected twice-once at 24-48 hours after birth, and again at the two week child care appointment, between 7-16 days after birth.

Completing both tests is critical to correctly identifying these treatable disorders. Blood is obtained by a small heel prick. The blood is collected on a screening card which is sent to the Utah Department of Health and Human Service's Public Health Laboratory.

#### Hearing Screening

Infants are screened for hearing loss before they are discharged from a hospital after birth. There are two tests that may be used to screen a baby's hearing: Otoacoustic Emissions (OAEs) or Automated Auditory Brainstem Response (AABR). Both of these tests are safe and do not hurt. Newborn hearing screening is very important as undetected hearing loss can affect brain development.

#### CCHD Screening

Critical congenital heart disease (CCHD) refers to a problem with a structure of the heart or the blood flow through the heart. CCHDs can be detected through a quick, safe, and painless test called pulse oximetry. Pulse oximetry measures how much oxygen is in the blood - a low oxygen level is a common sign of CCHD.

# What happens to stored bloodspots?

Newborn bloodspots (NBS) are stored in a secure walk-in freezer separated from identifying demographic information. After 7 years, the sample is destroyed by incineration. Bloodspot cards are kept for these reasons:

- If your child needs more testing in the future for a diagnosed health condition. Your consent will always be requested before doing any tests.
- To improve current testing procedures or develop new tests for other diseases.
- Quality control and assurance
- If you consent to using your child's blood sample for research on newborn screening diagnosis and treatment. Your child's blood sample will never be used for research without your consent.

## Parental consent for bloodspot storage

A consent must be signed by the parent or guardian indicating what they wish the newborn screening program to do with their child's bloodspot sample.

### If you DO consent to retention:

- Newborn screening testing will be completed and the bloodspot cards will be kept in a secure place for up to 7 years.
- You can change your mind at any time. Please contact the Newborn Screening program at 801-584-8256 for details.

### If you DO NOT consent to retention:

- Utah law requires newborn screening testing to be collected and completed.
- Newborn Screening program will keep the sample for 90 days to ensure no further testing is needed and then will destroy the sample. The sample will not be available for any future use to screen late-onset concerns such as congenital cytomegalovirus (cCMV).

## What happens after a newborn is screened?

After the **heel stick**, the baby's health care provider will be called if the test is abnormal. An abnormal result does not mean your baby has a disorder. Additional testing is necessary.

If your baby fails their **hearing screening**, it does not mean there is hearing loss, but further testing is needed and will need to be rescreened before 10 days of age. If your baby fails the second screen, they need to 1) be tested for congenital cytomegalovirus (cCMV) infection before 21 days of age and 2) get a diagnostic hearing evaluation by a pediatric audiologist as soon as possible.

If the **CCHD screening** identifies that your baby has low oxygen, the health care provider will order additional testing. A common test is an ultrasound of the heart, or echocardiogram, to check the structure and blood flow of the heart.

**For more information visit:** familyhealth.utah.gov/newborn-screening