

Newborn Bloodspot Screening Programme: *Result indicates Increased Risk of Cystic Fibrosis*

For parents who have been informed that the result of the Newborn Bloodspot (heel-prick) Test indicates their baby is at increased risk of cystic fibrosis.

What does my baby's screening result mean?

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

The screening test results suggest that your baby may have CF, though further 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 is cystic fibrosis?

Cystic Fibrosis 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 difficulties digesting their food. There are about 1,200 people with CF in Ireland.

What happens next?

As your baby does not need urgent treatment or special care you should continue to care for your baby as you have been.

The screening tests have to be confirmed with another test called the sweat test. The nurse will arrange for the test to be done and for you to see the doctor. The doctor is a specialist in children who have CF. The doctor will examine your baby and will tell you more about the tests and explain the results to you.

Sweat Test

When CF is suspected, babies have a 'sweat test'. People with CF have a large amount of salt in their sweat, and measuring the amount of salt in sweat will determine whether or not your baby has CF. For this test, a small amount of sweat is collected from the skin on the baby's arm or leg. This is a

painless test and takes about half an hour to complete. You will be given the results a few hours later. In one in ten small babies there may not be enough sweat to perform the test. If this happens the test will be repeated on another day.

If the results from the sweat test are normal then your baby does not have CF. Like at least one of their parents, your baby is a healthy 'carrier' of one altered gene that causes CF. To have CF you need two altered genes. Carrying CF is quite common; 1 in 19 people in Ireland carry an altered CF gene. They do not have CF. A person is only affected by CF when they have an alteration in both copies of the CF gene.

If all the tests support the diagnosis of CF, the specialist doctor will discuss with you the treatments available for your baby. You will meet a team of health professionals who take care of children with CF in your area. This team includes the specialist doctor, a specialist nurse, a dietician, a physiotherapist and other health care professionals. The CF team will be able to give you support and provide detailed information about your baby's diagnosis. They will carefully discuss what treatments your baby will need and what you can do to help keep your child well.

What treatment is available for cystic fibrosis?

Screening means that babies with CF can be treated early with an appropriate diet, medicines and chest physiotherapy. Treatments for CF are improving all the time, helping people with CF to live longer and healthier lives. There are 11 specialised CF centres in hospitals around Ireland, some of which are centres for children, some are centres for adults and some look after both adults and children.

How do you feel?

You may feel a sense of worry, shock or disbelief. These reactions are quite normal and are experienced by many parents in a similar situation. You will be able to discuss your concerns with the doctor when you go to the hospital for the appointment to find out whether or not your baby has 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)
24 Lower Rathmines Rd,
Dublin 6.
Tel: 01 4962433/ LoCall: 1890 311211
Email: info@cfireland.ie
Web: www.cfireland.ie

The CFAI provides an information pack and other supports if your baby is diagnosed with CF.