

Information for Parents/Guardians

Should I learn if my child is a carrier of a hemoglobin 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. A carrier does not have, and will not develop, a hemoglobin disease.

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 but can be requested from Newborn Screening Ontario (NSO). **Starting in October 2026**, carrier status for certain hemoglobin diseases (HbAS, HbAC, HbAD) will be offered to families by NSO.

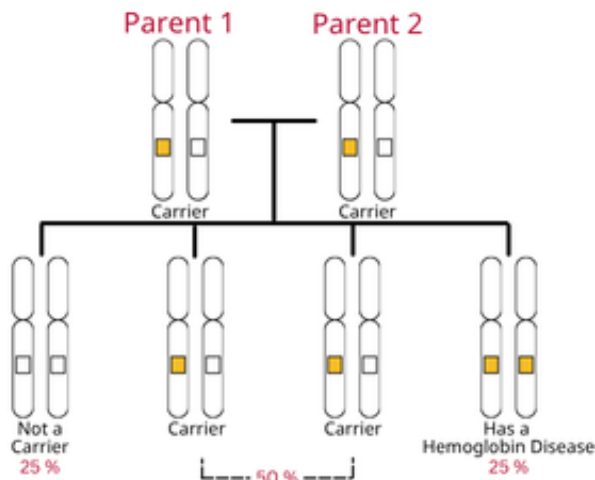
You may or may not wish to learn if your child is a carrier of a hemoglobin disease from newborn screening. **The purpose of the following information is to help you decide if you want your child's carrier results.** You can also talk with your child's health care provider before deciding.

What is a Hemoglobin Disease?

Hemoglobin diseases are a group of conditions that affect the hemoglobin in 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).

Some hemoglobin diseases require lifelong treatment.



How Does Someone Inherit a Hemoglobin Disease?

Anyone can inherit a hemoglobin disease. They are genetic and caused by problems in genes encoding hemoglobin.

- Genes are the instructions that tell our bodies how to grow and develop.
- Most people have **two copies** of the hemoglobin gene - one from each parent.
- A person with a hemoglobin disease has **two copies of the hemoglobin gene that do not work properly**. The type of hemoglobin disease a person has depends on the type of issue their hemoglobin genes have.
- For a couple to have a child with a hemoglobin disease, **both parents must be carriers of a hemoglobin disease**.

What is a "Carrier" of Hemoglobin Disease?

Being a carrier of a sickle cell disease is the same as having a sickle cell disease trait. This is an inherited genetic difference, where one copy of the hemoglobin gene is different and the other is not.

Someone with sickle cell trait makes both working cells and sickle cells, the normal cells carry enough oxygen to stop the sickle cells from changing shape. This is why people with sickle cell trait tend not to experience adverse symptoms in their daily life.

Passing Down Traits:

- Everyone has two copies of each gene.
- Each parent passes on one copy of each gene to their children.
- The child will have one copy of each gene from both of their parents.
- Each gene has a 50% chance of being passed on.

Learning your child's carrier status

Reasons for Learning Your Child's Carrier Results

Your future pregnancies

If a child is a carrier, it is almost certain that at least one of their 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. Knowing the carrier status in one child can help you plan.

Passing this information to your child

Some parents choose to learn their child's carrier result so that they can tell their child this information in the future.

Informing other family members

If a child is a carrier, it means that other family members (i.e. brothers, sisters, aunts, uncles, cousins) may also be carriers. Learning your child's carrier status may provide information to other relatives.

Obtaining Carrier Results

Carrier results from the newborn screen can be requested at any time by contacting NSO. Request forms are available online at www.newbornscreening.on.ca/sickle

Starting in 2027, carrier results for sickle cell disease (AS, AC, and AD) will be proactively offered to parents of screened infants.

Completed forms can be submitted online or sent to NSO using the email, fax, or mailing address at the bottom of this page.

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

If you have any questions, please contact NSO at newbornscreening@cheo.on.ca or 613-738-3222.

Reasons for Not Learning Your Child's Carrier Results

Learning this result is not urgent

A carrier does not have, and will not develop, a hemoglobin disease. Knowing your child's carrier status will not impact the medical care they receive. Because of this, some parents choose to wait until their child is old enough to make their own decision about receiving their carrier results.

Increased worry

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

Carriers of some hemoglobin diseases (for example, thalassemia) are not detected on the newborn screen

Not all forms of hemoglobin disease are detected by the newborn screen. Therefore, carrier results are not guaranteed to be comprehensive for all types of hemoglobin diseases.

It is not necessary to learn your child's carrier result if you want to know your own carrier status

A parent may be a carrier of a hemoglobin disease even if your child is not. If a parent is from a part of the world where hemoglobin diseases are more common, speak with your health care provider about OHIP-funded carrier testing. These regions include, but are not limited to, Africa, the Mediterranean basin, Western Asia and Southeast Asia.

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 hemoglobin disease can be performed at any age by their health care provider.

NOTE TO PARENTS/GUARDIANS:

This factsheet is provided for information purposes only. The fact sheet should not replace professional medical advice, diagnosis, or treatment.