



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

June 2017



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 for newborn babies

What is the objective of the heel prick test?

In the first week after your baby is born, a few drops of blood will be taken from your baby's heel. This blood is tested in the lab for a number of rare, serious diseases. Most diseases cannot be cured, but they can be treated, for instance with medication or a diet. Timely detection and treatment of these diseases will prevent or limit very serious damage to the physical and mental development of your child. That is why it is important that your child takes part in this screening.

The test is not compulsory

The test is not compulsory. That is why the screener will ask your permission to perform a heel prick test. Inform the health worker if your child is not participating in the heel prick test when he/she visits you, or if they call you to schedule an appointment.



Why is it important to register the birth of your child at the Civil Registry office?

The heel prick test can *only* be performed if you have registered the birth of your child at the Civil Registry office of your municipality. It is therefore important that you do this as soon as possible after the birth (*at the latest* within three days). Please keep in mind that the Civil Registry Office is closed on Saturdays, Sundays and on holidays.

After registration, the local authorities will send a digital message to the national RIVM registration system, called Praeventis. RIVM will then order the Youth health care services, the JGZ, (child health clinic, local Youth and Family Centres, Municipal Public Health Services (GGD)) to perform the heel prick test on a child.

Performing the heel prick test

The heel prick test will be performed at your home by a health worker from the Youth health care services (JGZ) or the midwife, several days after the child is born. If possible, the health worker will call you to make an appointment for this visit. If your child is in hospital, the heel prick test will be performed there.

During the heel prick test, a few drops of blood will be taken from your child's heel. These drops of blood are collected on a special card, the heel prick card. Your child may cry a little.

What if the heel prick test has not been performed within seven days?

What if the heel prick test has not been performed within seven days after the birth of your child? In that case, you should contact the RIVM regional office. The telephone numbers are listed on page 9.



Has your child already had a heel prick test in another country?

If your child is less than six months old, you will be offered the opportunity to have the heel prick test performed again in the Netherlands. Other countries do not always screen for the same diseases.

Which diseases does the heel prick test for?

The blood collected by the heel prick test is tested for:

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

Most of these diseases are hereditary, and do not occur often.

Would you like to find out exactly which diseases are tested?

If so, please go to: www.rivm.nl/hieiprik.

The heel prick test could also show that your child is a *carrier* of sickle cell anaemia. This means that your child 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 five weeks. If the results are normal, you will *not* be notified. If an abnormality is detected, you will be notified by your GP.

In some cases, the amount of blood collected is not enough for the test. This means that the heel prick test has to be repeated. Once again, you will not be informed if the results of the 'repeated first heel prick test' are normal. If the result is abnormal you will be notified by your GP.

In some cases, the result is indeterminate, and a 'second heel prick test' is performed. The regional RIVM office will inform you that more blood needs to be collected. The regional RIVM office will always notify you about a normal result of the second heel prick test. Is the result of this second test abnormal? In that case, your GP will inform you about this result.

Go to www.rivm.nl/hielprik for a video and frequently asked questions about the heel prick.

What happens if an abnormality is detected?

Your GP will inform you if the result of the heel prick test shows an abnormality. Your GP will refer your child to a specialised paediatrician as soon as possible. This paediatrician will perform follow-up diagnostic testing to determine if your child has one of the diseases that are screened by the heel prick test.

Carrier of sickle cell anaemia

The heel prick test is intended to track down children who have a disease. However, the heel prick test could also show that your child is a carrier of sickle cell anaemia. This means that your child does not have the disease itself. If the heel prick test shows that a child is a carrier, this means that one parent is carrier, or both parents are carriers of sickle cell anaemia. If the blood test shows that both parents are carriers, there is a risk of 1 in 4 of sickle cell anaemia for every next pregnancy. If a child is a carrier of sickle cell anaemia, the child's siblings and other relatives could also be carriers.

Do you object to receiving information about your child's carrier status? In that case, please inform the health worker performing the heel prick test. The health worker will ask you to sign the heel prick card. For more information, go to the website www.erfelijkheid.nl.

Other things you need to know

Costs

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

Are the results of the heel prick test 100% reliable?

There is a slight probability that the heel prick test shows abnormal results, while further testing at the hospital shows that your child does not have the disease. This is regrettably unavoidable. There is also a slight probability that the results do not show any abnormalities, even though your child has one of the diseases.

The heel prick test is at its most reliable if it is performed in the first week after the birth of your child.

The heel prick screens for a limited number of diseases. A normal result offers no guarantees about the health of your child.

