

INFORMATION FOR PARENTS/GUARDIANS: My Baby Has a Positive Sickle Cell Disease Newborn Screening Result

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 rare treatable diseases, including sickle cell disease.

What does it mean if my baby has a positive sickle cell disease newborn screening result?

This result means that your baby likely has sickle cell disease but more testing is needed to confirm the diagnosis and type of sickle cell disease. Babies with sickle cell disease can be healthier if treatment begins early, so it is important to have follow-up testing done to find out if your baby truly has sickle cell disease.

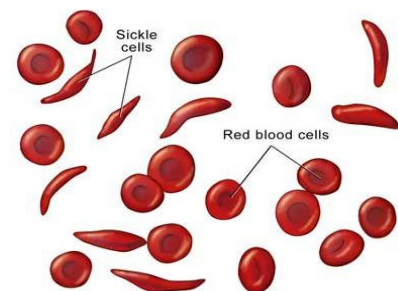
You may feel concerned or worried about your baby's screen positive result. Many parents in this situation feel this way.

What is sickle cell disease?

Sickle cell disease is an inherited (genetic) disease that affects the hemoglobin in the red blood cells. Hemoglobin is the protein in the red blood cell that carries oxygen to every part of the body.

Sickle cell disease causes red blood cells to "sickle" (change from a normal doughnut shape to a crescent moon shape). Sickled red blood cells can block blood vessels. This is called a sickling crisis. It can cause severe pain, damage to tissue and organs and stroke. If untreated, children with sickle cell disease are more likely to get serious infections and often have problems growing normally.

Anyone can have sickle cell disease but sickle cell disease happens more often in the African, Mediterranean, Middle Eastern and Asian communities. In some parts of the world, 1 in every 400 babies born will have sickle cell disease.



How do I find out if my baby has sickle cell disease?

Blood tests are done to find out if a baby actually has sickle cell disease.

When can my baby have these tests?

Your baby's doctor or a health care professional at a Newborn Screening Treatment Centre will call you to talk about the results of your baby's positive newborn screen and make arrangements for the follow up testing to happen as soon as possible.

Why screen for sickle cell disease?

Screening means that babies with sickle cell disease can be treated early to reduce the chance of serious infections (for example, with preventative antibiotics and urgent medical care if the baby has a fever) and parents can learn how to deal with the symptoms of a sickling crisis. Medications or therapies to help with pain can also be given when needed.

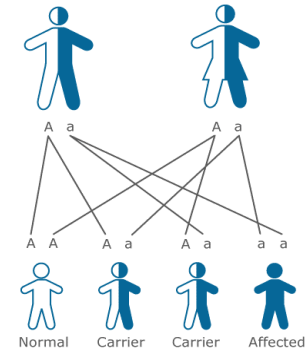
Sickle cell disease health problems can range from mild in some people to serious in others. The goal of screening is to help people with all types of sickle cell disease live healthier lives.

How does a baby get sickle cell disease?



Sickle cell disease is an inherited (genetic) disease that causes hemoglobin to be abnormal. Hemoglobin is made up of 4 building blocks, two alpha(α)-globin chains and two beta(β)-globin chains.

A baby with sickle cell disease inherited two copies of the β -globin gene that do not work properly, one from each parent (each parent is a "carrier" of sickle cell anemia or has sickle cell trait). The parents may not be aware that they are sickle cell carriers, or have sickle cell trait, because sickle cell carriers do not have, and **will not develop**, sickle cell disease.



Where can I get more information?

For more information on newborn screening, please visit the Parents section of our website at www.newbornscreening.on.ca or talk to your local health care provider.

For more information on sickle cell disease, please visit the Sickle Cell Association of Ontario website at www.sicklecellontario.com or call 416-789-2855, visit the Sickle Cell Disease Association of Canada's website at www.sicklecelldisease.ca, visit the Sickle Cell Awareness Group of Ontario Group's website at www.sicklecellanemia.ca, or visit the Your Genes, Your Health website at <http://www.ygyh.org>

NOTE TO PARENTS/GUARDIANS: This information is only for parents whose baby has had a positive newborn screening result for sickle cell disease. Please remember that this fact sheet was written for information purposes only. The fact sheet should not replace professional medical advice, diagnosis or treatment.