Having children when the parents are blood relatives

- When parents are blood relatives, there is a higher risk of disease and birth defects, stillbirths, infant mortality and a shorter life expectancy;
- Information about heredity and the risk of disease and birth defects

Helsedirektoratet

The vast majority of children born in Norway are healthy, but each year, some children are born with serious diseases or birth defects. The closer the kinship between the parents, the higher the risk. If parents are blood relatives, for example, first cousins, the risk of having children with diseases and birth defects is twice as high as when the parents are not related. The risk is also higher if there are many marriages between blood relatives in the family, so that the man and the woman are related to each other in several ways.

Close kinship between parents also increases the risk of stillbirths (death in mother's womb after the 20th week of pregnancy) and infant mortality (death in the first year of life), and shortens life expectancy (death at all ages up to adulthood).

There are many reasons why children are born with diseases and birth defects. In some cases, the reasons are in the genes we inherit from our parents. We all carry genetic defects that can lead to diseases in ourselves or in our children. Usually this does not happen because we have two copies of every gene. If the one fails to work because of a defect, the other can usually do the job. Both the mother and the father can have one or more genes that can lead to a disease without being ill themselves, and without any of their children being ill. For their children to get the disease, they have to inherit a defect in the same gene from both parents. The risk that the mother and the father both have the same genetic defect and that it will result in disease is usually small, but it increases when parents are blood relatives. This is because both may have inherited the same genetic defect from their common ancestors.

WHAT CONDITIONS ARE WE TALKING ABOUT?

Not all diseases and abnormalities are inherited. However, research indicates that the risk of having a child with birth defects and certain hereditary diseases increases if parents are close relatives. Conditions inherited due to kinship are often serious. Such conditions include metabolic diseases, skin diseases and blood diseases, physical and mental development problems, as well as problems with hearing and/or vision. These conditions often entail a high risk of repetition, that is, several children in the same family can inherit the disease. When mother and father have a defect in the same gene, there is a 25 per cent chance that their offspring will be born with that particular disease or deformity. The risk is the same for each pregnancy. Some conditions can lead to stillbirths, infant mortality and a shorter life expectancy. Close kinship between parents also increases the risk of other birth defects, although it is not known why.
It is nonetheless important to bear in mind that the overall risk of having children with severe congenital (inherited) conditions is small.

WHAT CAN YOU DO?

If you are blood relatives and you have had one or more children with a debilitating disease or birth defect, or if you know of someone in your family who has such problems, you will be offered genetic counselling before any (new) pregnancy. You can also receive genetic counselling if you are planning to have a child and wonder whether you have an increased risk of having children with hereditary diseases or congenital birth defects. Your family doctor can refer you to genetic counselling, which is offered at the largest hospitals in Norway.

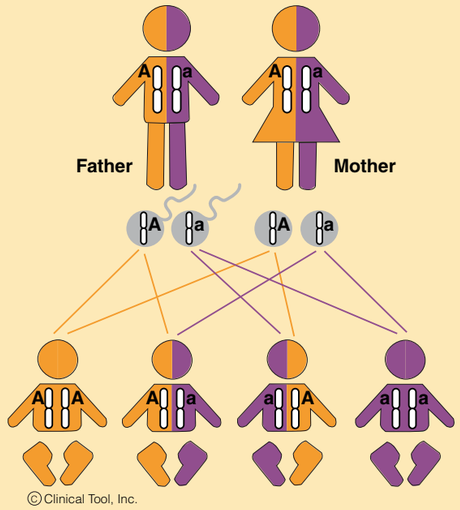
WHAT IS GENETIC COUNSELLING?

Genetic counselling involves a consultation with a health care professional who explains how diseases are passed down from parents to children and why the risk of having children with different diseases increases when parents are blood relatives. Genetic counsellors can also give parents information about what genetic work-ups entail, and what the work-ups can and cannot identify.

A TINY DOSE OF THEORY

The body is made up of cells. The cells contain genetic material (DNA) that is passed on from parents to children. DNA consists of thousands of different genes. Genes help decide how the body works. People inherit one set of all the genes from their mother and one set from their father. Since they have mutual ancestors, relatives have many genes that are identical.

