Family Fact Sheet

Positive Result:

Blood Spot Screen Result Notification

Minnesota Newborn Screening Program

Elevated C26:0-lysophosphatidylcholine (C26:0-LPC)

What was found on the newborn screen?

The newborn screen that was collected at birth found that your baby has a high level of C26:0-lysophosphatidylcholine (C26:0-LPC). A high level of C26:0-LPC means that your baby also has high levels of very long-chain fatty acids (VLCFAs).

What does this mean?

High levels of VLCFAs mean that your baby may have a condition called X-linked adrenoleukodystrophy (X-ALD). This result does not mean your baby has X-ALD, but it does mean your baby needs more testing to know for sure. Only boys have X-ALD. If your baby is a girl, she may just be a carrier for X-ALD.

What happens next?

Your baby's doctor will help arrange for more testing with specialists familiar with X-ALD.

What is X-linked adrenoleukodystrophy?

X-ALD happens when certain fats (VLCFAs) cannot be broken down in the body. These fats build up and cause health problems. The nervous system and adrenal glands are damaged the most.

There are three types of X-ALD found in males. The health problems and when problems start vary widely, even among family members. These types include: childhood cerebral, adrenomyeloneuropathy (AMN), and Addison disease. Newborn screening cannot tell the difference between these three types.

What health problems can it cause?

X-ALD is different for each child and depends on if the child is male or female. X-ALD is a lifelong condition that may result in serious health problems.

In males, the most severe type of X-ALD is the childhood cerebral type. If untreated, it can cause ADHD-like behavior, learning disabilities, seizures, paralysis, and death within a few years. AMN is an adult onset type of X-ALD that affects the spinal cord causing leg weakness. AMN may or may not have brain disease similar to the childhood cerebral type. Boys with Addison disease will only develop adrenal symptoms if untreated: vomiting, fatigue, low blood pressure, weakness, skin darkening, and coma.

Females who are carriers for X-ALD have milder symptoms that typically start in adulthood. Some women may never show any symptoms.

Children with X-ALD can benefit from specialized treatment.

What treatment options are available?

X-ALD can be treated. Possible treatments can include:

- Supportive therapies and management like physical therapy and medications
- Steroids
- Stem cell transplant - childhood cerebral type only

Children with X-ALD should see their regular doctor and doctors with expertise in X-ALD.

Resources

Genetics Home Reference:
http://ghr.nlm.nih.gov

Save Babies Through Screening Foundation:
www.savebabies.org

Baby's First Test:
www.babysfirsttest.org

DEPARTMENT OF HEALTH

Newborn Screening Program, 601 Robert St. N., St. Paul, MN 55155
Phone (800) 664-7772, Fax (651) 215-6285 ***interpreters available***

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