Rijksinstituut voor Volksgezondheid
en Milieu
*Ministerie van Volksgezondheid,
Welzijn en Sport*

Obstetricians, gynaecologists, family doctors and other obstetric care workers may order more copies of this folder at www.rivm.nl/pns/folders-bestellen.

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

The heel prick test for newborn babies

General information for parents

Population screening tests can be recognised by this logo:
bevolkingsonderzoek

Published by:
**National Institute for Public Health
and the Environment
(Rijksinstituut voor Volksgezondheid en Milieu)**
Postbus 1 | 3720 BA Bilthoven
www.rivm.nl

April 2011

This leaflet replaces all previous versions.

002544

Bevolkingsonderzoek

This leaflet gives information about the heel prick test for newborn babies: what you can expect to happen during and after the test, and who you can ask if you need more information.

The heel prick test for newborn babies

Aims

In the first week after your baby's birth, a health worker takes a few drops of blood from the baby's heel. This blood is then tested in a laboratory for the possible presence of a number of rare hereditary diseases. The heel prick test is important, because the early detection of these diseases can prevent serious damage to the baby's physical and mental development. Most of these diseases are incurable, but they can be effectively treated with medicines or a special diet. So it is in the interest of your baby's health that the heel prick test is carried out.
You will be asked for your permission before the heel prick test is done. You are free to refuse.

Test

A home health worker, the Municipal Health Authority (GGD) or your obstetrician will carry out the test, and they will come to your home to do so. You will be telephoned first, if this is possible, to make an appointment. If your child is in hospital, the heel prick test will be done there.
The screener uses a special instrument to make a pinprick in your baby's heel and squeezes a few drops of blood onto a special 'Guthrie card'. Your baby may cry, but it's all over in a moment.

Results

If the results are normal, you will receive NO further news. If you have heard nothing after four weeks, the results were normal. If the results showed the presence of a hereditary disease, your family doctor will send you a message about it.

Sometimes the amount of blood collected was too little for the laboratory tests to be done properly. In that case, the heel prick has to be done again; this is called a 'repeat first heel prick' (herhaalde eerste hielprik). Another heel prick will also be needed if the laboratory test results are unclear.
A second heel prick is usually done two weeks after the first. If your baby needs a second heel prick for any reason, you will ALWAYS be informed of the laboratory results within four weeks, even if these results turn out to be completely normal.

Which diseases does the test look for?

The blood is tested for a number of different diseases: a thyroid disease, an adrenal disease, sickle cell anaemia, cystic fibrosis, and several metabolic diseases. Most of these diseases are hereditary and rare. They cannot be cured, but they can be treated.
If you would like to see a complete list of these diseases, together with a short description of each one, go to www.rivm.nl/hielprik.

At www.rivm.nl/hielprik you can watch a video clip about the heel prick test.

Hereditary disease

If the test reveals that your baby has one of these diseases, this usually means that both parents are also genetic carriers of that disease. Carriers do not have the disease itself, and they cannot develop it, but if you are a carrier this may have consequences for your next pregnancy. Your obstetric care worker can tell you more, and detailed information (in Dutch) can also be found at www.erfelijkheid.nl.

Being a carrier of sickle cell anaemia or cystic fibrosis

The blood test may show that your child is a carrier of sickle cell anaemia or of cystic fibrosis. This means that one or both of its parents is also a carrier of that disease. This may have consequences for your next pregnancy. The fact that your child is a carrier of sickle cell anaemia or of cystic fibrosis can also be important to other family members, because it means that they may also be carriers.
The heel prick test detects all carriers of sickle cell anaemia, but only a small proportion of the carriers of cystic fibrosis.
If your baby is shown to be a carrier of sickle cell anaemia or of cystic fibrosis, you will be notified by your family doctor.
If you have an objection to being sent information about the carrier status of your baby, tell this to the person who is carrying out the heel prick. The screener will ask you to add your initials to the Guthrie card.

What happens afterwards to the heel prick blood?

After the heel prick blood test has been carried out, the blood sample is kept in the laboratory for a year so that test results can be checked if necessary. After this period, the blood sample may be retained for another four years for use in scientific research; this helps to prevent disease and to improve treatments. Scientific research anonymises the blood sample data. If a researcher wishes to make use of your child's personal details, your permission is ALWAYS requested in advance.

If you object to your child's blood sample being made available for scientific research, tell this to the person who is carrying out the heel prick. The screener will ask you to add your initials to the Guthrie card. If you withdraw your permission for the use of your child's blood sample for scientific research, the sample is destroyed after one year.

Useful details

Registering the baby's birth

The heel prick test is set in motion by the registration of the new baby with the Civil Registry (*Burgerlijke Stand*) in your city. So it is important to register your baby's birth as quickly as possible, at any event within three working days. Remember that the Civil Registry is closed on Saturdays, Sundays and national holidays.

Still no heel prick after seven days?

Has no-one done a heel prick by the time your baby is seven days old? In that case, please get in touch with the RIVM-RCP directly. The telephone numbers are on page 9.

Cost

The heel prick test is free.

Not a 100% guarantee

There is a small chance that the laboratory tests seem to show that a disease is present, while follow-up tests in the hospital reveal that nothing was wrong after all. There is also a small chance that the laboratory tests show normal results even though the child actually has a disease.

The heel prick test checks for a number of diseases, but a normal result does not guarantee that nothing at all is wrong. If you think there is something the matter with your baby, please get in touch with your family doctor.

Register your child as soon as possible after the birth,
and at any event within three working days.