Are you worried about your child's health? If so, please contact your GP.

Heel prick test and hearing screening

The heel prick test is usually combined with the screening of your child's hearing.

You must report the birth of your child as soon as possible. This must take place no later than three days after the birth of your child.

Legal information

Do you want to participate in the heel prick screening?

It is good to know what you can expect from the heel prick screening. Your obstetric health worker or gynaecologist will provide you with more information. Further information about the screening can be found on the RIVM website, or in this leaflet. You decide whether you want your child to be screened or not.

Information about the screening in a national information system

You must register the birth of your child at the Civil Registry Office as soon as possible. This must take place no later than three days after the birth of your child. In order to invite your child for the screening, the Civil Registry Office will provide the data on your newborn baby to RIVM. These data and the results screening will be registered in a national registration system (Praeventis). Does the screening show an abnormal result? In that case, your child's data and the results of the heel prick test will also be registered in the Neorah registration system. The treating physicians will add the results of the follow-up test to the details in Neorah. The registration systems are necessary to allow the screening to progress well and to monitor the quality of the screening. Anonymous information and test results are also used for national statistics and scientific research, to improve the screening and the treatment provided. RIVM asks TNO to create national statistics.

Privacy

The national information systems are well protected. The legislation for the protection of privacy is applicable here. Only those people who need to see the information about your child to perform the screening have access to the data. You do not want the screening data on your child to be documented in an information system after the heel prick screening? In that case, it is possible to disconnect your child's data from the screening results. These results can no longer be traced back to your child. Go to www.rivm.nl/hielprik/privacy for information about how to request this. This website also tells you about the available information systems and the data they store.

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

After the heel prick, the remaining drops of your child's blood are stored at the laboratory for five years. This is required to check the results of the test, and to ensure the quality. During those five years, the blood can also be used for scientific research. This only happens if an assessment committee has determined that this research is useful for disease prevention and/or to improve treatment. The researcher will receive the blood, without any details about you or your child. If a researcher wants to use the personal details of the child, you will always be asked for permission beforehand. If you do not want your child's blood to be used for scientific research, you can inform the person who is performing the heel prick test on your child. The health worker will ask you to sign the heel prick test card. In that case, the blood will be destroyed one year after collection.

Regional offices of RIVM-DVP

North-East	Groningen, Friesland, Drenthe, Overijssel, Flevoland and Gelderland	088 - 678 89 50
West	Utrecht, Noord-Holland and Zuid-Holland	088 - 678 89 30
South	Zeeland, Noord-Brabant and Limburg	088 - 678 89 40

Complaints

Do you have a complaint about the administration of the heel prick test? If so, please contact the responsible organisation. Do you have a general complaint about the heel prick test? You can find information about the complaints procedure at www.rivm.nl/contact.

More information

- For more information about the heel prick test, please go to the RIVM website: www.rivm.nl/hielprik. This website also contains a video about the heel prick screening.
- Please direct any questions about the heel prick test to your obstetric health worker.

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 Youth Health Care services (JGZ), the organisation that runs your well baby clinic. It will be carried out by a screener or maternity care worker.

When and where?

The test will take place at your home during the first week after birth, or at the well 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 well 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 well 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.

Costs

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 he or she has sufficient hearing 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 well 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 → English → topics: newborn hearing screening. If you have any questions you can ask the well baby clinic. 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.

Legal information

Are you participating in the hearing test?


It is good to know what you can expect from the hearing test. That is why you have received this leaflet. You can read more about this test on the aforementioned RIVM website. You decide whether you want your child to be tested. If you do not want your child to participate in the hearing test, you can report this to the screener or when you are contacted to make an appointment.

Test data in an information system

The hearing test data are recorded in an information system especially created for the newborn hearing screening. This is managed by your Youth Health Care organisation. This system is intended to ensure that all children participate in the hearing test at the right time, and to ensure that the test is performed in the proper way. The data can also be used for national statistics and for scientific research. Only anonymous information is used. The results of the hearing test are also stored in your child's digital file at the Youth Health Care organisation. Your rights regarding your child's digital file can be found on the website www.ddjgz.nl.

Your privacy

The information system is well-secured. Only those people who need to see your information to perform the test have access to the data. The administrator of this system complies with the legislation that protects your privacy. If you do not want your data to be used for research, or if you do not want your child's data to remain registered in an information system after the test, you can find out what to do on www.rivm.nl/gehoorscreening/privacy.



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.

Population screening tests can be recognised by this logo:

bevolkingsonderzoek

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