



Heel prick test and hearing test for newborn babies

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For digital versions of this leaflet in this and other languages, see
www.pns.nl/geboorte.

Heel prick screening test

Why is the heel prick test done?

In the first week after birth, a few drops of blood will be taken from your baby's heel. The blood will then be tested by a laboratory for a number of rare inherited diseases. These diseases can be treated by medicines or by a diet, for instance. Tracing these diseases early means that treatment can be started quickly and this can help to prevent any serious harm to your baby's development. This is why it is important that your baby has the heel prick screening test.

Register the birth

Register the birth of your baby at your local Civil Registry Office (*Burgerzaken*) as soon as possible. In any case, do this within 3 days after the baby is born, then you will know for sure that the heel prick test can be done on time. Please note that Civil Registry Office is closed on Saturdays, Sundays and public holidays. Some municipalities also let you register a birth online.

After the birth is registered, someone will visit you at home for the heel prick test. This will be either a Youth Healthcare services employee, a provider of obstetric care or a maternity carer.

If your baby is still in hospital, the procedure will be done there.

The person who performs the procedure is called a screener. At the time of the heel prick, the screener will ask you for some information.

Please have the following information at hand:

- the number of weeks of pregnancy at birth;
- your baby's birth weight;
- your general practitioner's name and telephone number.

Doing the heel prick test

For the heel prick test, the screener will prick your baby's heel and collect a few drops of blood on a special heel prick blood test card. Your baby may cry a little. If possible, the screener will tell you beforehand when you should expect them.

Seven days and still no heel prick test?

If the heel prick test has still not been done seven days after birth, contact your regional RIVM office. The screener will visit you as soon as possible. You can find the telephone number on page 6.

Which diseases does the test screen for?

- a disease of the thyroid gland (congenital hypothyroidism);
- a disease of the adrenal glands (adrenogenital syndrome);
- hereditary anaemia (sickle cell anaemia and thalassaemia);
- a disease of the lungs (cystic fibrosis);
- a number of metabolic diseases;
- abnormalities of the immune system (SCID);
- a disease of the muscles (SMA).

Most of these are inherited diseases, and they are rare. To learn more about these diseases, see www.pns.nl/hielprik/aandoeningen.

The results of the heel prick test

- If the test results are normal, you will get a letter from RIVM within five weeks.
- If there is an abnormality, your general practitioner (GP) will contact you about getting follow-up tests in hospital as soon as possible.

Sometimes, not enough blood is taken for the laboratory to do the test properly. In that case, the screener will come to your home again. If the results of the second heel prick test are normal, you will get a letter from RIVM within five weeks after this test. If there is an abnormality, your GP will contact you as soon as possible.

Sometimes, the test results may not be clear. In that case, the screener has to do another heel prick test. You will get the results of this second heel prick test within two weeks. If the test results are normal, you will get a letter from RIVM within two weeks. If there is an abnormality, your GP will contact you as soon as possible.

What if the results are abnormal?

An abnormal result means your child may have a disease. Your GP will refer you to a paediatrician for follow-up tests as quickly as possible. The paediatrician will examine your baby further.

Carrier of sickle-cell disease

The heel prick test is done to detect diseases in children. However, it can also show if your child is a carrier of sickle-cell disease. Sickle-cell disease is an inherited form of anaemia. Sickle-cell carriers are not and do not become ill with this disease.

If the heel prick test shows your child is a carrier of sickle-cell disease, it means that one or both parents are also carriers or that one parent has sickle-cell disease.

When doing the heel prick test, the screener will ask whether you also wish to know if your child is a carrier of sickle-cell disease. If so, you will be notified if your child is shown to be a carrier of the disease.

For more information, see www.pns.nl/hielprik/sikkelcelziekte (in Dutch).

Other things you need to know

Participation is voluntary

Before performing the heel prick test, the screener will ask if you agree to the procedure. Participation in the heel prick screening test is voluntary.

Costs

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

If more tests are needed after the heel prick test, they will be fully covered by your care insurer. If the test results are abnormal, parents sometimes need to be tested as well. These tests fall under the parents' insurance deductible.

Are heel prick test results 100% reliable?

Even if the test results are normal, there is still a slight risk that your child has one of the diseases. There is also a risk that the first test results are abnormal, but that follow-up tests show your child does not have a disease after all. Unfortunately, these risks cannot be avoided. Heel prick test results are most reliable when the test is done within the first week after the birth.

The heel prick test screens the blood for a limited number of diseases. If you are concerned about your child's health, please contact your GP.

Personal details

After you register your baby's birth, your municipality will give RIVM personal details about your child, including their name, address and birth date. This data is stored in an information system and ensures Youth Healthcare services are notified to offer you the heel prick test on time. These personal details will also be entered into an information system used to record heel prick test results.

Are you opposed to your child's personal details being stored in an information system? RIVM is unable to remove personal details, but it can unlink these details from the test results so they cannot be traced back to your child. To request this, please contact the regional RIVM-DVP office: www.pns.nl/hielprik/contact.

