



National Institute for Public Health
and the Environment
Ministry of Health, Welfare and Sport

Screening tests for newborn babies

Heel prick test
Hearing test

General information for parents



This leaflet provides information on the heel prick test and hearing test for newborn babies.

It explains how the tests are carried out and where you can get more information.

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Heel prick test for newborn babies

What is the objective of the heel prick?

A small amount of blood is taken from the heel of your newborn child in the first week after birth. This blood is tested in a laboratory for a number of rare diseases. Early detection and treatment of these diseases can prevent or limit serious impairment of the physical and mental development of your child. Most of these diseases cannot be cured but they can be treated, for example with suitable medication or a diet.

Participation in the heel prick is voluntary. Your permission for performance of this test will therefore be requested. The heel prick can be important for the health of your child, which is why participation in the screening is strongly recommended.

If you are already sure in the course of your pregnancy that you do not want to take part in heel prick screening, you can inform your midwife of this before your baby is born.



Why is it important to register the birth of your child?

The heel prick can only be performed if you have reported the birth of your child to the municipal Civil Registry Office. This must be done as soon as possible (no later than 3 days after the birth). Please note that the Civil Registry Office is closed on Saturdays, Sundays and public holidays.

After registration, the Civil Registry Office will send an electronic report to a national registration system of the National Institute for Public Health and the Environment (RIVM) known as Praeventis. The Child Health and Welfare service (JGZ) will then be informed, and they will instruct a screening assistant to visit you.

Performance of the heel prick

A member of the Child Health and Welfare service (JGZ) staff or your midwife will visit you at home a few days after the birth of your child in order to perform the heel prick. If possible, they will phone you in advance to make an appointment for this visit. If your child is in hospital, the heel prick will be performed there.

A pinprick puncture is made in your baby's heel, and a few drops of blood are collected on a special collection card known as the Guthrie card. Your baby may cry a little.

What happens if the heel prick has not been performed within 7 days?

If the heel prick has not been performed within 7 days of the child's birth, you should contact the regional RIVM office. The phone numbers are given on page 9.

What diseases are tested for by the heel prick?

The blood collected by means of the heel prick is tested for:

- a disease of the thyroid gland,
- a disease of the adrenal gland,
- a type of anaemia (sickle cell disease),
- a disease of the lungs (cystic fibrosis),
- a number of metabolic diseases.

Most of these diseases are hereditary, and do not occur often. For full details (in Dutch) of all the diseases involved, please visit www.rivm.nl/hieelprik.



The heel prick can also show that your child is a carrier of sickle cell anaemia but does not have the disease itself.

Will you be informed about the results of the heel prick?

The results of the heel prick are nearly always known within 4 weeks. If the results are normal, you will not be informed. If an abnormality is detected, your GP will let you know. In some cases, the amount of blood collected is not enough for all the tests that have to be performed. The heel prick will then have to be repeated. Once again, you will not be informed if the results of the repeat first heel prick are normal, but you will be informed if any abnormality is found.

It sometimes happens that the results of the heel prick are indeterminate. In that case, a second heel prick is usually performed within 2 weeks. The regional RIVM office will inform you if the heel prick has to be repeated. You will always be informed of the results of the second heel prick within four weeks.

A film about the heel prick (available with Dutch, Arabic, English or Turkish subtitles) and the answers to frequently asked questions may be found at www.rivm.nl/hieiprik.

What happens if an abnormality is detected?

Your GP will refer your baby as soon as possible to a paediatric specialist, who will carry out further tests to make sure whether the diagnosis is correct.

If your child is found to be a carrier of sickle cell disease, your GP will inform you of this.

Registration of abnormalities

If the heel prick reveals an abnormality, a doctor from RIVM will put your child's results in a secure database known as the NEOnatal Register of Abnormalities found in Heel prick screening (NEORAH). The definitive diagnosis made by your baby's paediatrician will also be included there.

If you do not want your child's data to be recorded in NEORAH, you can inform your GP or the doctor from RIVM of your wishes.

