



## For more information:

The Nebraska Newborn Screening Website has more information about the conditions screened in Nebraska's panel, and requirements of the regulations. Go to:

[www.dhhs.ne.gov/publichealth/Pages/nsp](http://www.dhhs.ne.gov/publichealth/Pages/nsp)



Another informative web site with links to reputable information about newborn screening:

[www.babysfirsttest.org](http://www.babysfirsttest.org)

# NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

### Newborn Screening Program

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## ▶ EARLY DISCHARGE AND YOUR BABY'S NEWBORN SCREEN



Tel: 402 471-0374

## Why do I have to get my baby screened before discharge, even if my baby is less than 24 hours old? I understand the testing doesn't give reliable results for everything on the early specimen. So why should we do this heel stick when my baby has to have another one the next day?



Nebraska regulations governing newborn screening require every baby to be screened prior to discharge or transfer from a licensed birthing facility, even if the baby is not yet 24 hours old.

It is true that specimens collected at less than 24 hours of age won't be tested for cystic fibrosis, congenital adrenal hyperplasia or congenital primary hypothyroidism because those tests tend to result in too many inconclusive or false positive results when collected early. Tests for MPS-I, Pompe Disease, and X-ALD also are not reported on early specimens. However the other 26 conditions for which newborn screening is done, are tested on these early specimens. It is especially important for some conditions such as galactosemia, MCAD or other fatty acid oxidation disorders which can be fatal to newborns within days or weeks. (In fact this is an especially good time to catch the fatty acid oxidation disorders because shortly following birth babies are catabolic, a condition under which fatty acid oxidation defects can be most apparent). Therefore it is good to get the specimen, let it dry, ship it and get the testing done as soon as possible. On average, results are available by 4.5 to 5 days of age.



Secondly, the regulation requiring a screen before transfer or discharge was put in place because of the many times we have experienced babies who did not get screened before leaving the birth facility, and then were not screened until much later. Without the early screen before discharge



the newborn screening program cannot help get these babies back in for screening in a timely way because in many cases we don't know about the birth until they are more than 30 days old.

**Signing a waiver promising to return between 24-48 hours is not legal for your health care provider to offer.** Because the regulations require the screen prior to discharge, the waiver does not protect your health care provider from liability. Even if you have the best intentions of returning the next day, unexpected things can and do happen, and avoidable delays can mean the difference between life and death, or a healthy baby vs. a baby with otherwise preventable disabilities.



Newborn screening is done to protect your baby's health. Without the blood test, most of the conditions will not be apparent with symptoms until damage has been done. Even if symptoms do occur, often they are non-specific, so it is difficult to diagnose and the screened conditions are rarely suspected at first. Having the newborn screening results helps ensure rapid diagnosis and treatment to prevent problems.

Ideally every baby would only have to have one heel-stick dried blood spot specimen collected at 24-48 hours of life. However, **if you choose to go home before 24 hours, your baby will have to get a screen before leaving, and you will have to return with your baby between 24-48 hours for the repeat.** (The laboratory does not charge for the required repeat).

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