

TO PARENTS

STATENS
SERUM
INSTITUT



BLOOD

SMP

LESS FROM

NEWBORN

BABIES

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ALL NEWBORN BABIES IN DENMARK ARE OFFERED BLOOD SPOT SCREENING, ALSO KNOWN AS THE HEEL PRICK TEST, WHICH CAN REVEAL WHETHER THE CHILD IS SUFFERING FROM CERTAIN SERIOUS HEALTH CONDITIONS

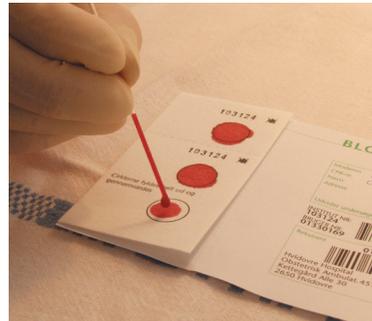
INFORMATION ABOUT THE HEEL PRICK TEST

To find out whether your child has a congenital disease, which is important to treat as quickly as possible, between 48 and 72 hours after the birth a health professional will take a blood sample.

The blood test depends on parents' consent to its being taken. If you do not give your consent, the sample will not be taken.

How does it work?

The blood sample consists of a few drops of blood collected on blotting paper, taken by 'pricking' the skin on the outer side of one of the child's heels. This rarely causes any great discomfort for the child.



What is the significance of the test for your child?

Even if a child seems totally healthy at birth, in rare cases he or she may have a congenital disease: for example, a fault in their metabolism. While the child is still in the uterus, s/he is protected by the mother's metabolism. That means that these kind of diseases are only apparent after birth. It can sneak up: for example, due to the accumulation of harmful metabolic products in the blood. Or it can happen suddenly: for example, in the form of metabolic crises that could endanger the child's life. The longer treatment is delayed, the greater the child's life is at stake, and the greater the chance of lasting mental or physical damage. That is why it is of the utmost importance for the child to identify the disease and start treatment as soon as possible.

What specific diseases are involved?

On the Statens Serum Institut website, www.ssi.dk/nyfoedte, you can find a list of the rare congenital diseases we currently look for. On the website you can also read more

about the individual diseases. You will also find individual examples of the diseases at the end of this leaflet. If your child is suffering from one of the diseases referred to, you will be informed immediately, and the child will be called in for further investigations and treatment. In most cases, this takes place in the local paediatric department in cooperation with the clinical genetic departments at Copenhagen University Hospital and Aarhus University Hospital.

How dependable is the test?

Because it is a so-called screening test, in rare cases, particularly involving premature babies, there may be results that suggest disease, without this actually being the case. A further examination will immediately be carried out and quickly reveal this. Similarly, the screening does not eliminate all kinds of diseases. Firstly, it is not technically possible to screen for all congenital diseases. Secondly, the screening only targets diseases, where early diagnosis provides better treatment options to benefit the child.

OTHER INFORMATION

What happens to the blood sample after the investigations have been carried out?

The sample is kept frozen in the Neonatal Screening Biobank at Statens Serum Institut in locked, secured facilities. The sample is stored for the following purposes:

1st priority. For the use of the child and family. It may be necessary to repeat the investigation, if any doubt about the diagnosis turn up at a later point, or to carry out supplementary analyses, which were not available at the time of birth. In rare cases, the sample has also proved to be important for the secure identification of a person, who later in life is the victim of an accident, a natural disaster or a crime etc. Every effort is made to ensure sufficient sample material for the above purposes.

2nd priority. To use in the ongoing quality assurance of screening of newborn babies and in the development of new analysis and screening methods.

3rd priority. To use in health research. Surplus sample material in the biobank also serves as a national research resource, which is of great importance for health research. This use of sample material always require the approval of Science Ethics committee. Projects using human biological material must also be conducted in accordance with the rules set out in the Personal Data Act and on the basis of the requirements laid down by the Danish Data Protection Agency (www.Datatilsynet.dk). The biobank's steering committee must also approve the use of sample material for this purpose.

Statens Serum Institut allocates a code number to each individual blood sample. That means that unauthorised persons cannot identify whom a sample comes from. Information about the child's name, date of birth, birth weight and gestation duration, together with the mother's name and social security number, are kept apart from the actual sample.

You have control of the sample on your child's behalf until he or she comes of age. If you do not wish the sample to be used in health research for scientifically approved purposes, you can inform the Danish Health Authority's tissue donor registry. For further information on this subject, visit www.sundhedsdatastyrelsen.dk.

If you do not want the sample to be stored at all, you can do so by writing a letter with the signatures of both parents to the Danish Centre for Neonatal Screening, Statens Serum Institut, Artillerivej 5, 2300 Copenhagen S, or sending an email via www.borger.dk, in which case you must use your digital signature (NemID) and select SSI as a recipient. The sample will then be destroyed.

Also visit the Statens Serum Institut website, www.ssi.dk/nyfoedte.

EXAMPLES OF CONGENITAL DISEASES

Endocrine disorders

Congenital hypothyroidism is caused by insufficient production of a hormone that regulates the child's metabolism. If untreated, hypothyroidism can lead to dwarfism and brain damage. If the disease is detected early enough, the child can develop normally with hormone treatment in tablet form. About 1 in 3,400 newborn babies has congenital hypothyroidism.

Cystic fibrosis

Cystic fibrosis (CF) is an inherited condition dominated by the formation of thick, sticky mucus. This causes lung/airway symptoms with repeated infections and problems with digestion. Early treatment involves prevention and intensive treatment of respiratory infections and digestive problems. It prevents serious complications and improves the well being and prospects of CF patients. About 1 in 4,800 newborn babies have CF.

Metabolic diseases

This is a large group of congenital diseases caused by a child's inability to metabolize certain substances. The diseases are hard to detect if one does not screen for them and can lead to organ damage, severely inhibited mental development and neonatal death. Treatment usually consists of a special diet, which restricts the intake of the nutrient, which the child cannot tolerate. Vitamin supplements and medication are also options. Overall, 1 in 3,000 newborn babies have a metabolic disease.

If the screening suggests that the child has one of the diseases, you will be informed immediately, and the child will be called back for further testing and treatment in the nearest paediatric department.

Deliver the letter with the filter paper blood sample to a post office.

Do not put the sample in a red post box.

It is important for the filter paper blood sample from a newborn baby to reach SSI quickly. Several of the diseases, for which a child is screened, appear a few days after birth and may threaten the child's health, if the diagnosis is not known and effective treatment is not implemented. In most cases the hospital take care of sending the sample to SSI, but in some occasions you may be asked to do it yourself. Post Danmark empties red post boxes twice a week. That means that the sample could take up to 5 business days to get to us.

That is why you must send your sample from a post office as a 'Quickbrev'.

This information has been compiled in consultation with the Danish Health Authority.