

## Who else can I talk to about my baby's screening result?

If you wish to discuss in more detail your baby's screening result and what this means for your child and your family, you should discuss this with your GP who can refer you to your local genetics centre.

## Where can I find more information or support?

For further information about cystic fibrosis, and what it means to be a carrier, contact the CF Trust.

### Cystic Fibrosis Trust

11 London Road  
Bromley  
Kent  
BR1 1BY

Telephone: 020 8464 7211

Website: [www.cftrust.org.uk](http://www.cftrust.org.uk)

# Results of Newborn Blood Spot Screening

## Carrier of cystic fibrosis gene



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All records kept relating to newborn blood spot screening meet the requirements of the 1998 Data Protection Act.

This leaflet is based on high-quality research evidence and the views of parents and health professionals. It has been produced for the Cystic Fibrosis Screening Programme based at the UK Newborn Screening Programme Centre, which is funded by the Department of Health for the whole of the UK.

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## What is my baby's screening result?

When your baby was about a week old, your midwife took some blood from your baby's heel. The blood was used to test for some rare conditions, including cystic fibrosis (CF).

The screening result suggests that your baby is a carrier of the CF gene. Approximately 3 million healthy people in the UK are carriers of the CF gene. This leaflet gives you some information about what your baby's screening result means.

## What does it mean to be a carrier of the CF gene?

We all have two copies of each gene in our body, one we inherit from our mother and one from our father. A baby with CF has inherited an alteration in *both* copies of a gene which together cause CF. If a baby inherits only *one* copy of the CF-causing gene, they will not have CF but may 'carry' the gene to the next generation, just like the parent they inherited the altered gene from.

## What is cystic fibrosis?

Cystic fibrosis (CF) is an inherited condition, affecting mainly the lungs and digestion. Children with CF can suffer from chest infections, and problems digesting their food. This means that they may not put on weight as well as they should.

## How will being a carrier affect my child?

As a carrier of CF, your child will not be affected by the condition and will not need any special treatment. Carriers can pass on the altered gene to their children, so you may wish to tell your child later in life that he or she is a carrier of cystic fibrosis. Approximately 3 million healthy people in the UK are carriers of the CF gene.



## Is it possible that my child does have cystic fibrosis?

Most babies who are found, through screening, to have one alteration in a CF-causing gene are carriers who do not have CF. However, there are uncommon alterations of the CF gene that are not recognised by the screening test. It is possible therefore that a small number, about 1 in 15 (or 6%) of babies with this screening result will have a second uncommon alteration and will have CF. If you are worried about your baby's health, you should discuss this with your GP. Your GP may refer you to a doctor who is a specialist in CF, who can talk to you about the likelihood of your baby being affected by CF, and can arrange further tests to find out whether or not your child has CF.

## If we have children in the future, could they have CF?

A baby who is a carrier must have inherited one altered gene from one parent. If *both* parents are carriers, they have a 1 in 4 (or 25%) chance in every pregnancy of having a child with CF. Your baby has been recognised to be a healthy carrier of CF, but there is still a small risk that if you have children in the future they may have CF. If you have any questions, please discuss this with your GP or Health Visitor.