Hereditary diseases

If the heel prick reveals that your child has a disease, this usually means that both parents are carriers of the disease in question. Carriers do not have the disease themselves, and can never get it. Carrier status can have consequences for any other pregnancies you are contemplating. But your brothers, sisters or other relatives can also be carriers. If you want to know more you can consult your midwife or visit the website www.erfelijkheid.nl for Dutch-language information on this topic.

Carriers of sickle cell anaemia

The main objective of the heel prick is to trace children who have certain (rare) diseases. However, it can also show that your baby is a carrier of sickle cell anaemia but does not have the disease itself.

If the heel prick reveals that your child is a carrier, then one or both parents will also be carriers of sickle cell anaemia or cystic fibrosis. If blood tests show that both parents are carriers, there is a 25% chance that a child born from a subsequent pregnancy will have the disease.

If your child is a carrier of sickle cell anaemia, any other children you may have or other members of your family may be carriers too. The heel prick detects all carriers of sickle cell anaemia.

If you don't want to receive information about your child's carrier status, you should tell the person who is performing the heel prick. You will then be asked to sign the heel prick card.

What happens to the rest of the blood from the heel prick?

After the heel prick, the remaining drops of blood collected from your child are kept in a laboratory for five years. They may be used to check the results and to ensure optimum quality of the test.

The blood may also be used for scientific research during this five-year period. This only happens if an assessment committee decides that the research is useful for disease prevention and/or in order to improve treatment.

The blood is provided to researchers on an anonymous basis. This means that it is impossible to derive any information about you yourself or your child from the blood or from the research results.

Under certain circumstances, the researcher may want to make use of personal data about your child. In that case, RIVM always requests your permission first.

If you don't want the blood to be used for anonymous scientific research, you should inform the person who is performing the heel prick on your child. You will then be asked to sign the heel prick card. The blood in question will not be used for scientific research, and will be destroyed a year after collection.

Other things you may need to know

Costs

You do not have to pay anything for the heel prick.

Are the results of the heel prick 100% reliable?

There is a slight probability that the laboratory tests on the blood taken from the heel prick indicate an abnormality while further tests in hospitals show that your child does not have the disease in question. This is regrettable but unavoidable. There is also a slight probability that the laboratory tests do not reveal any abnormalities even though your child does have one of the diseases tested for.

Furthermore, the heel prick is only used to screen for a limited number of diseases. Failure to detect any abnormalities is thus no guarantee that your child has no disease at all. If you are worried about your child's health, you should consult your GP.

Combination with hearing screening

The heel prick is usually combined with screening of your baby's hearing. This pamphlet also contains information on this hearing screening, starting on page 11.

Privacy

Great care is taken to protect the confidentiality of the data on you and your child. The

personal data and the medical data on the blood tests are recorded in RIVM's national registration system Praeventis. Praeventis is subject to the legal provisions of the Data Protection Act (Wet Bescherming Persoonsgegevens). The data are only used for the purposes for which they were intended. You can inspect your data on request at the regional RIVM office (see page 9).

Only if the heel prick reveals any abnormalities are your child's data also entered in a secure database (NEORAH) – as long as you do not object to this. This database is also subject to the legal provisions of the Data Protection Act (Wet Bescherming Persoonsgegevens). If your child is referred to a paediatrician, you can inspect the relevant data in this database during a visit to this paediatrician. You can also enquire at the regional RIVM office whether any data on your child are included in this database, and if so which.

NEORAH is a joint venture of the doctors employed by RIVM and the Dutch Association of Paediatricians.

You must report the birth of your child to the municipal Civil Registry Office as soon as possible (no later than 3 days after the birth).

Complaints

If you have a complaint about the way the heel prick was performed, you should submit this to the organization responsible for carrying out the heel prick. Details (in both Dutch and English) about the procedure for complaints about the heel prick in general may be found at www.rivm.nl/contact.

Further information

- Further information on the heel prick (including a film about the screening procedure) may be found at the RIVM website at www.rivm.nl/hielprk.
- The RIVM website also provides further information on hearing screening at www.rivm.nl/gehoorscreening.
- You can put any further questions you may have about the heel prick to your midwife.

