

California Prenatal Screening Program

Prenatal screening result and neural tube defects

What you should know when your blood screening result suggests there is **an increased chance** that your fetus may have a birth defect called a neural tube defect



Neural Tube Defects

www.cdph.ca.gov/pns



Prenatal screening result and a neural tube defect

The result of your screening suggests that your fetus may have **an increased chance** of a birth defect called a neural tube defect.

Why have you been given this booklet to read?

As part of your prenatal care, you consented to prenatal screening. Your blood was sent to a laboratory to screen for certain birth defects in your fetus.

The result of your screening suggests that your fetus **may have an increased chance** of a birth defect called a neural tube defect.

Does this screening result mean that the fetus has a neural tube defect?

No. Most women with this screening result have normal, healthy babies. Prenatal screening finds fetuses at higher risk. Follow up testing can help give more information and a clearer answer.

What is the neural tube?

The neural tube starts at the top of the head and ends at the bottom of the spine. The neural tube becomes the baby's brain and spinal cord.

What is a neural tube defect?

Neural tube defects are birth defects that involve the brain or spine.

What can you do next?

There are several ways to tell with more certainty if the fetus does have a neural tube defect. It is your choice whether to use the follow-up services offered.

What follow-up services are available?

Your prenatal care provider will offer follow-up services, including genetic counseling and ways to tell with more certainty if the fetus does have a neural tube defect.

Follow-up services are offered at locations that specialize in these services. These locations are called state-approved Prenatal Diagnosis Centers.

Follow-up services are available at no additional charge. You decide if you want follow-up services.

Follow-up services include:

- Genetic counseling
- Ultrasound exam
- Amniocentesis

What is genetic counseling?

Genetic counseling is the first service provided at a state-approved Prenatal Diagnosis Center. A genetic counselor discusses your screening result and what it means. You will also review your family's health history. The genetic counselor will give you information about the other follow-up services available to you.

The genetic counselor will explain that you have several options that include ultrasound and amniocentesis. Be sure to ask the genetic counselor any questions you may have.

You decide if you want any additional follow-up services after genetic counseling.

Remember: Most pregnant individuals with a screening result showing an increased chance of a neural tube defect have normal, healthy babies.

Ultrasound (sonogram)

Ultrasound is a way to tell if the fetus does have a neural tube defect. Doctors with special training can do a high-level ultrasound, in general starting from **12 weeks of pregnancy**. It gives a very detailed picture of the fetus.

An ultrasound also checks the age of the fetus and the number of fetuses.

You can have this ultrasound even if you decide not to have amniocentesis.



Amniocentesis

Amniocentesis is a test that can tell if the fetus has a neural tube defect. This test can be done starting from **15 weeks of pregnancy**.

For this test, an experienced doctor takes a small amount of the fluid around the fetus with a thin needle. The fetus is not touched. A lab will look for proteins in this fluid to confirm if the fetus has a neural tube defect. Amniocentesis can find neural tube defects that may not have been seen on the ultrasound.

Amniocentesis is considered a safe test when done by a medical expert at a state-approved Prenatal Diagnosis Center. The risk of miscarriage due to amniocentesis is small – less than 1 in 900.

The amniocentesis result is usually ready in two weeks.

What if ultrasound or amniocentesis confirms your fetus has a neural tube defect?

A doctor or genetic counselor will give you information about the neural tube defect and how it could affect the fetus's health and your family.

The neural tube is completely formed by five weeks after conception. Birth defects happen when the neural tube does not develop correctly.

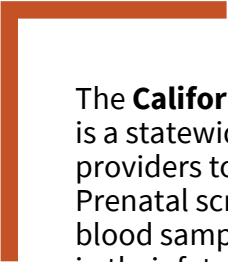
The two most common neural tube defects are **spina bifida** and **anencephaly**. These defects happen in about 1 in every 1,600 births.

Infants born with spina bifida have an opening in the bones of the spine that exposes the nerves. Spina bifida can affect fetuses differently. It may cause leg paralysis and loss of bowel and bladder control. Surgery may be needed.

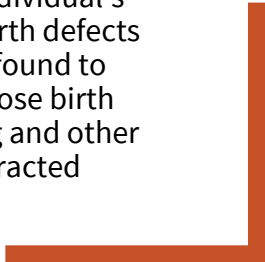
Anencephaly is when most of the skull is missing and most of the brain does not develop. This birth defect causes death for a fetus or newborn.

Your health care provider can discuss your options for the pregnancy with you. When reviewing your options, please remember that the decision on what to do is entirely up to you.

Medi-Cal and private insurance must cover all PNS Program fees, with only a few exceptions. Referral for additional medical care and support services are available, but these costs are not covered by the PNS Program.



The **California Prenatal Screening Program** is a statewide program offered by prenatal care providers to all pregnant individuals in California. Prenatal screening uses a pregnant individual's blood samples to screen for certain birth defects in their fetus. Individuals with a fetus found to have an increased chance of one of those birth defects are offered genetic counseling and other follow-up services through state-contracted Prenatal Diagnosis Centers.





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www.cdph.ca.gov/PNS

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