

Family action sheet for spinal muscular atrophy (SMA)

If a newborn blood screening result shows that your infant could have a serious condition called spinal muscular atrophy (SMA). This result requires further testing.

All babies born in California have a routine blood screen shortly after birth. The goal of this newborn screening is to find those at risk for serious medical conditions. Babies can look healthy at birth and still have one of these conditions. Babies with these conditions benefit from early diagnosis and treatment.

What is spinal muscular atrophy or SMA?

SMA is a condition where babies don't make enough of a specific protein to keep nerves and muscles healthy. This causes weakness and wasting of the muscles (atrophy).

SMA has other wide range of symptoms that can include difficulty breathing, eating, crawling, and walking.

Is there treatment for SMA?

Yes, there are multiple treatments to help the body make more of this specific protein. Babies with SMA should start treatment as soon as possible to help their chances of better outcomes. Supportive care may include use of medical equipment, respiratory, speech, physical, occupational, and nutritional therapies.

Newborn screening takes blood from a newborn's heel to screen for medical conditions.



Next steps

1. Your baby's medical provider will refer you to specialists with SMA experience.

The specialists will arrange for further testing and evaluation. More tests are needed to find what treatment or monitoring will be needed for your baby.

2. Work closely with your baby's medical provider and specialists and follow their recommendations.

It is important that you keep all appointments and start treatment if instructed.

Where can I get more information?

Your baby's medical provider and specialists are the best people to teach you about SMA. Find more information at these websites:

• Baby's First Test

(www.babysfirsttest.org). Type "SMA" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español"

• Cure SMA

(www.curema.org)

• Health Resources & Services Administration (HRSA)

(newbornscreening.hrsa.gov/conditions/spinal-muscular-atrophy)