RIVM - Regional offices

North	Groningen, Friesland and Drenthe	050 - 368 63 50
East	Overijssel, Flevoland and Gelderland	0570 - 66 15 20
Centre-West	Utrecht and Noord-Holland	0346 - 55 00 40
Southwest	Zuid-Holland	079 - 341 82 38
South	Zeeland, Noord-Brabant and Limburg	040 - 232 91 11

Hearing test for newborn babies



Why a hearing test?

Your baby will be given a hearing test in the first month after birth to check whether his or her hearing is good enough to learn to talk. It is also referred to as neonatal or newborn hearing screening.

Who does the test?

The hearing test is provided by the Child Health and Welfare service (JGZ), the organization that runs your baby clinic. It will be carried out by an expert JGZ or maternity care worker.

When and where?

The test will take place at your home during the first week after birth, or at the baby clinic, in which case it will be carried out during the second or third week after birth. You will be sent an invitation in this case. If the test is carried out at home your child will usually be given the heel prick test during the same visit. The health worker does not always make a prior appointment for the visit; often he or she will just drop in.

Is your child in hospital?

If your child is in hospital, the hearing test will be done once he or she is back home, so tell the baby clinic when your child is discharged. If your child needs to remain in hospital for some time the test can be carried out there. The JGZ will contact you in this case. If you do not hear anything from them, contact the baby clinic.

How to prepare

There is no need to make any special preparations, but the room must be quiet during the test. It works best if your baby is calm and asleep. He or she can remain in the cot or in your arms while the test is being carried out.

How does the test work?

The health worker inserts a soft-tipped earpiece in your baby's ear. This is connected to a device that measures your baby's hearing. The test only takes a few minutes and does not hurt. Your baby will hardly notice anything and will usually sleep through it.

You can see a video clip of the hearing test at www.rivm.nl/gehoorscreening.

Result

You will be given the result of the test straight away and the health worker will discuss it with you on the spot. The result is a 'pass' in about 95 out of 100 children. If the baby fails the test it will be repeated about a week later. If necessary a third test will be carried out after another week using a different device.

A fail does not necessarily mean that your child cannot hear properly. If your baby also fails the third test in one or both ears, his or her hearing will be tested at an Audiology Centre. You will receive more information in this case. An Audiology Centre is a clinic that specializes in investigating hearing, speech and language. It may be attached to a hospital.

The test is not compulsory

If you do not want your child to undergo the hearing test tell the health worker or the person who contacts you to make an appointment.

Cost

The hearing test is free.

Other important information



Why so young?

Good hearing is important to your baby's development. The hearing test enables a hearing problem to be detected early on. The sooner it is detected, the sooner treatment can begin. It is important to start treatment before the baby is six months old. Research shows that this has a beneficial effect on language and speech development.

Remain vigilant

If your child passes the hearing test it is almost certain that his or her hearing is working properly at that time. You still need to watch out for problems, however. Sometimes a hearing impairment does not develop until after the test, though fortunately this is very rare. If you have any doubts about your child's hearing, contact your GP or the baby clinic.

More information

You can find more information on the newborn hearing test on the National Institute for Public Health and the Environment (RIVM) website, www.rivm.nl/gehoorscreening, where you will also find answers to frequently asked questions. If you have any questions you can also ask the baby clinic. You can find the address and telephone number of the JGZ organization that runs your baby clinic on the RIVM website.

For more information on the hearing test you can also telephone the NSDSK (the Dutch foundation for hearing-impaired children) on 020 - 574 59 45.

Privacy

The medical details of your child's hearing test will be stored in a special database for the neonatal hearing screening programme by your JGZ organization. The purpose of this system is to check whether all children have had the hearing test on time and whether it has been carried out correctly.

Lastly, the medical details may also be used for national statistics and scientific research. Only anonymous data is used for these purposes, and everything is done to ensure that your child cannot be identified. The results of the hearing test will be stored in your child's digital file at your JGZ organization. You can find out what rights you have in relation to this digital file in your JGZ organization's privacy policy.



You will be given a copy of this leaflet by your obstetric health worker around the 35th week of your pregnancy and when registering the birth of your child with the Civil Registry.

Municipal civil registries, midwives, gynaecologists, GPs and other obstetric health workers can order additional copies of this leaflet at www.rivm.nl/pns/folders-bestellen.

Population screening tests can be recognised by this logo:

***bevolkings*onderzoek**

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