



## Heel prick test and hearing test for newborn babies

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## 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.

### **How to prepare for it**

*Register the birth as quickly as possible*

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 the Civil Registry Office is closed on Saturdays, Sundays and public holidays.

After the birth has been registered, the Youth Health Care services in your local area will arrange for someone to come to your home for the heel prick test. The person who does the test is called the screener. It could be an employee of the Youth Health Care services, an obstetric care provider or a maternity nurse. If your baby is in the hospital, the heel prick test will be done in the hospital.

*Please have the following information at hand when the screener visits*

When doing the heel prick test, the screener will ask you for a few details. These details are necessary to be able to assess the result of the heel prick test properly. It is important to know:

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

### **Doing the heel prick test**

A few days after your baby is born, the screener will come to your home to do the heel prick test. Sometimes the screener will contact you first to say when he or she is coming. Often your baby will have a hearing test at the same time.

For the heel prick test the screener will take a few drops of blood from your baby's heel. The drops of blood are collected on a special card called the heel prick card. Your baby may cry for a short time.

### **Seven days and still no heel prick test?**

If the heel prick test still hasn't been done by seven days after birth, then contact your regional RIVM office. A screener will come to your home as soon as possible. The telephone numbers of the RIVM offices are listed on page 6.

### **Which diseases is the blood tested for?**

The blood from the heel prick is tested 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).

Most of these diseases are inherited conditions and they are rare. If you want to know exactly which diseases are tested for, see [www.pns.nl/hielprik](http://www.pns.nl/hielprik).

#### *Extending the heel prick test*

Tests for more diseases will be added to the heel prick test in the coming years. More information about this can be found at [www.pns.nl/hielprik/uitbreiding](http://www.pns.nl/hielprik/uitbreiding).

See [www.pns.nl/hielprik](http://www.pns.nl/hielprik) for a short film and the most frequently asked questions about the heel prick test.

### **The results of the heel prick test**

If the result is good you will get a letter from RIVM within five weeks.

If an abnormality is detected, your general practitioner (GP) will contact you about follow-up tests in the hospital as soon as possible.

Sometimes not enough blood is taken for the laboratory to be able to do the test properly. The screener will then have to repeat the heel prick test. If the results of this heel prick test are good, you will get a letter from RIVM within five weeks after the extra test. If an abnormality is detected, your GP will contact you as soon as possible.

Sometimes the result for a disease is not immediately clear. Then the screener will do the heel prick test again. The RIVM will contact you about this separately. The results of this extra heel prick test are known within two weeks. If no abnormalities are detected, you will get a letter about this from RIVM within two weeks. If an abnormality is detected, your GP will contact you as soon as possible.

If you still haven't received the result after five weeks, then contact the RIVM office in your region (see page 6).

See [www.pns.nl/hielprik/uitslag](http://www.pns.nl/hielprik/uitslag) for more information about possible results.

### **Abnormal result, and then what?**

An abnormal result means that it is possible that your child has a disease. Your GP will refer your baby to a paediatrician (a doctor specialised in the care of children) for follow-up tests as quickly as possible. The paediatrician will then further examine your baby to see what the matter is.

### **Carrier of sickle cell anaemia**

The aim of the heel prick test is to trace diseases in children. However, the heel prick test can also show if your child is a carrier of sickle cell anaemia. Sickle cell anaemia is a form of inherited anaemia. Carriers of sickle cell anaemia are not ill.

If the heel prick test shows that your child is a carrier of sickle cell anaemia, then one or both parents are also carriers of this disease, or one of the parents has sickle cell anaemia. If a child is a carrier of sickle cell anaemia then it could mean that other children and family members are also carriers.

If you don't want to receive any information about possible carriership of sickle cell anaemia by your child, then tell the person who does the heel prick test. This person will ask you to sign the heel prick card. Then if your child proves to be a carrier of sickle cell anaemia, you will not be told about this.

For more information see websites [www.pns.nl/hielprik/uitslag](http://www.pns.nl/hielprik/uitslag) and <http://www.pns.nl/hielprik/sikkelcelziekte>.

