



Washington State Newborn Screening Frequently Asked Questions

Why is newborn screening done?

Newborn screening tests infants shortly after birth for a number of rare but treatable congenital disorders. If left untreated, these disorders can lead to stunted growth, blindness, brain damage, and sometimes death. Infants with these conditions usually appear normal at birth and, without screening, the disorders are not likely to be detected and treated before causing severe disability or death.

How common are newborn screening disorders?

Each year, about 200 infants born in Washington State are diagnosed with one of the 32 disorders included in the State screening panel and need prompt medical attention to prevent disability or death.

Some parents only want one newborn screen – which one should they do?

The first one – some disorders can be life threatening within the baby's first week of life. The first screen, collected between 18 to 48 hours of age, is critical for early detection and treatment to avoid severe disability or death (it is also the screen required by law).



Why collect a second screen?

The first screen will miss a small number of infants with the conditions, including severe, later-onset, or milder forms of the disorders. This is why a second screen is recommended between 7 to 14 days of age to catch anything not found on the first. If it is uncertain whether an infant has received newborn screening, a screen may be collected up to six months of age.

Who collects newborn screens?

It is the birth hospital or out-of-hospital birth attendant's responsibility to ensure that the initial newborn screening specimen is collected before 48 hours of age, even if they do not collect it themselves. If an infant is transferred to another hospital, NICU, or provider, the transfer facility/provider may collect the specimen.

Most routine second screens are collected at the infant's two-week well-child appointment at their pediatrician's clinic, though many are also collected at a hospital, laboratory, or by a midwife.

(Over)

What if the baby is not with a medical provider during the recommended 18-48 hour collection timeframe?

We recommend the initial screen is collected before the infant is discharged home from the hospital or, for home births, before the birth attendant leaves the family's home, even if this means collection prior to 18 hours of age. This complies with the law and is valuable for early detection of life threatening disorders.

Note: It is not necessary to wait for an infant to feed before collecting the newborn screening specimen.

How is newborn screening paid for?

Newborn screening is fully supported by fees collected for the newborn screening laboratory testing services. The Department of Health bills the facility that collected the infant's initial screen and the facility typically then bills the fee to patient insurance. The fee is one-time and includes all screens a child receives, such as the routine second screen or any repeat screens needed.

The infant's family has no history of these conditions – why do screening?

Since the disorders are so rare, most children who are born with these conditions come from families with no previous history of the disorders.

Can parents refuse screening?

Parents can legally refuse screening if it conflicts with their religious beliefs. Other concerns about newborn screening, such as not wanting to poke the baby, the collection timeframe isn't convenient, not wanting to pay for testing, or privacy concerns are not valid reasons for refusing screening. We ask health care providers help explain to families the risk of refusal and the importance of newborn screening if they have these concerns so their babies can benefit from newborn screening. There are instructions on NBS collection cards on how to legally document when parents refuse testing for religious purposes.

What if a screen is improperly collected or transported?

Improper collection or handling may cause a specimen to be unsuitable. Our laboratory tests all unsuitable specimens, however, the results are considered invalid and a repeat newborn screen is required from the submitting facility or from the infant's follow-up care clinic. If extreme values are found on an unsuitable specimen, the primary care provider will be contacted.

