



Public Health  
England



# NHS Newborn Blood Spot Screening Programme

Your baby carries the cystic fibrosis gene



# Your 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 tested for some rare conditions, including cystic fibrosis (CF). This test can also identify babies who are carriers of the CF gene.

Your baby's screening result shows they are a carrier of the CF gene. As a carrier, your baby does not need treatment. More than 2 million healthy people in the UK (about 1 in 25) are carriers of the CF gene. This leaflet gives you some information about what your baby's screening result means.

## What it means to be a carrier of the CF gene

Our genes allow us to inherit things such as eye colour and blood group. We all have 2 copies of each gene in our body – we inherit one from our mother and one from our father.

If a baby inherits 2 copies of the CF gene, they will have CF. If a baby inherits only one copy, they will not have CF but will be a carrier of the CF gene.

## How will being a carrier affect my child?

As a carrier of one copy of the CF gene, your baby does not need any treatment. Parents who are carriers do not need any treatment either.

Carriers can pass on the CF gene to their children, so it is important to tell your child later in life that they are a carrier of the CF gene.

## Could my baby have CF?

Your baby's screening test shows they have one copy of the CF gene. However, screening does not identify rarer types of the CF gene. Very occasionally, a child who is thought to be a carrier is diagnosed with CF later in life. If you are worried about your baby's health, please speak to your GP or health visitor. Tell them your baby is a carrier of the CF gene and that you are worried they might have CF.

## Future children

It is possible that both you and your partner are carriers of the CF gene (about 1 in 25 people in the UK are carriers). When both parents are carriers, all future children have a 1 in 4 chance of developing CF. You and your partner can find out if you are both carriers. Your GP can refer you for this testing, which is quite simple to organise.

## More information

For more information about newborn blood spot screening visit [www.nhs.uk/bloodspot](http://www.nhs.uk/bloodspot).

For further information about cystic fibrosis, and what it means to be a carrier, contact the Cystic Fibrosis Trust: [www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk).

Find out how Public Health England and the NHS use and protect your screening information at [www.gov.uk/phe/screening-data](http://www.gov.uk/phe/screening-data).

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**More information about newborn blood spot screening:** [www.nhs.uk/bloodspot](http://www.nhs.uk/bloodspot)

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