### **Other things you need to know**

#### *Taking part is voluntary*

Taking part in the heel prick test is voluntary. You will be asked for your permission before the heel prick test is done. If you do not want your baby to have a heel prick screening test, tell the screener when he or she visits or when they telephone to make an appointment.

#### *Costs*

You do not have to pay for the heel prick test. If your child needs follow-up tests after the heel prick test, then this will be completely refunded by the health care insurer. Sometimes the parents will also need to have tests after an abnormal heel prick test result. The tests for parents fall under their own obligatory deductible excess.

#### *Are the heel prick test results 100% reliable?*

There is a small risk that even if the result of the heel prick test is good, your child may still have one of the diseases. There is also a risk that the result of the heel prick test is abnormal, but follow-up tests show that your child does not have the disease after all. Regrettably this is unavoidable.

The heel prick test is most reliable if it is done within the first week of birth.

The heel prick test only looks for a limited number of diseases. A good result does not guarantee that there is nothing wrong with your child.

If you have doubts about the health of your child, please contact your GP.

#### *Have you moved to the Netherlands from another country?*

If you have moved to the Netherlands from another country and your baby is not yet six months old, then you will be offered the opportunity to have the heel prick test. Even if your baby has already had the heel prick test in another country. This is because not every country screens for the same diseases. It is up to you to decide if you want your baby to have the heel prick test in the Netherlands. If you are a Dutch

family who is resident abroad and you would like your child to have the Netherlands heel prick test, please contact the West region RIVM office (see page 6).

## Legal information

### *Information about the heel prick screening test*

It is good to know what you can expect from the heel prick screening test. This is why your midwife or gynaecologist will give you information about this. More information about heel prick test screening is also available on the website <http://www.pns.nl/hielprik>. It is up to you to decide if you want your child to have the heel prick test.

### *Information about the heel prick test in the national information system*

In order to be able to offer the heel prick test, the local council gives RIVM the information about your child. This information, together with the result of the heel prick test, is entered into a national registration system. This system is called Praeventis.

If the result of the screening is abnormal, then the results of your child's heel prick test will also be entered into the Neorah registration system. Paediatricians also enter the results of the hospital tests into the Neorah system.

The registration systems are necessary to ensure that the screening is carried out properly and that the quality of the screening is monitored. Anonymised information and results are used for national statistics and in scientific research. In this way, screening and treatment can be improved. The Netherlands Organisation for Applied Scientific Research (TNO) collects national statistics on behalf of RIVM.

If you do not want the information from the heel prick screening of your child to remain in an information system, then the personal details about your child can be unlinked from the screening results. The results can then no longer be traced back to your child. See [www.pns.nl/hielprik/procedure-verzoeken-ouders](http://www.pns.nl/hielprik/procedure-verzoeken-ouders) for information on how to request this.

### *Privacy*

The national information systems are well protected. It is subject to the law on the protection of privacy. A privacy statement containing further information can be found on [www.pns.nl/juridische-informatie-screeningen-bij-zwangeren-en-pasgeborenen](http://www.pns.nl/juridische-informatie-screeningen-bij-zwangeren-en-pasgeborenen). This website tells you about the information systems and the sort of information that is stored in them.

## What happens to the blood left over from the heel prick test?

After the heel prick screening test, the laboratory stores the heel prick blood that is left over. This is the remaining heel prick blood.

The laboratory stores the remaining heel prick blood without any personal details.

The remaining blood is kept for five years.

- The blood is needed to monitor the quality of the heel prick screening test. The blood for this is kept for one year.
- The remaining heel prick blood is also kept to use for **anonymous scientific research**. The heel prick blood needed for anonymous scientific research is kept for five years. Scientific research using heel prick blood can only be done

if a committee has determined that the research is useful. It is used for research to prevent diseases and/or to improve their treatment. The researcher will then be sent some heel prick blood but without the personal details of the child. The remaining heel prick blood will be destroyed five years after the heel prick test.

