

Testing for Cystic Fibrosis in Heel Pricks ('hielprik')

Information for parents

During the first week after the birth of your child, blood will be taken from the child's heel. This blood is tested in the laboratory for a number of disorders. The test is very important, as the early tracing of such disorders may prevent or limit damage to the child's physical and mental development. From January 2008, cystic fibrosis tests (CF) will be carried out also in your region. This brochure is intended to inform you about these supplementary tests.

The test

The test will be carried out with the same blood that is normally taken in heel pricks. In other words, the CF test will *not* put extra stress on your child.

The result

As is usual in the case of heel pricks, you will *not* be informed if the test shows that your child *does not suffer from* cystic fibrosis. If you have not been informed three weeks after the heel prick, you may assume that your child does not suffer from CF. In case of a different result, your GP will contact you.

What is CF?

CF ('taaislijmziekte') occurs on average in one in 4,000 newly born children. In children who suffer from CF, the mucous in their bodies becomes thicker and tougher in some parts of their bodies than is normally the case. These changes cause problems in the airways and in the gastrointestinal tract. Early treatment may help reduce these problems.

Heredity

CF is one of the most widespread hereditary disorders in the Netherlands. 'Hereditary' means that children who have the disease were born with it. A child with CF has 2 "diseased" CF genes. This means they received one "diseased" gene each from both their parents, causing the disease. Some children receive a single "diseased" gene and one "healthy" gene. These children do not become ill and are called 'carriers' of the disease. CF heel prick tests do not test for carriers of a single CF gene.

Permission

We request your permission to carry out a supplementary CF test on your child. The test is free of charge. If you do not wish to give permission for a supplementary CF test, you should inform the person who carries out the heel prick test. He or she will record this on the test form, and the CF test will not be carried out.

Privacy

The Dutch Personal Data Protection Act ('Wet Bescherming Persoonsgegevens') applies to the personal and medical details involved in the blood test. This means that such data will only be used for the CF test and will not be made available to third parties.

More information?

If you have any questions, please contact the CF screening test nursing officer (045 576 7222; CF-hielprikonderzoek@atriummc.nl) or visit the website www.rivm.nl/hielprik or www.NCFS.nl.

From January 2008, the heel prick sample of each newborn baby in the provinces of Gelderland, Limburg, Noord-Brabant and Utrecht will be used for an additional test on Cystic Fibrosis, as part of a preparatory study carried out by the Atrium MC (Heerlen) in conjunction with the RIVM (National Institute for Public Health and the Environment), St. Elisabeth Hospital (Tilburg), the VUMC and TNO Quality of Life, and supported by a subsidy from ZonMw. Following the preparatory study, the Ministry of Health, Welfare and Sport will decide about the nationwide introduction of heel prick CF tests.
For further details about heelprick CF testing, go to www.rivm.nl/hielprik or www.NCFS.nl.