

## NEWBORN SCREENING HEALTH CARE PROVIDER TIP SHEET: PARENT NOTIFICATION OF DRIED BLOOD SPOT (DBS) SCREEN AND DISCLOSURE OF POSITIVE RESULTS

### **Bedside health care provider to discuss with parents prior to DBS screening:**

- Newborn Screening Ontario (NSO) administers a screening program to test for over 25 rare but serious and treatable diseases in all babies who are born in Ontario.
- Babies who have these diseases usually seem well at birth, and best outcomes are achieved if they are detected and treated before symptoms develop.
- We will place a few drops of blood from a heel prick onto a filter paper and send this to the NSO lab at CHEO for testing. This small amount of blood is safe even for small babies.
- The sample is kept at NSO for further testing if your baby develops health problems later in childhood and to help with quality assurance of the program. If you want your sample returned or destroyed after the testing is done, you can request this as well.
- These screening tests are the standard of care for all babies born in Ontario, however you can opt out of these tests if you choose.
- More information about the program can be found on the NSO website at <https://www.newbornscreening.on.ca>

### **Physician or midwife to discuss with parents of a baby with a positive screen result:**

- Positive screen results need to be disclosed to parents by the most responsible physician or midwife who is caring for the baby.
- Parents should be reminded that a positive screening result is not a diagnosis; it is an indicator that the baby may be at a higher risk for having the disorder being tested for.
- A discussion with the family should include a brief description of what the condition is, an outline of the instructions provided by NSO about confirmatory testing that needs to be done, and reassurance of the baby's stability and plans for closely watching the baby for the development of any signs of disease while the testing is being conducted.
- If the physician or midwife is unsure about how to disclose the information, they can find more information about conditions screened on the NSO website at <https://www.newbornscreening.on.ca>