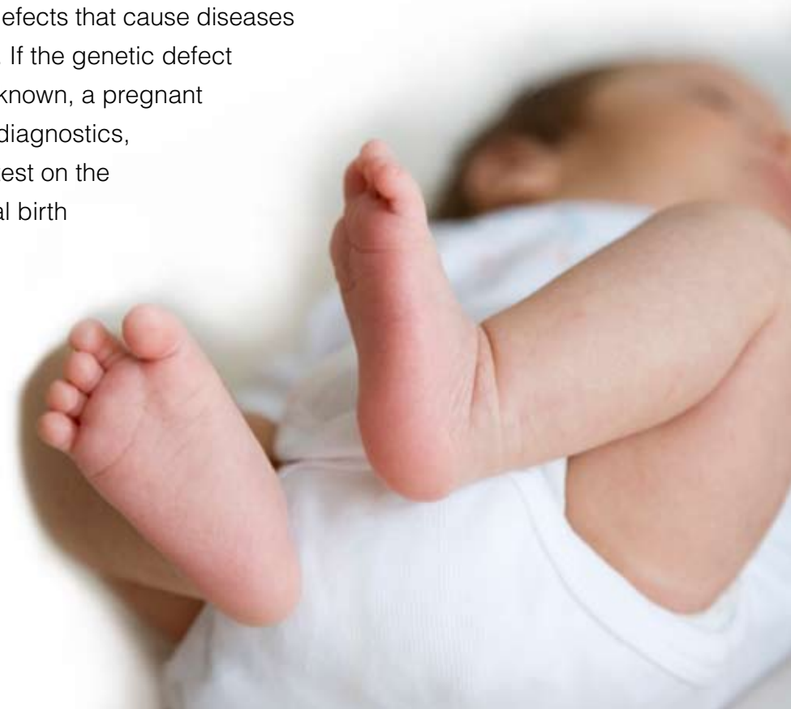
This drawing shows how genes are transferred from parents to children. In this case, the mother and the father have a defect in the same gene. The gene defect may result in a disease, but since a parent has one gene without defect A and one with defect a, he or she is healthy. These genes can be transferred from parents to children in four different ways. A child who has the combination A-A has not inherited the genetic defect, and will not get the disease. The two children who have the combination A-a and a-A have inherited the genetic defect from one of their parents. The children are healthy, but like their mother and father, they have a genetic defect that they can pass on to their children. A child with the combination a-a has inherited a genetic defect from both parents, meaning this child will get the disease. The child can be born with the disease or develop it later in life.



A consultation does not imply any commitment and does not necessarily involve examinations or tests. During the consultation, the counsellor will ask about the family's medical history. An evaluation can then be made to determine the risk of giving birth to a child with a disease. During the consultation, you can also discuss what you can do if you have a child/are expecting a child with a hereditary disease, whether the disease can be treated and who might be able to help the child and the family. Genetic counselling also includes information about the possibilities for screening and examinations for the man, the woman, the foetus, and any children and other family members.

SCREENING AND EXAMINATIONS

If the genetic defect that results in disease in the family is known, a gene test can determine whether or not an individual carries the defective gene. Even if there are cases of the disease in the family, the gene defects that cause diseases or birth defects are not always known. If the genetic defect that causes a disease in the family is known, a pregnant woman can be offered genetic foetal diagnostics, for example by performing a genetic test on the placenta. If there is a risk of congenital birth defects, special ultrasound techniques can be used to examine the foetus. The possibilities for screening and examining foetuses, children and adults will be discussed during the genetic counselling session. Gene tests are only offered if there is a known disease in the family.



PRACTICAL INFORMATION

A list of **family doctors** is available from NAV Helsetjeneste-forvaltning, telephone 810 59 500 or on the Internet: www.nav.no.

Pregnant women can get **pre-natal check-ups** with a midwife, at a public health centre or from their family doctor. All pre-natal check-ups organised by the municipality are free of charge.

Travel expenses in connection with pre-natal check-ups, genetic counselling or other examinations and treatment can be covered under the regulations laid down in the Act relating to Patients' Rights. For more detailed information, see: www.pasienttransport.no

The doctor or health care personnel will arrange for an **interpreter** if they feel it is necessary and/or you would like one. The municipality or the hospital will cover the cost of an interpreter.

For more information about the **rights** of parents who have children with disabilities, please check with the Social Services office at the hospital, public health centre or the local NAV office. Information is also available from Norwegian Federation of Organisations of Disabled People (FFO) Rights Centre, telephone (+47) 22 79 90 60

If you have questions about **your child's diagnosis** or you seek contact with other families that have children with a rare hereditary diagnosis, ring free of charge to the Directorate of Health's Public Service telephone (800 41 710).

Relevant websites

www.familienettet.no
www.rarelink.no
www.helsedir.no/sjelden
www.nav.no
www.ffo.no
www.mestring.no

Relevant information from the Directorate of Health:

- Information pamphlet «Children and young people with diminished functional abilities – What rights do the family have?» (IS-1298)
- Information for pregnant women on foetal diagnostics (IS-1313)

Both pamphlets are available from the Directorate of Health's Printing Office (telephone no. 810 20 050).

When parents are blood relatives, there is a higher risk of disease and birth defects, stillbirths, infant mortality and a shorter life expectancy. To have a child with severe diseases and disorders may cause heavy strain for the family in question.

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