

People from countries that are or have been infested by malaria have an increased chance of being carriers of hereditary anemia. This is because carriers of hereditary anemia are better protected from the lethal consequences of malaria tropica.

The carrier status of hereditary anemia is not a disease. Carriers may eventually suffer of a slight anemia but generally without medical complaints.

The Netherlands and other countries of Northern Europe are home to many people that originate or have parents or grandparents coming from Mediterranean, African, or Asian countries. Many Dutch citizens also have ancestors that originate from these areas because of colonial heritage.

These people have a higher chance of being a healthy carrier of hereditary anemia such as thalassemia or sickle cell disease. Healthy carriers do not have and will not develop the disease, but they may transmit the trait to their children.

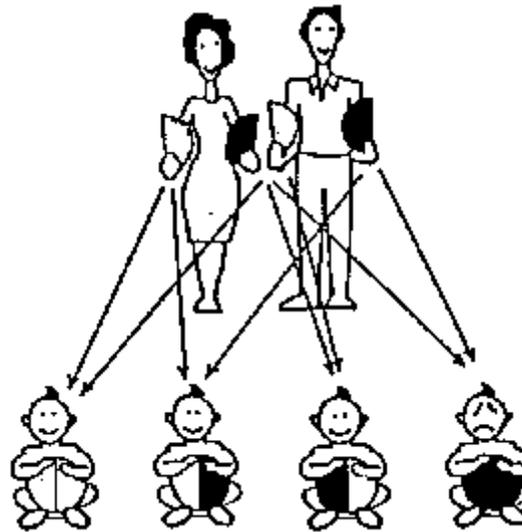
On average 1 of 20 people worldwide is a healthy carrier of hereditary anemia.

Average carrier rate of hereditary anemia in The Netherlands:

- About 1 of 1300 people of Northern-European origin.
- About 1 of 30 people with ancestors from countries (formally) infested by malaria.
- About 1 of 15 people from the 1st, 2nd, and 3rd generation of the people that have recently immigrated from Mediterranean countries (Turkey, Morocco, Italy, Greece etc.) Africa, Middle- and Far East (China,

India, Indonesia, Southeast-Asia) and the Caribbean area (Surinam, Curaçao etc.).

Although being carrier of hereditary anemia is not a disease there are still three important reasons why this person should know whether he or she is a carrier.



- Anemic patients are often treated with iron, but carriers of hereditary anemia usually have sufficient iron and do not need this treatment which, if prolonged, may be deleterious.
- Tiredness is often a complaint of anemic patients. Carriers of hereditary anemia may suffer tiredness because of a low hemoglobin level induced not by lack of iron but of Folic Acid, a vitamin needed to build up red blood cells.
- The third and most important reason is related to the risk of severe and incurable anemia in the children of parents who are both healthy carriers of hereditary anemia.

Blood analyses: you may establish whether you are a carrier of hereditary anemia by a simple laboratory analysis. You may ask for an analysis from your physician, and all that is needed is a small sample of your blood.

It is very important not to worry about hereditary anemia and to understand that being carriers of hereditary anemia is not a disease.

Carriers of hereditary anemia are not and do not get ill because of their trait. For them the important points are to avoid unnecessary iron treatment, to cure eventual complains of fatigue with folic acid (if needed), and above all, to establish if they are forming with their partner a couple at risk for severe hereditary anemia before having children.

You will form a couple at risk only if you and your partner are both carriers of hereditary anemia. If only one parent is a carrier, there is no risk for severe hereditary anemia in the children. Thus, if you are a carrier and you wish to have children, it is very important to know whether your partner is also a carrier.

Partners who are both carriers (couple at risk) may also have healthy children but with each pregnancy there is a risk of 1 in 4 to have a baby severely affected with thalassemia major or sickle cell disease.

For couples at risk that wish to have children, it is possible to prevent the birth of severely affected babies by different means, most likely by prenatal diagnosis.

If you live in The Netherlands and you wish to receive more information you may ask your physician or specialist to allow analysis of your blood or to refer you to one of the following Genetic Centers:

Amsterdam (AMC 020-5665281)
Amsterdam (VU 020-4440150)
Groningen (050-3632929)
Leiden (071-5266090)
Maastricht (043-3875855)
Nijmegen (024-3613946)
Rotterdam (010-4636915)
Utrecht (030-2503800)

Blood analyses:

The laboratories of the large hospitals in The Netherlands can establish whether you are a carrier of hereditary anemia. Otherwise they may refer you for analysis to one of the specialized laboratories.

The reference lab for research and diagnosis of hereditary anemia in The Netherlands is:

Het Hemoglobinopathieën Laboratorium,
Department of Human en Clinical Genetics at
Leiden University Medical Center. (Tel.: +31(0) 71
5269800)

Prenatal diagnoses are done at the DNA
Diagnostiek Laboratorium in the same department
(tel.: 071 5269800).



Erfelijke Bloedarmoede Is onderzoek bij u zinvol ?

Hereditary anemia

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Should you be checked for

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This information leaflet is provided by the:
Hemoglobinopathy Laboratory
Dept. of Human and Clinical Genetics at Leiden
University Medical Center
<http://www.hbpinfo.com>
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Engels