- Sometimes a researcher wishes to use the child's personal details for scientific research. In this case, the parents are always asked for their permission before the remaining heel prick blood can be accessed.
- A paediatrician may ask for the remaining heel prick blood for further research on behalf of a child who is their patient. Again, this is only allowed if the parents give their permission.

If you do not want the remaining blood to be stored for anonymous scientific research, tell this to the screener who does the heel prick. The screener will then ask you to sign the heel prick card. The remaining blood will then be destroyed after the first year.

Parents can make a request concerning their child's remaining heel prick blood. For more information about this see [www.pns.nl/hielprik/procedure-verzoeken-ouders](http://www.pns.nl/hielprik/procedure-verzoeken-ouders).

For further information see [www.pns.nl/hielprik/juridische-informatie](http://www.pns.nl/hielprik/juridische-informatie).

### *Complaints*

Do you have a complaint about the way the heel prick test is carried out? If so, please contact the organisation that carried out the heel prick test. Do you have a complaint about the heel prick test in general? More information about the complaints procedure can be found on [www.rivm.nl/contact](http://www.rivm.nl/contact).

### **For more information**

More information about the heel prick can be found on the RIVM website: [www.pns.nl/hielprik](http://www.pns.nl/hielprik). Here you can also watch a film clip and cartoon about the heel prick. Your midwife or gynaecologist will answer any questions you may have about the heel prick.

### *Regional offices of RIVM-DVP*

If your child has still not had a heel prick test seven days after birth, or if you want more information, then please contact your regional RIVM office.

If your child has had the heel prick test and you still have questions about it, you can get information from the regional office by telephone. You will need your BSN number and your child's BSN number. You will also need the heel prick card number. The heel prick card number can be found at the top right of the envelope given to you by the screener after the heel prick.

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 have 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. The hearing test is also called a neonatal hearing screening test, and hearing screening in the newborn.

### **Who does the hearing test?**

The Youth Health Care services (JGZ) offers the hearing test. Your Well Baby clinic will be involved in this. A screener will carry out the test. This will be an employee of the JGZ or a maternity care worker.

### **Where and when**

The hearing test will be done either in your home or at a Well Baby clinic. If the screening test is done in your home, this will usually be during the first week after birth. The screener will come to your home. Sometimes the screener will contact you first to say when he or she is coming. Often your baby will have the heel prick test at the same time.

If the hearing test is done at the Well Baby clinic, then this will be during the second or third week after birth. You will receive an invitation for this.

### **If your child is in hospital**

If your baby is in hospital, the hearing test will be done when your baby returns home. Please tell the Well Baby clinic when your baby leaves hospital. If your baby needs to stay in hospital for some time, the hearing test can be done there. The Well Baby clinic will contact you about this. If you don't hear anything from them, please contact them yourself.

If your child is on an Intensive Care department (NICU), a member of staff will do the hearing test there.

### **What does the hearing test involve?**

The screener will place a soft earpiece in your baby's ear. The earpiece is attached to a measuring device. This device measures your baby's hearing. The test lasts a few minutes and does not hurt. Your baby will notice very little and will usually sleep quietly through it.

You don't need to prepare anything for it. But it must be quiet in the room during the test. The test works best if your baby is sleeping peacefully. Your baby can either stay in bed or in your arms.

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

### **The result of the hearing test**

The result of the hearing test is known immediately. The screener will discuss the result with you straight away. In around 95 out of 100 babies, no abnormalities are found in the hearing test. If an abnormality is detected in the hearing test, the test will be repeated after about a week. If an abnormality is also detected in the second hearing test, then a third test will follow about a week later. The third test will be done with a different device.

Not getting a clear result does not always mean that your child has hearing loss. If the results of the third test are that your baby cannot hear properly in one or both ears, your baby will then have further tests at an Audiology Centre. You will be given more information about this. An Audiology Centre is a clinic that is specialised in testing hearing, speech and language. The centre is sometimes attached to a hospital.

