The Cystic Fibrosis Association of Ireland

Newborn Bloodspot Screening Programme:
Child is a Healthy Carrier of Cystic Fibrosis

For parents who have been informed following screening that their child does not have cystic fibrosis, but is a healthy carrier of cystic fibrosis.

What is my baby's screening result?

When your baby was three to five days old, your nurse took some blood from your baby's heel. The blood was used to test for some conditions, including cystic fibrosis (CF).

The screening test results suggest that your baby carries an alteration in one of their two CF genes. Approximately one in nineteen people in Ireland is a healthy person who carries an alteration in 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 gene?

We all have two copies of each gene in our body, one we inherit from our mother and one from our father. The genes are present from the moment of conception, and are in every cell in our body. If a baby has only *one* copy of the CF-causing gene, they will NOT have CF but 'carry' the gene, just like the parent from whom they inherited the altered gene. Carrying CF is quite common; 1 in 19 people in Ireland carry an altered CF gene – they do not have CF. A person is affected by CF when they have an alteration in both copies of the CF gene.

What is cystic fibrosis?

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

How will carrying cystic fibrosis affect my child?

Although your child carries CF, your child will NOT be affected by the condition of CF and will not need any special treatment. Each child of a person who carries an altered CF gene has a 50:50 chance of also carrying

the same altered CF gene. You may wish to tell your child later in life that he or she carries an altered CF gene.

Is it possible that my child does have cystic fibrosis?

People with CF inherited two altered genes, one from each parent, which together cause CF. The newborn blood spot screening (heel-prick) test has identified one altered gene in your child. As there is a possibility your child has a second altered gene that wasn't identified, a 'sweat test' was performed. The sweat test is the internationally recognised test to diagnose cystic fibrosis. This means it is the best test to decide if someone does, or does not, have cystic fibrosis. The good news is that your child's sweat test indicates they do NOT have cystic fibrosis.

If we have children in the future, could they have cystic fibrosis?

A baby who carries CF must have inherited one altered gene from one parent. This means that either Mum or Dad also carries CF. However, it is possible that BOTH Mum and Dad carriers carry CF and, purely by chance, did not have a child with cystic fibrosis on this occasion. If *both* parents carry CF, then each time they have a child together, they have a 1 in a 4 (or 25%) chance of having a child with CF. For this reason we refer all parents for genetic counselling. The genetic counsellor will discuss these issues in detail, and, if you wish, will organise for you to be tested – to see if Mum and/or Dad carries CF.

For Further Information

Talk to the doctor and the CF nurse in the CF Centre or contact your local GP.

You can also log on to www.newbornscreening.ie

or contact:

Cystic Fibrosis Association of Ireland (CFAI)
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Dublin 6.
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The CFAI provides an information pack and other supports if your baby is diagnosed with CF.