What happens to the blood sample after testing?

After the heel prick test, there is usually some blood left on the heel prick blood test card. The part of the card with the blood left on it is stored in a special freezer at RIVM. The part of the card containing personal details (name, address and birth date) is filed at the regional RIVM-DVP office. The leftover blood is used to monitor the quality of heel prick screening. Blood left over from the test is kept for one year.

If you wish the blood left over from your child's test to be returned to you, or if you want it to be destroyed before the end of one year, please contact the regional RIVM-DVP office: www.pns.nl/hielprik/contact.

Heel prick test data

The heel prick test is used to run tests on a blood spot sample collected from your child. The laboratory test results show if your child may have a disease. These results are part of your child's heel prick test data. The screener will also record your baby's birth weight and the duration of the pregnancy on the heel prick blood test card. This data may be needed to help assess the test results. This is also part of the heel prick test data.

All of this data is stored in an information system and becomes part of your child's heel prick test file.

The information systems for the heel prick screening test are all properly secured. RIVM operates in compliance with privacy legislation.

Consent for scientific research

After the heel prick screening test, the leftover blood and heel prick test data are retained for future scientific research.

The aim of this research is to improve the heel prick screening test. As from 1 January 2023, parents must give their consent for this.

If parents consent, blood left over from the test is retained for five years after the test. After that, it is destroyed.

Before any research can be conducted, an RIVM committee evaluates if the research will be useful. Otherwise, the researchers do not get any leftover blood spot samples or heel prick test data.

Researchers cannot see to whom leftover blood and heel prick test data belong.

For some studies, researchers do need to know to whom leftover blood belongs. In that case, parents are always asked for additional consent before the blood is given to researchers for that study.

A paediatrician may also request blood left over from the heel prick test to run additional tests on a child in their care. Parents' consent is needed for this as well.

For more information (in Dutch) about consent for scientific research using leftover blood spot samples and heel prick test data, see www.pns.nl/hielprik/toestemming-onderzoek. Or read the leaflet: www.pns.nl/documenten/hielprik-toestemming-onderzoek.

For more information and a privacy statement, see www.pns.nl/hielprik/juridische-informatie.

Complaints

If you have a complaint about the heel prick test, please refer to RIVM's complaints procedure at www.rivm.nl/contact.

If you have a specific complaint about how the heel prick test was carried out on your child, please contact the organization that carried out the test.

For more information

For more information about the heel prick test, see www.pns.nl/hielprik. There, you will also find a short film and a visual story about the heel prick test. If you have any questions about the heel prick test, please contact your midwife or gynaecologist.

Regional RIVM-DVP offices

If your child has still not had a heel prick test seven days after birth, please contact your regional RIVM-DVP office.

If you are telephoning with a question after your child has had the heel prick test, please have on hand your own and your child's citizen service numbers (BSN) and the heel prick blood test card number. You can find the heel prick test card number printed at the top right of the envelope given to you by the screener after the heel prick test.

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| North – East | Groningen, Friesland, Drenthe, Overijssel, Flevoland and Gelderland | 088 - 678 89 51 |
| West | Utrecht, Noord-Holland and Zuid-Holland | 088 - 678 89 31 |
| South | Zeeland, Noord-Brabant and Limburg | 088 - 678 89 41 |

Hearing test

Why is the hearing test done?

Your baby will have a hearing test in the first month after birth. This test checks if your child can hear well enough to learn to talk. This hearing test is also called the newborn hearing screening.

Who does the hearing test?

Youth Healthcare services (JGZ) provide the hearing test in association with the Well-Baby Clinic. The test is done by a screener, who is either a Youth Healthcare services employee or a maternity carer.

Where and when?

The hearing test is done either at home or in a Well-Baby Clinic. If at home, it will be done in the first week after your baby's birth. The hearing test is usually carried out at the same time as the heel prick test.

If the test is done in a Well-Baby Clinic, it will be in the second or third week after the birth. You will receive an invitation for this.

Is your baby still in hospital?

If your baby is in hospital, the hearing test will be done once your baby is back home. Please let the Well-Baby Clinic know when your baby will be home. If your baby needs to stay in hospital for a longer time, the test can also be done there. In that case, the Well-Baby Clinic will contact you to make arrangements. If you do not hear from them, please contact the clinic yourself.

If your baby is in a neonatal intensive care unit (NICU), the test will be done there by a staff member from the NICU.

What does the hearing test involve?

The screener will place a soft earpiece in your baby's ear. This earpiece is attached to a device that measures your baby's hearing. The test takes a few minutes and does not hurt. Your baby will barely feel it and may sleep right through it.

You do not need to do anything to prepare. However, the room must be quiet during the test. The hearing test works best if your baby is quiet or sleeping. Your baby can lay in your arms or in bed.

See webpage <http://www.pns.nl/gehoortest-baby> for short films about the hearing test.

