



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

# Extra test following the Heel Prick test (Guthrie test)

Information for parents

*Information in the context of neonatal heel prick screening*

## For whom is this information intended?

In the week following its birth, your child was given a heel prick test. A blood sample was taken at that time. This blood sample was tested for various rare, but serious, disorders.

These tests have shown that your child may have a congenital disorder. As yet, this is not absolutely certain. More tests are needed. These tests will be carried out in a hospital. Only then will we know exactly what the situation is. It is also possible that your child is entirely healthy. If, however, your child is found to have the disorder, then effective treatment is available in the form of medication or a diet, for example.

## Hospital tests

You will have to bring your child to the hospital for these extra tests. There, your child will be given a full examination. More blood samples will also be taken from your child, for further testing. The hospital staff will tell you when you can expect to receive the results of these tests. It may be necessary for your child to be admitted to the hospital for a short time.

## The results

The results of the extra tests can mean one of two things. Either your child has none of the disorders in question, or your child does indeed have a congenital disorder.

### 1 Your child has none of the disorders in question

The extra tests may show that your child has none of the disorders in question, even though the results of the heel prick tests appeared to show otherwise. This can happen from time to time, for various reasons. For you, as a parent, this can be very confusing. In the hospital, your child was given a full examination. Do you still have doubts about your child's health? If so, then you should contact your GP.

### 2 Your child has a congenital disorder

The hospital tests may show that your child has a congenital disorder. In addition to giving you details of the disorder in question, the paediatrician will also tell you about the available treatments. None of the disorders identified by the heel prick test can be cured. However, they can be treated with medication or a diet. The paediatrician will tell you all about the disorder in question. If you have any questions, you can of course discuss them with the doctor at this time.

## Tips for your visit to the hospital

- Write down your questions in advance. This can help you to get all the information you want, during the conversation with the paediatrician.
- Identify those questions that you definitely want answered.
  - What is the diagnosis?
  - What treatment is available?
  - What are the prospects?
  - What things should I watch out for?
  - What action can I take?
- Ask for clear explanations; it is vital that you fully understand the information you are given.
- Two sets of ears are better than one. So take your partner with you to the hospital, or someone else that you trust.

## Do you have any further questions?

- Further details are available at the RIVM website: [www.rivm.nl/hielprik](http://www.rivm.nl/hielprik)
- You can put your questions to your GP or to the doctor at the hospital.

## What will be done with your child's medical details?

In the Netherlands, the medical details of children who are referred to paediatricians for further examination are collected by TNO Quality of Life (TNO-QoL). The details recorded are the results of the heel prick test and the results of the paediatrician's examination.

Since 1 November 2011, the medical details of children with abnormal test results have also been recorded in Neorah, a system that enables digital information to be exchanged between the RIVM-RCP's medical advisor and the attending paediatrician.

If you do not want your child's medical details to be recorded in Neorah, you should inform the paediatrician of your objections. Further information about the registration of your child's medical details can be found at the following website: [www.rivm.nl/hielprik](http://www.rivm.nl/hielprik)

The screening programmes can be identified by means of this logo:

**bevolkings**onderzoek

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Centre for Population Screening

RIVM is responsible for the publication of this information. This information was drawn up together with members of the professional development committee, the National Programme Committee on Neonatal Heel Prick Screening (PNHS). RIVM exercises the utmost care and attention to ensure that all information is up-to-date, accessible, accurate, and complete. However, no rights whatsoever can be derived from the contents.

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