Sláinte Leanaí Éireann
Children's Health Ireland

mychild.ie

National Newborn Bloodspot Screening Programme

Information for parents of babies at risk of spinal muscular atrophy (SMA)

How was my baby found to be at risk of SMA?

Your baby's heel prick test showed that they are at high risk of having a condition called spinal muscular atrophy (SMA).

At this stage, we don't know whether your baby has SMA. However, most babies with a positive screening test will be found to have SMA.

As discussed on the phone, your baby now needs to come to Children's Health Ireland at Temple Street, Dublin. Your baby will have an appointment with a specialist doctor (paediatric neurologist).

The doctor will examine your baby. They will take a blood test to find out whether your baby has SMA.

What is SMA?

SMA is a rare inherited (genetic) condition. There are different types of SMA.

Some babies born with SMA can develop severe muscle weakness. Their body does not make enough survival motor neuron (SMN) protein. SMN is a protein you need for your spine and muscles to work properly.

What causes SMA?

SMA is an inherited condition. It is caused by a gene passed down from parents to their child.

Can SMA be treated?

Yes. SMA can be treated. There are very good treatments available.

If further testing shows that your baby does have SMA, the paediatric neurologist will talk to you about:

- the treatment options, and
- expected outcomes for your baby.

Treatment should start as soon as possible. We know that babies with SMA do much better if treated early.

What happens next?
Please bring your baby to Children's Health Ireland at Temple Street on the date and time provided to you by the paediatric neurology team. Your baby will usually be seen in the neurology department on the 3rd floor of the outpatient department.

The paediatric neurologist will examine your baby and take a blood sample.

The blood sample will be sent to the laboratory to check whether your baby has SMA. The blood test results should be available within approximately 5 working days.

Your baby may start on medication until the blood test results are available. If your baby does have SMA, starting them on treatment as early as possible is very important.

We do not expect your baby to become unwell in the short time before you are seen by the paediatric neurology team in Children's Health Ireland at Temple Street.

Does my baby need to stay in hospital?
The paediatric neurologist will advise you. They will tell you if your baby needs to stay in hospital until the blood test results are back, or if you can bring them home.

If your baby is well, it is likely that you will be able to bring them home until the blood test results are available. The paediatric neurology team will arrange another appointment with you in a few days' time, to discuss the test results.

There is a chance your baby may need to stay in hospital. Please be prepared and bring a few essentials for you and your baby in case you need to stay in hospital.

What happens if my baby does have SMA?
If the blood test shows that your baby has SMA, they will get expert medical care from the paediatric neurology team. The team is based at Children's Health Ireland at Temple Street, Dublin.

Is there anything else I need to know?
You can continue feeding your baby as normal (breastfeeding, formula feeding or both).

General information on caring for newborn babies is available on mychild.ie