Combined with the hearing test

The heel prick test is usually done in combination with a hearing test, but in a few areas in Gelderland and Zuid-Holland you will have to go to the baby clinic for the hearing test. You will be sent an invitation. In the hearing test, a soft-tipped earpiece is placed in your baby's ear. It makes a soft rustling sound that doesn't hurt at all. You will be given the results of the test straight away.

Privacy

Great care is taken with the information held about you and your child. Your personal details and the medical results of the blood test are kept in an administrative database, which is subject to the Dutch Data Protection Act (*Wet Bescherming Persoonsgegevens*). The data is exclusively used for the purposes for which it was collected. You can consult your own data by submitting a request to your RIVM-RCP office. The relevant telephone numbers are on page 9.

Complaints

If you have any complaints about the way the heel prick test was carried out, please contact the organisation that performed the test. If you have a complaint about the heel prick test in general, you can find detailed information on lodging a complaint on www.rivm.nl/contact.

More information

- There is more information about the heel prick on the RIVM website, www.rivm.nl/hielprik, where you can also watch a video clip about the heel prick screening.
- There is more information about the hearing test on the RIVM website at www.rivm.nl/gehoorscreening.
- If you have any questions about the heel prick test you can also ask your obstetrician or obstetric care worker.

RIVM – Regional Coordination Programmes

RCP North
Groningen, Friesland and Drenthe: 050 - 368 63 50

RCP East
Overijssel, Flevoland and Gelderland: 0570 - 66 15 20

RCP Centre-West
Utrecht and Noord-Holland: 0346 - 55 00 40

South-West
Zuid-Holland: 079 - 341 82 38

RCP South
Zeeland, Noord-Brabant and Limburg: 040 - 232 91 11

English In the first week after birth, children are tested for congenital disorders. This is done by drawing some blood from your child's heel. This test is known as the heel prick (hielprik). In this leaflet you will find more information about the test. This leaflet has been translated into English. You can find the English translation on www.rivm.nl/hielprik.

Français Le test de Guthrie (hielprik en néerlandais), qui permet de dépister les maladies congénitales rares, est réalisé dans la semaine qui suit la naissance du bébé. Ce test consiste à prélever quelques gouttes de sang par piqûre sur le talon du bébé. La brochure vous donne de plus amples informations sur ce test. La brochure traduite en français est disponible en ligne à l'adresse www.rivm.nl/hielprik.

Deutsch In der ersten Woche nach der Geburt werden Kinder auf angeborene Erkrankungen hin untersucht. Dazu wird dem Kind Blut aus der Ferse abgenommen. Diese Untersuchung wird Fersenblutentnahme (hielprik) genannt.In dieser Broschüre finden Sie Informationen zu dieser Untersuchung. Die Broschüre wurde in die deutsche Sprache übersetzt. Die Übersetzung der Broschüre finden Sie unter www.rivm.nl/hielprik.

Türkçe Yeni doğmuş bebeklere, doğuştan gelen bozuklukların teşhis edilmesi için bir test yapılır. Doğumdan sonraki ilk hafta içinde yapılan bu test için bebeğin topuğundan birkaç damla kan alınır. Zaten bu uygulamaya da "topuktan kan alma" (Hollandaca: *hielprik*) testi denmektedir. Bu broşürde testle ilgili ayrıntılı bilgileri bulacaksınız. Broşürün Türkçe çevirisi vardır. Türkçe metni şu internet sayfasında bulabilirsiniz: www.rivm.nl/hielprik.

Español Durante la primera semana tras su nacimiento, se efectúan controles a los bebes para ver si padecen posibles enfermedades. Esto se realiza mediante un pequeño pinchazo en el talón del bebé para recoger unas gotas de sangre. Este control se denomina la prueba del talón (hielprik). En este folleto le ofrecemos más información sobre esta prueba. Este folleto ha sido traducido al español. El folleto traducido lo puede encontrar en www.rivm.nl/hielprik.

عربي في الأسبوع الأول بعد الولادة، يتم فحص الأطفال للتأكد من عدم إصابتهم باضطرابات خلقية. ويتم ذلك عن طريق سحب بعض الدم من كعب طفلك. ويعرف هذا الفحص ب (وخز الكعب). في هذا المنشور سوف تجد المزيد من المعلومات حول الفحص. هذا وقد ترجم المنشور إلى اللغة العربية. ويمكنك العثور على الترجمة العربية على الموقع: www.rivm.nl/hielprik

Papiamentu Den e promé siman despues di nasementu, ta kontrolá beibinan riba malesa kongénito (malesa ku bo ta nase ku ne). Ta hasi esaki dor di kue poko sanger na e hilchi di e beibi. E investigashon médiko aki yama (hielprik). Den e foyeto aki bo ta haña mas informashon tokante e investigashon aki. A tradusí e foyeto na Papiamentu i bo ta haña e tradukshon na www.rivm.nl/hielprik.

中文 新生儿在出生后一周内，应接受先天性疾病检查，检查的方式是从婴儿的足跟采集少量血液，一般称之为"足跟采血"（荷兰文叫做"hielprik"）。在这份宣传手册中，您会了解更多关于这项检查的信息。宣传手册的内容已被翻译成中文。若想查看中文内容，请浏览 www.rivm.nl/hielprik。

Português Na primeira semana a seguir ao nascimento, as crianças são testadas em doenças congénitas. Isto é feito através de uma análise ao sangue retirado do calcanhar da sua criança. O teste é conhecido como o teste do pézinho (hielprik). Neste folheto irá encontrar mais informação acerca deste teste. Este folheto foi traduzido para Português. Pode encontar a tradução Portuguesa em www.rivm.nl/hielprik.