Provider Counselling Aid for **Newborn Screening**

MARITIME
Newborn Screening
Dépistage néonatal
DES MARITIMES

This counselling aid is meant to be used as a guide by healthcare workers providing informed consent to families about newborn screening dried blood spot testing. ***Ideally, this information is given prenatally.*** *For more information, call 1-902-470-2783 to speak with the Maritime Newborn Screening (MNBS) genetic counsellor.*

Points to discuss with the family:

- ✓ **Newborn screening is a routine test recommended for all babies.** It is considered standard of care but not mandatory. A blood sample is collected from a baby's heel when they are 1-2 days old. The blood is put onto a special piece of paper called a "blotter."
- ✓ **Newborn screening tests for severe but *treatable* conditions.** Over 25 conditions are tested on the screening panel (the full list is found on the website below). Newborn screening does not test for all serious medical problems.
  - Examples of tested conditions: sickle cell disease, cystic fibrosis, metabolic conditions affecting how a baby processes food (e.g., Phenylketonuria (PKU)).
- ✓ **Newborn screening can save a baby's life.** The conditions tested can affect health, including irreversible brain damage, or cause death of a newborn if not treated. A baby may look and seem healthy but need treatment. Newborn screening is done so these babies can be identified early and get treatment. This allows the baby to have the healthiest start in life.
- ✓ **All blotters in the Maritimes are sent to the IWK laboratory for testing.** Results are typically available by day 7 of life.
  - Data is stored on secure hospital servers and blotter samples are stored in a secure location for 10 years. Sometimes samples may be used *anonymously* to set up or check the performance of screening tests, as per standard laboratory protocols. Parents can say no to storage and ongoing use of blotters by contacting Maritime Newborn Screening (MNBS).
- ✓ Possible results from newborn screening:
  1. **Screen negative (normal):** Most babies have this result. No follow-up is needed.
  2. **Follow-up sample required**: ~10% of babies have a result that requires another sample to complete the screening. Many reasons including prematurity, sample quality, or biomarkers in borderline ranges can prompt a repeat sample collection. The family will be contacted by the primary care provider or birth hospital to schedule a repeat. It does **not** mean the baby has one of the conditions. Most follow-up samples result as screen normal.
  3. **Screen positive (flagged):** <1% of babies have this result, and it means **clinical follow-up is urgently needed**. It does **not** mean the baby has the condition, but there is an increased chance and more testing is needed. The family will be contacted by a healthcare provider from MNBS with further information and instructions.
  - **MNBS also reports hemoglobin traits, like sickle cell trait, which do not affect health or need treatment.** A baby's healthcare provider/clinic will be informed of this result and provided information to tell the family.

Common questions/concerns:

- ➢ Parents wondering if screening is needed when older children screened normal and/or there is no family history of the conditions.
  - ○ ***Response****: Yes, screening is still recommended for all babies. A baby can have a condition on newborn screening even if the siblings don't, or if there is no family history of the condition. Rationale: most but not all conditions on the newborn screen are genetic; most genetic conditions on the screen are recessive; new conditions are added over time.*
- ➢ Parents worried about pain for baby, taking blood from baby.
  - ○ ***Response****: We only offer tests to babies that we think are necessary/have a benefit. There are well-researched strategies to reduce pain during sample collection: skin-to-skin, breastfeeding, small amounts of sugar water.*
- ➢ Cost of the screening test.
  - ○ ***Response****: The newborn screening test is free for all babies born in the Maritimes, regardless of the health coverage of the parents.*

*** ***If a family is considering declining newborn screening for their baby****, explore the reasons why and if there is additional information you could give that would make them comfortable with having this screening test done*. ***They must understand that they are declining a test that can prevent death and serious illness****.* ***

More information for families:

- ❖ Website: www.maritimenewbornscreening.ca
- ❖ Call 1-902-470-2783 to speak with the Maritime Newborn Screening genetic counsellor