



Public Health  
England



# NHS Newborn Blood Spot Screening Programme

Cystic fibrosis is suspected



# 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).

The screening test results suggest your baby has CF, although more tests will be needed to confirm this. This leaflet gives you some information about your baby's screening result, and what you can expect to happen next.

## What happens next?

Your baby does not need any urgent treatment or special care now. You have a hospital appointment to see a doctor who specialises in children who have CF. The doctor will examine your baby and, if necessary, arrange more tests. The doctor will tell you more about the tests and explain the results to you.

## What is cystic fibrosis?

CF is an inherited condition, affecting mainly the lungs and digestion. A child with CF has inherited 2 altered genes, one from each parent, which together cause CF. Children with CF can suffer from chest infections and difficulties digesting their food. This means they may not put on weight as well as they should.

## Sweat tests

A 'sweat test' is used for some babies because people with CF have a large amount of salt in their sweat. Measuring the amount of salt in the sweat can help determine if your baby has CF. A small amount of sweat is collected from the skin on the baby's arm or leg. You will usually be given the test results later the same day.

If the sweat test result confirms CF, the doctor will discuss with you the treatment available for your baby. You and your baby will be referred to a team of healthcare professionals who care for children with CF in your area. This team often includes a specialist doctor, specialist nurse, dietician and physiotherapist. The CF team can give you support and detailed information about your baby's diagnosis. They will carefully discuss what treatment your baby will need and what you can do to help keep them well.

## Treatment and support

Babies with CF can be treated early with an appropriate diet, medicines and chest physiotherapy. Treatment is improving all the time, helping people with CF live longer and healthier lives.

You may feel a sense of shock, disbelief or anger. These reactions are quite normal and experienced by many parents in a similar situation. Remember, it is not yet known for certain that your baby has CF. You can discuss your concerns with the doctor at your hospital appointment.

# More information

For more information about newborn blood spot screening see:

**NHS Choices:** [www.nhs.uk/bloodspot](http://www.nhs.uk/bloodspot).

More information and support is also available from:

**Cystic Fibrosis Trust:** [www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)

**Contact a Family:** [www.cafamily.org.uk](http://www.cafamily.org.uk)

**Newlife the Charity for Disabled Children:**  
[www.newlifecharity.co.uk](http://www.newlifecharity.co.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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