

Hearing your baby's newborn bloodspot test shows 'suspected SMA'

You can also read this information on our website at smauk.org.uk/37b6 where you can follow all the links we give to further information.

This information is for any parent who has had a phone call from a specialist clinical team. The call has been to say that your baby's newborn blood spot test result shows 'SMA suspected'.

SMA is a rare condition. There are different forms of SMA. The most common and treatable form is called 5q-SMA. Your baby's newborn bloodspot screening test result shows '5q-SMA suspected'. To make it easier to read this information we refer to it as SMA.

You will have been given an urgent appointment to see a consultant specialising in spinal muscular atrophy (SMA). If possible, this will be for the day after the call. You will have been told that your baby's blood spot test shows altered SMN1 genes. This means your baby may have spinal muscular atrophy.

1. Hearing that your baby has suspected SMA

Parents describe feelings of shock and disbelief when hearing their baby may have a rare condition. They often think there must have been a mistake as their baby seems so well. They can't see any sign that anything is wrong.

2. What test did my baby have?

You may only vaguely remember your baby having a test for SMA. Life has been such a whirl since your baby was born.

Your baby's test result may have been because:

You live in an area that is part of the In Service Evaluation (ISE) for SMA.

This study starts in Scotland on 23rd March 2026. There are plans underway to offer newborn screening for SMA (NBS for SMA) in some parts of England.

A baby's test is usually done at home by a community midwife or health visitor when a baby is 5 days old. But it may have been done while you were in hospital or at another planned appointment.

The test is for 10 rare conditions. One of these is SMA.

OR

You signed up for the [Generation Study](#) >

Shortly after birth, your baby had blood taken from the umbilical cord or a heel prick. This study is testing for 200+ conditions. One of these is SMA.

3. Why is the specialist appointment so urgent?

There is no cure for SMA but there are effective drug treatments. If given before symptoms start, the drugs can stop them developing.

Early treatment can help babies with SMA have the best chance of a healthier future.

4. Why did they say SMA 'suspected'?

When you had the phone call, your baby's blood test showed they have altered *SMN1* genes. Further testing is needed to confirm whether your baby has SMA. Your specialist should have more information when you see them.

5. What will happen at the appointment?

When you see the specialist, they will explain all the test results to you and examine your baby. They should then be able to tell you:

- The Type of SMA they suspect your baby might have or might develop
- What drug treatment is available
- If your baby has drug treatment:
 - How they would expect your baby to develop
 - What other care and support they would expect them to need
 - How they will monitor your baby's progress
 - Where you can go for support and more information.
- If your baby has no drug treatment:
 - How they would expect your baby to develop
 - What other care and support they would expect them to need
 - How they will monitor your baby's progress
 - Where you can go for support and more information.

To check their diagnosis, the specialist will take another blood sample from your baby. This will be tested as quickly as possible. In most cases no drug treatment will be started unless this result confirms your baby has SMA.

Waiting to see the consultant and then waiting again for final test results will be very stressful for you and the people around you. Everything will be happening as quickly as possible for your baby and you.

6. Getting to the specialist appointment

Your appointment will be at the nearest possible location available. In some cases, however, this may mean travelling some distance.

If you need help with travel costs, [SMA UK can help with a Grant >](#)

7. More information about SMA

During the appointment the specialist will talk to you specifically about your baby and their diagnosis.

If you want to look for further general information online, we suggest you [go to the NHS website >](#). They signpost to our website as a trusted source of up-to-date information. Other websites may not provide the most up-to-date information about SMA screening and treatment.

Our website is accurate and up-to-date, but it does not have information that is specifically about your baby and their diagnosis.

You are always welcome to [contact our Support Team >](#).

You can also phone on 01789 267520 and ask to speak to a member of the Support Team.



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This publication, and its links, provides information. This is meant to support, not replace, clinical and professional care.

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If you have any feedback about this information, please do let us know at: information@smauk.org.uk .

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