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

### **NICU bedside RN team 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.
- At 24h of age we will place a few drops of blood from a heel prick (or from the central line) onto a filter paper and send this to the NSO lab at CHEO for testing. This small amount of blood is safe even for the smallest or sickest babies.
- This screening test is the standard of care for all babies born in Ontario, however you can opt out of this test if you choose.
- 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.
- More information about the program can be found on the NSO website at <https://www.newbornscreening.on.ca>

### **Regional Treatment Centre, NICU MD, or delegate to discuss with parents of a baby with a positive screen result:**

- NSO refers screen positive infants to a Regional Treatment Centre (RTC) whose staff are responsible for retrieval of the infant, which includes disclosure of results and coordination of diagnostic testing. While positive screen results are disclosed to parents primarily by Regional Treatment Centre staff, under certain circumstances (e.g. infant still admitted) they may ask the responsible physician or delegate on the NICU team to disclose results to the family and/or coordinate the follow-up testing required under their guidance.
- Parents should be reminded that a positive screening result is not a diagnosis; it is an indicator that the baby is at a higher risk for having the disorder being tested for.
- A discussion with the family should include a brief description of what the disease is, an outline of next steps, 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 health care team member is unsure about how to disclose the information, they should contact the RTC for support, and review the positive screen information with the attending neonatologist prior to meeting with the parents.
- More information about conditions screened, including information sheets for families, can be found on [the NSO website](#).