#### **INFORMATION FOR PARENTS/GUARDIANS:**

# My Baby was Born at Less Than 33 weeks Gestation and/or Weighing Less Than 1500 grams and Needs a Repeat Newborn Screen

#### What is Newborn Screening?

These are routine tests done shortly after birth on every baby born in Ontario. A small sample of blood is taken from your baby and is tested for 29 rare treatable diseases.

### Why do significantly premature and very low birth weight babies need repeat newborn screening?

Babies born before 33 weeks gestational age and/or who have a very low birth weight (less than 1500 grams) may have inaccurate newborn screening results on their first sample and require a repeat newborn screening sample at 3 weeks of age.

# What does it mean if my baby already had a normal newborn screening result?

Testing for most diseases is accurate even if your baby is premature and/or very low birth weight. However, significant prematurity and/or very low birth weight can affect newborn screening results for Congenital Hypothyroidism (CH) and Severe Combined Immune Deficiencies (SCID). To accurately screen your baby for these diseases, he or she needs a repeat newborn screen.

# What is Congenital Hypothyroidism (CH)?

CH is a condition that occurs when a baby does not make enough thyroid hormone. Normal amounts of thyroid hormone are important for normal growth and development of the body and the brain.

#### What is Severe Combined Immune Deficiency (SCID)?

Severe Combined Immune Deficiency is a disease that causes the immune system to not work well. The role of the immune system is to fight off infections. Children with SCID are at risk of getting serious infections.

## When should my baby have a repeat newborn screen performed?

Three weeks of age is the best time for the repeat newborn screen. If your baby is discharged from hospital prior to three weeks of age a repeat sample may be taken at the time of discharge, or you may be asked to return to the hospital for a repeat newborn screen.

#### Who should arrange the repeat newborn screen for my baby?

The hospital where your baby is admitted or your baby's primary health care provider (e.g. doctor, midwife) should organize a repeat newborn screen for your baby.

# Where can I get more information?

For more information on newborn screening, please visit the Parents section of the Newborn Screening Ontario website at <a href="https://www.newbornscreening.on.ca">www.newbornscreening.on.ca</a> or talk to your health care provider.

NOTE TO PARENTS/GUARDIANS: This information is only for parents whose baby is less than 33 weeks gestational age and/or less than 1500 grams. This fact sheet is for information purposes only and should not replace professional medical advice, diagnosis or treatment.

