

## Information Sheet on the Haemoglobinopathy Test

### What are haemoglobinopathies?

Haemoglobinopathies are genetic disorders that affect the red pigment (haemoglobin) in the body's red blood cells. The most common of these disorders are thalassaemia and sickle cell disease. Roughly 7% of the world's population are carriers of a genetic change in the haemoglobin genes, according to the WHO. Haemoglobinopathies can be transmitted from the donor to the patient through a blood stem cell transplant.

### Types of haemoglobinopathies

#### Affected individuals (homozygous expression)

- The genetic changes are present on both chromosomes (maternal and paternal).
- The disease requires regular medical care.

#### Carriers (heterozygous expression)

- The genetic changes are present on only one of the two chromosomes.
- Carriers are usually healthy, but can pass the anomaly on to their children who may develop the disease, especially if the other parent is also a carrier.

### Haemoglobinopathy test

This test screens for genetic changes in the haemoglobin genes and is carried out to prevent disease from being transmitted through a blood stem cell transplant.

#### When is the test performed?

- Only if the cord blood is requested for a transplant.
- Samples for the test are collected at the time of donation and may not be examined until years later.

#### How much does the test cost?

The test is free of charge for you.

### Results of the haemoglobinopathy test

#### Children under the age of 14

- Affected individuals (homozygous expression): The parents are informed as this condition affects the child's health.
- Carriers (heterozygous expression): Parents may decide whether they want to be informed that their child is a carrier.

**Teenagers aged 14 and over:** decide for themselves whether they want to know the test results.

#### Why this distinction based on age?

The age of 14 was chosen because we assume that most children of this age are capable of making their own decisions.

**Note:** The cord blood bank will contact you after the sample has been tested. **Please ensure that your contact details held by the cord blood bank are up to date.** The test might not be carried out until years after the donation.

If your child was born in Aarau, Basel or Bern, please contact:

  	<p><b>Cord Blood Bank Basel</b> Universitätsspital Basel Petersgraben 4 4031 Basel E-Mail: <a href="mailto:cbb@usb.ch">cbb@usb.ch</a></p>	 <p><a href="http://usb.ch/cbb">usb.ch/cbb</a></p>
---	---	---

If your child was born in Geneva, please contact:

  	<p><b>Banque de Sang foeto-placentaire de Genève</b> Hôpitaux Universitaires Genève Rue Gabrielle- Perret- Gentil 4 1211 Genève 14 E-Mail: <a href="mailto:hematopoiese.laboratoire@hug.ch">hematopoiese.laboratoire@hug.ch</a></p>
---	---

### Advice on test results

You and your child have the right to seek advice from a medical professional before or after the test results are announced. This consultation will not cost you anything.

### What if I do not want a haemoglobinopathy test to be carried out?

Cord blood donation is unfortunately only possible if you consent to the haemoglobinopathy test.