Hearing test results

You will get the results of the hearing test immediately afterwards. Around 95 in 100 babies 'pass' this hearing test. If your baby does not pass the hearing test, the test will be done again around a week later.

Not 'passing' need not mean your child has hearing loss. If the second test is also abnormal, a third test will be done using a different device around a week later.

If the third test shows your baby cannot hear properly in one or both ears, further tests will be done at an audiology centre. Audiology centres are specialised in testing hearing, speech and language. The screener will give you more information about this.

Other things you need to know

Costs

You do not have to pay for the hearing test.

Why so soon after birth?

Good hearing plays an important role in your child's development. The hearing test can detect possible hearing loss early on, so that treatment can start early. It is important to start treatment start before the age of six months. This is good for proper language and speech development.

Are hearing test results 100% reliable?

If you baby passes the hearing test, it means their hearing is almost certainly working well at that time. However, children can develop hearing impairments after the hearing test. Fortunately, this is rare. If you are concerned about your baby's hearing, please contact your GP or the Well-Baby Clinic.

Additional information

For more information about the newborn hearing test, see www.pns.nl/gehoortest-baby. You can also call the Well-Baby Clinic or the Dutch Foundation for Deaf and Hearing Impaired Children (NSDSK): 020 - 574 59 45.

Participation is voluntary

Before doing the hearing test, the screener will ask if you agree to the procedure. Participation in the hearing test is voluntary.

Information needed for the hearing test

To get the hearing test, you need to provide some details about yourself and your baby. This includes your names, full address and the duration of the pregnancy. The Well-Baby Clinic stores this information in a special information system for newborn hearing screening tests. The information is used to track if all children are getting hearing tests on time, what the results are and if more research is needed.

This information may also be used for the purposes of national statistics and scientific research. Your details are stored anonymously. This means they cannot be traced to

your child. If there is a study for which personal details are needed after all, you will be asked for your consent first.

Your child's hearing test results are added to their digital file at the Well-Baby Clinic. To read more about this file, see www.ddjgz.nl.

Privacy

The information system used to store hearing test data is secure. Only Well-Baby Clinic employees who need your details to do the hearing test can access this information.

Are you opposed to your own or your child's personal details being stored in an information system? Please see www.pns.nl/gehoortest/juridische-informatie to learn what you can do.

Main points

- Shortly after birth, your baby will have a heel prick test and a hearing test.
- Register your baby's birth with the Civil Registry Office within three days. This will ensure both tests are done on time.
- The heel prick test and the hearing test are usually done at home, on the same day.
- The heel prick test and the hearing test are in your baby's best interest, so it is important to get your baby tested.
- Participation is voluntary.
- You do not have to pay anything.

Heel prick test

- The heel prick test is done by collecting a few drops of blood from your baby's heel. A laboratory tests the blood for a number of rare but serious diseases.
- These diseases are treatable. Most can be treated with medicines or a special diet.
- Detecting these diseases at an early stage allows for early treatment. This helps prevent serious harm to your child's development.
- For this reason, it is important that your baby gets the heel prick test early on, within the first week after birth.
- You will get the results of the heel prick test within five weeks. In most cases, the results come back normal. If the results are abnormal, your GP will contact you as soon as possible.

Hearing test

- The hearing test is done by placing a small, soft earpiece in your baby's ear. Your baby will barely feel it.
- You will get the results immediately afterwards.
- The hearing test can detect possible hearing loss early on.
- Good hearing is important for learning to talk.
- The earlier hearing loss is detected, the sooner treatment can start.

Digital leaflet

You can find digital versions of the Heel Prick Test and Hearing Test leaflet in this and other languages at www.pns.nl/geboorte.

Voor de Nederlandse versie van de folder Hielprick en gehoortest kijk op www.pns.nl/geboorte (Dutch).

Yeni doğan topuk kanı taraması ve işitme testiyle ilgili bu broşürün Türkçe çevirisi www.pns.nl/geboorte (Turkish)

W celu uzyskania polskiej wersji ulotki na temat nakłucia pięty w celu pobrania krwi i badań słuchu należy odwiedzić stronę www.pns.nl/geboorte (Polish)

لدى حديثي الوالدترجمة هذا المنشور باللغة العربية حول وخز الكعب وفحص السمع لدحديثي الوالدة www.pns.nl/geboor

Visual stories (with translations)

For simple information about the **heel prick test** in the form of a visual story (with translations), see www.pns.nl/hieiprik/beeldverhaal

For simple information about the **hearing test** in the form of a visual story (with translations), see www.pns.nl/gehoortest-baby/beeldverhaal

The midwife or gynaecologist will give you this leaflet at the end of your pregnancy. The municipality will also give you information about the heel prick test and hearing test upon registration of your child's birth.

Obstetric care providers and municipal Civil Registry Offices can order copies of the Heel Prick Test and Hearing Test leaflet from www.rivm.nl/pns-folders.

Published by:
National Institute for Public Health and the Environment
PO Box 1 | 3720 BA Bilthoven
The Netherlands
www.rivm.nl

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December 2022