

Family action sheet for adrenoleukodystrophy (ALD)

If a newborn blood screening result shows that your baby could have a serious condition called adrenoleukodystrophy (ALD) or a related condition. 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 adrenoleukodystrophy or ALD?

Children with adrenoleukodystrophy (or ALD) have a range of mild to severe symptoms. Signs and symptoms can affect many parts of the body. The brain, spinal cord, and adrenal system are most affected. The adrenal system controls stress and energy in the body.

ALD mostly affects males. Some symptoms may occur soon after birth. Females may be affected by related conditions or at a later age. ALD is an inherited condition. This means it is passed from parents to children.

Is there treatment for ALD?

Yes, there are treatments for ALD. Early treatment can help slow or delay ALD effects on the brain, spine, and the adrenal system. These treatments include bone marrow transplant, gene therapy, and steroid replacement therapy.

It is important for medical providers to monitor ALD closely for signs and symptoms. This allows treatment to begin as soon as needed and before ALD affects the body.

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 an ALD specialist.

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 a treatment plan if instructed.

Where can I get more information?

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

• [Baby's First Test](https://www.babysfirsttest.org)

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

• [Health Resources & Services Administration \(HRSA\)](https://newbornscreening.hrsa.gov/conditions)

(<https://newbornscreening.hrsa.gov/conditions>). On the HRSA conditions page, go to letter "X" for "X-linked adrenoleukodystrophy."