### **Other things you need to know**

#### *Taking part is voluntary*

If you do not want your baby to have the hearing test, tell the screener when he or she comes to your home or when they telephone you to make an appointment.

#### *Costs*

You do not have to pay for the hearing test.

#### *Why so shortly after birth?*

Good hearing is important for your baby's development. The hearing test can help to discover any hearing loss at an early stage. The sooner this is discovered, the sooner treatment can begin. It is important to start treatment before a baby is six months old. Research has shown that this is good for the development of language and speech.

#### *Is the hearing test 100% reliable?*

If the result of the hearing test is a 'pass', this means that your baby's hearing is almost certainly functioning well at that time. However, it is important that you continue to pay attention to your child's hearing. Sometimes hearing loss does not develop until after the hearing test. Fortunately this is very rare. If you have any doubts about your baby's hearing, contact your GP or the Well Baby clinic.

#### *For more information*

More information about the newborn hearing test can be found on the RIVM website: [www.pns.nl/gehoortest-baby](http://www.pns.nl/gehoortest-baby). You will also find answers to frequently asked questions there. Your Well Baby clinic will also answer any questions you may have. For more information about hearing screening you can also telephone the NSDSK (Dutch Foundation for the Deaf and Hard of Hearing Child): 020 - 574 59 45.



## **Legal information**

### *Information about the hearing test*

It is good to know what you can expect from the hearing test. This is why you have received this information leaflet. For more information about this screening test see ([www.pns.nl/gehoortest-baby](http://www.pns.nl/gehoortest-baby)). It is up to you to decide if you want your baby to be screened.

### *Data on screening in an information system*

The information from your child's hearing test will be stored in an information system especially for neonatal hearing screening. Your Well Baby clinic will do this. The aim of this system is to make sure that all children take part in hearing screening early enough, and that the screening is done in the correct way. The information may also be used for national statistics and scientific research. Only information that has been anonymised is used for this.

The results of the hearing test will also be stored in your child's digital file at the Well Baby clinic. For information about your rights in relation to this digital child file, see website [www.ddjgz.nl](http://www.ddjgz.nl).

### *Privacy*

The information system is well protected. Only people who need your details to do the screening test can access the information. Anonymous data and results are used for national statistics and scientific research. The administrator of the information system complies with the legislation on the protection of your privacy. If you do not want your details to be used for research, or if you do not want your details or those of your child to stay in the information system, see [www.pns.nl/gehoortest-baby/juridische-informatie](http://www.pns.nl/gehoortest-baby/juridische-informatie) where there is information on what you can do about this.

## Main points

- Shortly after birth your baby will have a heel prick test and a hearing test.
- The heel prick test and the hearing test are usually done at home and on the same day.
- The heel prick test and the hearing test are in your baby's best interest. It is therefore important that your baby takes part.
- Taking part is voluntary. You don't need to pay for the screening tests.

### Heel prick test

- For the heel prick test a few drops of blood will be taken from your baby's heel. A laboratory will test the blood for a number of rare and severe conditions.
- These diseases can be treated, usually with medicines or a diet.
- By tracing these diseases early, treatment can be started quickly. This helps to prevent any serious harm to your baby's development.
- For this reason it is important that your baby has the heel prick test in the first week after birth.
- You will get the result of the heel prick test within five weeks. The result is usually good. If it is abnormal, your GP will contact you as soon as possible.

### Hearing test

- At the hearing test a small soft earpiece will be placed in your baby's ear. Your baby will hardly notice it.
- The person who does the hearing test will tell you the result immediately.
- The hearing test can help to discover hearing loss at an early stage.
- Good hearing is important for learning to talk.
- The sooner your baby's hearing loss is discovered, the sooner the treatment can start.

Your midwife or gynaecologist will give you this leaflet at the end of your pregnancy. You will also be given this leaflet when you register your child at the local council offices.

The digital version of this leaflet and its translations are available from [www.pns.nl/geboorte](http://www.pns.nl/geboorte)

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