INFORMATION FOR PARENTS/GUARDIANS:
Should I Learn if My Child is a Carrier of a Hemoglobin Disease (such as Sickle Cell Disease)?

In Ontario, newborn screening tests for Sickle Cell Disease. Screening may also find babies who are carriers of Sickle Cell Disease and some other hemoglobin diseases.

Carriers of a hemoglobin disease are **not** more likely to get sick than any other child. Learning your child's carrier status is optional. Your child's hemoglobin disease carrier status is not part of your child's main newborn screening report.

You may, or may not, wish to learn if your child is a carrier of a hemoglobin disease from newborn screening. The purpose of this brochure is to help you decide if you want these results. You can also talk with your child's health care provider before making a decision.

What is a hemoglobin disease (also called a hemoglobinopathy)?
Hemoglobin diseases are a group of conditions that affect the hemoglobin in the red blood cells. Hemoglobin carries oxygen around the body. When a person has a hemoglobin disease, their red blood cells do not work properly. This can cause problems including pain, serious infections and anemia (a lower number of red blood cells). Many hemoglobin diseases require life long treatment.

How does someone get a hemoglobin disease?
Anyone can have a hemoglobin disease but it is more common in people from Africa, the Mediterranean, Caribbean, Middle East, South East Asia, Western Pacific Region, South America, and Central America.

Hemoglobin diseases are genetic and are caused by a problem with the hemoglobin gene. Genes are the instructions that tell our bodies how to grow and develop. Most people have two normal copies of the hemoglobin gene - one from their mother and one from their father.

A person with a hemoglobin disease has two hemoglobin genes that do not work properly, one from each parent. The type of hemoglobin disease a person has depends on the type of hemoglobin genes they inherit. For a couple to have a child with a hemoglobin disease, both parents must be carriers.

What is a "carrier" of a hemoglobin disease?
A carrier has one normal copy of the hemoglobin gene and one copy of the gene that does not work properly. *A carrier does not have and will not develop a hemoglobin disease.*

REASONS YOU MAY NOT WANT TO KNOW YOUR CHILD'S HEMOGLOBIN DISEASE CARRIER RESULT FROM NEWBORN SCREENING:

1. Learning this result is not urgent.
   - Carriers of hemoglobin diseases usually do not have any health problems in childhood. Some parents wait until their child is old enough to make their own decision whether to learn their carrier results.

2. Increased worry.
   - Some parents say that learning their child was a carrier made them worry about their child's health or treat their child differently, even though their child did not have a higher chance to have any health problems.

3. Carriers of certain hemoglobin diseases (for example, thalassemia) are **not** detected on the newborn screen.
   - Only carriers of Sickle Cell Disease, Hemoglobin C, Hemoglobin D, and Hemoglobin E are detected.

4. It is not necessary to learn your child's carrier result if you want to know your **own** carrier status.
   - You and/or your partner may be a carrier of a hemoglobin disease even if you child is not. If you/your partner are from a part of the world where hemoglobin diseases are

415 Smyth Road
Ottawa Ontario K1H 8M8
Toll-free: 1877-NBS-8330 / Local: (613)738-3222
www.newbornscreening.on.ca @NBS_Ontario

more common, speak with your health care provider about carrier testing.

5. There are other ways to find out your child's carrier status besides the newborn screen.
   - A blood test to find out if a child is a carrier of a hemoglobinopathy can be performed at any age by their health care provider.

6. Non-paternity.
   - If a child is found to be a carrier, the parents are usually offered carrier testing to determine if either of them are also carriers. This testing could indicate that the person thought to be the child's father, is not actually the biological father.

REASONS YOU MAY WANT TO KNOW YOUR CHILD'S HEMOGLOBIN DISEASE CARRIER RESULT FROM NEWBORN SCREENING:

1. Your future pregnancies
   - If a child is a carrier, it is almost certain that at least one of the parents is also a carrier. More rarely, both parents could be carriers. If both parents are carriers, there is a 1 in 4 (25%) chance in each future pregnancy that they could have a baby with a hemoglobin disease. Most carriers do not experience any health problems.

2. Your child's future children
   - Some parents choose to learn their child's carrier result so that they can tell their child this information in the future when he or she is planning their own family.

3. Informing other family members
   - If a child is a carrier of a hemoglobin disease, it means that other family members (i.e. brothers, sisters, aunts, uncles, cousins) may also be carriers. There is also a small chance they could have a hemoglobin disease.

4. Health issues for your child
   - Most carriers of a hemoglobin disease do not experience any health problems related to being a carrier. Rarely, carriers can experience health issues, most that are minor. For additional details, see our website.

How do I obtain my child's carrier results?
Contact Newborn Screening Ontario (NSO) to request these results. Request forms are available online at www.newbornscreening.on.ca. Completed forms can be sent to NSO:

- By fax: 613-738-0853
- By email: NewbornScreening@cheo.on.ca
- By mail: Newborn Screening Ontario
  415 Smyth Road,
  Ottawa, ON
  K1H 8M8

You can also call NSO at 1-877-NBS-8330 (1-877-627-8330) to request these results.

Carrier results will be sent to your child's health care provider (HCP) or a NSO health care professional if your child does not have a HCP.

Where can I get more information?
For information on newborn screening and carrier screening for hemoglobin diseases, please visit the Parent section of our website at www.newbornscreening.on.ca or talk to your health care provider.

NOTE TO PARENTS/GUARDIANS: This information was written for information purposes only. The fact sheet should not replace professional medical advice, diagnosis or treatment.

Version: May 2015