

Newborn Screening in the NICU: Frequently Asked Questions

Why should NICU babies have screening?

- Newborn screening is important for all babies, including those that appear healthy or those that have been hospitalized for other reasons, because many of the diseases screened for are not apparent at birth.
- Newborn screening allows early detection of these diseases so that treatment can begin before problems occur, and finding these diseases early can prevent serious health problems and even save lives.
- The test requires only a few drops of a baby's blood and is safe for even the smallest or sickest babies.

What tests are done?

- The newborn screening dried blood spot test measures various markers in a baby's blood that can be abnormal in babies who have over 25 rare diseases.
- Screening for critical congenital heart disease uses a light probe wrapped around a hand and foot (pulse oximetry) to measure oxygen levels in the blood.
- Parents/guardians screen for biliary atresia (liver disease) by monitoring their baby's poop colour at home for one month after birth, using an Infant Stool Colour Card given to them after their baby is born.
- The Infant Hearing Program provides hearing screening after hospital discharge. This is performed by measuring the ear or brain's response to soft sounds played in a baby's ear and may use small stickers on the baby's head.

Can parents decline newborn screening?

- Newborn screening is the standard of care for all babies and is highly recommended. Newborn screening is not mandatory in Ontario.
- Any decision to decline testing should first be discussed with a health care provider. The health care provider will document this decision in the baby's medical record and parents will be asked to sign the decline form on the newborn screening card.

How does Newborn Screening Ontario (NSO) ensure that patient health information is secure?

- All personal health information is stored in the baby's record in NSO's electronic information management system which is located at CHEO and is protected by CHEO's secure IT systems: network firewalls, password access, key and swipe card access, and is accessible only to NSO staff on a 'need to know' basis.
- The systems meet all data privacy requirements and laboratory standards.

What happens if the newborn screening test is positive?

- This is a screening test to determine if there is increased risk of having a rare disease, but it is not a diagnosis. If the screen is positive further testing will need to be done to confirm if a disease is present. A member of the health care team will discuss the results of a positive screen with parents and outline what the next steps are.

Every year, about 350 babies in Ontario are born with one of the diseases that newborn screening blood spot testing looks for. About 450 babies are born with critical congenital heart disease. Most of the parents of these babies had no idea their baby could have one of these diseases.

These babies have the chance to live longer, healthier lives because of newborn screening

For more information, please visit the Newborn Screening Ontario website:

newbornscreening.on.ca

